



**The Competition and Markets Authority:**

**Self-funded IVF Research**

Qualitative Research Report

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## 1. Executive Summary

### 1.1 Background

1.1.1 The CMA are developing consumer law guidance for Fertility clinics and patients in the UK to ensure they are aware of their legal obligations and rights. To help with this, the CMA are working closely with the sector regulator, the Human Fertilisation and Embryology Authority (HFEA) to understand patients' experiences of buying fertility treatment and learn more about how clinics operate. Qualitative research was required to feed into this work and help inform the guidance the CMA will be producing.

### 1.2 Research objectives

1.2.1 Specifically, the research aimed to understand:

- What research the patient conducted prior to selecting a clinic?
- What factors informed the patient's choice of a clinic?
- What information was provided about the different aspects of fertility treatment and costs involved; specifically:
  - What was provided before the treatment started and what, if anything, was provided after the treatment started?
  - Did they buy any add-on or complementary treatments, when and who suggested that?
  - Was a costed treatment plan provided and what they understood about the treatment cost before the treatment started?
  - Were the terms and conditions provided, including payment terms, cancellation and refunds policy?
- What decisions were made about treatments and costs before the treatment started and what decisions, if any, after the treatment started?
- Was there a difference between what they paid in the end and what they thought they'd pay when the treatment plan was agreed?

### 1.3 Method and sample

1.3.1 The methodology for this research was qualitative and it involved paired depths (with the individual who had treatment and their partner) and individual depth interviews (with the individual who had treatment). Research interviews were 1 hour long and were conducted either by telephone or video conferencing platforms, depending on respondents' preference.

1.3.2 Fifty depth interviews were conducted in total. All respondents paid for IVF treatment in the last two years and came from across the UK. The sample was further structured to ensure a wide range of experiences were captured, specifically in terms of: different age groups, type of relationship, and whether patients paid for treatment in NHS or private clinics. Detailed sample criteria are provided in Section 3.2.

## 1.4 Main findings

### *Researching and choosing a clinic*

- 1.4.1 Most patients who paid for fertility treatment in this sample actively sought information to help them choose a clinic and understand their treatment options. Clinic websites and other patients, along with Google searches, dominated as sources of information. Conversely, only a smaller number used independent sources of information focusing on the sector, such as the HFEA website.
- 1.4.2 Overall, most respondents felt they had a choice of clinics, even if the extent of this choice varied. There were several key factors which influenced most respondents' choice of clinic, with some variations in how individual factors were prioritised and weighed against each other. The key factors were: location, cost, success rates and impressions of clinics. In addition, a smaller group of respondents' choices were influenced by some other factors, for example, recommendations from other patients.
- 1.4.3 Most respondents reviewed the success rates of different clinics on clinic websites. Most felt that they had been able to understand the different variables success rates were based on (e.g. age and type of treatment) and to compare them across clinics. Some amongst this large group felt that it had taken them a while to understand all the different variables, but that their understanding had improved once they had become more familiar with the information. That said, many objected to success rates being quoted based on pregnancies rather than live births (which was what respondents were interested in).
- 1.4.4 A small group of respondents stressed the difficulties they experienced when comparing success rates for different clinics due to a perceived lack of consistency in how success rates were reported. Another small group questioned the accuracy of success rates, based on greater experience of IVF treatment and/or a more informed perspective on statistics.

*Treatment information, decision-making and experiences*

- 1.4.5 Most respondents felt the clinics explained well what treatments they would have and when, as well as the rationale for them. There were some exceptions, where a small number of respondents felt that their clinics had not been sufficiently clear about the treatment options available to them.
- 1.4.6 There were mixed reports regarding the information provided about risks: while many recalled being told about the risks of medication, there was much less recall of the risks associated with tests and certain add-ons that the clinic offered.
- 1.4.7 There were mixed reports in terms of the information provided about patients' own personal chances of success i.e. based on test results. Although a few reported discussing their personal chance of success, most did not, and the specific basis for the individual discussions reported (i.e. whether test results, scans, age and previous history of IVF and any specific fertility issues) is unclear.
- 1.4.8 For most, the treatment agreed at the beginning of the process proceeded without adjustment (other than adjustments to medication, which were relatively common and which respondents knew might be required). However, a smaller number of respondents reported that further tests, scans or treatments were introduced part-way through the treatment. These were perceived as 'additional' to the treatment originally discussed and respondents wished they had been made aware of all the adjustments that might be needed during the process. This finding suggests that initial information about how treatment can vary needs to be more clearly communicated.
- 1.4.9 Just over a half of patients bought add-on treatments, which most purchased as optional extras, before treatment started. The most frequently bought add-on treatments were embryo glue and endometrial scratching, followed by time-lapse imaging. With one exception, where an NHS clinic sold endometrial scratch to a patient, all add-on treatments respondents had purchased were purchased from private clinics respondents used for their IVF treatment. In one case, an NHS clinic refused to provide add-on treatment that was requested, resulting in the respondent moving to a private clinic.
- 1.4.10 Most respondents learned about add-on treatments from private clinic websites (before engaging with the clinic) or from clinic brochures, price lists shared with them during consultations or from consultants (after engaging

with the clinic). A smaller group of respondents first read or heard about these treatments independently from the clinic they used. These respondents explained how they had heard positive comments about particular add-on treatments from friends and family who had used them or other patients who discussed them on fertility forums.

- 1.4.11 There was variation in whether add-on treatments were discussed with clinics or not. Some respondents reported that although the clinic materials had made them aware of these treatments, the topic was not subsequently raised, either by themselves or by the clinic. That said, a large group did discuss these treatments with their consultants. These discussions were often initiated by respondents, but sometimes also by the clinic staff.
- 1.4.12 There was variation in how private clinics advised patients who asked about add-on treatments. In some instances, participants reported that consultants had explained that certain add-on treatments could help increase their chances of success; in other instances, they reported that consultants had explained there was no evidence that these treatments did increase chances of success. Respondents did not recall that the risks of particular add-on treatments were discussed with them. Only one respondent recalled being signposted to consider the HFEA information and traffic light system about add-on treatments<sup>1</sup>.
- 1.4.13 In some instances, respondents followed their consultants' advice and either bought or didn't buy particular add-on treatments, as advised. In other instances, patients disregarded their consultants' advice. Some were determined to use particular add-on treatments, especially when they came to the clinic already minded to buy certain add-ons.
- 1.4.14 There were some consistent themes in how respondents who bought add-on treatments explained their reasons for this decision. In some instances, these respondents had experienced multiple unsuccessful IVF treatments and wanted to keep trying different treatments in the hope that one of them might work. A small group felt that a lack of clinical evidence supporting the effectiveness of add-ons did not necessarily mean that they were ineffective, particularly given their belief that effectiveness was likely to vary between patients because of their different medical characteristics. Lastly, many who bought add-on treatments felt that, in the context of high cost IVF treatment, add-on treatments were relatively affordable. As these respondents

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<sup>1</sup> <https://www.hfea.gov.uk/treatments/explore-all-treatments/treatment-add-ons/>

explained, having already invested such large sums of money in this treatment, they wanted to try everything they could as well as avoid the fear of not doing so (even when sceptical about the treatments themselves).

#### *Cost-related information and experiences*

- 1.4.15 HFEA advise fertility clinic users: *“Make sure you get a fully costed treatment plan before committing to a clinic. This should include everything from your tests to your drugs.”*<sup>2</sup> The findings around the ways in which treatment costs were provided suggest that there is considerable variation across the sector in terms of how and when treatment costs are provided. The data indicates that most clinics provided respondents with upfront treatment costs, but that the information provided varies in terms of clarity and level of detail. Certain aspects of treatment costs were less clear than others to respondents at the start of the process. In addition, a small number of respondents reported that they did not know the cost of their treatment before it started.
- 1.4.16 There was a perceived lack of clarity regarding the extent to which costs can vary, particularly in terms of medication costs, but also tests and scans.
- 1.4.17 In addition, the research identified other issues that affected a smaller number of respondents, including: a small group of respondents reporting not being given information about costs prior to treatment; patients being unaware at the start of the process of certain costs they would incur in the later stages of the process e.g. if the treatment results in a pregnancy; and patients being unclear about what was and wasn't included in the treatment plan they had agreed to before their treatment started.
- 1.4.18 Most respondents reported they were provided with payment details before starting their treatment. However, many could not recall any information about cancellation and refunds, which they reported was also had not been specifically discussed with them. Some surmised that the reason for this was due to both the clinics and patients wanting to be positive at the start of the process, rather than considering unsuccessful outcomes. However, a few respondents wished this had been discussed with them, so that they would have been better prepared for such an outcome.
- 1.4.19 The research further suggested that most clinics did not inform patients about whether they had the option to choose to get a prescription and purchase the drugs elsewhere. A few respondents who knew about this possibility - having

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<sup>2</sup> <https://www.hfea.gov.uk/treatments/explore-all-treatments/costs-and-funding/>

found out about it from friends and family - asked about this, were told they did have this option and chose to purchase their medication elsewhere, saving money in the process. Similarly, only a few respondents reported they were told they could get certain tests and scans from the NHS for free.

1.4.20 A large group of respondents claimed that their final costs were the same as what they had been expecting. This group includes:

- Those who felt that the final costs were roughly the same as expected, including: those who were not particularly clear about costs in the first place and therefore had very broad expectations about final costs; as well as those who were not particularly cost-conscious and were not paying particularly close attention to costs.
- Those who had a clearer expectation of cost, who included: those who bought packages and felt they were clear about the costs they were expected to pay; those who bought private treatment at NHS clinics and felt that they were clear about the costs they were expected to pay; and those who were on a budget and therefore paid close attention the costs they were paying. Even though this group may not have felt that they paid more than they had expected, this did not preclude them wanting greater clarity on treatment costs in future.

1.4.21 A small group reported that they had paid more than they had expected. The reported difference was mainly due to needing more medication, which had then increased the cost. Even amongst those expecting medication costs to vary, some were still surprised at the extent to which the medication cost increased, for example, by £1500-2500 in a couple of cases.

1.4.22 A small group also reported they paid more, but in their case respondents felt that these were unexpected costs. The unexpected items they paid for were often tests, scans or pregnancy medication, which some did not realise they would need. In three cases, the unexpected cost was due to ICSI being required once the treatment had started. Some of these respondents felt frustrated that this possibility was not discussed with them at the start.

1.4.23 A very small number of respondents were unable to say whether they paid more or not because they did not receive information about their treatment cost.



## 1.5 Conclusions

1.5.1 The research suggests the following improvements in the information provided by the clinics would be needed to enable patients to make more informed choices:

- Providing clearer and better information about the costs, particularly with regards to:
  - What is included in their treatment;
  - Which costs are certain and fixed e.g. scans, consultations;
  - Which costs are certain and variable i.e. medication and the extent to which these might vary;
  - Which costs are uncertain and variable i.e. costs that might arise during treatment due to a change in medical need;
  - What is excluded from their treatment i.e. add-ons.
  
- Addressing issues reported by a smaller number of respondents whose clinics did not provide any personalised costs in advance of the treatment or provided the bigger costs but not other smaller costs that were still necessary for the treatment (e.g. cost of additional scans);
  
- Ensuring that patients have both clinical and financial information at hand at the same time when agreeing to treatments, rather than separating medical from financial discussions;
  
- Discussing the refunds and cancellation policy with patients at the start, so they are better prepared for different possible outcomes and know their rights in the event of cancellation;
  
- Informing patients, if they have the option, to use different providers for medication, tests and scans, and supporting their choice to do so;
  
- Being clearer on the patient's personal chances of success at the outset and discussing risks with them with regards to all aspects of their treatment, including with regards to tests or add-on treatments;
  
- Signposting patients to the independent information provided by HFEA, particularly with regards to add-on treatments and success rates but also more generally;

- Consistently conveying information about the evidence for the effectiveness of add-on treatments to patients, that is, informing them there is little or no robust evidence, and of the risks where appropriate.

## **2. Background and Research Requirement**

### **2.1 Background**

2.1.1 The CMA are developing consumer law advice for Fertility clinics and patients in the UK to ensure they are aware of their obligations and rights. To help with this, the CMA are working closely with the sector regulator, the Human Fertilisation and Embryology Authority (HFEA) to understand patients' experiences and learn more about how clinics operate. Qualitative research was required to feed into this work and help inform the guidance the CMA will be producing.

### **2.2 Research Objectives**

2.2.1 The research needed to answer the following questions:

- a) What research the patient conducted prior to selecting a clinic, for example did they do one or more of the following:
  - Speak to their GP;
  - Look at websites;
  - Read brochures;
  - Go to any clinic open days/evenings or trade shows;
  - Consult social media forums;
  - Visit clinics;
- b) Whether any aspects of their treatment were performed abroad, if so which aspects?
- c) The factors that influenced their choice of clinic, for example, did one or more of the following influence their choice:
  - Advice and recommendations, if so by who?
  - A desire to stay with the same clinic that had provided the NHS funded treatment;
  - The location of the clinic;
  - The success rates of the clinic;
  - Cost of the treatment;
  - Really liked the staff and/or the clinic
  - Wanted a particular doctor
  - Anything else?
- d) What information was provided to them about the service they would be receiving and paying for, for example, did it cover:

- The treatment plan and an explanation of the treatment required
  - A detailed breakdown of costs<sup>3</sup>
  - An explanation as to why treatment and costs might vary
  - Their likely chance of success
  - Payment details
  - Cancellations and refunds if treatment not completed for any reason
- e) How, when and who provided the above information?
- f) Whether they paid more than they anticipated at the start of their treatment and if so:
- When did they learn they would have to pay more, for example half way through treatment?
  - Why did they pay more, for example:
    - Were there additional costs for necessary treatments;
    - Were there additional costs for extra medications; or
    - Did they buy optional add-on treatments?
    - Did the fact that they paid more come as a surprise, or did they feel fully informed about costs?
- g) Whether they purchased ICSI and, if so:
- Was this because of a medical diagnosis;
  - If there was no medical diagnosis, why did they purchase it?
- h) If they bought an IVF package, whether any add-on treatments were included in the price of the IVF package;
- If so, what add-ons?
  - If not part of a package of treatment, did they separately purchase any 'add-ons', if so:
- i) What add-ons did they purchase?
- Why did they purchase them, for example, was this because:
    - They had read about them, wanted them and asked for them?
    - The clinic raised and recommended their use?
    - If raised by the clinic, when were they first told about any add-on treatments, for example, at the consultation or on the first day of treatment;
    - When, did they decide to buy the add-ons, i.e. at what point of their treatment, for example, the beginning or part way through
    - What information was given about any 'add-ons', when and how was this provided, for example, was this given only verbally or verbally and in writing.

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<sup>3</sup> HFEA advises fertility clinic users: "Make sure you get a fully costed treatment plan before committing to a clinic. This should include everything from your tests to your drugs."

<https://www.hfea.gov.uk/treatments/explore-all-treatments/costs-and-funding/>

- j) If the clinic did not advise add-on treatments but the patient requested them, which add-ons were these and did the clinic provide any advice for or against the add-on? Did the clinic provide the add-on?
- Whether anyone tried to secure a refund if treatment could not progress:
  - If not, why not?
  - If so, did they obtain a refund?
  - If so, how much was the refund, relative to what they had paid?
  - Whether they were surprised by the cost of medication;
  - Whether they purchased all their medication from the clinic providing the IVF treatment, if so why?
  - Whether, if given a choice, they would have purchased their medication from elsewhere.

### 3. Research Methodology and Sample

#### 3.1 Methodology

3.1.1 As the topic of this research was exploratory and it needed to help understand complex experiences, the methodology for this project was qualitative. Specifically, it involved paired interviews with consumers who had bought IVF treatment in the past 2 years and their partners.<sup>4</sup> Research interviews were 1 hour long and conducted either by telephone (21 interviews) or video conferencing platforms (29 interviews), depending on respondents' preferences.

3.1.2 The discussion approach was structured around a **patient journey**, exploring the different stages of their experience from: researching and choosing a clinic, through discussing and agreeing the treatment and costs before the treatment started, to further decisions while in treatment and final costs. The different stages explored in the interview are shown on the diagram below:

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<sup>4</sup> In a smaller number of cases, one of the partners preferred not to be interviewed about their experience of buying IVF treatment and in those cases we conducted single depth interviews.

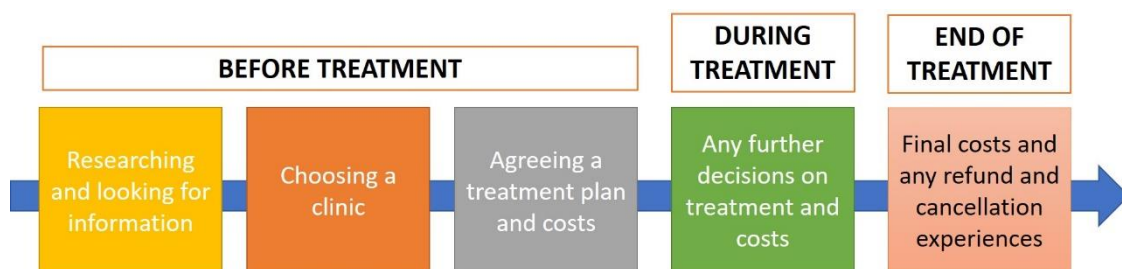


Diagram 1: 'Patient journey' stages explored in the interviews

3.1.3 Respondents were also asked to complete a brief pre-task ahead of their interviews. This involved answering a few questions and looking at cost-related information about their treatment they still may have to help them be more prepared for the interview.

## 3.2 Sample

3.2.1 All respondents bought IVF treatment in the past 2 years and were responsible for the decisions around choosing a clinic, their treatment and costs. Within this, most respondents have completed at least one full cycle of IVF treatment in that period, with only 2 having started their cycle but not having completed it at the time of the research. All had their IVF treatment carried out in the UK, with 2 participants who also had previous experience of IVF treatment outside of the UK (Czech Republic and Spain).

3.2.2 The sample was further devised to ensure the research could capture diverse experiences. An overview of the sample structure is provided below, followed by more detailed criteria.

Sample criteria		No of depth interviews
Age	Under 35	18
	35-37	13
	38-42	14
	43+	5
Type of clinic	NHS	9
	Private	41
Type of relationship	Mixed sex	39
	Same sex (female)	9
	Same sex (male)	1
	Not in relationship	1
Total		50

3.2.3 Furthermore, the sample split as follows based on additional criteria:

- **Previous experience of NHS-funded treatment:** 27 respondents previously had NHS-funded treatment (either at an NHS or private clinic) and 23 respondents did not;
- **Treatment outcomes:** 33 respondents had at least one successful treatment which resulted in live birth, whereas 17 respondents never had successful outcome;
- **Multi-cycle package:** 14 had bought a multi-cycle package (either directly from the clinic or from a third-party provider), 36 had not.
- **Surrogacy:** 4 respondents paid for IVF treatment involving surrogacy.
- **Ethnicity:** 43 respondents were White British or White Other, whereas 7 respondents were from Black and Asian ethnic minorities (BAME)
- **Socio-economic groups:** There were no quotas in this respect but the sample included a mix, as follows: 25 respondents were in occupations categorised as group B, 17 were C1, 4 C2 and 1 D.<sup>5</sup>
- **Location:** Participants came from across the UK: London (9), South East (6), East of England (4), South West (2), East Midlands (3), West Midlands (4), North West (8), Yorkshire and Humber (3), Scotland (5), Wales (2) and Northern Ireland (4).

3.2.4 Research was conducted between 4<sup>th</sup> May and 7<sup>th</sup> July 2020.

### 3.3 A note on methodology

3.3.1 Qualitative samples are purposive and quota-driven in nature; they are designed to achieve specific outcomes. Consequently, they have no quantitative accuracy in terms of identifying proportions of populations holding stated views.

3.3.2 For these methodological reasons, it is not appropriate to present qualitative findings in terms of the numbers of respondents expressing certain views. The

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<sup>5</sup> ABC1 and C2DE refer to particular social grades as defined by the classification developed by the British National Readership Survey (NRS) and widely used within market research since the 1960s. Social grade is a demographic classification system that allows classifying of households and its members based on the occupation of the Chief Income Earner. Groups A-E are defined as follows in terms of the occupations they include: A = High managerial, administrative or professional; B = Intermediate managerial, administrative or professional; C1 = Supervisory, clerical and junior managerial, administrative or professional; C2 = Skilled manual workers; D = Semi and unskilled manual workers; E = State pensioners, casual or lowest grade workers, unemployed with state benefits only. Note: Social grades of some respondents who used surrogacy were unknown as these respondents were recruited through stakeholder organisations and this information was not captured.

findings in this report are therefore described in qualitative terms. As a purely indicative guide: terms such as 'a small group' indicate a number in the region of 5-10 respondents; terms such as 'a very small group' indicate a number less than 5. 'A large group' refers to a group of 20+ respondents, whereas 'a very large group', 'most' or 'majority' indicate a significant proportion of respondents, i.e. over two thirds.



## 4. Main Findings

### 4.1 Researching IVF

4.1.1 Most respondents had actively sought out information prior to having self-funded IVF treatment. Typically, respondents looked to find out more about IVF treatments, as well as to scope out available clinics in terms of: their costs, success rates, travel time, opening hours and customer reviews. Common information sources for most respondents included:

- clinic websites;
- Google, e.g. for questions about treatments or costs;
- online forums, e.g. for customer comments about clinics;
- fertility support websites and charities for advice, e.g. Fertility Friends, Fertility Network;
- friends, acquaintances and family with recent experience of IVF services;
- calls to the clinic and clinic brochures sent by post.

*I did a lot of research. We researched [clinics] local to us. I looked at the cost of the treatments. There wasn't a lot between them. We looked at where we were on the train, and [one clinic] looked easier to get to. They also seemed to have better results, which is why we went there. [Mixed sex, 40+, Private, Yorkshire and Humber]*

4.1.2 Only a small number of participants used the HFEA website as a key information source. These respondents had identified the website as a source of information in a number of ways. Some of them came across the regulator through experience of IVF, either their own experience or their friends'. Others, who researched thoroughly and consulted independent sources, came across them on Google.

*I did look on HFEA website when starting my journey, and also to check the UK laws around surrogacy. I found it very helpful, especially regarding surrogacy. [Mixed sex, 40+, Private, London]*

*Initially, when I started out looking at IVF, I went on the HFEA website to research clinics. Other places I did seek advice from was Fertility Network, the charity. They obviously had a lot of information on their website. Also, on their forums [there was advice] from other men and women reporting their experiences and their situation and advice. [Single, 38-42, Private, London]*

- 4.1.3 Some participants also visited clinics to get a first-hand impression of the place and staff. Most from this group went to open evenings, whereas a smaller number also had free consultations or shorter meetings with other clinical and non-clinical staff, for example, a tour of the clinic. A few respondents also reported going to fertility fairs or events where they were able to speak to representatives of several clinics, which they found very useful.

*They had open evenings, and we went to an open evening at [a particular clinic] and found out more about the procedure of ICSI and IVF. [Mixed sex, 38-42, Private, North West]*

*We attended an exhibition day organised by [a particular clinic] in Harley Street. We wanted to get an idea of what our options were regarding IVF and to learn more about the laws concerning using donor sperm in the UK. We then attended a separate 'Future Families' exhibition which was held in a hotel in London. It was different to the previous exhibition where we only spoke to people from the Harley Street clinic – this exhibition invited multiple clinics and sperm banks, and we were able to visit the different stalls and understand their offering. [Same sex, 35-37, Private, London]*

- 4.1.4 While open evenings and shorter meetings were free, respondents paid for consultations. For this reason, only a very small number of respondents paid for consultations during their initial research phase. Once patients had paid for a consultation or other services, it was very rare for them to then decide to go elsewhere for treatment. The few who switched, did so where their impression of the clinic was very negative.

*We had a blood test there, but then decided not to go there. it felt like quite a cold place, felt like I was going to a business meeting; no chit chat or friendliness. [Same sex, 38-42, Private, London]*

- 4.1.5 Respondents typically researched three local clinics, but a small number were prepared to also look further afield. Those focusing on local clinics were largely concerned about the logistics of accessing treatment. For most of these respondents, local meant near home, but could also mean near work, especially for those commuting to work in London. Those considering clinics further away sometimes prioritised cost over location. In a couple of other cases, some respondents from Northern Ireland explained they considered clinics in England and Scotland to give themselves more choice.

*The clinic was quite accessible with work, we can get there within 10 minutes if there's no traffic. [Same sex, Under 35, Private, West Midlands]*

*We decided we would look outside of Northern Ireland. We went to other areas of Scotland that have got quite a high success rate. Some areas in England where you can fly into, and then stay with people we know. [Mixed sex, 38-42, Private, Northern Ireland]*

*It was a near clinic, we'd heard good things about it, so we thought well actually, yes, it was location really that clinched it for us. [Mixed sex, 38-42, Private, East of England]*

- 4.1.6 A smaller number of participants did not do much, if any research. Typically, these respondents' choice of a clinic was driven by one dominant factor, so they felt less need for research to help them decide. A few wanted to stay with the same clinic where they had their NHS-funded treatment before, particularly where the treatment had a successful outcome. Others in this group were driven by recommendations by friends or family or by wanting to be treated by a particular consultant, so hence chose the clinic where they worked.

*I think what drew us back to the [same hospital] was our success story with our little boy. We felt that, why are we trying to reinvent something? [Mixed sex, 43+, NHS, West Midlands]*

*I didn't really research it any further because I knew this consultant was one of the top fertility consultants, I knew the success rate was good [...] I just wanted to stick with him. That's why we went there. [Mixed sex, 38-42, Private, Northern Ireland]*

- 4.1.7 Finally, a few respondents felt they were tied to particular clinics for a period of time. For a couple, this was because they had a multi-cycle package arrangement with a particular clinic and thought they had to stay with them. For another few, it was because they had frozen embryos which were stored at the clinic they had previously used and which they did not want to transport.

*It was just fear... There were endless things I thought of – what if there's a crash on the M6? And then we looked at moving just three of the six [embryos]. [Mixed Sex, Not in relationship, Under 35, Private, West Midlands]*

*So, the reason I went back to them is because I was tied into a two-cycle package. [Subsequently] I actually left the clinic, and I'm in the process of starting with a new clinic. [Not in relationship, 38-42, Private, London]*

- 4.1.8 Overall, most respondents felt they had a choice of clinics, but the extent of this choice varied. While most reported that they had two or three geographically available clinics, there were some exceptions at both ends of the spectrum. At one end, respondents in London were conscious they had a very wide choice of clinics. At the other end, a respondent from Northern Ireland felt all the clinics employed the same doctors where they lived, so one had to travel further afield to get 'real' choice. Similarly, respondents who were interested in what they described as "medication-light IVF" treatment, sometimes felt their choice was limited and that they had to work harder to find suitable clinics.

## 4.2 Choosing a clinic

- 4.2.1 There were several key factors which influenced the choice of a clinic for most, with some variations in how these were prioritised. These four key factors were: location, cost, success rates and the impression about the clinic. In addition, a smaller group of respondents were influenced by some other factors in their choice of a clinic, such as recommendations from friends and other patients. For most participants, the process of choosing a clinic involved weighing key factors against each other to decide which of the clinics they considered scored best against most of their criteria.

### Location

- 4.2.2 Location of the clinic was a dominant factor for most, as respondents prioritised easy and practical access to the clinic, as they knew that treatment involved a large number of face-to-face appointments. Some explained how they wanted to minimise time off work or travel after medical appointments where they may feel uncomfortable. The travel distance from home most respondents found acceptable ranged from 30 minutes to an hour. The chosen clinic was, therefore, most commonly located in the nearest city.

*Because of the number of appointments, you don't want to travel too far. In our opinion it was a good clinic. If it was a poor clinic, we might have thought differently. [Mixed sex, Under 35, Private, Yorkshire]*

*This clinic was important geographically, it was close to work and easy to get to. [Same sex, Under 35, Private, Wales]*

- 4.2.3 In a few cases, location was de-prioritised where reducing the cost was more important or where respondents looked for greater choice than locally available. Respondents with budget constraints, therefore, sometimes looked further afield to find treatment options that were more affordable to them, even after including travel costs.

*We live in Scotland but travel down south because it's a third of the price. It was all to do with cost. [Mixed sex, Under 35, Private, Scotland]*

## **Cost**

- 4.2.4 Cost of the IVF treatment was an important factor for most, however, respondents varied in terms of how they weighed cost against other key factors i.e. for some cost was more of a priority than other factors, for others other factors were more of a priority than cost. Cost was a priority for a small group of respondents with considerable budget constraints. In some cases, respondents had saved up for IVF treatment over a long period of time or had to rely on credit cards to fund their treatment. Respondents in this situation would sometimes explain to the clinic that they only wanted a 'basic IVF', so no optional treatments.

*Nothing extra was included. As our parents paid for this, we were conscious of not adding to the price. [Mixed sex, 38-42, Private, South East]*

- 4.2.5 A number of respondents explained how they felt it was difficult to raise the topic of cost within the context of fertility treatment – when respondents felt that they should be demonstrating how much they wanted a baby:

*We then had four embryos. He made me feel a bit guilty for not wanting to freeze them. It was purely down to cost for that. [Mixed sex, Under 35, Private, Scotland]*

*The clinical director said that there is a medical trial going on with this drug and that she highly recommended it. So of course we said yes. I remember walking out and saying to [partner], 'I've got no idea how much that costs'. But when you are in your gown, you are about to go in, you don't say 'how much is that going to cost?' [Mixed sex, Under 35, Private, West Midlands]*

*It was on the injections until I was twelve weeks, which obviously they didn't foresee, because they should have stopped in the first, I think four weeks or something. But then they were like, no, you need to carry on for another three months sort of thing, so they were quite expensive. That was like a thousand pound extra, and we couldn't get them from the NHS until we got to twelve weeks and they hand you over to the NHS. So obviously you're still tied to the private until twelve weeks. So we had to buy that on top. Yeah, so that was a bit of a surprise, wasn't it? And you can't sort of say, well we can't afford it, we're not going to do that. [Mixed sex, Under 35 years old, Private, East of England]*

*You're so hopeful for success and you want to keep positive all the time, so any kind of conversation about it being overly expensive or out of reach is not a conversation you want to have. [Mixed sex, 40+ years old, Private, East Midlands] When I was there I said I don't want nasty shocks with money... If they think you've got a bottomless pit, or you can afford this, they might try it on, so I just said that to them anyway. Yeah, we want a baby, but, you know, don't take the mickey and screw us over. We're not that desperate. [Mixed sex, 36-39 years old, Private, North West]*

- 4.2.6 Cost was further a priority in particular circumstances. For example, it was particularly salient when moving from NHS-funded to paid-for treatment. Respondents who experienced this transition often explained how managing the cost of treatment added another layer of stress to their experience of IVF treatment. In addition, the importance of keeping cost down sometimes increased with the number of IVF treatments respondents had. A few respondents who had 5+ number of cycles switched to clinics abroad to manage the costs over a long period of time.

*The main driver was cost initially, plus reputation. It's significantly cheaper [abroad]. In the UK, an IVF cycle costs between £6-7k. In a Czech clinic it would be max £2k, including air fares and accommodation. [Mixed sex, 38-42, Private, South East]*

- 4.2.7 Those concerned about cost and the risk of needing several treatments sometimes chose multi-cycle packages. They appreciated the reassurance of knowing that they would pay a set price for a certain number of cycles. In some instances, third party packages also offered refunds if multiple cycles were unsuccessful. Respondents who bought such packages felt reassured that they would receive all or a significant portion of their money back if they were unsuccessful. All respondents who bought multi-cycle packages appreciated that they would pay more for a single cycle if they were successful on their first attempt and did not need the further cycles

purchased. However, they felt comfortable taking on this ‘gamble’ (as they perceived it).

*It’s a gamble. If you get pregnant on the first cycle, it’s more expensive. The third time you’re saving. It’s a gamble you have to take. That’s what we decided to do because it made sense to us. If we paid £11,000 and got pregnant, we wouldn’t care, because we got a baby. If we got pregnant on the third go, it would have saved us money in the long term. We’ve still got one more cycle to go, and if we don’t walk away with a baby, we’re walking away with 70% of our money back. [Mixed sex, Under 35, Private, Scotland]*

4.2.8 Cost was, however, much less of a priority to a small group of better-off respondents, who prioritised other factors in their decision-making. This group tended to be over 40 years old and included those with the largest number of failed treatments who were still seeking success. This included one respondent who reported they had never added up the total cost of their most recent treatment.

*We’re a bit in a fortunate position, so cost wasn’t really the most important thing. We weren’t looking for the cheapest. [Mixed sex, 43+, Private, South East]*

### Success rates

4.2.9 Like cost, success rates at particular clinics were an important factor to be weighed against others. Their importance in respondents’ decision-making tended to increase with the number of unsuccessful IVF cycles and age. Their importance was also heightened where respondents were advised to consider success rates by a health professional or friend who was experienced with IVF.

*I have a couple of friends who have had IVF. One of my friends has had a lot of IVF treatment, so I got their opinion;; she’d done a tonne of research, so I listened to her recommendations. My friend also pointed out I should be looking at the success rates. [Mixed sex, 35-37, Private, Northern Ireland]*

4.2.10 Across the sample, there were still significant variations in respondents’ attitudes in this respect. Respondents could be broadly grouped as follows in terms of how important success rates were to their choice of clinic:

- **Success rates were the most important factor:** This was a small group which included respondents with a high number of unsuccessful IVF treatments or who felt success rates became more important with older

age for patients. These respondents prioritized success rates over other factors.

*If I was going to do it one more time, this would be the last ever time. I'm 39 - it's not going to work much longer. I spotted there's a clinic in London. Obviously, that's going to come with its complications of having treatment there [as have to travel], but I just think, as a last one-off shot, it's got amazing success rates for my age range, much higher, so perhaps I would go there. [Mixed sex, 38-42, Private, North West]*

- **Success rates were very important:** About one quarter of respondents perceived success rates as one important factor among others. Typically, success rates would then be weighed against other factors, such as cost and location.

*All the clinics are a similar cost really. The cost is tied into the success rate of the clinic – the higher the success rate, the more likely you are to go with them, even if the cost is a bit higher. But there's not a great difference in prices – if you're spending £10k then you might as well spend £500 more if you think it's the best choice. [Mixed sex, Under 35, Private, East of England]*

- **Success rates were important but not a differentiating factor:** Another quarter of respondents thought success rates were important, but found they were similar for the clinics they considered. Consequently, these respondents did not think that success rates could be used to differentiate between different clinics. For some in this group, success rates were used to make sure they avoided any particularly under-performing clinics, rather than help them choose one.

*[I checked] their success rates, although they're pretty much of a muchness. I don't recall somebody saying we've got 90% and another saying 17%. The older you get the percentage drops quite dramatically. So, it was the cost involved in the treatment and the costs of travelling to and from. [Mixed sex, 38-42, Private, Northern Ireland]*

- **Other factors were more important:** Another quarter of respondents thought other factors were more important, e.g. costs, clinic approach etc. Some of these respondents also questioned the accuracy of clinic information on success rates, e.g. whether this was checked by anyone.

*Who checks these success rates? Is there a governing body that is checking them? That's really important because they could be saying*



*anything to entice people in. [Mixed sex, 40+ years old, Private, South East]*

Others thought that everyone was different, so generic statistics seemed less relevant to them.

*Everyone's different, aren't they? Everybody's different, every – I imagine every sperm and every egg is different, so you can't really group a bunch of random people throughout the country together, and say because of them – theirs worked, so yours must work. It's all different. [Mixed sex, 35-37, Private, North West]*

- **Respondents avoided looking at success rates:** One respondent consciously did not want to look at success rates as they worried this might give them 'false hope' of success.

*That's not something I tend to look at because it gives you false hope. That's information I wouldn't want to see. [Mixed sex, 35-37, Private, South West]*

4.2.11 Typically, most who considered success rates looked at this information on the clinics' websites and a small number also looked at the HFEA website. The few respondents who used the HFEA website sometimes learned about it from others with professional or extensive personal experience of IVF, for example, a relative who was a medical professional or a friend who had multiple cycles. Some of these respondents also tended to be more critical in their scrutiny of success rates, noting the complexity of the statistics involved and questioning the accuracy of some information.

*I haven't actually come across them [HFEA], although now I'm aware of them, that's good to know. You're basing [it] on the clinics telling you the truth. [Mixed sex, 38-42, Private, Northern Ireland]*

*It's much more standardised [on the HFEA website]. They tend to maybe not have the detail that the clinics would have on their web page. If you were trying to compare like for like, it was much easier to do on the HFEA website. [Not in a relationship, 38-42, Private, London]*

4.2.12 Participants varied in how easy or difficult they found success rates to understand. Most respondents felt they were able to compare success rates across different clinics and understood there were different success rates based on age and type of treatment. Some in this group felt it took them a while to understand all the different variables, but that they were fine once they got used to them.

*Initially, I wasn't sure what I was looking at, because I think some clinics measure success rate in terms of embryos [im]planted, and some do it on birth rates. I tried to work out whether I was comparing an apple with an apple to make sure I was comparing like with like. I also had to look at success rates for age, as well. You had to read through a lot of small print to work that out, but I managed eventually. [Mixed sex, 35-37, Private, Northern Ireland]*

*Very easy. It went against the age of the female, against the treatment that she was getting, so if it was the standard IVF treatment and she was aged between 30-45, you knew what success rates that category of group was having. It was very simple to understand, and very simply communicated to you, for that information to come through. [Mixed sex, 38-42, Private, West Midlands]*

- 4.2.13 A small group of respondents stressed the difficulties in comparing success rates for different clinics due to variations in how success rates were reported. One respondent also reported they could not find live birth success rates for two clinics.

*They all structure it slightly differently. It might have been the age ranges were slightly different, but it was quite clear that we weren't necessarily comparing apples to apples. [Mixed sex, 38-42, Private, East of England]*

*[For that clinic] It's quite difficult to understand because we were looking at them last night and we still don't really understand them. They have the success rate of live births, if they've got 39% success rate on pregnancy & 41% on live births, is that 41% of the 39% pregnancies or is it of the whole cycle in which case it makes no sense as how can you have a higher % of live births than pregnancies? [Same sex, Under 35, Private, London]*

- 4.2.14 Many objected to clinics presenting success rates based on pregnancies, as respondents were only interested in those based on live births.

*They gave two [success rates statistics], one was pregnancy, and one was live births. We ended up getting pregnant last year only to have a miscarriage. For the clinic though, that was considered a success in terms of treatment. It wasn't a success for me though. [Same sex, 35-37, Private, South East]*

### **Positive impression of staff**

- 4.2.15 Respondents' initial impression about staff and the clinic was an

important factor for most, when choosing a clinic. Many felt that having friendly and supportive staff, a personalised approach and good communications was critical, considering they were going through a potentially stressful experience. In some instances, this was so important that a negative initial impression about the clinic atmosphere – for example, the clinic seeming cold and impersonal when they visited it – was the main reason for not choosing it.

*I wanted a kind, supportive clinic with very good communication to support us through the process. [Mixed sex, 38-42, Private, London]*

4.2.16 This factor was particularly important for a small group, who had additional reasons for needing support. For example, a respondent who was single at the time of her IVF treatment felt that having supportive staff was even more important in that situation. This group also included a few respondents with prior negative experiences with another clinic, who did not want a repeat of that.

*It was really important to me – getting a sense of how they treat the patients, particularly as I'm a single person doing it. How they perceived that and how they supported people with that was very important. It goes back to your instincts as a person, if something is right for you in that environment as well. I would say there was one clinic that I didn't get a good sense for. [Not in relationship, 38-42, Private, London]*

### **Other factors**

4.2.17 Additionally, there were some other factors that influenced smaller numbers of participants:

- **Recommendation of family, friends or forums:** While many respondents considered other patients' experiences of particular clinics, a few chose their clinic solely or mainly on these grounds. For example, a couple in the North West chose a clinic because their cousin recommended it and had a successful IVF treatment there. Because they decided on this basis, they did not research other clinics available to them.

*I used the fertility forums where you chat to people going through the same thing and the clinic we chose was so highly recommended by so many people. [Mixed sex, Under 35, Private East of England]*

- **Wanting particular consultants or specialists:** A very small number of respondents chose their clinic on this basis. For example, a respondent in Northern Ireland explained how they developed a good relationship with an NHS consultant while undergoing investigations for their fertility problems. Once the respondent decided to buy IVF treatment, they knew they wanted to go use the private clinic where the same consultant also worked. In another example, a respondent chose a clinic because they had specialists for endometriosis which the respondent suffered from.

*I did previously attempt the NHS clinic, but I wasn't eligible for treatment there. So, I met my consultant there, who also worked at a private clinic and developed a bit of a relationship with him. That's why I went to the private clinic. [Mixed sex, 38-42, Private, Northern Ireland]*

- **Looking for medication-light cycles:** Respondents interested in what they described as “medication-light” IVF treatment specifically looked for the clinics providing this and then chose their clinic from this smaller pool.

*We just liked the fact that they were using less drugs. [Mixed sex, 43+, Private, South East]*

- **Looking for particular add-ons:** A respondent who was frustrated that the NHS clinic they were using would not give them the add-on treatments they requested, saying that they were of no benefit. They subsequently moved to a private clinic to be able to have this treatment.

*If you want additional treatments, especially through the private sector, it is really plain and simple for you to actually look at it and find that information. The NHS on the other hand, they very rarely offer you any additional services, because I think, in my opinion, there's a lot of red tape around certain things, and they don't necessarily believe in certain treatments to support your full cycle. [Mixed sex, 38-42, Private, West Midlands]*

- **Staying with the clinic where they had their previous free NHS treatment:** Some respondents who had NHS-funded treatment and were satisfied with their experience decided to stay with the same clinic once they had to pay for their treatment, and did little or no research into other clinic choices.

*I think what drew us back to the [NHS clinic] was our success story with our little boy. We felt that, why are we trying to reinvent something? If*

*it worked there, we felt comfortable. The same nurses were still there, so it made sense to us to stick with it really and ignore the fact that materialistically it didn't look as clinical or modern. From doing our own research, we established that they had the best doctors and gynaecologists, so we felt quite comfortable with that. [Mixed sex, 43+, NHS, West Midlands]*

- **Feeling 'locked-in' with a particular clinic:** A few respondents, which included a small number who would have otherwise considered moving, stayed at a particular clinic because they had a multi-cycle package with them or frozen embryos which they did not want to 'disturb' by transporting them.

*The whole reason we were doing it at that clinic was not to move the embryos. [Same sex, Under 35, Private, London]*

4.2.18 Respondents who were paying for their IVF treatment and decided to change clinics did so for one or more of the following reasons:

- Negative experience at the previous clinic, for example, poor communications;
- Unsuccessful IVF treatments, so wanting to try a different clinic;
- Wanting to try a different approach to IVF treatment, for example, medication-light IVF;
- Wanting to switch from an NHS clinic to a private clinic to avoid waiting times or have a more personalised experience of treatment.

*Communication was such a big problem with the first clinic. They gave very short notice for scans etc. which meant we ended up spending thousands of pounds on train tickets as we had to book last minute. I remember crying at work because we hadn't heard from them. [Mixed sex, Under 35, Private, East of England]*

*We just felt going private would be quicker than waiting for appointments with the NHS. [Mixed sex, 38-42, Private, South East]*

### 4.3 Treatment and cost decisions before the treatment started

4.3.1 The research explored various elements of information provided to the patient and decision-making around the patient's treatment plan prior to the treatment starting. The section below details findings in this respect across a

number of areas, including: information about treatments and costs (and specifically costed treatment plans), potential providers of particular treatments, add-on and complementary treatments, payment details and cancellation and refunds policy.

### Explaining treatment

- 4.3.2 On the whole, respondents across the sample felt they were told what treatments they would have and when, before the treatment started. Most reported how they received a protocol listing all the elements of the treatment by date. In addition, many reported their clinics provided a rationale and explained why they advised them to have particular treatments.

*We went along saying we wanted to do IVF and they explained the different routes and extra costs. They said that if the sperm test came back and was not what they were looking for they would recommend ICSI because the sperm wouldn't travel as fast to the egg, so then that would be the recommendation for a higher success rate. They said that if my ovaries over-stimulated, we would maybe have to go down the frozen transfer route. We were explained the different scenarios where we would maybe have to go off track from the plan we had gone with. [Mixed sex, Under 35, Private, Scotland]*

- 4.3.3 Within this overall experience, there were some exceptions. A very small group felt that there was little discussion about the rationale for treatment, or some uncertainties over the treatments they might need. For example, a couple of respondents who paid for IVF treatment at NHS clinics felt their approach was paternalistic and not personalised. These respondents reported how they were just told which treatments they needed to have, without much discussion of different options available to them and rationale for them. A few other respondents highlighted uncertainty over whether they would need additional treatments at some point in the process (e.g. additional scans and medication). The uncertainty arose because these respondents were told that additional treatments may be used if needed, but they did not know at the outset whether they would need them or in what circumstances they might be needed.

*I made an appointment to see a consultant. In that consultation, I really expected some more information to tell me about options. But really, they just have a way it works and then say, "When do you want to do it? Now? Next month? The following month?" Then they give you a leaflet with that information [on the protocol you need to follow] and another leaflet with a breakdown of costs for each of the things. [...] They don't tell you, here are the options, this and that, it's just the way*

*it's done. [...] For example, nobody told me I had this option [of natural IVF for a frozen transfer] at all, but I asked for it because I knew about it. [Mixed sex, 38-42, NHS, South East]*

- 4.3.4 Many respondents also reported they were told about potential risks involved. However, the risks respondents recalled being discussed mainly concerned those associated with medication, for example, over-stimulation. Most did not recall other risks being discussed with them, for example, risks associated with particular tests or add-on treatments.

*They do tell you about the drugs, what it does, why they use it, how one counteracts the other. Like any medication, there are risks. [Mixed sex, 43+, Private, Yorkshire]*

- 4.3.5 Many respondents further reported that success rates of IVF treatment were generally discussed in generic rather than personalised terms. Most commonly, respondents explained that the clinics went through the general statistics on success rates for particular treatments and age groups, as relevant to them. There were some exceptions to this where respondents reported that more personalised chances of success were discussed, although the specific basis for these individual discussions (e.g. test results, scans, age and previous history of IVF and any specific fertility issues) remains unclear.

*No, they didn't. I suppose they didn't want to commit to that. They probably couldn't give an answer on that. [Mixed sex, Under 35, Private, Yorkshire]*

*The consultant did take us through each stage with his predictions, as well as averages and facts. [Mixed sex, Under 35, NHS, North West]*

- 4.3.6 Just under a quarter of respondents had ICSI during their IVF treatment. They reported different reasons for having this treatment. While some of them were told this was for medical reasons such as low sperm count, others explained ICSI was advised due to previous unsuccessful IVF cycles in the hope that it may increase their chances of success.

*There was no medical reason for it, but we thought it might give us a better success rate, because we had had an unsuccessful treatment previously. [Mixed sex, 38-42, Private, Northern Ireland]*

*I normally only had a low number of embryos retrieved, so it was to ensure the best rates of fertilisation. My partner also had lower sperm quality, so it helped with that as well. After that, I always asked for ICSI. [Mixed sex, 38-42, Private, London]*

### **'Costed treatment plan'**

- 4.3.7 HFEA advise fertility clinic users: *"Make sure you get a fully costed treatment plan before committing to a clinic. This should include everything from your tests to your drugs."*<sup>6</sup> The findings around the ways in which treatment costs were provided suggest that there is considerable variation across the sector. The findings suggest that most clinics provided respondents with upfront treatment costs. However, the information provided varied in terms of clarity and level of detail, and certain aspects of treatment costs were less clear than others at the start of the process. In addition, a small number of respondents reported that they did not know the cost of their treatment before it started.
- 4.3.8 Respondents' recall of what cost information they received, when and how, was highly variable. However, most respondents claimed that they received a document providing information about their treatment costs prior to the treatment starting, even if the clarity of these documents and the level of detail provided was perceived to vary. When discussing the cost information they received, many respondents were not familiar with the term or idea of a 'costed treatment plan'. Instead, respondents tended to use other terms and talk about documents such as their treatment protocol, clinic price lists and invoices.

*After consultation, we had the treatment plan details emailed to us, as well as being given a hard copy plan to take away. It included a breakdown of what was involved, complete with costs. [Mixed sex, 38-42, Private, London]*

- 4.3.9 The treatment and cost information were mainly sent shortly after the initial consultation and by email. There were, however, also other ways in which this information was shared with some respondents, including: by post; through an online account; by circling treatments and costs on a generic price list; and providing a printed or handwritten list of treatments and costs after the consultation at the clinic.

*Every single cycle I've had, I've always been given a treatment plan. I've got a few paper ones in front of me. The more recent ones are on the portal online. That would always tell me what I'd be doing at what time, what drugs I'd be taking and the amount of drugs. [...] It does have the costs in there. You'd have the process, a little about the cost, a little bit about what might happen, potential risks, what would happen*

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<sup>6</sup> <https://www.hfea.gov.uk/treatments/explore-all-treatments/costs-and-funding/>



*if we have to cancel and at what stage. [Mixed sex, 38-42, Private, North West]*

4.3.10 There were also further variations in how the treatment cost information was provided.

- Firstly, most respondents who bought single cycles received itemised costs, but those who bought multi-cycle packages had a total price and a list of items included.
- Secondly, most respondents were provided with a personalised price breakdown, but a small group were given generic price lists. Participants given generic price lists then tried to add up the costs, but only two of them managed to do so as they asked clinic staff to circle their treatments.
- Thirdly, some respondents had all the costs listed in the same document, whereas others had their costs split across 2 or more documents, for example, IVF treatment package costs, medication costs and initial consultation and tests costs.

Typically, respondents who were given generic price lists and some whose costs were split across different documents felt they had to work harder or struggled to understand the total costs.

*We went to an appointment and were given a pack which broke down the price list. On that price list, they kind of made reference to the areas that would be relevant to us as a couple. The drugs that would be required, dependent on the type of treatment we were having. We'd confirmed we were having the IVF, so then they went through on this yellow piece of paper a list of the drugs treatments and then the prices next to it. Then there would be a total bit at the bottom. [Mixed sex, 43+, Private, West Midlands]*

4.3.11 Those who bought a single cycle of IVF treatment reported two different approaches to paying for their treatment. A large group reported that the cost of medication prescribed at the start of the treatment was included in the price that they paid the clinic at the start of the process:

*It covered medication from the start of the process, through to the first confirmation scan of pregnancy. [Mixed sex, 36-69 years old, Private, North West]*

*The option direct from the clinic included everything for one try, whereas the Access Fertility options did not include everything, there were charges on top of that for different medications and stuff. So, the packages weren't as clear cut as they indicated. We only were looking to have one more go anyway, so it was just lining up which was the most financially viable for what we wanted to do, and the clinic had a better package on offer. The only thing we'd have to spend over the amount would be the donor sperm and the storage of that. [Same sex, 36-39 years old, Private, London]*

- Another large group reported that the price they paid the clinic at the start of the process did not include any medication costs. These were paid to a drugs company the clinic was working with at the beginning of the process:

*No, the cost didn't include meds. They are quite open about that, they do say it doesn't include medicine. [Mixed sex, 36-69, Private, North West]*

- 4.3.12 Those who bought multi cycle packages reported that that medication costs were always separate when buying multi-cycle packages from clinics or third party finance providers.

*For the 3 cycles it was around £6,400, something like that, and then there was obviously the cost of the drugs. The reason they don't make that fixed is that they don't really know what's going to be needed. [Mixed sex, 40+ years old, Private, South East]*

- 4.3.13 The research also highlighted some differences in how clear the costs of particular aspects of the IVF treatment were to respondents. While most respondents were clear on the cost of the initial consultation, tests, egg retrieval and embryo transfer, many were less sure what the medication cost would be. Whilst respondents were told that medication cost could vary depending on their response to the treatment, a large group stressed they were not clear by how much this cost could vary for them personally. A few who were given a range for medication costs, still felt this range was too wide and not personalised enough.

*For drugs, you can pay from £300 to £2,000. That wasn't really made clear to me. [Mixed sex, 35-39, Private, North West]*

- 4.3.14 There were several cases where respondents had been unaware that pregnancy tests and drugs were going to be additional costs:

*The only medication it doesn't include was when we had a positive [pregnancy] test. There were progesterone suppositories I had to use from the transfer through to the test, and because I had a positive test, I had to keep taking them. They said they would send me the medication up. That then cost me £100 because it was a very expensive medication. That was the only extra cost that I didn't agree with, because I thought the medication should all be covered regardless of whether you have a positive test. I asked them about it, and they said they charged me for it because it's extra medication. It's quite unclear, to be honest. [Mixed sex, Under 35, Private, Scotland]*

*I was shocked at [a particular clinic] that they charged me for my pregnancy scan. I thought that would be included. And my pregnancy blood test. [Mixed sex, Under 35, Private, South East]*

*The only cost that we didn't know about was for the two blood tests. When I got pregnant, they were checking that my levels were going up and we agreed to the two optional tests. We didn't realise there was an extra cost, about £45 per test. I think they just forgot to say, but I was pregnant at that point, so we didn't care as it was a relatively small amount. [Same sex, 38-42, Private, South East]*

4.3.15 Research also highlighted certain other practices that made it difficult for patients to decide whether they needed a particular treatment and, hence, whether they should incur that cost:

- **Separating clinical from financial information and discussions:** A few respondents reported how consultants would not discuss costs of treatments they suggested and signposted them to a finance person for that. The finance person, on the other hand, could then only provide the information on costs of particular treatments but not answer any further medical questions respondents had. Respondents felt that they needed to have both clinical and financial information at the same time in order to make decisions about whether to buy certain treatments.

*I would like a full breakdown of how my money is being spent. I think that would be quite nice to have. Better communication. You don't want to go through three different people to pay your bill. The doctor will say I don't know the price, speak to the nurse. The nurse will then say, I don't know the price, speak to the admin. If you can have that admin person with your doctor at the consultation so you can discuss in the one room and you're not waiting around and being carted from person to person, that would be quite nice. [Mixed sex, Under 35, Private, South East]*

- **Failing to provide costs of ad hoc items when these needed to be administered promptly:** A few respondents reported how they had tests or scans after the treatment had started, without knowing their cost before having them. Typically, this situation was prompted by treatment or a test being needed quickly e.g. because of something shown in a previous test and scan results or how they responded to the treatment. In one other case, a respondent was told they needed a womb surgery in the middle of their treatment, which the respondent had without knowing the cost.

*The only bad experience I had with add-ons was at [a previous clinic I used]. There was a particular non-standard blood test that they suggested: something to do with fragmentation, to see if something was incompatible between me and my partner. The clinic asked if we wanted to do it and then sent someone in to draw blood straight after the consultation. It ended up being £250 each, which was a huge add-on we hadn't anticipated. We should have been told the cost beforehand. They also could have suggested that we tried another lab, in case we wanted the test done independently. [...] They were a great clinic and their doctors were brilliant, but the only other bad experience I had was when they picked up on adhesions in my uterus. They then did surgery, but again they didn't give me a quote. It was £2,300. [Mixed sex, 38-42, Private, London]*

4.3.16 Finally, there were a small number of respondents who explained that they were aware that they had not known the cost of their treatment before it started. Their experience differs from most, who recalled being given information about price that enabled them to formulate a reasonable idea of how much they would be expected to pay. Examples of such experiences where respondents lacked this cost information included:

- A few participants who were provided with generic price lists and then had to add up and work out the total treatment cost on the basis of their consultation, but struggled to do so;

*So they have a pricelist on their website and it's also up on the wall in the clinic, in the reception area, but obviously it's listing every individual thing, and you just don't really know how many of those things you're going to need, how much it's going to cost. They might be changing the dose of your medication on a daily basis. So, it's pretty much impossible to know. At the initial consultation, they give you a sort of rough idea of what the approach is going to be and I think they give you some sort of suggested figure, but you know, it could be an awful lot more than that, basically. [Mixed sex, 38-42, Private, London]*

- A small number of cases where clinic had a particularly iterative approach to treatment so all treatment decisions and costs evolved throughout the process. Satisfaction with this iterative approach depended on the extent to which it had been clear from the outset:

*I think they say that, on average, patients are likely to spend X on this part of the treatment, but be aware that there could be additional costs, depending on what is advised medically. That's part and parcel or what you buy into. [Mixed sex, 40+ years old, Private, London]*

*It was probably naïve on our part, but you felt like you couldn't ask [about cost], because you didn't know [what to ask]. Because everyone is different it's probably hard for them to say what it's going to cost, if they don't know what additional costs are going to pop up. [Same sex, Under 35 years old, Private, West Midlands]*

- A few cases where participants were clear on some main costs (e.g. frozen embryo transfer), but not on certain other costs (e.g. tests, scans, storage).

*I knew what that £1,650 was including. One scan, the transfer, the defrosting of the embryo. We discussed at that initial consultation that I might need a blood test to check my progesterone levels beforehand, but that price was never mentioned. You just pay it. [Mixed sex, Under 35, Private, London]*

4.3.17 In these cases, respondents reported that they found out about costs via the invoices they received had consultations, treatments or tests;

*It was very awkward. All of a sudden, we'd be phoned up to make the payment, so they could phone the surrogate. We'd already paid the clinic £13,000, and for them to phone me a minute before they were going to phone the surrogate was unprofessional. There was no structure. I said I'd rather pay whatever I had to pay in advance, because it's embarrassing. [Same sex, 38-42, Private Scotland]*  
*Costing isn't discussed. I wait for an invoice. I look on the website before, so I have a rough idea. [Same sex, Under 35, Private, London]*

*I remember coming out of the egg collection when she was drowsy and having to pay the balance – a couple of thousand pounds – when I'm thinking 'I've got to get her home'... It was all very much, we've done this today, so you've got to pay this now. [Same sex, Under 35, Private, West Midlands]*

## Treatment and cost variations

4.3.18 The findings suggest that patients would benefit from clearer and more personalised information on both which treatment costs can vary and when in the process, as well as a more personalised estimate by how much their treatment costs can vary.

4.3.19 Most respondents claimed that their clinic explained that the treatment costs could vary, particularly for medication. However, some participants reported that they were unaware of the extent to which the cost of medication can vary. These participants reported that they either had no information on how much medication costs could vary or they were given a very wide range, for example, £500-£2500.

*That [medication cost] bracket is 'I'm a 38-year old woman with X AMH and therefore we recommend you would have higher medications. If you're a 24-year old young woman with good AMH, you may only need a really small level of stimulation, therefore your drugs would be £500'. They never said to me that my drugs would be £2,500+. The bracket wasn't an individualised bracket. [Not in relationship, 38-42, Private, London]*

*One drug bill could come to £50 and one come to £600 and you never knew which way. [Mixed sex, Under 35, Private, West Midlands]*

4.3.20 There was also less awareness that non-drug treatments can vary or investigations. Respondents were, therefore, less aware that they may need to pay for additional tests or scans, so this came as a surprise to a small number of respondents.

## Medication, test and scan providers

4.3.21 Most respondents in this sample were not told by their clinic whether they had the option to buy medication from elsewhere. A small number who knew about this possibility typically learnt about this from family and friends and only in a couple of cases from the clinic nurse. Most of these respondents decided to use this option and buy their medication elsewhere, as a way of reducing the costs. While there were some variations in where they bought their medication, Asda was frequently used because of being cheaper.

*We didn't buy the drugs from there. We asked them for a prescription rather than paying them for the drugs, because we looked into that and Asda pharmacy was a lot cheaper. My mum works for Asda and when we told her we were going to do IVF, that's when she told us about it. [Mixed sex, 43+, NHS, West Midlands]*

4.3.22 Some of these respondents also objected to how their clinics reacted to their wish to buy medication elsewhere. For example, a Northern Irish respondent reported how the Scottish clinic they used was not supportive about this decision and also charged them for prescriptions.

*They just told me I could get it from them and it would get delivered to the house and you inject yourself. It was my friend that told me, actually you should be able to get it from any pharmacy and it will be cheaper. A lot cheaper. I asked them about that, and they said, "No, we don't normally do that." I said it was possible and they wanted to charge us for the prescription. So, I thought it would be easier just to get the drugs from them rather than giving myself another job. I think you should be able to get your drugs from anywhere because the mark-up they add just adds an unnecessary cost to an expensive procedure. [Mixed sex, 35-37, Private, Northern Ireland]*

4.3.23 Similarly, only a few respondents reported how the clinics informed them they do certain tests and scans at the NHS and reduce their costs in this way. The respondents who knew this took this opportunity and appreciated being given this choice. Other respondents were unaware of this option.

*The consultant mentioned a number of tests we had to get done - bloods, SDI tests etc – and advised we could get a number of them done via the NHS for free. So, when we went to the finance person, he highlighted which ones we could get via the NHS, and also the ones that weren't usually offered by the NHS, or where there's a long waiting period. We were really happy with that as we could see the costs mounting up. [Same sex, 35-37, Private, London]*

## Add-on treatments

4.3.24 Most participants who bought add-on treatments reported that these were purchased as optional extras, rather than automatically included as part of a package. The exceptions to this pattern mostly included third party finance provider packages which often included certain add-on treatments, such as embryo glue, endometrial scratch and time-lapse imaging. In a couple of other cases, respondents explained how their clinics included endometrial scratch or embryo glue as part of their 'standard approach'.

*The add-ons get complicated because of the research involved. You're left wondering whether to try it or not. The evidence doesn't always stack up, but you're willing to try anything if you think it would make a significant difference. A good thing about the [third party finance provider multi-cycle] packages is that they bundle a lot of that in, so it takes the decision away from you. [Mixed sex, 43+, Private, East Midlands]*

*At the [private clinic name] they have as standard a hysteroscopy before your IVF cycle, and that includes the endometrial scratch. But it's not only for the purpose of the endometrial scratch, it's also so they're checking that there's nothing else in your womb, they look inside the womb to check that there's anything they need to be concerned about. [Mixed sex, 43+, Private, London]*

4.3.25 A large group bought some form of add-on treatment as part of their most recent or past paid for IVF treatments. The most frequently bought add-on treatments were embryo glue and endometrial scratching which many of these participants bought, followed by time-lapse imaging. A very small number of participants also bought some other add-on treatments, such as IMSI, immunology treatment, PGD and ACGH testing, elective freeze, ERA test and lipids drip.

*Before the fourth cycle, we decided we wanted to have additional services, like the embryo glue which helps the embryo attach to the lining better, in theory, there's some science behind that. There's also another thing called the scratch, which is supposed to scratch part of the lining. Then when the embryo is transferred back to you, it attaches itself to that place where it's re-growing. It's supposed to make it better. It could be the placebo effect, but we bought it all and paid for it all. As far as I'm concerned, it worked for me, because I have the living proof of it. [Mixed sex, 38-42, Private, West Midlands]*

4.3.26 All add-on treatments were bought from private clinics and most were



provided by the same clinics where participants had their IVF treatments. An exception were two respondents who bought endometrial scratching at a private clinic separately while they were having free IVF treatment at NHS clinics. In all but one case, patients who used NHS clinics reported that these clinics did not provide add-on treatments as part of either free or paid for IVF cycles.

*I read a lot about the add-on options – but we were never offered them and they were never discussed as options available. On the paperwork, there was an option for scratching at an add-on price but not the glue, although no one discussed it with us. I'd done my research, but I didn't think it was something that I needed or wanted.*

*[Mixed sex, 36-39, NHS, West Midlands]*

4.3.27 Most respondents had heard of at least a couple of add-on treatments. There was variation in how they had learned about them. Most respondents learned about these treatments from private clinic websites (before engaging with the clinic) or from clinic brochures, price lists shared with them during consultations or from consultants (after engaging with the clinic). A smaller group of respondents read or heard about these treatments independently from the clinic they used. These respondents explained how they heard positive comments about particular add-on treatments from friends and family who used them or other patients who discussed them on fertility forums.

*I'd already done research around different things. After four years, I was pretty clued up on everything. So, I knew what I wanted, what I thought we should have. I went in and said I would like a scratch. I think I asked if they thought it'll make any difference. To be fair, they never tried to push anything on us, and I'd already made my mind up that I was going to have it anyway. [Mixed sex, Under 35, Private, North West]*

4.3.28 There were a few respondents who were not aware of any add-on treatments. This group mainly consisted of respondents who had paid for IVF treatment at NHS clinics who did not offer add-on treatments, but not exclusively.

4.3.29 There was further variation in whether add-on treatments were discussed with the clinics or not, what the clinic advised and whether participants decided to buy add-on treatments or not:

- **Variation in whether add-on treatments were discussed with clinics or not:** Not all those whose clinics listed add-on treatments on websites or in

brochures proceeded to discuss these treatments with their consultant. Some reported that although clinic materials had made them aware of these treatments, the topic was not raised either by themselves or by the clinic. That said, a large group did discuss these treatments with their consultants. These discussions were often initiated by respondents who asked to find out more about particular treatments, but sometimes also by the clinic staff. A small group of those who already thought they already knew what these treatments involved from other patients reported they asked for these treatments to be included in their treatment plan.

*The ERA test and Intralipids were suggested by the clinic when we asked about different things that could be done. ERA is a fairly new test. Intralipids I never really understood, but the ERA test and scratch made sense to me. The clinic didn't strongly recommend anything, they weren't forceful, we asked about what we could do to help. If anything, the clinic could be a bit more prepared to recommend things as they know it's not that clear. The discussion was more from our side as time and finances were running out. [Mixed sex, 38-42, Private, South East]*

*I read a lot about the add-on options – we were never offered them and they were never discussed as options available. On the paperwork, there was an option for scratching at an add-on price but not the glue, although no one discussed it with us. I'd done my research, but I didn't think it was something that I needed or wanted, and as it wasn't circled that was fine. [Mixed sex, Under 35, NHS, North West]*

- **Variation in whether add-on treatments were advised by the clinic or not:** respondents reported that, with one exception, all the NHS clinics they had used did not offer add-on treatments and explained there was no or little evidence for their effectiveness. There was variation in how private clinics advised patients who asked about add-on treatments. In some instances, participants reported that consultants had explained that certain add-on treatments could help increase their chances of success; in other instances, they reported that consultants had explained there was no evidence that these treatments did increase chances of success. Respondents did not recall that the risks of particular add-on treatments were discussed with them.

*They said it helps it stick more. I remember them saying we put it in a bath with glue and it can help it stick. Just in a little petri dish of glue. You think, I've spent £9,000-10,000 at this point, what's another £200-300? So, you say, just do it. [Same sex, Under 35, Private, West Midlands]*

*No add-ons were recommended to me personally. I was initially given a list of all the extra costs, but they weren't included within my recommended treatment plan. [Not in relationship, 38-42, Private, South East]*

*They didn't mention it. We just asked if we could add it on. I think it's because extras like that aren't guaranteed and I don't think there's enough research into them for the clinic to push it. It's just another option [Mixed sex, 35-39 years old, Private, North West]*

- Research suggests that information about the clinical evidence about the effectiveness of add-on treatments is not consistently provided by the private fertility clinics in the UK. In addition, only one respondent recalled being signposted to the HFEA website to review information about add-on treatments, whereas a few others were signposted to sources of information but they could not recall what these were.
- **Variation in whether add-on treatments were bought or not:** Participants' response to information and advice they received from their clinics also varied. In some instances, patients followed their consultants' advice and either bought or didn't buy particular add-on treatments, as advised. In other instances, patients disregarded their consultants' advice. Some were determined to use particular add-on treatments, especially where they came to the clinic already minded to buy certain add-ons. For these respondents, the wish to use certain add-ons did not change, even where the consultant informed them there was no evidence for their effectiveness. In other cases, patients decided not to buy add-on treatments which they perceived to be unnecessary costs, even when offered by clinic staff.

4.3.30 There were some consistent themes in how respondents who bought add-on treatments explained their decision. In some instances, these respondents have had multiple unsuccessful IVF treatments, so they wanted to keep trying different approaches in the hope that one of them may work. As they reported, sometimes clinics also had a similar approach to test and try different methods in subsequent cycles, where the respondent had had unsuccessful outcomes previously.

*At the time, when we were going through NHS, I didn't really know a lot about embryo glue, so at the time it didn't seem important. Then, when we had two failed attempts through the NHS, that was like my*

*goal. I wasn't settling for anything unless it included embryo glue.*

[Mixed sex, Under 35, Private, Wales]

*I talked to the clinic, got the pamphlet, and talked to a friend. I also researched it on Google.....Does it actually make a difference? Does it hurt? My reasoning in the end was 'anything that might help to make it happen'. The clinic said the research is not definitive, but that it can help. [Mixed sex, 36-39 years old, Private, London)*

*I talked to the clinic, got the pamphlet, and talked to a friend. I also researched it on Google.....Does it actually make a difference? Does it hurt? My reasoning in the end was 'anything that might help to make it happen'. The clinic said the research is not definitive, but that it can help. [Mixed sex, 36-39 years old, Private, London)*

4.3.31 A small group amongst those who bought add-on treatments felt that a lack of clinical evidence supporting their effectiveness did not mean that they were ineffective, particularly given their belief that effectiveness was likely to vary between patients because they would have different medical characteristics.

4.3.32 Lastly, many who bought add-on treatments felt that, in the context of high cost IVF treatment, add-on treatments were relatively affordable. As these respondents explained, since they already invested such large sums of money in this treatment, they wanted to try everything they could and avoid the fear of not doing so (even when sceptical).

*I remember him [the consultant] saying, in terms of how beneficial it is, that it was difficult to say, but there's no disadvantages, so you might as well, just in case it does work. [Male participant] I remember challenging him on that a little bit, and he said the jury's out, 50/50. He said it wouldn't harm it, and there was no reason not to. It was a small amount of money, which doesn't mean anything when you're trying to have a baby." [Female participant] [Mixed sex, Under 35 years old, Private, East Midlands]*

*There's no proof of success, but it's a peace-of-mind thing. [Mixed sex, 35-39 years old, Private, North West]*

4.3.33 Lastly, many who bought add-on treatments felt that, in the context of high cost IVF treatment, add-on treatments were relatively affordable. As these respondents explained, since they had already invested large sums of money in this treatment, they wanted to try everything they could (without necessarily being convinced about efficacy). They worried that if they were

unsuccessful, they may regret not trying something ‘just’ because of £200-£300, a sum they felt was dwarfed by the thousands they were already paying.

*I also had Intralipids – a type of drip. I thought it was a bit hocus-pocus, but I did it anyway. The research on it was inconclusive but we didn’t have time to wait until it was proven. We thought we’d try it as it wasn’t a ridiculous amount of money. [Same sex, 38-42, Private, South East]*

*They just told me what it [scratch] was and how it could be beneficial, so at that point it’s like, it’s only an extra £250, we might as well. If it doesn’t work, then you’re going to think, well, if only I had spent that £250 extra and it could have worked. [Mixed sex, under 35, Private, E England]*

4.3.34 Respondents who did not buy any add-on treatments reported a range of reasons for this decision. Common scenarios and reasons included:

- Respondents who paid for private treatment at NHS clinics where add-ons were not provided, did not have the choice available to them at that clinic and did not want to buy the add-ons at a private clinic.
- Another reason was respondents wanting as little intervention as possible, which was the case with a couple of respondents using private clinics who provided what they described as ‘IVF light’.
- Some respondents with ‘unexplained infertility’ thought add-on treatments aimed to address particular fertility issues, so were not relevant to them.
- A few respondents reported that private clinics explained there was no evidence to support their use and respondents followed this advice.
- Several other respondents did not buy any add-ons due to budget constraints, although a couple who were unsuccessful were now considering buying add-on treatments for their future IVF cycles.

*We didn’t really want to do too much other than, you know, the basics. [Mixed sex, 35-39, Private, North West]*

*We discussed the cost as well and the IVF was as much as we could stretch to. They did mention other things in passing, but there wasn’t a lengthy discussion because there wasn’t the money there to have anything else. [Mixed sex, 38-42, Private, Northern Ireland]*

4.3.35 Finally, there were some patients– namely, some of those who bought third party multi-cycle packages – who found that certain add-on treatments were

included. These respondents were generally pleased that add-on treatments were included. They reported that they understood these add-ons would be used during their treatment, if needed. However, some reported that their clinics advised them not to use these treatments, explaining either that there was no medical need for them and/or that there was no evidence for their effectiveness. Consequently, some did not use the treatments that were included in the package they bought, and they did not challenge this.

*We got assisted hatching, embryo glue, time-lapse technology - that was all included in our [third party] package. But with regards to additional treatment, based on our medical stats, there was no need for anything extra, so they [the clinic] didn't recommend it. Things like the endometrial scratch, they said there was no requirement for it. [...] But we didn't challenge it, because it's there if you need it. It wasn't an issue. [Mixed sex, Under 35, Private, Scotland]*

### **Complementary treatments**

4.3.36 Most participants did not buy complementary treatments. A small group who did bought them from other providers, not from the clinic where they had IVF treatment. Often, they did not even discuss these treatments with their consultants, with only 2 participants reporting they discussed having acupuncture with their consultant.

*I think I had reflexology, about four or five sessions of that, but that wasn't anything to do with the clinic, it was from someone who does that separately. I'd had reflexology before, years ago, just as a spa day treatment, and I thought it was really good. So, I thought I'd give it a try. [Mixed sex, 35-37, Private, Northern Ireland]*

*For my third cycle, I did do acupuncture, just because, again, I'd heard it helped with blood flow to the uterus. It wasn't something that [the clinic] had pushed in any way. It was just something that I'd read. I think I'd had a [author name] IVF handbook, and it was in there, because she seems to be quite big on all the complementary therapies. [Mixed sex, 38-42, Private, North West]*

4.3.37 Participants who had complementary treatments explained how they hoped these treatments would put their body in the best possible state to be receptive to IVF treatment, for example, feel more relaxed and reduce stress.

*It's a combination of where I have endometriosis...Acupuncture is meant to be much better for blood flow to the uterus, so we felt that it couldn't hurt. The reflexology was also meant to be quite relaxing,*

*which it was, but the acupuncture, I don't like needles, so it wasn't really relaxing. [Mixed sex, 43+, Private, East of England]*

*None of that was included in either my first or my second packages. I did actually do acupuncture privately myself, and I did discuss that with the consultant, as to whether they recommended it. They were very clear that whilst there is no confirmed statistics on it increasing success rates, that a lot of patients found it really relaxing, and if they were more relaxed that is a positive thing. He said if it was something I wanted to look at then they would support it. [Not in relationship, 38-42, Private, South East]*

### **Payment details**

4.3.38 All who received their treatment and cost information were also provided with payment details. Most respondents explained they knew when and how they would be making their payments, even if approaches to scheduling payment varied between clinics.

4.3.39 Half reported that they paid as they went along, i.e. either in instalments or as and when they had treatments. The other half paid for the bulk of their treatment before it started, paying lesser sums for tests and additional medications as they went along e.g. pregnancy drugs or further tests. Participants who took out multi-cycle packages typically paid most of their costs upfront, often split in 3 payments: initial costs (e.g. consultation, scans, tests); a payment for the package; and variable payments for medication.

*We paid [a third-party finance provider] a lump sum upfront. We then paid for the drugs separately via [a separate pharmacy]. [Mixed sex, 43+, NHS, East Midlands]*

*We were given a couple of options – we could pay up front or there was an interest free plan. We paid it all upfront. [Mixed sex, 35-37, Private, South East]*

### **Cancellation and refunds**

4.3.40 Recall of information about cancellation and refunds varied. Most struggled to remember whether this information had been provided. Most did not recall this topic being raised and speculated that this information must have been included in the paperwork they received. Some in this group also wanted to point out that neither they nor the clinic would have wanted to focus on failure early in the process, and that this may have been the reason why refunds and cancellations were not discussed.

*I can't really remember [refund and cancellation policy]. We didn't really concern ourselves with it. We were trying to be positive, really.*  
[Mixed sex, 43+, Private, South East]

4.3.41 A smaller group of respondents recalled the information they received on cancellation and refunds. Most remembered cancellation and refunds policy were explained with regards to the cycles that had to be abandoned on medical grounds. Respondents understood that certain treatment costs would be refunded in this situation.

*The refund cost, they are very clear about that. They tell you at this stage, you would get this much back. If we have to cancel your cycle because your body's not responding, you just have to pay for the scans you've currently had.* [Mixed sex, Under 35, Private, North West]

#### **Factors influencing level of patient vulnerability**

4.3.42 There were a number of factors that suggested that all respondents appeared, to varying degrees, potentially vulnerable when purchasing IVF treatment. All had made the decision to put themselves through a physically, emotionally and financially demanding experience. As non-medical professionals, all were being asked to make decisions about and participate in complex treatments within a context many did not fully understand. All were fully invested in achieving positive outcomes which, in itself made them vulnerable consumers. A drive to achieve a positive outcome overwhelmed other typical consumer considerations (e.g. satisfaction with service and the possibility of needing to follow refund policies) and behaviour (e.g. asking clarification questions about price).

4.3.43 Previous personal experience of IVF treatment was helpful in some ways. More experienced respondents became more familiar with the IVF process, learned from past experiences and therefore knew what questions to ask (e.g. regarding success rates) and tended to be more comfortable to challenge clinics (e.g. regarding lack of success). However, greater experience also increased respondent vulnerability in other ways, particularly for those with experience of multiple unsuccessful cycles or those looking for an explanation for their fertility issues. Those who were well off were vulnerable to paying larger amounts for IVF treatment overall, as well as paying more for different optional add-on treatments. In a context where unsuccessful consumers had little control over outcomes, purchasing add-ons was one way of trying to take some control.



- 4.3.44 A small number of respondents explained that they felt it was difficult to raise the topic of cost within the context of fertility treatment – when respondents felt that they should be demonstrating how much they wanted a baby, above all other considerations. The sense that the topic of cost was taboo was least likely to affect respondents who were on a budget, who – out of necessity - needed to pay close attention to costs and voice any concerns.
- 4.3.45 The overall high cost of IVF treatment and value placed on a successful outcome also had an effect on respondents' perceptions of cost. This was clearest when respondents talked about their attitude towards paying for add-on treatments, which were perceived as relatively inexpensive for all except the very most budget-conscious. Thus, additional treatments of hundreds of pounds were not considered expensive in the context of IVF treatment costing thousands of pounds and a potentially 'priceless' outcome. The 'priceless' outcome also affected the likelihood of respondents challenging costs or pursuing refunds. Those who were successful were much less likely to do so, particularly compared to those who were unsuccessful.
- 4.3.46 The treatment itself was also felt to make respondents feel vulnerable, which many attributed to the large amounts of medication being taken, but also due to the stress of undergoing treatment within strict time constraints. In time-pressed situations, respondents were sometimes not told (and did not ask) how much individual treatments or tests would cost. For example, a respondent was asked whether they wanted to use a particular drug when gowned up ready for the embryo transfer. When under time pressure, convenience became a more important factor than price e.g. being sent medication by courier became more appealing than sourcing the medication from elsewhere.

#### **4.4 Treatment and cost decisions after the treatment started**

- 4.4.1 A large group reported that they paid what they perceived were additional costs after treatment started. However, these were not 'additional' costs, but 'higher' than expected costs for things like medication.
- 4.4.2 However, there were also a few respondents where other additional treatments or investigations were added after the treatment started. For example, some participants recalled that they had to have additional tests, scans or appointments. Furthermore, a very small number of participants

were told they needed ICSI during treatment (which they had not been previously told). Another very small group reported that embryo glue and/or endometrial scratching were offered to them after the treatment started.

*I had to do a longer protocol, because I wasn't growing eggs quick enough. The cost spiralled a bit, just based on that reason alone, and having to do additional tests. [Mixed sex, 38-42, Private, West Midlands]*

*At the last minute, they literally came in, I think on the day of the egg retrieval, and said, "Now our best option will be ICSI." I said, "Oh, okay, I didn't know that was going to happen." And they said that will be the best option, we should just do that. [...] I think they could have been more upfront with us with regards to the ICSI. [Mixed sex, Under 35, Private, East of England]*

#### 4.4.3 Examples of add-on treatments that were added after the treatment started included:

- One other participant decided to buy endometrial scratching after she started taking medication. The participant explained how they phoned the consultant to ask about that treatment. The consultant said it can increase chances of success and the participant decided to add that treatment in.
- One participant was called every day by their clinic who updated them on the progress of their embryo. During one of these calls, they were offered embryo glue – reportedly - 'because it helps it stick better'.
- Another participant reported finding out that the clinic was going to use embryo glue as they were waiting for the embryo transfer, which would be an additional cost. They were not given the option to not have this treatment.

*That was probably after you've had your egg collection. I think the egg collection, you had a transfer on day 5. It was probably the day she had the egg collection, they phoned us every day after to tell us how the embryos were developing, and then said, 'Do you want the glue? It improves your chances.' [Same sex, Under 35, Private, West Midlands]*

## 4.5 Final costs, cancellations and refunds

### 4.5.1 Respondents sometimes found it difficult to assess whether and if so, by how much, they paid more than what they had been expecting. Respondents in

this sample can be broadly split into several groups in terms of how their final costs compared to what they had been expecting:

- **Final costs the same as quoted:** A large group claimed their final costs were the same as what they had been expecting. This group includes:
  - Those who felt that the final costs were roughly the same as they had expected, including those who were not particularly clear about costs in the first place and therefore had very broad expectations about final costs; as well as those who were not particularly cost-conscious and therefore were not paying particularly close attention to costs;
  - Those who had a clearer expectation of cost, who : those who bought packages and felt they were clear about the costs they were expected to pay; those who bought private treatment at NHS clinics and felt that they were clear about the costs they were expected to pay; and those who were on a budget and therefore paid close attention the costs they were paying. Even though this group may not have felt that they paid more than they had expected, this did not preclude them wanting greater clarity on treatment costs in future.
  
- **Final costs higher, but variation expected:** a small group reported that they had paid more than they had expected. The difference was mainly due to needing more medication, which had then increased the cost. Even amongst those expecting medication costs to vary, some were still surprised at the extent to which the medication cost increased, for example, by £1500-2500 in a couple of cases.

*We had to pay for more medication because we went for a scan and I wasn't ready for retrieval, so we needed a few more days drugs. [Same sex, 35-37, Private, London]*

*I think they could have helped by saying, look, it [medication] can vary as much as £1000 or £1500, so just be prepared for that. [Mixed sex, under 35, Private, East of England]*

*The only thing was that I needed an extra jab to get my eggs up to a certain size, but we knew that at the time, because they told us we had 10 days of jabs, and we'd need an extra one. We just paid with the clinic direct, and they give it to you there and then. [Same sex, under 35, Private, London]*

- **Final costs higher and unexpected:** a small group also reported they paid more, but in their case they felt that these were unexpected costs. The unexpected items they paid for were often tests, scans or pregnancy medication, which some did not realise they would need. In three cases, the unexpected cost was due to ICSI being required once the treatment had started. Some of these respondents felt frustrated that this possibility was not discussed with them at the start.

*There was the additional cost for the bloods, which came out of nowhere. Also, the HFEA fee, which is only £80. I remember that being a new cost that they hadn't discussed with us. They're keeping that as a separate cost, so we understand it's an additional thing. It would still have been good for them to have included that in the total. What we were probably missing was this personalised quote. If we had that, it probably would have picked up on the fact that bloods would have been a thing, and the fee would have been there as well. [Mixed sex, 43+, Private, East Midlands]*

*Because the NHS referred us, they had done a few of the basic tests which probably would have helped but being a private clinic, they wanted to do all of them. So, even though I could save £400-500 on tests, they wanted to do them all again at the clinic. I didn't know that until later on. So, it could be an average of £7,000, but we had to put together £8,000-9,000 just in case. [Mixed sex, 38-42, Private, Scotland]*

- **Not able to tell if they paid more:** A very small number of respondents were unable to say whether they paid more or not because they did not receive information about their treatment cost. For this reason, they lacked the benchmark to compare the final costs to.

*It's just receiving an invoice and then you pay it. [...] I would know a rough ballpark from my own research. There were times when I would be totally wrong. There was a time where I received an invoice for about £8k and I was expecting £2K. I think that was when I first found out that you were charged 80% even if the transfer was abandoned. [Mixed sex, Under 35, Private, West Midlands]*

4.5.2 Only a small number of respondents reported they were told that they were eligible for refund. The few respondents who received refunds had different circumstances and experiences, as follows:

- A participant who used a private clinic in London was refunded after they had not responded to the stimulation and the cycle was cancelled. They only paid for what they had used up to that point.
- A participant in the North West got a full refund after the cycle was cancelled because they were diagnosed with cancer shortly after the stimulation started.
- A respondent received an itemised price list, which stated that freezing eggs cost a certain amount. When participant asked for the money back - because the egg collection had not resulted in any eggs to freeze - she was told that it shouldn't have been itemised. It took her a month to get her money back.
- Participants initially paid around £2000 for PGS but changed their minds and received a refund.

#### 4.6 Respondents' reflections

4.6.1 Respondents were asked to consider what they would like to have known or what they would have done differently. Reflecting on their experiences, they made a number of suggestions and observations, as outlined below:

##### **Signposting and supporting patient choice over source of medication:**

4.6.2 Patients who bought medication from sources other than their clinic thought that the clinic should have informed them that medication could be sourced elsewhere if they wished. Instead, they learned about this possibility from family and friends. They also thought that clinics should have supported them in their choice to buy medication elsewhere. In addition, only a few respondents reported being told they could get certain tests and scans on the NHS, whereas most others were unaware of this possibility to reduce the costs.

*They tried to get us to source medications through them, but we knew from previous experience we could get them cheaper from Asda, so we wanted them to prescribe them. [...] The consultant said that they could provide the medication. We went home and did a bit more reading to check we were right, then we rang up and asked if we could have it prescribed when it came to the point when we needed it. They said they'd have to get back to us because it wasn't standard protocol to have it prescribed. We said we knew it's £200 cheaper at Asda. Then eventually they posted out the prescription, so it was basically the receptionist and nurses going back to the doctor getting him to sign it off. [Same sex, Under 35, Private, East Midlands]*

### **Better information about treatment costs**

4.6.3 Many wanted greater clarity on treatment costs i.e.

- What is included in their treatment;
- Which costs are certain and fixed e.g. scans, consultations;
- Which costs are certain and variable i.e. medication
  - As well as the extent to which these costs might vary;
- Which costs are uncertain and variable i.e. costs that might arise during treatment due to a change in medical need;
- What is excluded from their treatment i.e. add-ons.

4.6.4 A few participants felt that explaining the costs associated with different stages of the process would be helpful i.e. initial costs (consultations, scans, tests); egg collection; embryo transfer; post-embryo transfer.

*[You need] a full breakdown of what you are going to need 100%, from day 1 to 12 weeks. Because it's not just the treatment, it's the aftercare. It's a 4-6-month process, up until you're 12 weeks pregnant. [Same sex, Under 35, Private, West Midlands]*

4.6.5 A few respondents highlighted the issue of ad hoc costs, which they had not appreciated could be incurred suddenly. This was particularly the case where tests, scans or treatments were added part-way through the treatment and where they were needed urgently. Respondents with this experience felt that clinics should ensure that patients were always provided with the price prior to buying something, no matter how quickly investigations or treatments were needed.

*It needs better communication around ad hoc, high prices items. You're vulnerable and you don't have unlimited funds. [Mixed sex, 38-42, Private, London]*

### **Better management of information, communications and administration**

4.6.6 A few respondents wanted the clinics to manage better the volume of patient information shared at the beginning of the process by prioritising key information. Another couple of respondents wanted better administration and communication more generally:

*In a lot of IVF clinics, you have to drive the process quite a lot as the patient. You have to follow up particularly administration or anything to do with organisation. In both the clinics I've been at, [there's] lack of resource on administration and organisation, which makes it quite stressful for the patient because you're thinking, "Well, I haven't got these blood test results. You haven't sent me this prescription." And*

*there's a lot of that kind of stuff all the way through it. [Mixed sex, 38-42, Private, London]*

### **Being more flexible in the approach to treatment**

4.6.7 A few respondents wished their clinics were more flexible and open to different approaches, for example, medication-light IVF treatment. Another respondent wished her clinic accepted their preference for a particular brand of medication, which the respondent had a positive experience with.

*The first time around I wish they had given me the option of the natural IVF. I wish they were more open-minded about it. This medicine they're using, it's crazily expensive. The first time round it was free for me, but it's costing the NHS, so why do it if it's not necessary. I wish they had a more personalised approach, rather than one-fits-all. [Mixed sex, 38-42, NHS, South East]*

### **Being more forthcoming and candid about realistic chances of success**

4.6.8 A few respondents with experience of unsuccessful cycles wished the clinics they used had been clearer and more candid about their own chances of success. In particular, a couple of respondents felt their cycles should have been abandoned sooner. One other respondent felt that the clinic was too optimistic about her chances of success from the start, so she was not as prepared as she could have been for the possibility of unsuccessful outcome.

*I think [we need] more honesty around the treatment isn't successful for everybody. I met lots of women doing this, I think that's something we all feel isn't explained enough at the start of this. [Not in relationship, 38-42, Private, London]*

### **Complaints about the excessive cost of IVF treatment at private clinic**

4.6.9 This was a common theme for many respondents, some of whom felt the cost of medication was inflated at private clinics when compared to the same medication bought elsewhere. Others, with experience of IVF treatment abroad, were shocked at the difference in cost for the same items between the UK and Spain or Czech Republic. Yet, a few others complained over what they perceived as unnecessary costs, for example, paying around £200 for a 20-minute consultation about what IVF treatment involved which they knew already from their previous experience.

*It's going to cost you a fortune. Looking back on it, my friend from Poland had been telling me about her experience. I would probably consider going even further afield if the price could be significantly reduced, the way hers was. If they offered to do treatments in English. I*

*do think in the UK it's more expensive than it really needs to be. [Mixed sex, 35-37, Private, Northern Ireland]*

*The difference between private here and private there [Spain] is that they're not cashing in. The tests there were all 12 euros. Here, the blood test is £169. Where does the difference come from? It's a big margin. [...] It's quite funny when you tell them how much a blood test costs in the UK. They can't get their head round it. I looked at my files before I spoke to you, and Barcelona broke down everything down to my anaesthetic costs what was included. They don't do that in the UK. [Mixed sex, Under 35, Private, South East]*

## 5. Areas for improvement

- 5.1 The research highlighted that the following areas could be improved in terms of access to, or clarity of, information about the treatments or costs provided by fertility clinics.
- 5.2 Considering the limited use of independent sources of information by patients, there is scope for HFEA's information to be more prominent and better publicised. The research suggests there is a need to increase awareness of the HFEA as an independent source to help patients make informed choices.
- 5.3 The research also revealed the need for more consistency and clarity in how information about treatment costs was provided. In particular, the following areas were highlighted as in need of improvement, before treatment starts:
  - Addressing the complete or partial lack of treatment cost information in some cases;



- Differentiating better between the different types of cost i.e:
    - Known, fixed costs e.g. consultations, scans, tests, egg collection, embryo transfer;
    - Known, variable costs e.g. routine medications, number of scans, tests etc (as well as providing a clearer and more personalised range in terms of how medication and other costs can vary);
    - Fixed costs that may arise during the process e.g. ICSI, embryo freezing;
    - Optional costs i.e. add-ons.
  - Ensuring patients have both the financial and medical information regarding particular treatments at the same time to help them make decisions, rather than splitting this across medical and financial staff roles.
- 5.4 To ensure patients are able to make an informed choice about whether to have add-on treatments, clinics need to ensure that information about the evidence for their effectiveness and the risks is consistently provided, based on recognised, independent sources, such as the HFEA.
- 5.5 The research suggests that clinics rarely informed patients if it was possible for them to buy medication from elsewhere (or get certain tests and scans on the NHS) and some clinics were not supportive of patients making this choice. Patients valued these choices, if available.
- 5.6 There is also a need for greater clarity about the potential for cancellations and refunds and related policies at the start of treatment as well as when relevant, as many did not recall this information.
- 5.7 In addition, the few who experienced cancelled treatments wished they had been better prepared for this possibility. The research suggests that clinics need to be clearer about the patient's personal chances of success at the outset and discuss risks with them with regards to all aspects of their treatment, including with regards to tests or add-on treatments.

## Research Report Appendices

### Appendix 1: Recruitment questionnaire

#### **J.2121 Competition and Markets Authority: IVF Research RECRUITMENT QUESTIONNAIRE FINAL 30-5**

Good morning/afternoon/evening, my name is \_\_\_\_\_, from Research Works Limited, an independent market research agency. We are conducting research on behalf of the Competition and Markets Authority (CMA). The CMA is an independent, non-ministerial department<sup>7</sup> and is the UK's lead competition and consumer authority. It works to ensure that consumers can make informed choices and get a good deal when buying goods and services, and that businesses operate within the law.

On 7 February 2020, the CMA launched a project into raising awareness of consumer law in the IVF sector. As part of this they will be producing consumer law guidance for clinics and advice for patients. This research, by capturing patients' experiences, will help inform this work.

#### **INTERVIEWER – ALWAYS SHOW RESPONDENTS THE CMA BONA FIDES LETTER OF EXPLANATION.**

The research will involve two stages:

- Firstly, there will be a short interview today which will help us to identify a range of people who have paid for and undergone at least one full cycle of IVF treatment within the last 2 years
- Secondly, a longer interview would be conducted at a later stage, which will ask individuals to describe their experiences of paying for IVF treatment. This interview will be held at an agreed date, time and either over the phone or online depending on your choice.

To confirm, the following short interview is completely in confidence and is for research purposes only.

Would you mind answering a few questions to see if you would be eligible to participate in our research project?

<sup>7</sup> Non-ministerial government departments (NMGDs) are a type of [British government department](#), headed by [senior civil servants](#) (not a member of the Prime Minister's Cabinet). Some, like the CMA, fulfil a [regulatory function and others have an inspection function](#), and their status is therefore intended to protect them from political interference.

**Q1 Have you ever taken part in either an individual interview or group discussion before?**

Yes	1	<i>Ask Q2</i>
<hr/>		
No	2	<i>Ask Q4</i>

**Q2 How long ago did you take part?**

Less than 6 months ago	1	<b>Close</b>
<hr/>		
Longer than 6 months ago	2	<i>Ask Q3</i>

**Q3 Was the subject of the research anything to do with IVF services?**

Yes	1	<b>Close</b>
<hr/>		
No	2	<i>Ask Q4</i>

**Q4 We need to interview people in certain trades and professions. Could you please tell me if you work in any of the following?**

Fertility clinics and services	1	<b>Close</b>
NHS or private healthcare	2	<b>Close</b>
In a health-related role within central or local government	3	<b>Close</b>
Health-related public bodies or organisations	4	<b>Close</b>
Advertising and marketing	5	<b>Close</b>
Journalism	6	<b>Close</b>
Public relations	7	<b>Close</b>
<hr/>		
None of the above	8	<i>Continue</i>

The research is focussed on the experiences of those that have paid for at least one full cycle of IVF treatment. I'd like to ask you some questions about your experiences .

**Q5a Have you, either individually or jointly, paid for IVF treatment within the last 2 years (i.e. since April 2018)?**

Yes, individually	1	<i>Continue</i>
Yes, jointly	2	<i>Continue</i>
<hr/>		
No	3	<b>Close</b>

**RECRUITER NB: RESPONDENT MAY HAVE ALSO HAD FREE NHS TREATMENT WITHIN THE PAST 2 YEARS, BUT THE FOCUS OF THIS RESEARCH IS ON THOSE THAT HAVE PAID FOR TREATMENT (WHICH MAY HAVE BEEN PROVIDED BY AN NHS CLINIC (WHO TREATS PRIVATE AS WELL AS NHS PATIENTS) OR A PRIVATE CLINIC )**

**Q5b Can I check: was the IVF treatment you paid for within the past 2 years carried out in the UK, or mainly carried out in the UK?**

Yes	1	<i>Continue</i>
<hr/>		
No	2	<b>Close</b>

**Q6 Who provided the IVF treatment that you paid for within the past 2 years?**

A private clinic	1	Q7
<hr/>		
An NHS clinic that treats both NHS funded and privately funded patients	2	<b>Close</b>
<hr/>		
A mix of NHS and private clinics [recruiter: check with the office]	3	

**ALL TO HAVE USED PRIVATE CLINIC**

We need to talk to people who have had responsibility for making decisions about undertaking and paying for IVF treatment within the past 2 years.

**Q7 Which of the following decisions, if any, did you have sole or joint responsibility for making? *Select all that apply***

- Researching IVF treatments / clinics 1
- Choosing a fertility clinic 2
- Choosing a treatment plan 3
- Choosing additional treatments 4
- Talking to the clinic about treatments 5
- Other IVF-related decisions
- (write in ..... 6
- I discussed all key decisions with 7
- my partner/the person having/paying
- for the treatment

**ALL RESPONDENTS MUST CODE AT LEAST 3 OPTIONS ABOVE – OR OPTION 7**

It’s very important that we talk to people with a range of experiences of paying for IVF treatment within the past 2 years. The following questions are all designed to capture a mix of experience.

**Q8a Who was the recipient of the IVF treatment that you paid for within the last 2 years?**

- I had the IVF treatment 1
- My partner had the IVF treatment 2
- A surrogate had the IVF treatment 3

**PLEASE LET US KNOW IF YOU COME ACROSS ANY WHO HAVE USED A SURROGATE, WHETHER OR NOT THEY FIT OTHER QUOTAS**

**Q8b What age was the recipient of the IVF treatment that you paid for within the past 2 years (at the time of the treatment)?**

- Under 35 1
- 36 – 37 years old 2
- 38 – 40 years old 3
- 41 – 42 years old 4
- 43+ years old 5

**THERE ARE NO AGE QUOTAS**

**Q9a When you were involved in paying for IVF treatment within the past 2 years, what was your relationship status?**

I was in a relationship	1
I was not in a relationship	2
My relationship status changed during treatment	3

**PLEASE LET US KNOW IF YOU COME ACROSS ANY WHO WERE SINGLE AT THE TIME OF IVF, WHETHER OR NOT THEY FIT OTHER QUOTAS**

**ASK THOSE CODING 1 AT Q9a**

**Q9b What relationship were you in when you paid for IVF treatment within the past 2 years?**

Same-sex relationship	1
Mixed-sex relationship	2

**THERE NO QUOTAS ON RELATIONSHIP**

It's also important that we talk to people with a range of experience of IVF treatment overall. Once again, the following questions are all designed to capture a mix of broader experience.

**Q10 What, if any, is your experience of NHS funded IVF cycles?**

I/we have been provided with NHS funded IVF cycles within the past 2 years	1
I/we have been provided with NHS funded IVF cycles, longer than 2 years ago	2
I/we have not been provided with NHS funded IVF cycles ever	3

**NO QUOTAS ON EXPERIENCE OF NHS FUNDED CYCLES**

**Q11 Which of the following best reflects your experience?**

I/we have experience of an IVF cycle which resulted in pregnancy 1

I/we have experience of an IVF cycle which resulted in live birth 2

I/we do not have experience of an IVF cycle which resulted in pregnancy 3

**CHECK QUOTA SHEET : WE ARE KEEN TO INCLUDE SOME WHO DO NOT HAVE EXPERIENCE OF AN IVF CYCLE RESULTING IN LIVE BIRTH**

We also need to ensure that we include people in different stages of IVF treatment. The following questions are designed to capture a range of current situations.

**Q12a Thinking about your current situation, which of the following applies to you?**

I/we have completed the most recent IVF cycle 1

I/we have not completed the most recent IVF cycle 2

**MOST TO CODE 1**

**Q12b Have you ever bought a multi-cycle package of IVF treatment (ie paying upfront for more than one round of IVF)?**

Yes – bought multi-cycle package of 2 treatments 1

Yes – bought multi-cycle package of 3 or more treatments 2

-----  
No 3

**PLEASE TRY & INCLUDE ONE INTERVIEW WITH THOSE WHO HAVE BOUGHT MULTI-CYCLE PACKAGE**

**Q13 And thinking about your future plans, if you have any, which of the following best describes your situation?**

I plan to have further IVF cycles

- |   |   |
|---|---|
| within the next year  | 1 |
| I do not have plans to have any further IVF cycles within the next year | 2 |
| I'm not sure if and when I will have any further IVF cycles             | 3 |

We'd now like to ask you some more general questions about your background.

**Q14 Which of the following applies to you?**

- |        |   |
|--------|---|
| Male   | 1 |
| Female | 2 |
| Other  | 3 |
- 

(please write in how respondent identifies their gender)

**Q15 Please record occupation of chief income earner of your household: (RECORD FULL DETAILS)**

Job: \_\_\_\_\_ Industry: \_\_\_\_\_ Company: \_\_\_\_\_

Record Social Grade:

- |    |   |
|----|---|
| AB | 1 |
| C1 | 2 |
| C2 | 3 |
| DE | 4 |

**NO QUOTAS BUT AIM FOR A MIX OF SOCIAL GRADES**

**Q16 Which of these would you use to describe your ethnic group? (SINGLE CODE)**

- |  |   |
|--|---|
| White                                  |   |
| British                                | 1 |
| Irish                                  | 2 |
| Other White background (specify) _____ | 3 |

Mixed



White and black Caribbean	4
White and black African	5
White and Asian	6
Other Mixed background (specify) _____	7
Asian or Asian British	
Indian	8
Pakistani	9
Bangladeshi	0
Other Asian background (specify) _____	V
Black or black British	
Caribbean	X
African	Y
Other black background (specify) _____	Z
Chinese	1
Other ethnic background (please specify) _____	2

### **CHECK YOUR QUOTA SHEET**

### **FINAL INTERVIEW SET-UP INFORMATION AND QUESTIONS**

**Ask respondent whether they would be interested in participating in a 60-minute long depth interview about their experiences of paying for IVF treatment.** This interview would be held at an agreed date and time and either over the phone or online depending on your choice.

If respondent says yes, please explain the following.  
If respondent says no, thank them for their time.

**Recruiter: please explain the following and ask respondent to sign (below) to indicate that they have received the written information provided (i.e. bone fides letter and invitation).**

- This research is about understanding consumers' behaviour, experiences and choices/decision-making during the process of buying IVF treatment. It will involve a detailed discussion about your experience of deciding how to go about buying IVF treatment, including the choices you made and your knowledge about the costs involved.
- The interview will be an informal discussion about your experiences – there are no right or wrong answers, we will just be asking you about your experience.

- All the information given will remain private and confidential.
- You will remain anonymous, no one, including the Competition and Markets Authority, will know who has taken part in the research.
- We like to audio record our interviews so that we have a record of the conversation to use for transcription and analysis after the interview, if that is OK with you. If you'd prefer not to be recorded, we are happy to take notes. We'll ask you about your preference about how we record your data when we meet.
- When we meet for the interview, we will also ask you to give your written permission for Research Works Limited to collect, process and retain your data, as required by the General Data Protection Regulation (GDPR). You 'own' your data: you have a right to access your data, or for it to be amended or deleted whilst it is held by Research Works Limited.

**Our first priority is that you feel comfortable to participate in the research.**

**Q19 Is there anything else you need/would like to know before you agree to the interview? If so, what?**

RECRUITER TO NOTE AND CONTACT THE OFFICE

**Q20 What is your preferred interview format?**

One individual depth interview (i.e. by yourself)	1
Two individual depth interviews (one with you and another separate interview with the partner who shared the experience of buying IVF treatment within the past 2 years)	2
Paired depth interview (with the partner who shared the experience of buying IVF treatment within the past 2 years)	3
Paired depth interview (with a supporter who did not necessarily share the experience of buying IVF treatment within the past 2 years)	4

**Codes 2 & 3: please ask for partner's details so that they can also be screened.**

**Q21 Which of the following would you be happy to use to do the interview? Please tick all that apply**

Telephone	1
Research Works' telephone conference call system	2
Zoom video call	3

**Q22 Explain there is a small task to do before we meet for the interview:**

We would like them to look to see if they have kept any relevant information or paperwork related to the IVF treatment they paid for in the last 2 years that can help jog their memory. For example, we'd like them to remind themselves about: **the research they did to help them with their choices; what information from the clinic they were given on treatment options and costs, for example did they get a costed treatment plan<sup>8</sup>; what were they told about the costs of medication, when payments would need to be made, and refunds; and what the actual costs were eventually.** Once they reminded themselves, we would like them to answer a few simple questions before the interview, which we would send to them. We would like them to be able to refer to any relevant information they found and their answers, if possible, during the interview.

Are you happy to complete the pre-task?

Yes            1 Continue

No             2 **Close**

**Q23** We may wish to recontact you after the interview to ask a couple of follow-up questions (about this research only) – would that be acceptable to you?

Yes            1            Continue

No             2            Continue

**Recruiter: leave with respondent**

- 1. The bona fides letter from the Competition and Markets Authority**
- 2. Respondent invitation**
- 3. Pre-task document**

**Please point out the number to contact if they no longer wish to take part/have any questions**

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<sup>8</sup> The fertility sector is regulated by the HFEA. It is a requirement in their code of practices that clinics must provide a costed treatment plan before treatment starts.

**Please ask respondent to sign below to confirm that they have received this written information.**

**I confirm that I have received an invitation to participate in the research.**

**I also confirm that I have received a letter from the Competition and Markets Authority which explains more about the research.**

**I confirm that I understand that I may choose to access, amend or delete my data, whilst it is being held by Research Works Limited.**

**NAME OF RESPONDENT:** \_\_\_\_\_

**Respondent signature:** \_\_\_\_\_

**INTERVIEWER NAME:** \_\_\_\_\_

**I certify that I have carried out this interview according to instructions received from Research Works Limited and in accordance with the MRS codes of conduct and the respondent is not a relative/friend of mine.**

**Interviewer's Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## Appendix 2: Topic Guide

### 2121 CMA IVF RESEARCH Discussion Guide (Draft 3 – post pilot)

#### PART 1 – INTRODUCTION

##### 1. Research introduction and warm-up (5mins)

*This section reiterates information about the research project, research sponsor and research agency that have been communicated at the recruitment stage.*

- Introduce self and **Research Works Limited**, an independent market research agency
- The research is being conducted on behalf of the **Competition and Markets Authority**
- Reiterate that the conversation will be about experience of choosing and buying private IVF treatment, rather than the experience of the treatment itself
- Introduce the research project and process – MRS Code of Conduct, confidentiality
- Ask permission to record the interview
- Explain that the respondent can stop the interview at any time or decline to answer specific questions – just let the moderator know
- Invite any questions about the research process
- Ask respondents to introduce themselves

##### 2. Context (5 mins)

*This section aims to capture some key contextual information about respondents' past experience/s with IVF treatment, their most recent treatment and any future plans.*

###### **Most recent IVF treatment**

*Moderator to explain we'd like to start with a brief overview and some **basic facts** about your most recent self-funded treatment. Moderator to reiterate we will mainly focus on this particular treatment for the purposes of this discussion and remind respondents to refer to their pre-task if needed.*

- Can you tell me **when** you had your most recent IVF treatment (which you paid for yourself/yourselves)?

- And **where** did you have it?
  - Was it an NHS clinic that provides private treatment or a private clinic?
  - Were any aspects of your treatment conducted abroad? If so, which aspects?

### ***Past and future IVF treatments (for context)***

- Prior to this treatment, have you had any other IVF treatment/s? If yes:
  - How many were NHS funded? How many did you pay for?
  - *Moderator to listen out for any comments on the present suspension of IVF treatments due to the Covid-19 outbreak and how respondents feel about that BUT do not probe about this, just be alert to and show an understanding of the sensitivities involved*

## **PART 2 – BEFORE TREATMENT STARTED**

### **3. Research prior to the last private IVF treatment (5 mins)**

*This section explores if and how respondents did any research prior to their most recent, self-funded treatment.*

*Moderator to share **Stimulus A – Customer Journey** and explain we will now go through their most recent experience of arranging and paying for IVF treatment step-by-step, starting with any research they did prior to choosing a clinic*

- Before buying the most recent private IVF treatment, **did you actively seek out any information?**
  - If yes, what information did you look for? *Probe: costs, clinics, treatments, other*
  - If no, did you seek out this information for any previous cycles? *Probe: where did you know that from, what did you know*

*If looked at information about clinics:*

- **Did you look for information on more than one clinic? How many?**
  - What did you want to know about these clinics? *Probe: their success rates, costs, staff, location, anything else?*
  - What did you find out about how many clinics were available to you locally / were within a reasonable travel distance for you?
  - Where did you look/who did you ask for information on clinics? *Listen to spontaneous comments, then show **Stimulus B – Information sources** and probe the information sources identified.*
  - *If respondent visited clinics as part of research, probe:*
    - Did you visit one or more clinics?
    - Did you have to pay for any initial consultations/tests?

- If yes, how much did these cost?

#### 4. Choosing a clinic (10 mins)

*This section explores the decision-making process respondents went through when choosing a clinic to provide the most recent treatment which they paid for.*

*Moderator to explain we will now proceed to discuss your experience of choosing the clinic where you had your most recent private IVF treatment:*

- **What sorts of things did you consider when choosing the clinic?** *Moderator to listen out for spontaneous responses and then use **Stimulus C – Factors when choosing a clinic***
- Thinking about these different factors, probe for specific factors if relevant to respondents:
  - **Advice and recommendations:**
  - **Wanting to stay with the same clinic that provided previous treatment:**  
What was it about that clinic that made you want to stay with them?
  - **The success rates of the clinic:** Did you look for any information on this?  
Where did you look / who did you talk to?
    - What did you find out about different clinics' success rates? How did you feel about this?
    - How easy / difficult was that information to understand? Why do you say that?
    - Did you look for any independent advice on IVF treatment success rates? *Probe: For example, were you aware you could get advice about this from the HFEA<sup>9</sup> website? If so, did you look at that?*
  - **Cost:** How much of a consideration was the cost when researching clinics?
  - **Positive impression about the staff or the clinic**
  - **Wanting a particular doctor**

Was there anything else important that influenced your choice of a clinic?

#### 5. Treatment choices and decisions (20 mins)

*This section explores choices and decisions that were made about the treatment and information provided by the clinic prior to starting the treatment*

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<sup>9</sup> Moderator to explain that HFEA stands for Human Fertility and Embryology Authority which regulates and inspects all clinics providing IVF treatment in the UK.

*Moderator to explain that: we will now go through treatment choices and decisions that were made once you chose the clinic but prior to starting the treatment, as well as the information that was provided to them by the clinic at that stage*

- Can you talk me through **what information they provided** to you about the treatment you would need? *Moderator to reiterate this is information they received before the treatment started*

*Moderator to listen to spontaneous response and then probe to understand if this information covered the topics listed below, using **Stimulus D1-6 – Information provided by clinics** where helpful to remind respondents of information they received*

*Treatment plan and costs*

- Were you provided with a document detailing your treatment and cost, this may have been called a costed **treatment plan**? *This plan, may have listed the overall price, or itemised prices, for all the services, treatments and the medications, you would be getting for one or more cycle of fresh IVF.*
  - Were medication costs included in your costed treatment plan?
  - If not, were you given an indication of what the medications might be?
- How and when did you receive your costed treatment plan? *For example, was this provided in writing, sent by post, prior to starting treatment or later after treatment started?*
- If prior, how far in advance of treatment starting?
- Were you given explanations of the treatment you would need?
- Did you receive any explanation as to why treatment and costs might need to vary? *(Probe whether it was explained, for example, that different treatment may be needed due to a change in medical circumstances or that additional medications or scans may be required, at additional cost.)*
- Did the treatment plan include intracytoplasmic sperm injection (ICSI)? If so, was this because of a medical diagnosis that this was necessary?
- Were you told about:
  - Risks associated with any treatments?



- Your specific chance of success?
- What were you told about where you could buy medication? *Probe: were you told you had to buy the medication from the clinic or were you told you had the option to go elsewhere if you wished?*
- Which of the following did you decide to buy at this stage:
  - Did you buy just the one fresh cycle of IVF from your chosen clinic, at this time?
  - Did you buy more than one fresh cycle of IVF from your chosen clinic, at this time?
  - Did you buy a multi-cycle package of fresh IVF treatment, from a third party<sup>10</sup>, who has arrangements in place with a number of clinics, that you can choose from to carry out your treatment?

#### Add-on treatments

Moderator to then explore if **add-on treatments** were bought at this stage and what information was given about this:

- Were any add-on treatments included automatically in your costed treatment plan, as part of the price?
  - If so, which ones were included?
  - Did the clinic explain:
    - What they were? How they might benefit you? The clinical evidence of their usefulness? Any risks involved?
  - Did the clinic refer you to the HFEA website to see its advice about add-on treatments? *Probe: did you ever see the HFEA traffic light information on add-ons?*
- If (some) add-on treatments were not included automatically in your package, did you decide to buy them at an additional cost?
  - If so, which ones did you buy?
  - When and why did you decide to buy these add-on treatments?
  - Were they suggested by the clinic or did you ask for them?
    - If you asked for them, why did you do so? How and what did you know about them?

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<sup>10</sup> This third party is not a clinic, it is an intermediary, acting between a patient and a clinic in offering a financial arrangement for multi cycle treatment. This intermediary will have arrangements in place with a number of clinics who can perform treatments, if chosen. This financial arrangement is more like an insurance policy.

- Did the clinic provide any advice for and against the add-ons it suggested or you requested?
- Did the clinic provide the add-on treatments you bought? If, not who did?
- [If not discussed already] Did the clinic advise you to look at the HFEA website, for information about add-ons?

### Complementary treatments

*Moderator to then explore if any **complementary treatments** were bought at this stage and what information was given about this:*

- Were any complementary treatments, such as reflexology and acupuncture, included automatically in your treatment, as part of the price?
  - If so, which ones were included?
  - Did the clinic explain:
    - What they were? How they might benefit you? The clinical evidence of their usefulness?
- If complementary treatments were not included automatically in your package, did you decide to buy them at an additional cost?
  - If so, which ones did you buy?
  - When and why did you decide to buy these complementary treatments?
  - Were they suggested by the clinic or someone else? Or did you request them?
  - Why did you decide to have these treatments? What did you know about them?
  - Did the clinic provide any advice for and against these treatments?
  - Did the clinic provide the complementary treatments you bought? If, not who did?

### Payment details

*Moderator then to explore information about payments provided about the **cost** by the clinic*

- **Were you provided with information about payment details?**
  - How and when
  - When were you required to make payments:
    - Before treatment started, in full?
    - At different stages, as treatment went along?
    - Or after treatment finished, in full?

- **Were you provided with information about cancellations and refunds?**
  - Did that cover covering cancellation and refunds policy if treatment was not completed for any reason?
  - If so, what were the cancellation and refund terms for the treatments you bought? *Moderator listen out for any differences depending on whether respondents bought one or multi-cycle package*

### **PART 3 – AFTER TREATMENT STARTED**

#### **7. Subsequent decisions about treatment (after it started) (10 mins)**

*This section explores decisions about treatment(s), with any associated cost implications, after treatment had started.*

*Moderator to explain that: we will now go through, if relevant, your experience of considering further treatments, and any associated cost implications, after treatment has already started and been agreed.*

- *As your treatment progressed:*
- Were you told you would **need** further or different treatments?
  - What reasons were given for the treatment(s) being needed?
  - What were the cost implications of that?
- Did the clinic suggest any optional treatments? *Moderator to use Stimulus D2 and D3 if helpful to remind of add-on and complementary treatments*
  - What optional treatments did they suggest? *Probe with stimulus to understand which specific add-on treatments and/or complementary treatments*
  - At what point during the treatment were they suggested?
  - What reasons were given for those optional treatments?
  - Did the clinic provide any advice for and against the optional treatments it suggested?
  - Did you decide to buy any of these optional treatments?
  - Did the clinic provide the optional treatments you bought? If, not who did?
  - [If add-ons suggested] Did the clinic advise you to look at the HFEA website, for information about add-ons?

- Did you request any optional treatments? *Probe with stimulus to understand which specific add-on treatments and/or complementary treatments*
  - When and why did you request them?
  - What did you know about them and how?
  - Did the clinic provide any advice for and against these optional treatments you requested?
  - Did you decide to buy any of these optional treatments?
  - Did the clinic provide the optional treatments you bought? If, not who did?
  - [If add-ons suggested] Did the clinic advise you to look at the HFEA website, for information about add-ons?

## 8. Final costs, cancellations and refunds (10 mins)

*This section covers final costs and experiences of cancellations and refunds*

*Moderator to use the Customer Journey stimulus to focus on particular points in time if helpful, as well as Stimulus D2 – Cost information*

### Final costs

- **To what extent did the price, you ended up paying reflect the treatment cost agreed with the clinic before your treatment started?**
  - Did you pay more than what had been agreed at that point?
  - If so, why did you pay more? *Probe to understand reason if no clear already from discussion in the previous section:*
    - Were there additional costs for necessary treatments / extra medications? *Probe: was there a medical need for these?*
    - Did you buy optional add-on treatments, and if so, did you buy these from the clinic where you were having treatment or elsewhere??
    - Did you buy any complementary treatments, such as reflexology or acupuncture and if so, did you buy these from the clinic where you were having treatment or elsewhere?
  - At what point(s) in your treatment were these additional costs raised?
    - What information, if any, was provided about them before that?
  - Did having to pay more come as a surprise? Or did you feel fully informed about how and why costs may rise? Why do you say that?

### Refunds and cancellations

- **Did you, for any reason, not complete your treatment or not complete it as originally intended?** *Probe extremely sensitively: for example, if treatment could not go ahead or it was cancelled by the clinic or them*

*Moderator to use Stimulus D6 – Refund and cancellation information where useful*

*Moderator to also explain to respondent that for this question they can refer to any past experiences of IVF treatment, not just the last one*

- If the treatment was not completed / could not go ahead as planned, did this create any contractual problems for you, for example in respect of cancellations and refunds?
  - If yes, what were those problems?
  - Were you offered a refund?
  - If there were no contractual issues, did you consider trying to secure a refund? Why/why not?
- Did you obtain a refund?
  - If you did, how much was the refund relative to what you had paid?
  - If not, what were the reasons why not?

*Moderator to understand any differences in cancellation and refunds experiences depending on whether respondent bought one cycle of IVF treatment package or a multi-cycle package direct from a clinic or from a third party.*

## **10. Looking back (5 mins)**

*This section asks respondents for final thoughts on the subject*

- Having discussed all this, is there anything you would have wanted to be different about your experience of buying private IVF treatment? *Moderator to explain they can draw on their past experiences of IVF treatments too, if they wish*
  - Different in terms of what information was provided, when and by whom?
  - Different in terms of how information was presented?
  - Different in terms of the choices you had over the treatment plans / packages?
  - Anything else that you think would have made a positive difference?
- If you were to give one piece of advice to consumers about buying private IVF treatment, what would that be? Why do you say that?

**Thank respondents and close**