

# Patients' experiences of buying fertility treatment

**Qualitative research report** 

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### **1.1 Executive summary**

### 1.2 Key findings

The below section provides an overview of the findings taken from the main body of this report.

#### 1.2.1. The context of buying fertility treatment:

- Fertility treatment was seen by research participants as one of the most important purchases, if not *the* most important purchase, that patients are likely to make in their lifetimes. Patients often described finding it incredibly difficult to make purchasing decisions without their strong desire for a child being front-of-mind at all times, i.e., the purchase of fertility treatment is not like other consumer choices where it is easier for someone to stay emotionally detached. This meant that those who buy fertility treatment can be a highly vulnerable consumer group.
- Across the board, research participants described the experience of researching fertility treatment online as overwhelmingly complicated and daunting. This was due to both the sheer volume of information on offer combined with the importance of the decisions that patients were making.
- Most patients responded to this challenge by conducting extensive research to inform their purchasing decisions. However, there was a group of patients who did little to no research at all. The reasons for this varied. For example, for some it was due to wanting to stay with the clinic that had treated them previously, whilst others went directly to a particular clinic following a recommendation from someone they knew.

#### **1.2.2.** When patients commit to a clinic and choice of treatment:

- The way research participants navigated the process of buying fertility treatment differed substantially depending on their past experiences, such as whether they had had previous rounds of NHS-funded or private treatment. As a result, the amount of research undertaken, the particular sources of information used, and the number of clinics considered within patients' shortlists varied across the sample.
- However, despite this variation, most participants (43 out of 45 patients) only went to one clinic for a consultation, and they all went on to have treatment at the same clinic. They reported being minded already to have treatment at that clinic before paying for their initial consultation there.
- The majority of patients who began having fertility treatment with funding provided by the NHS were likely to continue to buy further treatment from the same clinic (when going on to pay for treatment).
- Patients' thinking about which treatment(s) to buy were informed largely through their research process. However, the final decision about which exact treatment(s) patients would buy took place following the initial consultation with their consultant and often after a set of tests had been carried out.
- How patients paid for their treatment also had an impact on their choices. Patients who funded their treatment predominantly using funds which were either borrowed (in the form of credit/loans) or which were gifted by family members were more likely to spend longer deliberating over which treatment(s) to buy. They were also less likely overall to purchase add-on treatments.

#### 1.2.3. The process of choosing a clinic:

- This research found that most patients buying fertility treatment for the first time carried out a shortlisting process to determine which clinics they were interested in looking at further.
- This shortlisting process was carried out first and foremost online using clinic websites before patients moved onto other sources of information to decide which particular clinic they would buy treatment from.
- For most patients, the shortlisting process included the comparison and weighing up of three main factors, these being the location of clinics within the patients' region, clinic prices, and success rate information.
  - A first sift of clinics was carried out based on two factors: <u>location</u> and <u>pricing</u>. Patients decided how far they were willing to go and then selected all the clinics within that distance. They then used the price information on clinic websites to build a sense of which clinics offered treatment that was broadly in line with their budget, as well as which clinics were priced competitively compared to others in their local area.
  - Once clinics that were accessible and appropriately priced had been identified, more thorough research on this smaller set of clinics began.
     Patients most commonly then used clinic websites to look at clinic <u>success</u> <u>rates</u>, as well as to start to gain an understanding of different treatments and to build a <u>sense of how each clinic treated its patients</u>.
- From the information gathered most patients created a shortlist of around two or three clinics that they were particularly interested in.
- Others, such as those who initially had NHS-funded treatment, as well as those who switched clinic, conducted variations of this shortlisting process. The former group carried out a much lighter-touch comparison to ensure they were not missing out on treatment offered by other local clinics by continuing to buy treatment in the same place they received their last round. The latter group followed the same shortlisting process as first-time purchasers but used these three key factors of location, success rates and price slightly differently in their decision-making.

#### **1.2.4.** The roles played by different sources of information:

- This research investigated the role played by a range of sources of information (from earlier CMA research) known to be provided by clinics for prospective patients. The main focus within these sources of information was clinic websites, but the research also looked at the role of open days and evenings, clinic social media, communications between patients and clinics prior to booking in an initial consultation, and finally the consultations themselves which were paid for by patients once they had decided where they wanted to buy their treatment from.
- The majority of patients used clinic websites at the early shortlisting stage during their research process to pick out a few clinics they were interested in buying treatment from. Therefore, for the majority of patients, clinic websites played an important role in helping patients to narrow down and decide which clinic they wanted to buy treatment from and what treatments they may want to buy. First-time

purchasers in particular were very unlikely to buy treatment from a clinic that was not on the initial shortlist they drew-up using the information provided on clinic websites.

Some patients, after they had created their initial shortlist of clinics following a review
of clinic websites continued their research using other sources of information. This
included open days or evenings (mostly virtual due to Covid-19 restrictions) and clinic
social media, as well as communication with clinics ahead of booking and paying for a
consultation.

#### 1.2.5. Patients' experiences of raising issues when unhappy with clinics:

- Patients typically felt that raising a complaint about fertility treatment was different from raising a complaint about other products or services.
  - The inherently emotional nature of fertility treatment differentiated it from buying other services or products. Patients described not only investing a lot of their money into fertility treatment, but, unlike other (high cost) purchases, they invested a lot of emotion, too.
  - Furthermore, the fertility treatment sector is one where not everyone is able to access treatment by default. Patients either have to be able to self-fund or meet the eligibility criteria for NHS-funded treatment in their area <u>if</u> there is NHS funding in their area, and there may not be. Patients in this study, who were all able to self-fund, expressed a sense of feeling fortunate for being able to afford the treatment, especially compared with others who might not be in the same position.
  - To a lesser extent, those who accessed fertility treatment during the pandemic also felt fortunate for being able to access the services during this time.
- On top of this, for many patients, purchasing fertility treatment tended to be a uniquely private experience. As a result, many patients felt that there was no understood 'norm' in relation to how someone should be treated or what they should reasonably expect from a clinic.
- For patients who raised an issue with their clinic, having a trusting relationship with at least one member of the clinic staff was often an essential factor in patients feeling able to do so. However, the relationship with the clinic could also act as a barrier to raising an issue, i.e., patients felt extremely dependent on a clinic to make their desire to have children become a reality and therefore didn't want to do anything to damage the relationship.
- Just over half of those who experienced an issue chose not to raise it with their clinic. Many told us they didn't want to add any further stress to their experience. Given the emotional toll of going through treatment, particularly when patients had an unsuccessful outcome, many patients were focused on getting through this time rather than making their lives even more difficult by adding the stress of complaining to the clinic on top of this. For those that experienced an issue but who had a successful outcome from their treatment, their lives were taken over by being pregnant, meaning that making a complaint to their clinic was low on their priority list.
- Patients who described encountering no issues during their most recent round of fertility treatment typically hypothesised that they would have raised an issue with their

clinic if something unsatisfactory had occurred. However, these patients potentially overestimated how willing they would have been to raise an issue.

 Certain patients in our sample (those who had never received a successful outcome from fertility treatment and who weren't currently pregnant from their latest round of treatment) appeared to be considerably more likely to raise issues with their clinic compared with others we interviewed. Since this was not something discussed during interviews, it is difficult to determine the root cause of this finding. However, it is possible that patients who experienced an unsuccessful outcome were more likely to reflect on and review their experience. This, in turn, could make them more likely to identify issues that they then raised with their clinic.

### 1.3 Background and objectives

In 2020, the CMA conducted <u>qualitative research</u> to explore the different stages of patients' fertility treatment journeys. This research informed, in part, the CMA's <u>consumer law guidance</u> <u>for fertility clinics</u> and a <u>guide</u> and <u>video</u> for patients on their consumer law rights.

In early 2022, the CMA commissioned BritainThinks to conduct further research on aspects of the patient (consumer) journey to help with the CMA's work in the sector.

As its objectives, this research sought to explore:

- a. The point at which patients become committed (emotionally/mentally, even if not contractually) to having treatment at a particular clinic, including:
  - a. In what circumstances, and to what extent, are they prepared to set aside and substitute their initial selection of clinic(s), if at all?
  - b. What compromises and trade-offs, if any, do patients make (and why do they make them) in sticking with a given clinic for treatment?
- b. The importance of clinic website information, relative to other information provided by clinics, in the decisions that patients make about:
  - What treatment to buy; and
  - Which clinic to buy treatment from.
- c. The role of clinic events, such as open evenings or open days, in patients' decisionmaking.
- d. When do patients decide on their treatment options?
- e. When and how does the price information provided by clinics have an impact on patients' decision-making?
- f. When and how does the success rate information provided by clinics have an impact on patients' decision-making?
- g. Where patients were unhappy with the clinic they used for their treatment, did they raise the issue with the clinic concerned?
  - a. If yes:
    - i. What did they do to raise the issue?

- ii. How comfortable were they with raising the issue?
- iii. What barriers to raising the issue did they experience, if any?
- iv. Were they satisfied with the outcome?
- v. (If dissatisfied with the outcome, and patients pursued it further) Who with, and was it then resolved to their satisfaction?
- vi. (If dissatisfied with the outcome, and patients did not pursue it further) What prevented them from doing so?
- b. If no:
  - i. What prevented them from doing so?
  - ii. What, if anything, did they do instead?
- h. Where patients were satisfied with the clinic they used for their treatment:
  - a. What would they have done (if anything) to raise an issue with which they were unhappy?
  - b. How comfortable would they have been with raising the issue with the clinic?
  - c. What, if anything, would have prevented them from raising an issue with the clinic?

### 1.4 Methodology

The approach used in this research consisted of 45 60–75-minute qualitative in-depth interviews that took place on Zoom. All interviews were carried out with patients who had purchased at least one round of self-funded fertility treatment in the UK since 1st January 2019. Of these, 28 interviews took place with both the patient and their partner to draw on both individuals' experiences, and 17 interviews took place with the patient alone. The flow of the discussion was very similar across both types of interviews.

The fieldwork was conducted iteratively, starting with a pilot stage that was designed to ensure that the topic guide (included in the Technical Annex) was working effectively. This comprised two individual depth interviews and three paired depth interviews. After the pilot stage, it was agreed to make the following key changes to the research materials:

- a. **Structural amendments**, including moving information types (i.e., pricing and success rates) to before information sources (i.e., clinic websites/open days/consultations) so that this section followed on from the 'main considerations' discussion in the context-gathering part of the guide.
- b. **Wording/ language amendments**, including additional wording in the complaintraising section to let participants know they did not need to share full details of their complaint and a note to clarify for participants the moderators' level of knowledge and awareness on the issue of fertility treatment.
- c. **Including additional lines of questioning**, including the impact of contact with clinics prior to having a consultation and the influence of reviews and social media.

Interviews took place between 21st March 2022 and 20th May 2022. The CMA and BritainThinks kept the research materials under constant review throughout the fieldwork period, drawing on our two rolling analysis sessions (which took place on 20th April and 12th May respectively) to add lines of questioning and probes to explore emerging themes and maximise insight.

#### 1.5 Sample breakdown

The below table sets out key information about the patients who formed the final sample. At the point of recruitment, specific quotas were put in place to ensure that the sample overall included a range of patients with different experiences. This included, for example, the way in which their fertility treatment to date had been funded (i.e. whether they had ever received NHS funding or had always self-funded their treatment), the type of clinic in which they had received their most recent round of treatment (i.e. a private clinic or an NHS setting that provided private treatment), and the outcome(s) from their previous treatment (i.e. whether any of their previous rounds of treatment had resulted in the live birth of a child or had all been unsuccessful). All patients needed to have received their last round of treatment in a UK clinic and since 1<sup>st</sup> January 2019, but some patients within the sample had received treatment outside of the UK in previous rounds of treatment.

Specific efforts were also made to recruit patients who had received their last round of treatment as recently as possible to try to mitigate any challenges that patients may have in recalling how and why they made the decisions they did. In addition to this, specific efforts were made to recruit patients who had bought fertility treatment at more than one clinic in order to understand more about patients who switched clinics and why they did this.

More information about the research materials used to recruit and support participants throughout the research process can be found in the Technical Annex.

	Nº		Nº		Nº
Type of clinic that the patients' last round of treatment was received in		Region		Socio-economic grade	
Private clinic 32		London	6	А	1
NHS clinic	13	South East	4	В	16
			4	C1	19
		East of England	4	C2	8
		Midlands	9	D	1
		North West	6		
		Yorkshire & Humber	5		
		Scotland	2		
		Wales	2		
		Northern Ireland	3		
Outcome of most recent round of treatment		Patient age at the time of recruitment into the research*		Relationship type	
Successful	24	Under 35	14	Mixed-sex	39
Unsuccessful	20	35-40	18	Same-sex	5
ŀ		41+	13	Single	1
Funding history (whether a patient had received NHS- funding before or not)		Patient ethnicity		Experience with the clinic and staff	
Previous NHS funding	20	White	37	Somewhat or very positive	31
Always self-funded	25	Ethnic minority	8	Neutral	3
				Somewhat or very negative	11
Treatment type					
IVF	44	Egg freezing	1		

\*Please note that patient ages in both the table above and included in verbatim quotations throughout the report relate to a patients' age at the time of their inclusion in the research process as opposed to their age at the time of their last round of fertility treatment.

### 2.1 The context for purchasing fertility treatment

For most patients (consumers), the starting point for thinking about buying fertility treatment is one which is typically charged with a sense of vulnerability and high emotion.

Data from the Human Fertilisation and Embryology Authority (HFEA) shows that, in 2019, mixed-sex couples undertook the majority of IVF cycles (94%), with patients in female samesex relationships or with no partner undertaking 4% and 2% of cycles respectively<sup>1</sup>. In order to ensure this research sample was representative of the fertility treatment market, the majority of patients we spoke to were those in mixed-sex relationships, with a proportionate number of patients coming from same-sex couples as well as single patients.

When thinking about buying fertility treatment, mixed-sex couples had typically been through a long period (usually at least two years) of trying to conceive naturally already. While many patients had an understanding of why they were struggling to conceive naturally, several patients also told us that their infertility was unexplained and that the testing they had undergone provided few answers as to why they had been unsuccessful to date. However, regardless of whether patients understood why they were having difficulties, most felt that buying fertility treatment might be their only chance to have a child of their own.

Same-sex couples typically didn't have the same history of a long period of trying to conceive naturally as mixed-sex couples did. However, they did enter into treatment feeling that this would be the only way to have a child of their own. Same-sex couples described placing their desire for a child in the hands of the clinic and its staff, with similarly limited knowledge of what the process would look like and what it would entail as mixed-sex couples embarking on fertility treatment for the first time.

For both mixed-sex couples and same-sex couples, buying fertility treatment felt like a very emotional purchase. This sense was compounded by the fact that many patients in our sample went to considerable lengths to secure funding so that they could buy their treatment. However, despite the significant effort most patients went to in order to ensure they had the means to purchase fertility treatment, patients were not necessarily in a 'consumer' mindset. For example:

- Patients placed very high levels of trust in the hands of their consultant and their chosen clinic as experts given the complexity of infertility and (at the outset, at least) their low level of knowledge around the treatment process. This meant they were less likely to critically evaluate the different aspects of the service they were buying in the way a consumer may do in regard to another purchase of similar value in another sector.
- Due to the importance that patients placed on the treatment and the desire to start it as soon as possible once a choice of clinic had been made, patients were very unlikely to not go ahead with treatment at their chosen clinic once they had paid for

<sup>&</sup>lt;sup>1</sup> Human Fertilisation and Embryology Authority (HFEA), 2021, Fertility treatment 2019: trends and figures. *Accessible at*: <u>https://www.hfea.gov.uk/about-us/publications/research-and-data/fertility-treatment-2019-trends-and-figures/#Section6</u>

their initial consultation there. This was the case even in instances where patients subsequently faced issues or poor service after their initial consultation had taken place.

• Finally, latent stigma around infertility meant a significant portion of patients in this sample told us they chose to go through the purchasing process without telling family or friends. For patients who chose to go through this process privately, their understanding of what was 'normal' was built up only through the research they conducted online, something which varied considerably from patient to patient.

Finally, a further contextual consideration specifically for patients who were starting a new round of treatment following a previous failed round(s) was the emotional and physical toll of the treatment process on their minds and bodies. Specifically, the extreme disappointment of having an unsuccessful outcome from the previous round of treatment meant that patients (as consumers) were even less able to make purchasing decisions without the weight of their desire to have a child being front-of-mind. There was some indication that patients were more likely to invest in, for example, add-ons when they had already had unsuccessful rounds of treatment. These patients were often looking for new things to try which, they hoped, might offer them a better chance of success.

# The specific timing of this research meant that patients also experienced some impact from the Covid-19 pandemic.

Restrictions brought into place as a result of the Covid-19 pandemic meant that many patients had attended appointments, scans and tests alone throughout their treatment. This meant they missed out on emotional support from their partner. Some patients also felt this led to them missing important information due to not being able to take it all in themselves (especially since they were often in a state of high emotion).

Many partners highlighted how the Covid-19 restrictions made them feel somewhat disconnected from the very personal and emotional experience that fertility treatment should have been. They also felt that the restrictions meant they were less able to provide the support they would have wanted to provide for their partner.

"You get used to it [Covid restrictions not allowing partner to be there], but it does just get lonely. I missed certain things in conversations because I wasn't there mentally, so it would have been good to have someone there to listen and hear things when I couldn't."

- 36, Midlands, Private clinic

A small number of patients, who had already started their fertility treatment before the pandemic, had it disrupted when restrictions came into place. For these patients, treatment journeys tended to take slightly longer than expected as some clinics either closed for a short period of time or experienced delays in processing patients (for example, because they were not able to carry out tests or scans). This added to the stress of the process for these patients who were all keen to move forward through their treatment plan as quickly as possible so as not to lose any time to get a, hopefully, positive result.

"It felt awful to stop treatment halfway because of Covid as it was very abrupt. The hormones turn you into a crazy person and there was no definitive date to restart treatment. There were lots of uncertainty and there was no staff - they were all put on Covid wards." - 44, South, NHS clinic

For individuals who began researching fertility treatment after the pandemic had already begun, the greatest impact was being unable to carry out in-person research to make decisions about which clinic to buy treatment from. This 'missing part' of the experience was something that these patients typically reflected on in hindsight; patients normally hypothesised that they would have made the same decisions about where to buy their treatment from even if restrictions had not been in place.

"Now that I talk to you about it, I think it's bizarre that you would spend so much money without visiting the clinic. I don't know why I didn't ask if I could go. Maybe you can put it down to Covid, I'm just not sure what the normal process is."

- 41, North, Private clinic

### 2.2 Funding fertility treatment

Interviews found that patients were most likely to fund their treatment using savings – either savings alone or in combination with another means of funding.

The following table sets out the variety of different ways that the 45 patients in the sample funded their fertility treatment.

Type of funding	Nº	Type of funding	Nº
Own savings	29	Family (gifts/loans/inheritance)	20
Alone	11	Alone	5
With funding from a family member	12	With savings	12
With borrowing (i.e. credit cards/loan)	3	With earnings	3
With earnings	1		
With re-mortgaging	1		
With borrowing and an unexpected sum of money (inheritance from a non-family member)	1		
Borrowing (loans/credit cards)	7	Earnings <sup>2</sup>	7
Alone	3	Alone	3
With savings	3	With savings	1
With an unexpected sum of money (inheritance from a non-family member) and savings	1	With funding from a family member	3
Re-mortgaging	2	Unexpected sums of money	2
Alone	1	Redundancy payment – used to cover full cost of treatment	1
With savings	1	Inheritance from a non-family member – used in combination with savings and borrowing	1

In total, 29 of 45 patients either fully or partially funded their treatment using their own savings. However, the financial impact on patients of using savings to fund their treatment varied significantly, as some patients had other important plans for the money concerned which they had to forego to afford treatment, such as home ownership.

• The largest group among those who used savings to either fully or partially fund their treatment were 12 patients who combined their savings with money they received from a family member, typically from a parent or from a sibling, either as a loan, a gift or as an inheritance.

<sup>&</sup>lt;sup>2</sup> Here, "earnings" refers to patients' and, where relevant, their partners' salaries from work.

"My mum gave me some money...she loaned me some money and said we could pay that off when we were able to. But then when it came to paying the last little bit, she was like "Don't worry about it", so that was a little bit of help there. So altogether, it was me and my husband who paid for it [treatment] together with our savings, and my mum."

- 32, London, Private clinic

"It [how we funded our treatment] was our money and our family, so my partner's mum and my dad. Otherwise, we wouldn't have been able to afford it alone, we would have had to go down the bank loans route."

- 46, North, Private clinic

• Following this, 11 out of 28 patients told us they were able to use their savings alone to cover the full cost of treatment without needing to draw on any other funds.

"Because we're a bit older, we both had savings, so the money we used just came from our savings that we had."

- 44, South, NHS clinic

"We had a bit of savings as we were looking at buying a house, so we thought we can use all of that, we'll have a child instead of a house!"

- 36, South, Private clinic

• Three patients used their savings along with borrowing in the form of a personal loan or credit card to pay for their treatment.

"We budgeted a lot and cut down on a lot of things, things that were not essential, and just saved. Initially we took a personal loan out when we first started, just to make sure we had enough for the living room and the IVF, and then we just saved to make sure we had enough money."

- 34, North, NHS clinic

• One patient supplemented their savings with their earnings to pay for treatment, while another patient used savings along with money obtained by re-mortgaging their home to cover the cost.

"Doing it in the UK, the cost was just off the scale, so I re-mortgaged my one-bedroom flat and used the money. 95% of the money came from re-mortgaging my property. It was a little bit of savings, but if I'm honest with you it was the re-mortgaging, because the bills were just adding up."

- 44, South East, Private clinic

• One patient used a combination of their savings along with funding they acquired through borrowing as well as an unexpected sum of money in the form of an inheritance payment from a neighbour.

"It was a massive financial investment. We had £5,000 from the neighbour. I moved £4,000 from a credit card in a bank transfer for a rate of 4%. So £9,000 came from there, and I had about £3,000 in savings. We were debating it for some time because of the costs involved, but because of the £5,000 that our neighbour left us in her will, that gave us the courage to go for the multi-cycle package."

- 41, North, Private clinic

Patients who didn't use savings to fund all or part of their fertility treatment used a variety of other methods to pay.

• Five patients had all of their treatment funded by a family member, typically a parent or, for some, a sibling. However, three patients used money they received from a family member and topped this up with money from their earnings in order to cover the cost of treatment.

It's [my partner's] sister who ended up being in a good position because they had a holiday home that they sold. So we've been borrowing from them. I would say that we're only 11 months in of trying now, and what we owe them is up to about £35,000. I said to [my partner] there is nothing I would want more than this. I don't care about going on holiday or having nice clothes, I just wanted our little boy to have a sibling.

- 31, North, Private

• Three patients borrowed money in order to cover the entire cost of treatment as opposed to part of it by taking out a personal loan or by using one or more credit cards.

"I took a personal loan [to pay for my treatment] and the monthly payments were quite high... I opted out of the pensions scheme from work to help pay them. Then, just when we started, we noticed the medication wasn't included, so we had to put medication on credit cards. When you read that you're buying a multi-cycle package you just assume that meant the medication too. But you're so far in by that point, you're not going to back out."

- 41, Scotland, Private clinic

• Three patients used their earnings as well as their partners' earnings in order to cover the cost of their treatment. One of these patients in particular didn't have savings, and also felt uncomfortable asking for loans from friends or family. Instead,

she and her partner worked extra hours and went for promotions in order to be able to afford treatment.

"It was a lot of overtime at work, we took as much overtime as we could do and that's what we did for years. It was also a big reason for both of us going for promotion, because we needed that extra injection and we both managed to get into those roles to be able to fund it. We sacrificed other things to afford it. We moved into this house in 2019, you know, we definitely needed a new bathroom but we're only getting that done next month now because that was something we just couldn't afford with the fertility treatment as well."

- 31, Midlands, NHS clinic

• One patient re-mortgaged their home to pay for all of their treatment, while one received a redundancy payment that they then used to cover the cost involved.

"We re-mortgaged our house in 2019 so we had some equity sitting there for that. It was meant for other things, but we decided to get on with this instead."

- 37, North, NHS clinic

### Within the sample, two patients described the impact of not being able to fund their treatment at the time they wanted.

One patient who funded their treatment using savings combined with money they received from a family member described delaying the start of their treatment while they saved more money to be able to afford it; this was specifically to finance the medication needed.

"The reason that we've left it a few months in between [rounds of treatment] is because I wanted save up for the medication before we start again."

- 32, Midlands, Private clinic

Another patient said that if they had not been eligible for NHS treatment for their first round of treatment, they would have needed to wait much longer for their first (self-funded) attempt given the time it would have taken them to save up.

"I think we would have saved and done IVF privately [straightaway] if NHS funding wasn't available, but of course we wouldn't have been able to do it so quickly if we hadn't gotten it on the NHS as it would have taken us ages to save."

- 37, North, NHS clinic

# The way in which patients funded their treatment appeared to influence how likely they were to buy add-on treatments.

Patients who funded their treatment entirely using funds from family members or who took out credit cards or loans to cover the full cost of their treatment appeared to be less likely overall to purchase add-on treatments. They also described going through longer periods of deliberation about how likely it was that a particular add-on treatment would positively influence their overall treatment result and, therefore, how much it felt like a 'worthwhile' additional purchase.

"It is the extra add-on treatments that make it get really expensive. You always wonder, do I really need this? Are they just trying to make money out of us? I think if my dad hadn't been paying for our treatment, we might have considered it a bit more, but because he was, we just wanted to keep the cost down as much as possible. We already felt so guilty."

- 44, South East, NHS clinic

# The extent to which patients felt they would be able to fund subsequent rounds of treatment had an impact on how likely patients were to purchase multi-cycle packages.

An additional factor which influenced purchasing behaviour was the extent to which patients felt they would manage to find funds for subsequent rounds of treatments if their next round of treatment was unsuccessful. The minority of patients for whom this was a concern (who analysis showed were often in older age groups too) were more likely to purchase multi-cycle packages in order to maximise their chances of success.

"Honestly the finances were the biggest consideration for me. I really had to think about how if it wasn't successful the first time, I would have to pay for it all again, so I really couldn't blow it all on one round. That's why we chose the multi-cycle package so we would definitely have another two shots even if it didn't work first time."

- 52, London, Private clinic

### 3.1 Decision-making in purchasing fertility treatment

This research specifically set out to understand the point at which patients become committed (emotionally/ mentally, even if not contractually) to having treatment at a particular clinic when purchasing fertility treatment.

While the individual nature of fertility treatment means there is no one 'typical' consumer journey, there was a high degree of commonality amongst most patients as to when and what had influenced their choice of clinic and what treatments to buy from them.

#### 3.1.1 Deciding which clinic to buy treatment from

# Patients typically made their decision about where to buy treatment from directly prior to booking their initial consultation.

Regardless of how much research any one patient had undertaken prior to booking their initial consultation, almost all (43/45) only booked and paid for one consultation at one clinic and then went on to have treatment at the same clinic. Some patients went through an in-depth research process comparing several clinics against one another, whereas others did very little to no research at all. What was consistent, however, was that patients decided at the conclusion of their research where they would buy their treatment from. They then contacted the clinic either by email or by phone in order to schedule an initial consultation.

"We'd already established that they were a good clinic before we called them. The package and location were both important. From when I found out about the package, it confirmed to me that not only did I want IVF, but I wanted IVF with a package from that clinic because it was local to us."

- 41, North, Private clinic

"I was already set on that clinic before the consultation, and we booked our cycle in the waiting room after our consultation." - 39, Northern Ireland, Private clinic

# Only two of the 45 patients behaved differently and paid for an initial consultation with more than one clinic.

These two patients booked initial consultations with more than one clinic and described being happy to pay for more than one consultation. They considered these consultations to be an extension of the research process. Following the consultations, they decided which consultant they liked and trusted the most, as well as which clinic they felt most comfortable attending.

This provides further evidence that decisions about where to buy treatment from are typically made at an earlier stage *prior* to booking, paying and attending an initial consultation with a clinic.

#### 3.1.2 Final decisions about which treatment(s) to buy

### Final decisions about which treatment(s) to buy took place after the initial consultation with the clinic and after any initial testing.

All patients went into their consultation with at least some idea of the type of treatment(s) they wanted to buy. This was either based on their own research or on their experiences of/ results from prior rounds of treatment.

However, all patients described placing huge trust in and reliance on their consultants to recommend the best treatment options for them. Following the consultation, these recommendations were strongly weighed against what patients had previously been considering. This was true even amongst those who went into consultations with strong convictions about which treatment(s) they wanted to buy.

Following the consultation, some patients had further tests or had further conversations with nurses about their options, whereas others confirmed straight away their final decision(s) about which treatment(s) they wanted to buy.

"Before I went into the consultation, I had a vague idea of what I wanted, what my money would get me, what we thought was going to be more beneficial to having a live birth. The consultant pretty much confirmed what we thought and so we moved forward with that treatment plan as soon as we could afterwards."

- 44, South, Private clinic

"There was a lot of add-ons and they are contentious things because there is very little evidence around some of it. Like the scratch, you kind of feel like they were recommending it but there hasn't been enough research to say whether it successful and you're kind of going on their word."

- 41, East of England, NHS clinic

"We went into our consultation thinking we wanted IVF, but we had a really in-depth conversation with the consultant about our previous rounds of treatment and their outcomes, and he actually advised us that ICSI [IVF with ICSI] might be a better option. I did more research about this after on my own, and we had quite a few more discussions about it between ourselves. In the end we did choose the ICSI [IVF with ICSI] since our previous rounds with IVF had already failed twice."

- 34, Midlands, NHS clinic

"The clinic offered treatment add-ons that would improve chance of success. We opted to go for glue add-on and we did that because it gave you a higher chance of working. We turned down the counselling add-on but maybe would have gone for it if pregnancy was unsuccessful."

- 37, North, NHS clinic

# 3.2 How patients' behaviour differed depending on whether their fertility treatment began with self-funding or NHS funding

Within the sample, 25 out of 45 patients recruited had self-funded all of their fertility treatment(s). Considering the high cost of fertility treatment, patients told us they had tended to do this for one of the following reasons:

• Because they knew already (or discovered following an unsuccessful referral to the NHS service) that they did not meet the eligibility criteria to receive NHS-funded treatment in their area (23 patients).

"We knew we weren't eligible for NHS treatment because my partner has a child from his previous relationship, so we just went straight to paying for our treatment ourselves."

- 38, North, Private clinic

"We did some tests with the NHS but found that we weren't eligible. After that, we saved a bit more and put the rest on credit cards to buy one round of treatment. Thankfully I got pregnant and had my little girl...we wouldn't have been able to afford another round after that."

- 32, North, NHS Clinic

• Because they did not want to wait to go through the lengthy waiting list for NHSfunded treatment to begin, even though they were eligible for NHS-funded treatment in their area (two patients).

"I was on the waiting list for the NHS for a very long time, so that's why we decided to go private [self-fund] and now I am 14 weeks pregnant. I only found out that I was at the top of the list when I actually fell pregnant."

- 41, Scotland, Private clinic

"We were considering doing the treatment through the NHS, but 8 months was just too long to wait for a consultation and to start the process. So then we spoke to a friend that had successful treatment and she recommended another clinic close to us."

- 35, West Midlands, Private clinic

Twenty of the 45 patients interviewed had accessed NHS-funded fertility treatment before going on to self-fund at least one round of fertility treatment themselves. The

# process of accessing NHS-funded treatment typically began following a referral to the service by their local GP.<sup>3</sup>

"We went to our GP after trying to conceive on our own for five years. We just wanted advice and to see if they could help. Because we had been trying for so long, they actually fasttracked our referral and we had a round of treatment paid for by the NHS. Unfortunately, that wasn't successful, so we then had to pay for our own treatment."

- 37, Northern Ireland, Private clinic

"It was my GP that turned around and said - obviously they were aware I've had several miscarriages, and they put me in touch with a clinic in Leicestershire where we were eligible for treatment that would be paid for by the NHS. At the time, we'd only recently moved to this county, so we hadn't realised we'd be eligible for something like that."

- 31, West Midlands, Private clinic

# 3.2.1 Patients who started their fertility treatment journey with NHS-funded treatment

Patients who began fertility treatment by having NHS-funded treatment (whether in an NHS or private clinic setting) tended to ask relatively few questions about different aspects of what they were experiencing (e.g., different treatment options or the potential success rates of treatment(s)) due to trusting the NHS practitioners and the process they were undertaking. They also tended to view themselves less as "consumers" during their NHS-funded round compared with patients who self-funded their treatment from the outset because they received their treatment 'for free'.

These factors shaped these patients' approaches when they were looking into buying fertility treatment for the first time. Although they already had an understanding of the different steps of the treatment process itself, they had built up little further understanding of the wider fertility treatment sector itself and how to navigate it as a consumer. Therefore, when these patients were looking into paying for treatment for the first time, their starting point was very similar to patients who were buying their first round of treatment and had not accessed any fertility treatment before, whether NHS-funded or otherwise.

"I think because we were getting the treatment for free, we didn't want to cause a fuss or be a bother. We didn't ask many questions at all and didn't really have a sense of what was coming next as we went further through the process."

- 39, Midlands, NHS clinic

<sup>&</sup>lt;sup>3</sup> These patients also all lived in locations where NHS funding was available to them and met the eligibility criteria to access NHS-funded treatment.

# Patients who had a positive experience with their NHS-funded treatment (even if it was unsuccessful in its outcome) tended to return to the same clinic when paying themselves for treatment.

Of the 20 patients who received NHS-funded treatment, 13 later decided to self-fund further treatment at the same clinic. When thinking about where to pay for their next round of treatment, those who had only received NHS-funded treatment to date were less likely to conduct much (if any) research into other clinics. This tended to be because:

- Another round of treatment (even if paid-for) was often viewed as a continuation of the previous round of treatment;
- Many saw moving elsewhere as 'starting all over again' and did not want to waste valuable time; and
- They had developed a relationship with clinic staff who they felt knew them and who they felt 'knew my body'.

"We actually chose to stay with the doctor we had on the NHS. Looking around, all the different prices were around about the same, so because we had knowledge of who she was and how she worked, and we ended up staying."

- 34, North, NHS clinic

"We decided to stay where we were because we knew it, they knew us, and it had been successful so there was no real need to start again."

- 37, North, NHS clinic

# In contrast, those who had a poor experience of NHS-funded treatment tended to buy further rounds of treatment at alternative clinics.

Seven out of 20 patients purchased fertility treatment from a different clinic after completing their NHS-funded treatment. These patients tended to feel that they had not been treated as an individual during their NHS-funded treatment and / or were looking for faster timelines than their original clinics were able to accommodate.

Importantly, these patients tended to have other people in their life who had paid for fertility treatment already and who were able to offer their perspectives on the fertility treatment sector. They also lived in regions which offered a variety of clinics to choose from.

Two of these seven patients also did specific research into success rates, which led them to feel that they would have a better chance of success at an alternative clinic.

"I didn't have a good experience in the NHS hospital with the first round of IVF, and I didn't want to go back there to pay them for further rounds of treatment. For that reason, I went to a private clinic."

- 37, Northern Ireland, Private clinic

"We were on the waiting list quite a while for the NHS and I think that we didn't really understand anything about fertility treatment. After the NHS round, I started to get a bit more desperate and pretty determined to start exploring private treatment so I could get going again as soon as possible."

- 39, Northern Ireland, Private clinic

# 3.2.2 Patients who began fertility treatment by self-funding or who chose to self-fund at a new clinic following NHS-funded treatment

Patients who began fertility treatment by self-funding or who chose to pay for treatment at a new clinic following NHS-funded treatment were faced with large quantities of information to comprehend in order to form decisions about where to buy treatment or which treatment(s) to buy.

These patients appeared to be the most vulnerable consumers within our sample due to:

- Having the highest number of decisions to make (e.g., which clinic to buy treatment from, which treatments to buy, whether and which add-ons to buy);
- Having little prior understanding of what to expect in terms of the choices they would have to make throughout the process; and
- Having different levels of motivation to carry out research about the purchase. Some patients felt less able to conduct research due to time constraints or a lack of confidence in conducting internet research on what they perceived as a complex and emotionally charged topic.

The process of researching fertility treatment was described by most as "daunting", "scary" and "overwhelming" due to the sheer amount of information on offer. A minority also commented on the perceived lack of a neutral and centralised resource to go to for information, which they felt would have been helpful in the research phase.

"The whole thing can be very overwhelming, you have to take your time, do as much research as possible so you don't rush into anything."

- 40, South, Private clinic

"I don't think you can fully take it in until you've been through the process. It doesn't really make sense, it's a lot to take in."

- 30, Midlands, NHS clinic

"I think a go-to place, with everything you needed to know in layman's terms would have been good. The websites are still very overwhelming, it's hard to know what you should go for."

- 41, Midlands, NHS Clinic

# 3.2.3 The research and decision-making process for first-time purchasers and patients who switched clinics<sup>4</sup>

In order to make decisions about which clinic to buy treatment from, most patients carried out a shortlisting process to narrow down the options on offer.

The typical four-stage process of shortlisting was as follows:

Step 1	A first sift of clinics was carried out based on two factors: <b>location</b> and <b>pricing</b> . Patients decided how far they were willing to go and then selected all the clinics within that distance. They then used the price information on clinic websites to build a sense of which clinics offered treatment that was broadly in line with their budget, as well as which clinics were priced competitively compared with others in their local area.
Step 2	Once clinics that were accessible and appropriately priced had been identified, more thorough research on this smaller set of clinics began. Patients most commonly then used clinic websites to look at each clinic's <b>success rates</b> , as well as to start to gain an understanding of different treatments. At this stage, patients also used the clinic websites to begin to build a <b>sense of how each clinic treated its patients</b> (i.e., the extent to which clinics treated their patients as individuals with tailored treatment packages versus treating all patients the same or 'as numbers', as patients described). Some patients also used clinic websites to learn more about the potential practitioners that they might be seen by, particularly patients who had very specific medical backgrounds and who looked for practitioners that had experience of providing treatment to people like them. From the information gathered in steps 1 & 2, most patients <b>created a shortlist of around two or three clinics</b> that they were particularly interested in.
Step 3	Some patients then did more research on this smaller set of clinics by <b>requesting</b> <b>clinic brochures or packs.</b> Some patients looked at <b>online reviews</b> or <b>social media</b> (both run by clinics themselves as well as not) where they built a sense of other patients' experiences. Some patients also chose to speak directly to clinics via <b>phone</b> or <b>email</b> in order to get further information.
Step 4	Once patients had completed their research process, most then <b>made a decision</b> about which specific clinic they would like to buy treatment from before contacting the clinic concerned by phone or by email to <b>book in their initial consultation</b> . (Only two patients in the sample booked, paid for and went to consultation appointments with more than one clinic before making a final decision about which of their shortlisted clinics to buy treatment from.)

<sup>&</sup>lt;sup>4</sup> This shortlisting process was not followed by patients who had received NHS-funded treatment and who then continued to pay for treatment at the same clinic where they had received their NHS-funded treatment. Further detail is included throughout the report to draw out distinctions between the steps taken by this patient group and others.

To bring this shortlisting process to life, three patients' experiences of making their decision about which clinic to buy treatment from are set out below:

#### Case study 1: Keisha

Keisha and Mike live in London. It was important for them to go to a local clinic as both were working full time so they would need to schedule appointments around that. There were three clinics in their area, so they looked at these.

After location, price was an important consideration. They found the pricing information online and then called the clinics to confirm the prices. This helped them cut down the list from three to two, as the price offered by one clinic did not include medication.

The final decision came down to success rates, which they found on the clinic websites. They also used the HFEA website for this.

#### Case study 2: Tracy

Tracy is in her 40s and lives in the North of England with her husband. As they had already been trying for a child for a long while, it was imperative that they could get started quickly.

As neither of them can drive, they needed to pick a clinic that they could access easily on public transport.

After location, and after looking at prices and feeling they were fairly similar across clinics, they looked at Google and Trustpilot reviews because they wanted to hear from real people about their experiences. The clinics with the best reviews remained on the shortlist.

The final stage was calling the clinics to see who they could get a consultation with first.

#### Case study 3: Gemma

Gemma and her partner live in the Midlands. They had struggled for a while to conceive naturally. Because Gemma's partner had children from a previous relationship, the couple was ineligible for NHS funding in their area. However, they did have initial tests done through the NHS (her egg count and his sperm analysis).

They had a really good relationship with the doctors at the NHS clinic. One of these doctors referred them to a local private clinic, of which he was the director. As they knew they could afford one round and trusted this doctor, they were happy to go with this recommended clinic based on his advice rather than doing any research.

Patients' descriptions of the process they undertook to choose a clinic to buy treatment from demonstrated that first-time purchasers predominantly weigh up three main factors:



Initially, patients used broad location as a means of assessing which clinics were accessible to them. From these clinics, they looked at price information to see if the clinics' advertised prices were within their budget and comparable with other clinics in their local area. Finally, patients looked at success rate information to check whether the clinics in scope appeared to offer similar chances of success.

However, following patients' first round of treatment, it was the outcome of that round of treatment which became the *most* influential factor in determining where patients would buy future rounds of treatment (if this was something the patient wanted and could afford to do).

For patients who had **successful treatment** from any round of treatment (whether their first round or a later round), future purchasing behaviour was highly predictable. These patients consistently returned to the same clinic if and when they wanted further rounds of treatment.

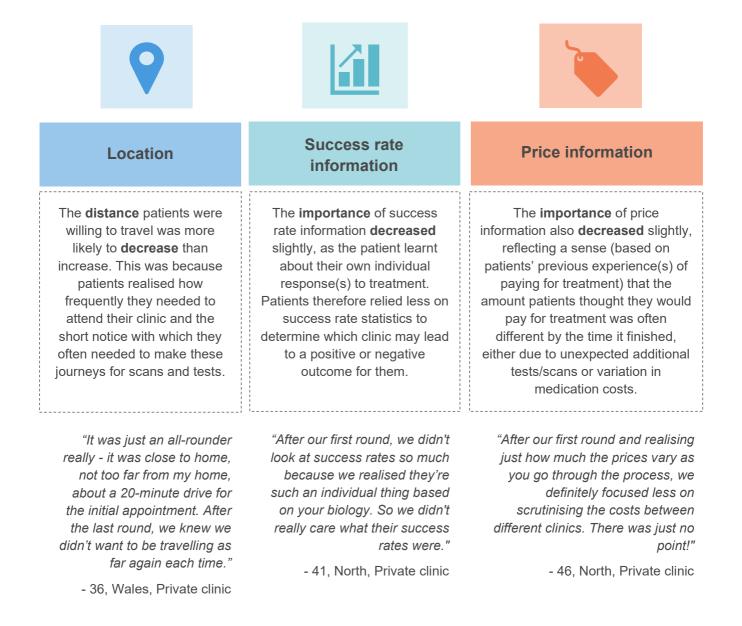
"We already looked at success rates at the start, but we didn't look very much after our first round. I wasn't going to change clinics after a successful pregnancy."

- 44, South, Private clinic

"For me, it was having treatment in the same place as before. It is important for me to go back to the place where we had a successful outcome and trust the doctors."

- 27, Midlands, Private clinic

However, for those who had unsuccessful treatment and who went on to purchase further rounds of treatment, the three main factors being weighed up in the decisionmaking process were consistent, but the importance placed on each of the factors changed somewhat.



#### A small number of patients bypassed the research and shortlisting process altogether and took a different path to making decisions about their treatment purchase.

Three patients bought treatment from a clinic because they knew someone else who had successful treatment there (or in one case simply had a positive experience with the outcome of treatment still unknown). In these cases, the emotional draw to the clinics concerned was incredibly strong and little other information, which few sought, could have persuaded these patients to consider treatment elsewhere.

Two patients chose one of the first clinics they came across (and were only concerned with it passing basic checks such as having reasonable prices, success rates and reviews) so as to shield themselves from the emotional and mental impact of sifting through large volumes of information online about such an important decision.

"I had put up on my Instagram that I was considering donor egg and got chatting to a girl who lives near me who had donor eggs in [a clinic] and who had a really good experience. I got in touch with [the clinic] and they said they do get a lot of people from Northern Ireland because at the time it just wasn't available. The girl on the phone was so nice and immediately put me at ease and I thought 'Yes...this is the place for us, we have to go here'."

- 37, Northern Ireland, Private clinic

"To me I was quite committed without considering other providers quite early on. Once I'd emotionally decided that this clinic was going to be great, I just got it in my head that I was going to go with them."

- 41, North, NHS & Private clinic

# There were also patients who, due to their specific location, felt they had a very limited choice of clinics and therefore conducted minimal research.

Patients in our sample who were based in certain areas of the country (around Glasgow, in Cornwall, parts of the East of England and in Northern Ireland) had tended to do less research than those living elsewhere because they felt they had only one or two local clinics to choose from and did not wish to travel further afield.

"If there had been more choice in terms of other local clinics then we'd definitely considered other options but because you had such little choice there isn't much point."

- 39, Northern Ireland, Private clinic

"There's only one clinic in Glasgow so there wasn't much choice. I didn't do that much research, we just went to the closest one, so the one that was accessible because of tests."

- 41, Scotland, Private clinic

#### 3.3 Decision-making in relation to additional rounds of treatment

Even if they were having unsuccessful outcomes, patients who had a positive experience with the clinic and its staff tended to buy further rounds of treatment (typically two or three) from the same clinic before they considered moving to another.

A range of factors contributed to patients' thinking when deciding whether to stay with their current clinic for further rounds of treatment or to look elsewhere.

- **The nature of their relationship with the clinic**: Patients usually stayed at the same clinic (despite having an unsuccessful outcome) if they had a positive relationship with and felt understood by the clinic and its staff.
  - In this context, patients felt that remaining with a clinic that understood their medical history would increase chances of future success.
- Wanting to start the next round of treatment quickly: Many patients described wanting to start the process of their next round of treatment as soon as possible so as to increase their chances of success. In most instances, this led to patients wanting to remain with their original clinic (assuming a positive relationship), because researching alternative clinics and going through the initial stages of a consultation and re-explaining their history with fertility treatment was felt to take too long.
- **External influences**: Being exposed to additional influences since carrying out their initial research (e.g., receiving a recommendation, from someone they knew, about a different clinic or reading about an alternative local clinic nearby that appeared to have significantly higher success rates) increased the chances that patients would move elsewhere. Patients who did not come across such influences were more likely to stay with their original clinic.

"For me, it was the same nurses and consultants, they were great, and we wanted people who knew us. The nurses get to know you and you don't want to start all that again with other nurses. It's quite emotional."

- 40, Scotland, NHS clinic

"I don't think we thought about going anywhere else because we were treated so nicely. Even the women at the front desk, the receptionist knew us by name. And you could tell they made an effort to remember people's names."

- 30, Midlands, NHS clinic

However, patients who had unsuccessful treatment at the clinic where they first paid for treatment, *and* who had a poor experience with the clinic and its staff, tended to look elsewhere when considering buying their next round of treatment.

When considering a second round of treatment, patients who had a less than satisfactory experience with their first clinic *at the very least* began researching other clinics, and some found a new clinic to purchase treatment from for their second round of treatment.

"We had an unpleasant experience at the first clinic where my wife wasn't treated well with regards to her specific condition. So, trying to get a sense of what the staff were like at the other clinics we were looking into became a key priority for us."

- 36, Midlands, Private clinic

The likelihood of moving elsewhere was heightened for patients who also:

• Knew someone else who had successful treatment at another clinic in their area.

"I looked into doing our last round at a different clinic nearby and it was quite pricey. But I was intending on going through with that until I had a friend who had a successful pregnancy with her clinic and she was singing their praises. I did a little bit of research of them online and then went for the initial consultation, so I decided on our last clinic based on a personal recommendation. I had looked at other clinic statistics and success rates and things like that, but I think that the personal touch was how I made my decision."

- 52, South East, Private clinic

 Wanted a different treatment to that which the current clinic was able or prepared to offer.

"Our first fertility clinic was quite niche. We tried there with my own eggs but that didn't work. They always said you had to try with your own eggs first and then after that, we got the results, and it was like 'OK, how to plan for going to the donor?'. But the waiting list and for what we were looking for, they said it could take ages. They had no timescale at all. So we then tried again at a different clinic where they are known for their frozen eggs and donor eggs."

- 46, North, Private clinic

"At our first clinic, I felt pushed to have IUI even though we had gone into it wanting to do IVF. The consultation was very much like 'that is your best option'. We didn't know so much about it then, we trusted their thoughts and opinions. It wasn't until it wasn't working that we thought, 'Why can't we just go to a different clinic?'. At the next clinic, the consultant was great, we told him what we wanted, and he said, 'no problem', he didn't seem to have an agenda."

- 30, East of England, Private clinic

• Did further research about success rates and learnt their current clinic appeared to have poorer success rates compared with other clinics within their desired area.

"We actually bought our first round of treatment from the same place where I'd had my NHS-funded treatment. But after the round finished that we'd paid for, my husband looked into success rates and we realised that the place we'd been getting treatment had much worse success rates than other clinics in our area."

- 45, South, Private clinic

# 4.1 The role of different information sources in the purchase of fertility treatment

From the CMA's <u>previous research</u> into fertility treatment, several sources of information were already known to feature in patients' decision-making processes for choosing and buying fertility treatment. This research was designed to understand what role each of these sources of information played in more depth. The key information source explored within the research was:

• **Clinic websites**: in order to understand what impact clinic websites had on patients' decision-making about where to buy treatment and which treatment to buy.

Additional sources of information that were important for the CMA to understand in greater depth were:

- **Open days or evenings**: specifically understanding the type of information shared with patients at these events
- **Consultations:** to understand what role these played in patients decision-making about where to buy treatment or which treatment to buy

Interviews uncovered two additional sources of information which some patients described as influential in the decisions they made about which clinic they would buy treatment from and which treatments they would buy. The additional sources of information which were included in the research as areas of focus following the pilot interviews stage were:

- Clinic social media, e.g., their own Facebook pages, Instagram accounts
- Social media accounts about (but not run by) specific clinics (i.e., patient-generated and managed), independent review websites, and word of mouth; and
- Direct communication with clinics prior to booking in a consultation, via email or telephone

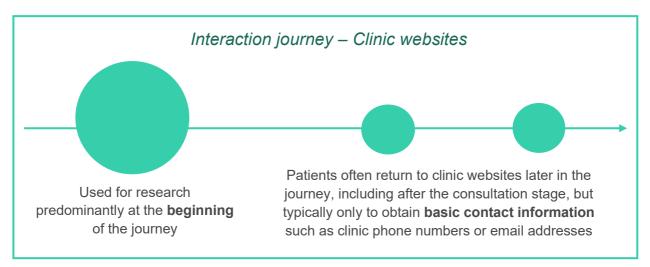
Analysis showed that these different sources of information were used at different stages of the patient journey and provided patients with different types of information.

Starting the process of deciding whether to have treatment, who to buy it from and which treatments to buy Ending the process of making a decision about where to buy treatment from and which treatments to buy	Clinic websites Clinic social media	At the outset of their research, most patients used clinic websites as their main source of information about a clinic's location, success rates, and prices. They also used clinic websites to gather a sense of the overall approach of the clinic and to request information or pricing packs. Sources of information such as the social media pages run by clinics themselves (e.g., Facebook, Instagram) were used only by a minority of patients. These pages were used predominantly to look at reviews from patients who had previously attended a specific clinic, but patients often expressed their concern that clinics were unlikely to share negative reviews of their treatment
	Informal sources of information (not clinic- affiliated/ controlled)	on pages they had control over. At least half of the patients we heard from used sources of information such as word of mouth, independent review websites and social media accounts about, but not run by, specific clinics to do further research on a set of specific clinics that had been identified. Through these interactions with information which wasn't set up or run by specific clinics, patients gathered what they felt was trusted insight from people with lived experience of purchasing treatment from specific clinics.
	Direct communication with clinics prior to booking in a consultation	For those who had further questions about a particular clinic, they often contacted that clinic by phone or by email. Within these interactions, the warmth of the staff and how personal the clinic's response felt were key in shaping perceptions and decisions.
	Open days or evenings	A minority of patients attended open days or evenings run by the clinics they had a strong interest in. They attended these sessions to get a better understanding about specific clinics' ways of working (e.g., how personal is the service) as well as to understand more about the treatments on offer at that particular clinic.
	Consultation	By the time patients booked and paid for an initial consultation and tests at a particular clinic, the majority were already certain that they would pay for their treatment at the same clinic. In consultations, patients discussed their prior medical and fertility treatment history as well as the different treatment options offered at the clinic. In total, 43 out of 45 patients bought treatment from the clinic they booked their initial consultation with. Only two of 45 patients scheduled initial consultations with more than one clinic to help them decide which one they would buy treatment from.

#### 4.2 Clinic websites

Clinic websites are fundamental, particularly in the earliest stages of a patient's research process, in helping them to build an understanding of which clinics they might want to buy treatment from and which treatments they may want to buy.

Clinic websites were typically used by patients to make decisions at the beginning of the journey about which clinics to shortlist as potentials for buying treatment from and what treatments to buy, with additional information then gathered in a variety of other ways later on in the research process.



For patients buying treatment for the first time and who weren't going to use the clinic where they had received NHS treatment before (if applicable), looking at clinic websites was typically the first thing they described doing when starting their research. Clinic websites provided patients with key information such as a clinic's specific location, success rates, prices, and indicators as to how clinics treat their patients. As such, clinic websites were used most distinctly to help these patients make early-stage decisions about which clinics they were interested in doing more research about as well as which clinics to eliminate (most often due to inconvenient location or non-competitive pricing). Once further research had been carried out on clinics that had been shortlisted, a process which included returning to clinic websites to read the information again, most patients purchased treatment at one of the clinics they had initially shortlisted by looking at its website earlier on in their research process.

The key information that patients used clinic websites for, in the early stage of their research and shortlisting process, were:

• **Convenience and access to the clinic**: Patients were first and foremost looking to determine which clinics were near to their desired location. Due to the need to attend the clinic in person on a number of occasions to receive treatment or carry out scans or tests, patients tended to look only at clinics that they could easily reach. This was even more so the case for patients who had already been through at least one round of treatment (whether this was self-funded or funded by the NHS) since these patients had an even greater awareness of the requirement to regularly attend the clinic, often at short notice.

"When we were looking at clinics, location was a really big factor for us. We needed somewhere that was nearby so that we could both dip out of work if they needed us there for appointments or at short notice. With the clinic where it was, we could do that, we'd have gone and been back at work within the hour"

- 31, Midlands, Private clinic

Information about a clinic's prices: Clinic websites were a key source of information for initial cost comparison between clinics. However, patients were not looking for an exact figure about how much their specific treatment package might cost. Instead, they were looking to build a general idea of which clinics offered treatment in line with their general budget as well as to what extent each specific clinic's pricing was competitive compared with other clinics in their local area. Patients took this approach since, at this early stage of the research process, there were many more decisions to make about where to buy their treatment and which treatments to buy, aspects that could both have an impact on the exact cost of their treatment.

"Pricing was important, but I think we would've paid it regardless of what it was – It was more to check that we weren't being ripped off and paying ridiculous amount."

- 26, Midlands, Private clinic

"Knowing what we know now, I would probably look at a lot of different factors, not just price. We were very naïve... it doesn't tell you how much the medication is, doesn't tell you what to expect going forward."

- 34, North, Private clinic

• Information about available treatments and a specific clinic's success rates: Once they had determined which clinics were in their preferred location and within their budget, patients then tended to use clinic websites to conduct an initial comparison of success rates and the treatments on offer at each clinic to understand which clinics were most successful in delivering the type of treatment they were interested in. Some patients already knew at this stage which specific treatment they would like to have (something they discussed in more detail with their consultant at their initial consultation), whereas others were less sure and so tended to compare success rates, for example, between IUI and IVF. A minority of patients didn't engage with success rates on clinic websites at all for a variety of different reasons such as not wanting to overburden themselves with complicated statistics or not trusting the data (for more information, please see section 5.2). However, many relied on the success rates shown on clinic websites to help determine, alongside geographical location and price, which clinics to take forward into their final shortlist.

September 2022

"I got the information about success rates from the clinic website. I didn't even think about looking elsewhere, I just went off what was on the website."

- 52, South, Private clinic

"In the initial stage I was looking around at success rates [on clinic websites], and I whittled a few of them [clinics] off the list based on that."

- 42, South, Private clinic

Building a sense of how a clinic treats its patients: Outside of information that • was directly provided to prospective patients through clinic websites, another influential aspect was the 'look and feel' of the website. This was regularly described by patients as something they looked at to try to build a sense of how they might be treated by a particular clinic. Patients wanted to buy treatment that would be as closely tailored to their needs as possible, and for this reason they were looking for clinic websites which firstly provided a sense of professionalism to maintain the patients' trust that the clinic's practitioners were experts in the field. However, importantly, this needed to be paired with warmth to reassure the patient that they wouldn't be treated 'as a number' and that they would have a treatment plan which was carefully based on their past test results and treatment outcomes and met their individual needs. This meant that some patients discarded clinics from their shortlisting process if the type of service portrayed on the clinic website did not meet their expectations, something which even patients themselves described as highly subjective and personal to them. Testimonials from past patients on clinic websites were also read by some patients as a way to gauge how a clinic treated its patients, but most felt that this information was less worth taking into account in their decisionmaking because of its potentially biased nature (whereby a clinic would likely show only positive reviews from their past clients).

"The websites were quite significant because if I thought they had a bit of a dodgy website, I just moved on. So, it did play a role when I was making my shortlist."

- 52, South, Private clinic

"Clinic websites do play a part as you get a feel of what that clinic is like from their website."

- 39, South, Private clinic

Once patients had engaged with this key information through clinic websites at the beginning of their research process, and formed their shortlist, most patients then continued to engage with other types of information in order to reach their final decision about where to buy treatment (e.g., informal sources of information, open days or evenings, or communications with a clinic prior to the consultation stage).

However, these patients overwhelmingly tended to buy treatment from a clinic they had initially shortlisted using information on clinic websites. This shows that clinic websites play an

important role in shaping patients' decisions about where to buy treatment, even if further research is also done to supplement the information patients come across on clinic websites.

Patients in other circumstances also tended to buy treatment from a clinic they shortlisted using clinic websites, such as:

- Patients who had received NHS-funded treatment at a clinic but who had a negative experience and who therefore looked into buying treatment from a different clinic
- Patients who were looking to buy a round of treatment again but at a new clinic

The exceptions to this rule were patients who were influenced by a word-of-mouth recommendation or who knew someone that had successful treatment at a nearby clinic, or those who had NHS-funded treatment and decided to continue to pay for treatment at the same place, meaning they did not go through this shortlisting process.

### An additional requirement around clinic websites was the need for patients to be able to download or request clinic brochures or packs as well as to quickly access clinic contact information such as email addresses or telephone numbers.

While not all patients did this, a significant proportion used clinic websites to request clinic brochures or packs from clinics they were interested in learning more about. Some patients found that clinic websites did not include price information, or that only a limited amount of data was available regarding success rates. Therefore, for these patients, requesting a clinic's brochure or pack was a way to access information they didn't already have. However, many patients felt satisfied with the information included on the clinic's website, but given the scale and importance of the purchase, requested a clinic's brochure in order to have access to the full range of information offered by the clinic they were interested in. Patients typically requested the brochures or packs from clinics on their final shortlist, usually between two or three clinics. Some patients described these brochures and packs as more detailed versions of the websites, potentially due to the brochures presenting the information in a more easily digestible format than on the website (as opposed to actually including more information).

"With a lot of the clinic websites I was looking at, you don't get the pricing straight up on the internet [i.e., the clinic's website], so I did have to contact a few to ask for their brochure."

- 42, South, NHS clinic

"They sent me a brochure which I looked through. It had more detail on the process and the medical treatment."

- 41, North, Private clinic

Additionally, it was important for patients to be able to easily access general contact information about the clinic, most commonly the clinic's email address and telephone number. These contact details were used more in the later stages of the research process and were most frequently used to book in a consultation once a patient had decided that they would buy their treatment from that specific clinic. However, some patients also used these contact details to ask specific questions to the clinic via email or by telephone before deciding that

they definitely wanted to buy treatment there, with the nature and outcomes of these calls often playing a role in the decisions patients made. It is worth noting that the inability to easily find contact information on a clinic website raised concerns for some patients, where a perceived lack of lack of transparency was a red flag for a purchase of this size and importance. In some cases, this led patients to exclude a clinic from their shortlist altogether.

"We looked for contact information on the websites of the two clinics ...called them both and went for the one that had an appointment sooner and was nicer on the phone. The clinic felt really helpful, kind, empathetic, knowledgeable."

- 40, South, Private clinic

## As referenced earlier in this chapter, there is some variation in the way that other patient groups (other than those buying treatment for the first time and who haven't had NHS-funded treatment before) use clinic websites.

Patients who *had* received NHS-funded treatment in their previous round(s) of treatment and had a positive experience with the clinic itself (despite not having a successful outcome), and therefore intended to continue with the same clinic for their self-funded treatment, tended to use clinic websites to compare other clinics in the local area with the one they had already received treatment at.

These patients described spending less time on clinic websites than those who had not received NHS-funded treatment before or whose experience of NHS-funded treatment was not positive. These patients tended to focus solely on price information and success rate information to check they were not missing out on treatment offered by other clinics in their local area that either looked considerably more affordable or looked like it had considerably higher success rates. Patients said that small differences in success rates or prices at other local clinics were insufficient reasons to change clinics: they were looking for substantial perceived improvements in order to consider moving. However, more substantial differences were also treated with caution. Clinics that offered treatment at significantly lower prices than most other clinics were not necessarily trusted by patients. Given the requirement to maximise chances of success, clinics that did not align with the rest of the 'pack' tended to be removed from consideration. Therefore, while clinic websites played a slightly different role for patients in this position, they were still an important tool in helping them to weigh up the prices and success rates of their previous clinic with others in their local area.

"We did have a quick look around at other clinics in the area, just to check out other prices, but we didn't want to move clinics as had been there already, knew the staff and built good relationships with everybody. There was nothing wrong with the actual clinic, we'd had good treatment. We knew what to expect."

- 40, North, Private clinic

Patients who had NHS-funded treatment but who had an experience negative enough to push them to consider buying treatment at a new clinic used clinic websites in a

### similar way to patients who had no NHS-funded treatment before and who were buying treatment for the first time.

Whilst these patients tended to have a better sense of the treatment process and typical treatment options, the variety of choice in clinics tended to be something they were far less familiar with. Therefore, clinic websites were used by these patients in a very similar way to those who were looking to buy treatment for the first time and who hadn't received any NHS funding before. Patients in this position stated that they went through the same shortlisting process to survey the clinics available to them, the different treatments on offer, and their options around pricing and success rates.

# Finally, patients who were looking into switching clinics described using clinic websites in a way similar to patients who were buying treatment for the first time and who had not had any NHS-funded treatment. (This was true even when these potential switchers had, in fact, had NHS-funded treatment.)

Patients who had paid for at least one round of treatment and who then decided they wanted to switch clinics (though this more frequently tended to happen after paying for at least two rounds of treatment at the same clinic) described following the same shortlisting process as those who were buying treatment for the first time and who hadn't received NHS-funded treatment previously. However, while they followed the same process, they tended to approach the information included on clinic websites somewhat differently, as outlined in section 5.3:

- Patients who were potential switchers tended to use clinic websites to look for clinics that were either no further away or closer in distance due to the higher awareness of needing to travel to the clinic regularly and sometimes at short notice.
- Patients looking to switch also tended to pay less attention to price information on clinic websites because (in keeping with other patients who were buying additional rounds of treatment but who were not switching their clinic) they had experienced the cost of their previous round of treatment increasing unexpectedly while it was underway – mostly due to additional tests or scans, or changes to the type or amount of medication they needed. When choosing a new clinic, these patients still required potential clinics to offer treatment within an acceptable budget range and to be comparable to other local clinics, but they gave price information less weight when making their final decisions.
- Patients looking to switch also tended to pay less attention to success rate information on clinic websites when looking for a potential alternative. Given that they had data from their previous failed rounds, they were more likely to feel that the success rate on clinic websites did not give them an accurate representation of what their own chances of success might be.

"We didn't look into pricing particularly deeply. Because we'd had treatment at different clinics before, we assumed it would all be relatively similar, and it's dependent on your body. It was our last turn - we were like 'we'll pay for whatever it needs'."

- 45, South, Private clinic

"Success rates are very important, but it does go case by case ... it's individual, you know, there are so many medical reasons why things don't happen"

- 42, South, Private clinic

### 4.3 Other sources of information

Four out of 45 patients had browsed the clinic's own social media accounts, typically on either Facebook or Instagram.

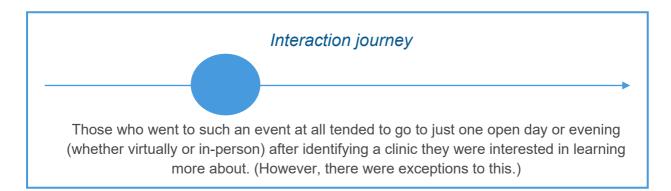
In general, these pages added very little to the information already on clinic websites but did offer access to reviews from other patients. Social media accounts operated by the clinics themselves were not felt to be particularly influential in the process of deciding which clinic to choose or what treatment to select. Instead, they were considered to be a hygiene check, i.e., a means of seeing whether there were any bad reviews (although there was some suspicion that clinics might delete negative reviews from their social media accounts, just as they wouldn't post negative reviews on their websites).

Patients are far more likely to engage with informal sources of information that are not operated by specific clinics, most notably word of mouth, non-clinic social media and review websites. Around half of patients said that they had used at least one of these sources of information, and the impact of doing so was felt to be far greater than that of the clinic's own social media accounts. This was felt to be an effective way to compare and check this information against other people's experiences. Reading other people's real-life experiences was felt to be the most trusted way of doing this.

These different sources of informal information all served similar purposes in that they allowed patients to hear views from people who weren't 'selling' them something.

### 4.4 Open days and open evenings

While only a minority of patients attended clinic open days or evenings, those who did attend said that such events had a significant impact on their final decision about which clinic to purchase treatment from, and which treatments to purchase.



Most patients in the sample were unaware, prior to interview, that some clinics might run open days or evenings for prospective patients. Others knew that some clinics did usually put on events of this kind but didn't get to attend because the events were cancelled due to the pandemic.

Patients who didn't attend an open day or evening were split in their views about whether they would *in theory* attend such an event, if they had been aware they were taking place:

- For those who felt they would not attend, the key barrier was doubt that open days or evenings would provide sufficiently specific information for their own individual circumstances. Some also wanted to keep their treatment journey private and felt that attending such an event put this anonymity at risk.
- Others, though, felt they would have benefitted from an opportunity to find out more information ahead of time.

"It wasn't offered but I have seen it on the Facebook and Instagram page. But it wasn't something we felt we needed to go to. My partner found it quite hard to adjust to us needing IVF so to go to an open day was too big a step."

- 32, Midlands, NHS clinic

Of the 45 patients interviewed, seven did attend an open day or evening (five in person pre-Covid-19, two virtually once the pandemic began). They had tended to find out about the events on clinic websites, through the clinic's own social media accounts, or through paid adverts (e.g., on Facebook or on the tube). Importantly, these events were felt to be particularly influential in helping patients to make their decisions about where they wanted to buy treatment from:

- Five of the seven said that attending the open day or evening led them to book a consultation with the clinic concerned.
- The remaining two had added the clinic to their shortlist (though they ultimately bought treatment from another clinic).

One of these seven patients attended a particularly high number of open days or evenings, whereas the remaining patients typically attended only one or two. With this greater level of experience, the patient who had attended several open days and evenings said:

"We have joined so many evenings and seminars. Some are like PowerPoint presentations that go through the different practitioners at the clinic, others had hosts with different speeches talking about different aspects of treatment. Some were very interactive with a specific Q&A section where other women would ask questions anonymously and then you might learn something you hadn't ever thought about before. During Covid-19, sometimes no one else would book onto the sessions and so it just ended up being you and the consultant which was basically like a free 1-hour question and answer session – those were great! Those in particular were very personal."

- 36, Midlands, Private clinic

## Open days typically provided patients with the opportunity to learn more about the clinic, the treatments it offered, and to ask questions that were relevant to their own situation.

For those who attended, open days or evenings offered a number of benefits:

- They allowed patients to get a feel of the clinic (particularly for those who attended in-person prior to the pandemic), as well as a chance to meet some of the practitioners who would providing treatment
- They allowed patients to hear from practitioners about the different treatments on offer and to hear about the difference between these options from an expert;
- They allowed patients to begin to develop a rapport with the clinic staff; and
- They created an opportunity to have information explained verbally, which was felt to be a helpful addition to receiving information online.

## Several of the open days or evenings attended by patients (whether in-person or virtually) had distinct Q&A segments where patients were able to gain information further to that which is available on clinic websites or in clinic brochures.

This led to patients having the ability to ask more detailed questions around the pricing of treatments, the types of treatment a clinic offered or questions about the clinic's success rate information. This was especially true for patients who attended open days/evenings in person prior to Covid-19 restrictions, as well as sessions that were run solely as Q&A sessions. Typically, though, all open days or evenings featured at least a specific Q&A segment at the end of a session where prospective patients could ask these questions. As a result, for some patients, these events were the most informative part in their process of looking into fertility treatment.

Open days or evenings (whether carried out in-person or virtually) were also an important opportunity for prospective patients to start to build a relationship with the clinic and their practitioners. This relationship and sense of rapport with the clinic's staff was a fundamental component in patients' decision-making when choosing which clinic to purchase treatment from.

One of the seven patients who attended an open day or evening was also given the opportunity to save money on their consultation fee by using a discount code they received at the open day. While this opportunity to save money was not a factor in their eventual choice, they ultimately used the code, saved £100 on their consultation fee, and did go on to buy treatment from the clinic.

#### Case study: Dani

Dani and her wife Mel attended an in-person open day at a London clinic as a way to learn more about the process of IVF in their very early stages of thinking about trying to start a family.

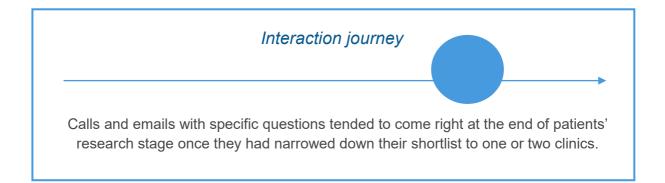
At this open day, they were incredibly impressed with the clinic's inclusivity towards samesex couples and were intrigued to be introduced to the idea of shared motherhood.

The couple then spent two years going through a referral and testing to access treatment on the NHS, only to find out that they weren't eligible.

Dani and Mel went straight back to the clinic whose open day they had attended during the pandemic to buy their first round of treatment. This was an easy choice for them, and they did no further research into other clinics after remembering how welcome they felt several years prior.

### 4.5 Direct communication with clinics prior to consultation stage

A sizeable minority of patients had contact with a clinic prior to paying for an initial consultation, which in all cases contributed to the patient's decision to go with that clinic.



In total, 12 out of 45 patients told us they had significant further contact with their clinic after their web-based research and prior to booking in and paying for a consultation (significant being defined as more than contacting a clinic to request information packs or pricing lists). These patients all subsequently paid for a consultation and went on to buy treatment from the clinic they contacted (or for the minority, one of the clinics they contacted).

The majority of these communications took place via telephone (ten out of 12 patients used this method and the others emailed).

Patients called clinics typically when they were still considering one or two clinics with a specific question(s) in mind, often around waiting times, treatments offered or pricing questions. However, ultimately, these calls became an opportunity for a clinic to build trust and rapport with the patient.

Some of these patients described making calls to other clinics at the same time but choosing to book a consultation with one clinic over another due to the perceived warmth, helpfulness and friendliness of their conversation(s). These interactions helped to build confidence that their treatment would be designed with their individual needs in mind, versus being treated as simply 'another number'.

"We looked at two places but the first place we didn't like the attitude of the person on the phone so didn't go for that one. We made a phone call to the second clinic and they were just amazing from that phone call and got us in the same day that we enquired."

- 29, Midlands, Private clinic

### **4.6 Consultations**

Initial consultations were, for the vast majority of patients, not used to discuss whether a specific clinic was right for a patient (since this decision tended to have been made already by this point). Instead, initial consultations were used to discuss the best treatment for an individual's needs.

Altogether, 43 out of 45 patients chose to have an initial consultation at only one clinic who then went on to purchase treatment from that same clinic. These patients had already made a provisional decision that the clinic where they booked and paid for their initial consultation would be the clinic they would buy treatment from. A number of considerations drove this tendency to decide on the clinic before the initial consultation:

- Patients generally considered their initial consultation to be the beginning of their treatment process. This reduced the likelihood that they would subsequently look elsewhere or schedule multiple consultations with multiple clinics.
- As noted elsewhere, patients were keen to begin their treatment quickly. In this context, spending time going to lots of separate consultations was felt to waste valuable time.
- The price to be paid for the initial consultation acted as a disincentive to having multiple consultations.
- Patients with particularly complex circumstances avoided attending multiple consultations as a way to protect their own mental health as they felt repeating their story in detail on a number of occasions would be distressing.
- Finally, the selection of the clinic often followed extensive research: patients felt sufficiently informed to make the decision.

## The nature of the conversations within consultations also meant that patients were subconsciously taken past the point of considering whether the clinic was the right clinic for them.

Instead, they were looking forward with the consultant to which treatment options would give them the best chance of success.

"We only had a consultation at the clinic we chose. We got referred there by the NHS for our first round which had been funded by the NHS. We then did a bit of research, knew it was the best place to go, felt comfortable, felt confident, and knew it was the next step to get the treatment."

- 30, Midlands, NHS clinic

### Instances of patients choosing to pay for initial consultations at more than one clinic were minimal; just two patients did this.

One patient decided she would have initial consultations with both of the clinics she had shortlisted, and accordingly booked and paid upfront for two appointments. At the first clinic, she felt she did not have good rapport with the consultant. At the second clinic, she liked the consultant, and chose to buy treatment from the second clinic.

"I decided I'd see what both of them [the two shortlisted clinics] were like since I'd made the wrong choice before [in previous rounds]. I didn't get a good feeling from the first consultant at all, and thankfully the consultant at the second clinic was great, so that's where we decided to go."

- 36, North, Private clinic

The other patient booked three initial consultations with three different clinics, all of which she then attended, and determined afterwards which consultant she trusted most, how confident she was that they could help *her*, as well as which clinic she felt most comfortable in. She then bought treatment from the clinic that "ticked all the boxes".

"I wanted to see what kind of people they were, whether I liked them. When I rang up for one - I had shortlisted four - and I couldn't get into that clinic in the timeframe I wanted to. For the other three, I wanted to meet the doctors and see if I liked the person and hear first-hand what they had to say."

- 52, South, Private clinic

### Consultations varied in both their length and cost, but the content of discussions was consistent.

For the patients in our sample, consultations lasted 30-45 minutes on average. However, two patients said they had consultations that were only ten minutes long, whereas several patients had consultations lasting up to an hour.

Patients consistently described consultations as involving discussion about two things:

- Their previous medical and fertility treatment history, including outcomes from any previous rounds of treatment or testing.
- Then, based on this, the different treatment options on offer to them at the clinic, paired with the consultant's recommendations about what treatment(s) they thought would give the patient the greatest chance of success.

While it was not a focus of this research, it is also worth noting that some patients mentioned undertaking tests either prior to their initial consultation (and then discussing the results within their consultation) or undertaking testing after their initial consultation and then discussing the results in further appointments prior to the commencement of their treatment.

## 5.1 The importance of different types of information in decision-making when buying fertility treatment

### 5.2 Information about success rates

Among those patients who were actively considering where to have treatment, i.e., not continuing at the clinic where they had NHS-funded treatment or a previous round of treatment, success rate information was important for the overwhelming majority.

Success rate information tended to play a leading role in patients' shortlisting process (alongside location and, to a lesser extent, cost), and was used to guide final decision-making around which clinic to buy treatment from. A minority of patients used success rate information in a different way: less to decide on a particular clinic to buy treatment from, and more instead to weigh up the different types of treatment on offer (e.g., IUI vs. IVF) as well as add-on treatments for those who were interested in them or had been recommended to consider add-ons.

Analysis suggests that patients in lower SEGs (C2D) were somewhat more likely to say that success rate information was a more important factor in their decision-making compared with those in higher SEGs (ABC1). This difference was likely due to the flexibility that different financial situations permitted, meaning that those with less flexibility and/or ability to fund multiple rounds of treatment tended to put more weight on the importance of success rate information. Analysis also showed that success rate information was looked at more closely by patients in older age groups (specifically patients aged over 40), since these patients started with the knowledge that their age may mean that their chances of success were lower and so greater interrogation of success rate information was required in order to choose a clinic where their chances of success would be high.

"They have it [information about success rates] on the website and also on that board in the waiting room and it's one of the highest success rates in the country. It felt like we were in good hands."

- 37, North, NHS clinic

"Whatever is going to get you the best outcome, that's where you're going to go. It wasn't about bargain hunting or shopping around. It was about what's the best thing to do, and where does the best results happen."

- 30, Midlands, NHS clinic

### Information about clinic success rates was typically accessed during the research process on clinic websites.

In addition to this, six patients also looked at what they perceived to be 'impartial' and 'unbiased' success rate information on the HFEA's website. However, while they welcomed the availability of this centralised resource, some of these patients claimed that much of the data was outdated and so wasn't helpful to them as they shortlisted clinics or made decisions.

"I know when we were looking at the success rates on the HFEA website, a lot of their data seemed quite outdated. So we didn't find that very helpful, you couldn't really rely on it"

- 30, Midlands, NHS clinic

## A substantial minority of patients did not look at success rate information published by clinics, a large portion of whom were patients who had accessed NHS-funded treatment initially.

Approximately two in five patients overall stated that success rate information published by clinics had little impact on their decision-making.

• Many of these patients were those who had received NHS-funded treatment and who then decided to pay for further treatment at the same clinic. While some patients in this position did a quick check to satisfy themselves that other clinics in their area didn't have significantly different success rates, many patients who came out of NHS-funded treatment didn't look at success rates at all. The reason for this tended to be that they weren't exposed to success rate information during the NHS-funded treatment process. A small number of patients who received NHS-funded treatment even stated that they were completely unaware that this type of information was available because it was not something that had been discussed with them during their NHS-funded treatment round. It was only after concluding the NHS-funded round of treatment and doing research about buying fertility treatment that they came to realise that this data was available.

## Outside these two groups, there was a small proportion of patients who had not accessed NHS-funded treatment before but who also chose not to consider success rates as a factor in decision-making.

This group of patients often felt that success rate information would not give them a clear steer on their personal chances of success, and so paid more attention to other factors such as location and whether they felt they would be well looked after by a prospective clinic and staff.

- Within this cohort, there was a small group who were openly sceptical as to how clinics derived their success rate statistics. For example, some had read (typically on social media) that some clinics only accepted certain patients in order to keep their success rates high, whereas others believed that some clinics might manipulate or carefully choose which data they shared to give the appearance of higher success rates.
- An equally small group stated that they preferred not to engage too closely with any success rate information at all. This was either out of fear of getting their hopes up about a greater chance of success from their own research than the clinic advised was likely at the consultation stage, or simply not wanting to deal with an overload of complex information at what is already felt to be a stressful and emotionally taxing time.

"I didn't want to read too much because I didn't want to get my hopes up too high about what my chances might be like."

- 35, North, Private clinic

"I'll tell you what we didn't look at, we didn't look for success rates because I read online somewhere that some clinics only accept certain women so that their success rates will stay high."

- 41, North, Private clinic

## Most patients did look at success rate information in more detail at the consultation stage, regardless of the extent to which they'd considered success rates in the earlier stages of the process.

At the consultation, success rates tended to be brought up as part of the tailored discussion on what type of treatment was suitable in an individual patient/ couple's case and what their chances would be of success.

While most patients had already decided by this stage (emotionally even if not contractually) where they would buy treatment, the conversation about success rates that took place during their consultation tended to feel more impactful than the information accessed earlier on in the research process. This was because the success rate information had been tailored by the consultant to be relevant to them specifically based on previous test results (if patients had them) and/or other medical information. While the sharing of this information had very little impact on decision-making about where to buy treatment, other than further cementing that the decisions patients had already made were the right ones, it did lead patients to feel even more emotionally bought-into the process.

"It was mainly at the consultation that I thought about success rates, but it was a consideration when I was looking at websites, too."

- 52, South, Private clinic

"I think we were smart enough to understand that success rates on websites would be useless information for us. We just went off the success rate that the consultant gave us which was based on our individual circumstances."

- 41, North, Private clinic

"I think we looked at their websites for success rates. There are also links to the HFEA websites with all the true statistics. We did have a look around, but we listened to the doctors."

- 30, Midlands, NHS clinic

### 5.3 Information about price

Price information was most significant in patients' decision-making at the early stages of the short-listing process where it was, for the majority, used to determine which clinics provided treatment in line with patients' overall budgets, as well as which clinics were competitive with other local clinics.

Patients carried out this shortlisting process most closely when buying treatment for the first time and when they hadn't received NHS-funded treatment before. For patients in this position, price information was specifically used to determine if a clinic's pricing was in line with patients' overall budget, as well as whether a clinic's pricing was in line with treatment offered by other clinics in the local area.

"We looked at prices, then we could see if we could call someone for more information, and then we'd look at price again. It was a bit like getting insurance quotes. We cross-referenced them all against each other."

- 36, Midlands, Private clinic

Patients typically looked at prices and location at the same time, and generally only engaged with the pricing information of clinics that were accessible to them in terms of location.

"We did compare pricing to other clinics to be honest, and we rang around to see if the pricing was like that at other clinics, but they were all coming up pretty much the same sort of marks."

- 26, Midlands, Private clinic

Once a set of clinics had been identified as broadly within budget and in a suitable location, other factors were then prioritised more strongly, such as success rates and the reputation or 'feel' of different clinics. As a result, patients told us that price information was rarely a driving factor in their final decision about where to buy treatment from. This applied even to those with smaller budgets or who had secured funding for treatment in different ways, e.g., by taking out loans or having treatment paid for by family.

For a minority of patients who were particularly concerned about being able to find further funding for treatment following the purchase of their next round, multi-cycle packages presented an alternative route to managing both chances of success and costs.

Analysis showed that patients considering multi-cycle packages were more likely to be in older age brackets (35-40 and 41+). The fact of being older was an additional consideration for these patients: they were conscious of having lower chances of success as a result of their age. Taking these factors into consideration, the patients concerned viewed multi-cycle packages as a way of maximising their chances of successful treatment with the funds they

had. This was under the assumption that they may need to go through several rounds of treatment before they had a successful outcome.

"We decided to move onto private clinics [after the initial NHS-funded treatment] because of the lack of financial packages at the NHS. If it didn't work, you would lose all your money but at other clinics there was the option for other forms of payments. For example, pay for three and if it didn't work you'd get your money back."

- 40, North, Private clinic

"These [multi-cycle] packages aren't offered everywhere. Once I'd learnt that these packages existed, I didn't want a single round of IVF. If I had to start my search again, I would have gone for who offers packages. Multi-cycle packages became very important to me in terms of justifying that value."

- 41, North, Private clinic

## Despite starting with a lower understanding of what treatment might cost, patients who were buying treatment for the first time developed knowledge about treatment prices through the shortlisting process.

However, compared with those who had bought treatment before, first-time buyers were less aware the price of treatment could change throughout the course of their treatment (i.e., compared with the price information they saw on a clinic's website at the initial research stage). In contrast, for patients who had already bought at least one round of treatment, their previous experience suggested that the final sum was likely to be higher.

## Patients also tended to engage with price information again in their initial consultation with their chosen clinic. However, by this stage, the vast majority of patients had already decided where they would buy their treatment from.

During their consultations, most patients in our sample were provided with more in-depth cost breakdowns for different treatment options as well as what the overall cost was likely to be for their personal treatment choices. By this stage, however, patients had already decided to have treatment at that specific clinic, and the only further decisions they made were about which treatment(s) they would choose. At the consultation stage, therefore, the price information provided by clinics did not have an impact on decisions about where they would buy their treatment.

"We'd already decided we were going to have treatment there because we liked [name of clinic] and that's why we went for a consultation there, but we wanted to start things as soon as we could because I am anxious of my age. The doctor explained the pricing list very well to us, he broke it down into what it would cost and explained the different [treatment] options to us. They didn't push us into anything, it was our decision."

- 46, North, Private clinic

"We'd made the decision [about which clinic to buy treatment from] before going to the consultation. Me and my partner didn't want to go to a consultation and just mess everyone around, so we just went to the one we knew we were going to go for. The consultation was pretty important to be honest, because obviously you don't know the dangers and stuff, and you don't know fully what you're going to go through [when treatment begins]. They did explain it quite well to be fair, what to expect, what we had to do and how long it'd take and stuff like that. And in terms of actually deciding what treatment we wanted to buy, we decided that about two weeks after the consultation."

- 26, West Midlands, Private clinic

### Patients whose previous round of treatment was NHS-funded and now were buying treatment for the first time used price information slightly differently.

This patient group was less likely to interrogate price information as closely as those who hadn't received a prior round of NHS-funded treatment and were buying treatment for the first time. While these patients still carried out checks on price information for a range of clinics in their local area, they typically did so in less depth than those who self-funded from the start. Mainly, this was done to check that prices at the clinic they'd used previously were not significantly higher than other options in their local area.

The lower level of engagement with pricing amongst this patient group may be attributable to the fact that they were purchasing treatment from a clinic with which they had an alreadyestablished relationship. Patients said that this relationship was important because it meant their previous clinic had the knowledge of how well (or not) their previous round of treatment had gone and why. It also meant that they had formed relationships with staff. These patients were therefore placing a level of trust in their existing relationship, which mitigated the perceived need for extensive research on pricing, beyond the high-level research described above. This tendency is also in line with the perception, as described in section 3.2.1, that their first paid-for round of treatment was a continuation of their previous round of treatment which had been funded through the NHS.

The exception to this lower level of research was amongst patients who received a round (or more) of NHS-funded treatment but who had had a more negative experience and were therefore looking at other clinics. This group tended to carry out the same process as first-time buyers without any experience of NHS-funding as is outlined at the beginning of this chapter.

#### Patients purchasing a subsequent round of paid-for treatment following their first were also less likely to base their final decisions about where to buy treatment or which treatments to buy around pricing.

These patients were likely to place less importance on price information because they had experienced the cost of their previous treatment changing (for some, substantially) once treatment had begun due to the unexpected cost of additional tests, scans and medication.

### This is not to say, though, that the money patients spent on treatment did not represent a significant investment to them.

In fact, due to the sums of money that patients invested in their treatment and the incredibly strong desire they had to have a child, patients' main priority was to ensure that the money they spent on treatment gave them the greatest chances of success.

Providing a clinic's pricing was perceived to be broadly in line with that of other local competitors and within their broad budget range, patients were more likely to choose a clinic based on a sense of how successful their treatment there would be. This perception was built in part based on clinic success rate information as well as other aspects such as the perceived reputation of the clinic and its staff.

As a result, therefore, patients may have chosen a clinic that was either more or less expensive than another if they felt their chances of having successful treatment there was greater. This tendency was further supported by a perception that the price differentials between clinics were not, in the end, hugely significant in the context of the overall spend.

## Regardless of how patients funded their treatment, they tended to be consistent in how they used price information, in so far as other factors were considered more important when it came to deciding where to buy treatment.

When making a <u>final</u> decision about where to buy treatment, factors other than price information tended to be more important for patients. In particular, success rate information outweighed price information in importance for many patients, since it was this information that helped patients to get a sense of their likelihood of success at a particular clinic.

"It was the statistics about the success rates [that I used to decide where I'd buy treatment]. Mainly that, and then the pricing structure was something I was also considering but to a lesser extent. I rang the clinic but also looked at their website. But I did actually ring them up to confirm I was understanding all the success rate statistics correctly."

- 52, South East, Private clinic

### 6.1 Willingness to raise a concern or complaint with clinics

This research sought to understand what action patients took, if any, if they were unhappy with the clinic they bought treatment from or aspects of the treatment they received. As such, in this chapter we explore the context for raising a concern or complaint and the types of concerns and issues that patients experienced throughout their treatment process, if any. We also look at what patients, who experienced an issue, did as a result, including both formal and informal ways of addressing an issue, and at the levels of satisfaction with the result.

### 6.2 The context for raising a concern or complaint

For a number of reasons, patients typically felt that raising a complaint about fertility treatment was different from raising a complaint about other products or services they had bought. Patients described three main factors which distinguished raising a complaint about fertility treatment from other purchases.

1. The inherently **emotional nature of fertility treatment** differentiated it from buying other services or products. Patients described not only investing a lot of their money into fertility treatment, but, unlike many other (major) purchases, they invested a lot of emotion, too.

"If you're complaining about a TV you bought and it's not working, obviously that's a different thing. [With fertility treatment] you're talking about people, you're talking about emotions, sensitive matters."

- 46, North, Private clinic

2. The fertility treatment sector is one where **not everyone is able to access treatment**. Patients either need to be able to access NHS funding, which is not available to all, or they need to have access to the financial resources to be able to self-fund. Patients in this study, who were all able to self-fund, expressed a sense of feeling fortunate that they could afford the treatment and often reflected on how fortunate they were compared with others who might not be in the same position.

"We both have jobs that are safe, so we were very lucky that we had the money to be able to do it."

- 34, Midlands, Private clinic

3. To a lesser extent, those who accessed fertility treatment **during the pandemic** also felt fortunate for being able to access the services in the first place.

"With the last round, it was just as the Covid-19 rules changed, which impacted us. We're just grateful we could go through with it still."

- 43, North, NHS clinic

As a result, the specific nature of fertility treatment coupled with the sense of feeling very fortunate put patients in a more emotionally vulnerable place. Patients were in a different frame of mind from how they would normally operate as consumers. This meant that when issues arose or when things went wrong, the ways that patients chose to interact with their clinics did not always align with how they might have acted if they were consumers in another sector, and ultimately meant the decision about whether or not to complain was less straightforward.

Additionally, patients' frame of reference for accessing healthcare tended to be what they had received for free through the NHS, and for a minority, this blurred their expectations of what service levels to expect when they were paying for treatment. One couple, for example, had received no NHS-funded treatment but had paid privately for multiple rounds of treatment in an NHS hospital (without success). Nevertheless, they had simply accepted long wait times and limited treatment options because 'this is what it's like in the NHS'.

### On top of this, purchasing fertility treatment tended to be seen as a uniquely private experience with no understood "norm".

Without having a point of reference for this type of purchase or an obvious place to seek advice, some patients felt unsure about what they should expect from a clinic. This meant that when something did fall short of their expectations, many patients were unable to assess whether it was something that many patients experienced or whether it was something more unusual that may warrant a complaint, whether formal or informal.

"We didn't even tell our family the first time we went for treatment, you don't openly talk about it. [When we experienced our issue,] I wish we'd had somebody to ask then [for advice about what they thought we should do]."

- 40, South, Private clinic

"The problem is you don't really know what is the norm, so it's hard to know are we getting a bum rap or is this what it is like everywhere? It's new, we don't know what to expect."

- Partner, Midlands, Private clinic

### 6.3 Types of concerns and complaints

Around two in three of the patients interviewed said they had experienced some sort of issue with their clinic. These issues ranged from issues such as unappealing waiting room décor right up to duty of care or medical issues. The way in which patients responded to these issues varied significantly, even for the same type of issue, as can be seen in the table below.

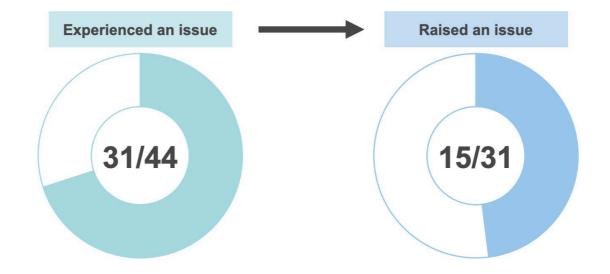
Type of issue	Description of issue	Incidence	Action taken	
	Not enough face to face / phone contact due to Covid-19	6	No action taken	
	Dissatisfactory clinic environments, e.g. waiting area	1	No action taken	
	Unprofessional clinic environments, e.g. disorganised	2	No action taken	
Clinic, administrative			1 x Formal complaint	
and staff issues	Long waiting times	5	1 x Raised informally	
			3 x No action taken	
	Unkind or dismissive staff		2 x Formal complaint	
		10	4 x Raised informally	
			4 x No action taken	
		6	2 x Raised informally	
Financial issues	Unexpected / unclear costs	0	4 x No action taken	
	Package price quoted didn't apply to patient's age group	1	Raised informally	
Medical issues	Medical mistake		1 x Legal action	
		5	2 x Raised informally	
			2 x No action taken	
Clinic brushed off patient's bleeding		1	Raised informally	

As shown, unpleasant interactions with clinic staff was the issue most commonly experienced by patients, and in two instances resulted in the raising of formal complaints. Six patients told us that they experienced unexpected or unclear costs from their clinic but, of these, four decided not to raise the issue at all and the two remaining patients only did so informally. Of the five patients who told us there had been medical mistakes during their treatment, two had raised the issue informally and one look legal action, meaning that two patients still chose not to take any action at all.

### 6.4 Comfort with, and barriers to, raising a concern or complaint with clinics

### As detailed in section 6.3, a number of patients said they had experienced some sort of issue with their clinic, but not all went on to raise a formal or informal complaint.

Thirty-one of 44 patients<sup>5</sup> experienced an issue, around half of whom went on to raise it with the clinic; the rest chose not to raise a complaint either formally or informally.



### For those who raised an issue with the clinic, having an established relationship with at least one clinic staff member was an essential factor in feeling able to do so. However, this relationship also acted as a barrier for some to raising an issue.

Patients felt extremely dependent on their clinic to make their desire to have a child become a reality. They were very conscious that their desire to complain must not jeopardise or damage their relationship with the clinic and individual members of staff. Therefore, patients who had an issue and raised it (15/31) felt comfortable about doing so mainly because they

<sup>&</sup>lt;sup>5</sup> A technical difficulty meant that one of the 45 interviews we conducted was cut short before we reached this part of the discussion. As a result, this section of the report is based on interviews with 44 patients.

had built a trusting relationship with the staff who worked at the clinic. These relationships were based on open and honest communication throughout treatment where patients felt they could ask questions, share their feelings about what was happening, and receive clear answers, clinics and their staff represented a 'safe space' in which patients could voice their frustrations or concerns.

"I did put a complaint in one time to the nursing manager and she phoned me, this allowed me to speak through my concerns and feelings. It was really helpful to let me offload and express how I feel."

- 41, Scotland, Private clinic

A secondary motivation for raising a concern or complaint with a clinic – which tended to become more pronounced as patients went through further rounds – was the fact that the cost of fertility treatment amounted to a significant financial investment and patients therefore expected a certain level of service. If these service levels weren't met, they usually felt it within their rights to raise it with the clinic.

"I had to make a complaint last week because the wait times were absurd... If you don't have enough nurses to cover appointments then you need to hire some, this is a private business, definitely not struggling for income so it should be better than that."

- 36, South, Private clinic

"I think as time goes on you remind yourself you're paying for this. If I'm expecting a phone call, then I want the phone call or a message to say why I won't get a phone call. It's a vulnerable journey and you are paying a lot of money."

- 32, Midlands, Private clinic

### For those who experienced an issue but did not raise it, a primary barrier was the perception that their issue was not significant enough to warrant complaining about.

Of the 16 patients who experienced an issue but did not raise it, some didn't believe their issue was complaint-worthy. This reflected a sense that obtaining and undergoing fertility treatment was such an important, potentially life-changing event that issues faced in this context felt insignificant. This was particularly the case for the issues perceived by patients to be less pressing, such as long waiting times or a lack of in-person contact due to Covid-19 restrictions.

"Our consultant was very late, but we did just let it go. I think the clinic staff were doing everything they could, and they weren't doing anything to make us feel uncomfortable or like it was our fault."

- 36, South, Private clinic

### However, for those who did feel as though their issue was worth raising and still chose not to do so, the main reason for this was the extra stress it might cause them.

Many patients reported feeling too vulnerable to deal with any additional stress either while their treatment was ongoing or once it had concluded. Given the significant emotional toll of going through treatment, as well as the impact it had on patients' bodies, many patients were looking for ways to make their experience of treatment as manageable as possible. Therefore, even if they did experience small issues, they were more likely to ignore them in order to not create extra worry and stress for themselves.

"Some things [in the IVF process] you have to swallow and accept it because it's not worth the stress."

- 36, Midlands, Private clinic

"You just feel so grateful to even get an appointment to be honest. Where I was in the process physically, I wouldn't have felt strong enough to make a complaint to be honest."

- 39, Northern Ireland, Private clinic

"I was emotionally not in the right place to make a complaint. I didn't want to do a formal complaint; I would've just sent an email to see if it was a pattern of behaviour. But for the next month or so I wasn't in the place to do it, and then I had moved on."

- 40, South, Private clinic

What's more, no matter how well-established the clinic-patient relationship was, patients felt extremely dependent on their clinics to make their desire to have a child become a reality.

This is due to the specific emotional aspect of purchasing fertility treatment, with patients feeling very invested in their chosen clinic, contributing to a minority feeling worried about how raising a concern or complaint with the clinic might have impacted the treatment they received.

"I would feel uncomfortable raising a complaint against the person who was doing the treatment... If it's something serious, then yes you do raise it at the top, but I would not transfer during a cycle. You raise issues before you start the cycle."

- 43, North, NHS clinic

"I needed them more than they needed me, and I couldn't be without them, so I'd have rather had a bad service than no service."

- 31, Midlands, NHS clinic

Certain patients in our sample (those who never had a successful outcome and were not currently pregnant from their latest round of treatment) appeared to be

### considerably more likely to raise issues with their clinic compared with others we interviewed.

The outcome of fertility treatment played a role in the likelihood that patients would raise a complaint, with those who had never had a successful outcome – and who were not currently pregnant (7/11) – more likely to raise a complaint than those with a successful outcome in the past or who anticipated a positive outcome due to pregnancy (7/20). Whilst patients rarely expressed it openly, our assessment of their views indicates that a general frustration with the lack of success made patients more likely to raise issues with their clinics.

Those who experienced successful outcomes, on the other hand, were often so happy to be pregnant that they often preferred to focus on having a child rather than raising an issue they had experienced with the clinic.

"I don't think I raised it with them. It would've been fine, it would've been absolutely fine [to discuss it with them] but I think just being so happy with being pregnant, and for it to have been achieved - you know, my life goal, having a child - I didn't feel that it was necessary to do that."

- 42, South, NHS clinic

### Those who felt they had no reason to complain about the clinic (13/44), appeared to overestimate how comfortable they *would* be with raising an issue.

Those who didn't experience an issue with their clinic were almost twice as likely to say they would have raised it with their clinic or its staff (10/13) than those who actually experienced an issue and did raise it (15/31). This indicates that patients who had positive experiences with their clinic may overestimate their willingness to complain *were they* to experience an issue.

"I would definitely voice my concern and make sure it's heard by the person it needs to be heard by."

- 46, North, Private clinic

Of the minority who said they wouldn't have felt comfortable (3/13), one worried about how complaining might have impacted their treatment, and the other two said they were simply not the type of people to complain.

"The clinic treated us like a number, but it's not in our nature to complain." - 44, South, Private clinic

### 6.5 Methods of raising concerns or complaints with clinics

Amongst patients who experienced an issue, the action they took in response varied greatly.

As shown in the table in section 6.3, the action that patients took in response to the issues they experienced varied greatly. The majority of those who experienced issues during their fertility treatment process (12/15) chose to raise them informally with the clinic. This involved speaking with a member of staff that the patients were familiar with, typically a nursing or practice manager.

"It was harsh language that she used. It wasn't the positivity we were used to. We raised it informally with the clinic, I don't think it needed a formal complaint, and we didn't see her again, so they responded to our feedback."

- 30, South, NHS clinic

"When they didn't accept my test, I had some stern words with the practice manager so that she would make changes in the future."

- 36, Midlands, Private clinic

For those who felt as though the issues they experienced warranted formal complaints, they did so either by emailing senior administrative staff or accessing the complaints form on the clinic portal.

"There was an online form where I could input feedback and then I had a call and a Zoom with the Director to go through everything I said. On the portal there was a box you could tick for it to become a formal complaint and then they got in touch. They were really on it in terms of welcoming feedback and correcting anything I said."

- 35, Midlands, Private clinic

"Somebody forgot to tell me about a medication I was supposed to be on for a week and I had to write a very firm letter about it."

- 36, South, Private clinic

## Patients felt satisfied with how a concern or complaint was dealt with when the clinic responded swiftly and apologetically and demonstrated new or different behaviours as a result.

The majority of patients who made a complaint (13/15) felt satisfied with the result. This is because they reported clinics responding immediately to their concerns and offering apologies. For those who continued to have further treatment at the same clinic, satisfaction came from how future engagement with the clinic differed, proving that they had taken the feedback on board.

"We knew the treatment had failed four days after because I started bleeding. They brushed it off and said bleeding was normal so I said to them you should take it more seriously; I knew my progesterone level was too low. They laid out what would they do next time to make sure these issues wouldn't repeat themselves. So, for the next cycle they tested my progesterone two weeks before transfer and gave me daily injections. So, they completely responded to my concerns. I liked that they do listen to me and adapted it and recognised that I know my body and know what I'm talking about."

- 31, North, Private clinic

### Clinics failing to adequately address concerns or complaints raised didn't necessarily make the patients take it further.

One of the two patients who were unhappy with the response to their concerns or complaints decided not to take further action. This patient felt as though they had already been through a lot of physical and emotional stress and did not consider further action to be worth it.

"She was very insensitive when I asked to hear the heartbeat again. I escalated it to the office manager but it didn't really go anywhere at the end of the day. I was at the end of my journey, everyone was saying to me "Don't get yourself stressed", and I didn't want to, so I just left it."

- 44, South, Private clinic

However, the other patient who was dissatisfied did take further action and decided to seek legal aid. After a mistake on the clinic's part meant that her eggs had to be discarded, the clinic was unresponsive to all emails and calls. The patient was unaware of a formal complaint process and did not know any other way to further her complaint given the lack of communication from the clinic. As a result, the patient felt that she had no option but to find a lawyer.

"I didn't know of any other ways to raise a complaint outside of the clinic. So, I just found a lawyer because I was feeling like they had blocked me, wouldn't return my calls, gave me no reason why they were going to suddenly destroy my eggs. It was a horrific experience and still is. Nobody told me where I could go, what I could do, so I just had to panic and find a lawyer who helped me."

- 52, South, Private clinic

### **Technical Annex**

### **Recruitment screener**

The recruitment screener used for this project was drafted in partnership with the CMA team to act as a briefing document and guide for our recruitment partners. It lays out the specific quotas we were aiming to meet so that we heard from a range of patients, including quotas for the various regions in which we wanted to recruit participants. The number of participants per location were determined based on HFEA data for 2019, published in 2021. For a full breakdown of the sample, please see page 76 of the report.

This research methodology includes a total of 45 interviews:

- Min 30 of these interviews will be carried out in a paired depth format:

   Patient (consumer) to be accompanied by an individual who was involved in their fertility treatment process (most likely a partner)
- 2. Min 10 of these interviews will be carried out in an individual depth interview format with the patient (consumer) alone

The following quotas will be treated as 'hard quotas' across the full sample and will be prioritised first throughout the recruitment process:

- All to have paid the full cost of at least one cycle of fertility treatment **in a UK clinic** since 1<sup>st</sup> January 2019.
- A mix of **clinic type** for treatment:
  - Min 23 to have paid the **full cost** of at least one cycle of fertility treatment that was carried out **in a private clinic**
  - Min 8 to have paid the full cost of at least one cycle of fertility treatment that was carried out in an NHS hospital that provides private treatment
    - N.B. Patients who are part-funders are out of scope for this piece of work. This refers to patients who choose to "top-up" their free NHS-funded treatment and self-fund certain add-ons. Those who have only done this and who have therefore not paid in full for at least one cycle of "main" fertility treatment are to be excluded from the sample.
- A mix of outcomes from all past treatments for patients engaging specifically in IVF:
  - Min 15 to have had successful treatment(s), i.e., resulting in a live birth
     Min 15 to have had unsuccessful treatment(s), i.e., not resulting in a live
  - birth
- A mix of **funding history** (for those engaging specifically in IVF treatment):
  - Min 8 to have paid the full cost of at least one cycle of IVF treatment since 1<sup>st</sup> January 2019 *without previously having any free NHS provision*
  - Min 6 to have paid the full cost of at least one cycle of IVF treatment since 1st January 2019 *following at least one cycle of IVF paid for by the NHS*
- A mix of fertility treatments:
  - Min 35 to have paid the full cost of at least 1 cycle of IVF treatment since 1<sup>st</sup> January 2019
  - Max 10 to have paid the full cost of at least 1 cycle of egg freezing in the UK since 1<sup>st</sup> January 2019

The following quotas will be treated as 'soft quotas', meaning they will be prioritised once hard quotas have been met:

- A spread of **ages** across the sample:
  - $\circ$  Min 10 aged under 35
  - Min 20 aged 35-40
  - Min 5 aged 41 or over
- A mix of **experiences** with clinics in relation to their latest round of treatment (which must have taken place in the UK):
  - Min 10 patients who describe their experience, irrespective of the outcome, as somewhat or very positive
  - Min 10 patients who describe their experience, irrespective of the outcome, as somewhat or very negative
- A spread of **socio-economic grades** across the sample:
  - Min 20 ABC1
  - o Min 12 C2DE
- A mix of **ethnicity** across the sample:
  - Min 8 patients (consumers) to come from a minority ethnic background
- A mix of **relationship status** across the sample:
  - Min 24 in a mixed-sex relationship
  - Min 4 in a same-sex relationship
  - Min 2 to be without a partner (single)
- A range of **regions** represented across the sample, broadly following the below breakdown:
  - Min. 10 to be "North" (GOR North West, GOR North East, GOR Yorkshire & Humberside)
    - With a minimum of 5 to be in GOR Y&H (North Yorkshire, West Yorkshire, South Yorkshire, East Riding of Yorkshire)
  - Min. 11 to be "Middle" (GOR West Midlands, GOR East Midlands, GOR East of England)
    - With a minimum of 6 to be in GOR East of England (Hertfordshire, Bedfordshire, Cambridgeshire, Norfolk, Suffolk, Essex)
  - Min. 14 to be "South" (GOR South West, GOR South East, GOR London)
    - With a minimum of **6** to be GOR London
    - With a minimum of **4** to be GOR South East,
    - With a minimum of **3** to be GOR South West
  - Min. 2 and max. 4 to be based in Wales
  - Min. 2 and max. 3 to be based in Scotland
  - o Min. 2 and max. 3 to be based in Northern Ireland

#### On a best efforts basis, we will try to reach:

- Patients (consumers) who have chosen a clinic and paid for treatment in the UK, or chosen a clinic and agreed to pay for treatment in the UK, as **recently** as possible
- Patients (consumers) who have chosen and paid for treatment at **more than one UK clinic**, allowing for a mix of reasons as to why they decided to change clinics

#### SECTION 1 – RESEARCH INTRODUCTION AND INFORMATION

Hello,

I am looking to recruit people to take part in a research project. The research is being conducted by BritainThinks, an independent market research company, on behalf of their client, the Competition and Markets Authority. The CMA is an independent government department and the UK's lead competition and consumer authority. It works to ensure that consumers get a good deal when buying goods and services, and businesses operate within the law.

This research is looking to speak to people who have had, are currently underway with or about to embark on at least one cycle of fertility treatment since January 2019 that they paid for in full. This could be either a cycle of IVF (which might be referred to as IVF, IVF with ICSI or just ICSI) or a cycle of egg freezing, the cost of which was not covered by the NHS.

The research will involve an interview lasting about an hour or an hour-and-a-quarter between a BritainThinks researcher and you as someone who has paid for or is currently paying for/ about to pay for at least one cycle of fertility treatment in the UK since January 2019. If anyone else was closely involved in decisions about the clinic and/or treatment – whether that's a partner, family member or friend – they can take part in the interview too, but only if you're happy to involve them.

If you are interested in taking part, I just need to ask you a few questions. Please be reassured that all information will be kept securely, and any information that would make you personally identifiable will not be shared with anyone outside of BritainThinks.

#### **SECTION 2: DECLARATION**

Firstly, I'd like to ask you about your previous participation in research.

Q1: Are you currently participating, or scheduled to participate, in any market research?

Yes	Thank and close
No	Continue

#### Q2: Have you taken part in any market research before?

Yes	Go to Q3
No	Go to Q5

Q3: If yes, how many market research discussions or interviews have you taken part in, in the past 6 months? And in the past 12 months?

Past 12 months	Record:
Past 6 months	Thank and close

### Q4: Please list all topics covered in all previous market research discussions or interviews you have taken part in, in the past 12 months.

Record:

**Thank and close** if participated in any market research on the topic of fertility clinics and services, NHS or private health or social care in the past 12 months

#### Q5: Have you taken part in any research with BritainThinks in the last 12 months?

Yes	Thank and close
No	Continue

#### SECTION 3: YOUR EXPERIENCE OF FERTILITY TREATMENT

Now I'd like to talk about your experience with fertility treatment. As mentioned earlier, these questions will be focused on things like the type of clinic you used or are using, how your treatment was funded or is being funded, and how many cycles of treatment you have had. I will also be asking about the outcome of your treatment, and will let you know before we reach this point. Please let me know at any time if you would like to take a break or if you do not wish to continue.

#### Q6. How would you describe your current treatment 'status'?

I am currently underway with a round of treatment	Record and continue
I am just about to embark on a round of treatment	Record and continue
My most recent round of treatment is complete, and I'm scheduled to have further treatment in due course	Record and move to Q8
My most recent round of treatment is complete, and I am not currently scheduled to have further treatment	Record and move to Q8

#### Q7. Is this your first round of treatment?

Yes	Thank and close
No	Continue to Q8

#### Q8: Did you complete your last round of treatment prior to the 1<sup>st</sup> of January 2019?

Yes, I completed my last round of treatment prior to January 2019	Thank and close unless currently underway or about to embark on a round of treatment (i.e., code 1 or 2 at Q6)
No, I completed my last round of treatment after the 1 <sup>st</sup> of January 2019	Record and continue

#### Q9: Have you had any NHS-funded rounds of treatment?

Recruiter note: do not read out the list of options – code answer against the following so that participants can self-describe. If it is unclear which option they should be coded under, please gather as much information as possible and refer to BritainThinks.

No, never – the patient has always self-funded ( <i>self-funder</i> )	Recruit min. 8 across the sample
Yes – but the patient has paid in full for at least one round of treatment since 1 <sup>st</sup> January 2019 ( <i>self-funder</i> )	Recruit min. 6 across the sample
Yes – they have had NHS-funded treatment which the patient topped-up (to cover the cost of some add-on treatments), but they have never paid in full for a round of treatment ( <i>part-funder</i> )	Thank and close
Yes – the patient has neither topped up nor paid in full for a round of treatment, and has always had their treatment fully funded by the NHS ( <i>NHS-funded</i> )	Thank and close
Other	Record and contact BT

### Q10: Since 1<sup>st</sup> January 2019, in which country have you had / are you going to have your treatment(s)?

All in the UK	Recruit min. 35
Both in and outside the UK	Recruit max. 10
All outside the UK	Thank and close

#### Q11: What kind of fertility treatment have you had / are you going to have?

IVF or IVF with ICSI	Recruit min. 35
Egg freezing	Recruit max. 10
Both	Record and continue
IUI (Intrauterine insemination)	Thank and close
Other	Thank and close

### Q12: How many rounds of treatment have you had since 1<sup>st</sup> January 2019?

Recruiter note: Please only count completed rounds of treatment, and record with "+ current round" if they are about to embark on/are underway with a round of treatment. For those that have bought multi-cycle packages, please record the number of cycles within each package.

0 + current round	Record and continue to Q14
1	Record and continue to Q14
More than 1	Record and continue to Q13

## Q13A: [ASK ONLY THOSE CURRENTLY UNDERWAY OR ABOUT TO EMBARK ON TREATMENT] In terms of the clinic where you are having/ are about to embark on your treatment, is this ...?

The same clinic as my previous treatment(s)	Record and continue
A different clinic to my previous treatment(s)	Record and continue

## Q13B: [ASK ONLY THOSE HAVE COMPLETED THE LAST ROUND OF TREATMENT AFTER JANUARY 2019] In terms of where you've had your treatment(s), has this been ...?

at the same clinic	Record and continue
at different clinics	Record and continue

### Q14: For clarity - may I just double-check whether you had any rounds of fertility treatment before 1<sup>st</sup> January 2019?

Yes	Record and continue
No	Record and continue

### Q15A: [ASK ONLY THOSE CURRENTLY UNDERWAY WITH OR ABOUT TO EMBARK ON A TREATMENT] How would you define your current relationship status?

In a relationship / married	Continue to Q16
Single	Continue to Q17

Q15B: [ASK ONLY THOSE WHO HAVE COMPLETED THEIR LAST ROUND OF TREATMENT SINCE JANUARY 2019] Thinking about the most recent round of treatment you have paid for, how would you define your relationship status at the time?

In a relationship / married	Continue to Q16
Single	Continue to Q17

NOTE TO RECRUITER: RECRUIT MINIMUM 2 WITHOUT A PARTNER (SINGLE) ACROSS THE SAMPLE

### Q16: Please could you let me know whether this relationship is/was with someone of the same sex or the opposite sex?

Same sex (same-sex relationship)	Recruit min. 4
Opposite sex (mixed-sex relationship)	Recruit min. 24

Q17: For the purposes of this research, would you like to take part with someone else who was/is closely involved in decisions about the clinic and/or treatment, or would you prefer to take part independently?

With another involved individual	Code as paired depth and recruit min. 30
Independently	Code as depth and recruit min. 10

## Q18A: [ASK ONLY THOSE CURRENTLY UNDERWAY WITH OR ABOUT TO EMBARK ON TREATMENT] Thinking again about your current round of treatment that has started or will be starting, how would you describe your experience with the clinic so far?

*If further clarification is needed:* By this, we mean your experience engaging with the clinic and their staff.

Very positive	Aim to recruit min. 10
Somewhat positive	
Neither positive nor negative	Record and continue
Somewhat negative	Aim to recruit min. 10
Very negative	

Q18B: [ASK ONLY THOSE WHO HAVE COMPLETED THEIR LAST ROUND OF TREATMENT SINCE JANUARY 2019] Thinking again about your last complete round of treatment, how would you describe your experience with the clinic, irrespective of the outcome of your treatment?

*If further clarification is needed:* By this, we mean your experience engaging with the clinic and their staff.

Very positive	Aim to recruit min. 10
Somewhat positive	
Neither positive nor negative	Record and continue
Somewhat negative	Aim to recruit min. 10
Very negative	

#### Q19: [ASK ONLY THOSE WHO HAVE HAD IVF TREATMENT (NOT EGG FREEZING)]

Finally, the following question is sensitive in nature as it involves us asking about the outcome of the fertility treatment you've had so far. Please let us know if you would like to take a break before answering.

Thinking about the fertility treatment you've had so far, which of the following comes closest to describing you?

Recruiter note: No further details need to be collected further than that listed below. If the patient says they have a mix of live birth/no live birth experience, code to "successful".

I have experience of an IVF cycle which resulted in a live birth	Code as successful and recruit min. 15
I do not have experience of an IVF cycle which resulted in a live birth	Code as unsuccessful and recruit min. 15

#### **SECTION 4: ABOUT YOU**

Thank you very much for sharing your responses to my previous questions.

I'd now like to finish off with some short questions about you which should take no longer than 2 or 3 minutes.

#### Q20: Firstly, please can I ask your age?

Under 35	Aim to recruit min. 10
35-40	Aim to recruit min. 20
41 or over	Aim to recruit min. 5

#### Q21: How would you describe your ethnic background?

Recruiter note: do not read out list of options – code answer against the following so that participants can self-describe.

White	Record
Mixed	
Asian / Asian British	Aims to no empitancia. O
Black / African / Caribbean / Black British	Aim to recruit min. 8
Other	

### Q22: What is your occupation?

Record SEG using tables below

А	
В	Aim to recruit min. 20
C1	
C2	
D	Aim to recruit min. 12
E	

#### SEG Reference:

А	Higher managerial / professional / administrative (e.g., established doctor, solicitor, board director in a large organisation (200+ employees) top level civil servant/public service employee)
В	Intermediate managerial / professional / administrative (e.g., newly qualified (under 3 years) doctor, solicitor, board director small organisation, middle manager in large organisation, principal officer in civil service/local government)
C1	Supervisory or clerical / junior managerial / professional / administrative (e.g., office worker, student doctor, foreman with 25+ employees, salesperson), student, homemaker
C2	Skilled manual worker (e.g., skilled bricklayer, carpenter, plumber, painter, bus/ ambulance driver, HGV driver, AA patrolman, pub/bar worker, etc.)
D	Semi or unskilled manual worker (e.g., manual workers, all apprentices to be skilled trades, caretaker, park keeper, non-HGV driver, shop assistant)
E	Any of the following casual worker – not in permanent employment, retired and living on state pension, unemployed or not working due to long-term sickness, full-time carer of other household member

#### Q23: Which county do you live in?

Recruiter to note down response and assign participant's region based on GOR regions.

Record county

<u>South England</u> (Aim to recruit min.	GOR London	Aim to recruit min. 6
	GOR South East of England	Aim to recruit min. 4
14)	GOR South West of England	Aim to recruit min. 3
Middle England	GOR East of England	Aim to recruit min. 6
(Aim to recruit min.	GOR West Midlands	No min quota, max. 2
11)	GOR East Midlands	No min quota, max. 2
North England	GOR Yorkshire & Humberside	Aim to recruit min. 5
(Aim to recruit min.	s	No min quota, max. 3
10)	GOR North East	No min quota, max. 2
Wales	Recruit min. 2 and max. 4	
Scotland	Recruit min. 2 and max. 3	
Northern Ireland	Recruit min. 2 and max. 3	

#### SECTION 5: FINAL INTERVIEW SET-UP INFORMATION AND CONSENT QUESTIONS

The research will focus on exploring the experiences of a wide range of individuals and their interactions with clinics and staff providing fertility treatment, as well as the research process undertaken by the individual prior to proceeding with treatment.

We expect the interviews to take place via Zoom and to take place across April and May this year / *If recruiting for pilot interviews:* to take place between 17<sup>th</sup>-22<sup>nd</sup> March. These would be arranged at a time that is most convenient for you.

#### Recruiter question: Are you happy to proceed on this basis?

If yes: Continue

If no: Thank and close

The interview would be carried by an experienced researcher from within an all-female team at BritainThinks. As a way of thanking you for your time, you would receive  $\pounds$ 50 [individual] /  $\pounds$ 100 [paired] which would be paid via a secure online payment platform called Particity.

We are aware that the nature of this topic may be extremely sensitive and difficult for some individuals, and so we have arrangements in place to ensure taking part in the research is as comfortable as possible. You will be able to take breaks whenever needed; if there are any questions that you would prefer to not answer, you don't have to; and you can also withdraw from the research process at any time, including after the interview has been completed. The interviews will be informal, and will also include completing a short task beforehand which would ask you to reflect on your experience of choosing a clinic. This will be shared with you at least 3 days before your interview is scheduled to take place.

Q24: As part of this research, we would like to record the Zoom sessions that take place. This would be for internal use by BritainThinks only in order to help with analysis of the data collected as part of this research. These recordings will not be shared with anyone outside of BritainThinks and will be securely deleted 12 months after the end of the project.

Are you happy to proceed on this basis?

No	Thank and close
Yes	Continue

Q25: Please note that by signing your consent to participate, you consent to BritainThinks using and storing the personal data we have recorded about you in this questionnaire. Personal data is data that allows a living individual to be identified (either directly or indirectly). This includes 'special category' data about your treatment history. BritainThinks will use and store your personal data for the purposes of this research project only. All personal data is kept securely for up to 12 months after project completion, and it is then securely deleted from our systems.

Your personal data will not be shared with any other third party, including our client the Competition and Markets Authority, in a way that would allow you to be individually identified. You are also consenting to the CMA processing aggregated data from which you cannot be individually identified – in the form of the report we supply to the CMA – for the purpose of [state purpose].

Are you happy to proceed on this basis?

No	Thank and close
Yes	Continue

## Q26: Do you have access to the internet, an internet-enabled device, and Zoom, and would you feel confident using this technology to take part in the research?

Yes	Continue
No	Record and go to Q30

# Q27: It may be possible for us to conduct these interviews via telephone. Would you be interested in taking part in the research on this basis?

Yes	Record and contact BT
No	Thank and close

#### **SECTION 6: YOUR DETAILS**

Finally, I need to take details of your name, email address, and telephone number.

Name:	
Email address:	
Telephone number:	

#### SECTION 7: INTERVIEWER DECLARATION

Q28: Is there anything else the researcher should be made aware of? E.g., any accessibility requirements?

Record all details

No two people should know each other. Please note telephone numbers are mandatory.

I CONFIRM THAT THIS IS A TRUE RECORD OF A SCREENING INTERVIEW WHICH HAS BEEN CONDUCTED WITH A RESPONDENT WHO IS NOT A RELATIVE OR FRIEND OF MINE:

RECRUITER'S SIGNATURE:	
DATE:	

## Sample breakdown

	Nº		Nº		Nº	
Type of clinic that the patients' last round of treatment was received in		Region		Socio-economic grade		
Private clinic	32	London	6	А	1	
NHS clinic	13	South East	4	В	16	
		South West	4	C1	19	
		East of England	4	C2	8	
		Midlands	9	D	1	
		North West	6			
		Yorkshire & Humber	5			
		Scotland	2			
		Wales	2			
		Northern Ireland	3			
Outcome of most recent round of treatment		Patient age at the time of recruitment into the research*		Relationship type		
Successful	24	Under 35	14	Mixed-sex	39	
Unsuccessful	20	35-40	18	Same-sex	5	
		41+	13	Single 1		
Funding history (whether a patient had received NHS- funding before or not)		Patient ethnicity		Experience with the clinic a staff	nd	
Previous NHS funding	20	White	37	Somewhat or very positive	31	
Always self-funded	25	Ethnic minority	8	Neutral 3		
				Somewhat or very negative	11	
Treatment type						
IVF	44	Egg freezing	1			

## Participant pre-interview information sheet

This information was shared with participants via email prior to their interview with the BritainThinks Team as part of the safeguarding process. This was to provide participants with information about the focus of the research, what we would do with any data provided to us, as well as providing instructions for the optional pre-interview activity and details for the Zoom meeting which would be used for the interview.

#### Dear participant,

Thank you very much for agreeing to take part in this important piece of research.

Ahead of your interview, we have pulled together the information below so that you feel confident about the purpose of the research and what taking part will involve. If you have any questions which are not covered here, please do get in touch with either Sophie (sgiles@britainthinks.com) or Honor (hsullivandrage@britainthinks.com) so that we can answer them for you. It is important to us that you feel as comfortable as possible taking part.

As you know, this research is being conducted by BritainThinks, an independent market research company, on behalf of our client, the Competition and Markets Authority (the CMA). The CMA is an independent government department and the UK's lead competition and consumer authority. It works to ensure that consumers are protected when buying goods and services and to ensure that businesses operate within the law.

#### What is the research about?

This research will explore the experiences of a wide range of individuals who have paid for fertility treatment. We will be asking you about the things you did, and your interactions with clinics and staff, both while you were deciding whether to pay for treatment, which clinic to choose and what treatment(s) to buy, and also afterwards. We are aware that parts of this conversation may include sharing sensitive information, but you will not have to share anything with us that you prefer to keep private. The interview will be informal in nature, and you will also be able to take a break at any point during the discussion.

#### What are we asking from you?

Taking part in the research will involve an optional pre-interview activity which you can complete in your own time, as well as an interview with a female BritainThinks researcher lasting around one hour if we talk to you on your own, or around an hour-and-a-quarter if someone joins you for the discussion. The details for the optional pre-interview activity are listed below.

We would like to record the interview for our analysis purposes but would not share this recording with anyone outside of BritainThinks. We will delete the recording, as well as the personal information you have shared with us, no later than the end of October 2022. Our report for the CMA on findings from this research will not include any information that allows you to be identified as an individual, and we will not share your personal data with any third party, except in the very unlikely event that we are required to do so by law.

#### About taking part

#### What happens if I feel uncomfortable or want to end the conversation?

You will not have to share anything you don't want to, and you will be able take a break at any point. You will also be able to end the interview completely if you would like and can do this simply by telling your interviewer.

#### **Optional pre-interview activity**

Ahead of your interview, we'd like to ask you and, if applicable, the person who will be joining you for the interview, to spend some time thinking about your experience when considering whether to pay for fertility treatment, which clinic to choose and which treatment(s) to buy (as far as you can remember). If you still have it, it might be helpful to go through any paperwork you kept to prick your memory, but if you don't still have this paperwork or you can't find it, that's not a problem! If you have any questions about the activity, please get in touch.

#### About your data

By signing your consent to participate in this research, you consent to BritainThinks **using** and **storing** (processing) the personal data we have collected from you during your recruitment to the research and any further personal data you share with us during your interview.

To explain what we mean by this, personal data is data that allows an individual to be identified (either directly or indirectly). This includes 'special category' data about your treatment history, your ethnic background, your sexual orientation (based on any information you provided about your relationship status), and depending on the answers you give us during your interview, it may also include data revealing your religious or philosophical beliefs.

BritainThinks will <u>use</u> and <u>store</u> (process) your personal data for the purposes of this research project only.

Your personal data **will not be shared with our client**, the Competition and Markets Authority, in a way that would allow you to be individually identified. Please note that you are also consenting to the CMA processing aggregated data from which you cannot be individually identified, in the form of our report on the findings from the research for the CMA. All personal data will be kept securely and deleted from our systems no later than the end of October 2022.

#### What next?

If you have any further questions, please do not hesitate to get in touch with us at BritainThinks via email at <u>sgiles@britainthinks.com</u> or <u>hsullivandrage@britainthinks.com</u> or by phone at 020 8142 3889.

Now you have read this information sheet, please click <u>here</u> to access the consent form. You can withdraw your consent at any time during the research if you change your mind about taking part by contacting us using the details above.

## **Discussion Guide**

This document was developed in partnership with the CMA to act as a guide for moderators. This document ensured all interviews covered the core research objectives. This was provided to all moderators prior to interviews, and was used flexibly in order to tailor all interviews to the participants specific situations.

Section and objectives	Key discussion points and probes	Time for 1-2-1	Time for paired
Introduction	<ul> <li>My name is [XXX] and I'm a researcher from an independent research agency called BritainThinks.</li> <li>We're conducting this research on behalf of the Competition and Markets Authority, to understand more about aspects of people's experiences of choosing and buying private fertility treatment.</li> <li>Before we begin the interview, I'd like to spend a couple of minutes telling you (both) about the format of the interview and what we will do with the information you share with us today: <ul> <li>To reiterate, this interview will focus on your experiences of choosing and buying private fertility treatment (IVF or egg freezing), as opposed to the medical experience of the treatment itself.</li> <li>I am not an expert on fertility treatments, so please forgive me if I ask you to explain some of the language you use or if I ask for further explanation of some parts of what you tell me.</li> <li>I'm here only to gather your honest views and opinions, and there are no right or wrong answers to any of the questions I will be asking.</li> <li>There are no obligations to answer any questions that you would rather not, and if you would like to take a break at any time during the interview, you are more than welcome to do so.</li> <li>You can also opt out of the research at any time, just let me know you'd like to stop.</li> <li>Your identity, along with any comments you share, will be fully anonymised within all our reporting.</li> <li>There is only one exception to this anonymity, which is if you say something that gives us reason to believe that you or someone else is at immediate risk of harm, in which case BritainThinks may have a duty to report this to the relevant authorities.</li> </ul> </li> </ul>	5 (5)	5 (5)

	<ul> <li>We'd like to record the interview in order to help us with our analysis. This recording would not be shared with anyone outside of BritainThinks, and we will delete the recording no later than the end of October 2022.</li> <li>Confirm participant is happy to proceed and begin recording, also offer the opportunity to ask questions about research process.</li> <li>To begin with, it would be great to get to know you (both) a bit. Please could you introduce yourself(ves).</li> <li>If not mentioned spontaneously, moderator to probe on: where they live, who they live with, what they do for work (if anything).</li> <li>What does a typical week look like for you (both)?</li> <li>If not mentioned spontaneously, moderator to probe on: any hobbies or interests</li> </ul>		
Understanding the	To get started, and if it's OK with you, I'd like to confirm some details about the treatment(s) you have had since January 2019.	3 (8)	5 (10)
participants' treatment journey	I believe you [moderator to refer to information collected during the screening process and confirm their understanding of this is correct]. Is that right?		
	Moderator to clarify any points from the below lists that are unclear:		
	If the patient paid for treatment <i>following</i> NHS-funded treatment		
	Regarding the patients' NHS-funded treatment, moderator to understand:		
	<ul> <li>Whether patient received NHS-funded treatment and their funding ended, and they therefore decided to pay for treatment; or</li> <li>Whether patient investigated getting NHS-funded treatment</li> </ul>		
	• but couldn't get this, and so they decided to pay.		
	With regards to the treatment the patient paid for, moderator to understand:		
	<ul> <li>How many cycles of treatment they have paid for in full (1)</li> <li>Whether all cycles of treatment they have paid for have taken place at the same clinic or multiple clinics (2 – not needed if answer at (1) is one or about to have/underway with first)</li> </ul>		

	<ul> <li>When they first paid for treatment in the same clinic where they had their last round of treatment(s)/are about to have/are having their current round of treatment(s) (3)</li> <li>Where this treatment took place – i.e., in the same place as the NHS-funded treatment vs. a different treatment facility (e.g., in another NHS hospital or in a private clinic) (4)</li> <li>If they have paid for one or more cycle(s) of treatment outside of the UK at any point – if so, when was and why did they choose to go abroad (<i>Moderator note: we are not interested in any individual elements of a cycle of treatment the patient may have had abroad, only full cycles of treatment</i>.) (5)</li> <li>If all treatment has been paid for in full by the patient, moderator to understand</li> <li>How many cycles of treatment they have paid for in full (1)</li> <li>Whether all cycles of treatment have taken place at the same clinic or multiple clinics (2 – not needed if answer at (1) is one or about to have/underway with first)</li> <li>When they first paid for treatment in the same clinic where they had their last round of treatment(s)/are about to have/are having their current round of treatment(s) (3)</li> <li>Where this treatment took place (in an NHS treatment facility or in a private clinic) (4)</li> <li>If they have paid for a cycle of treatment facility or in a private clinic) (4)</li> <li>If they have paid for a cycle of treatment outside of the UK at any point – if so, when was this along the journey and why did they choose to go abroad (Moderator note: we are not interested in any individual elements of a cycle of treatment the patient may have had abroad, only full cycles of treatment the patient may have had abroad, only full cycles of treatment the patient may have had abroad, only full cycles of treatment the patient may have had abroad, only full cycles of treatment the patient may have had abroad, only full cycles of treatment the patient may have had abroad, only full cycles of</li></ul>		
Contextual building	Thank you for this. In this interview, we are going to be exploring the different things that shaped your decisions while you were deciding <i>whether</i> to pay for treatment, <i>where</i> to have treatment, and <i>which</i> treatment(s) to have.	7 (15)	10 (20)
	<i>[If patient had NHS-funded treatment:</i> We are no longer referring to any treatment you had through the NHS.]		
	[If patient has accessed treatment at more than one clinic: For the purpose of my next question, I'd like you to focus on the clinic where you most recently paid for treatment.]		
	I'd like to try and understand a bit about what was happening in your life at the time you were thinking about <i>whether</i> to pay for treatment, <i>which</i> treatment(s) to have, and <i>where</i> to have treatment.		

If you can remember, please can you tell me a bit about what was going on in the rest of your life at this time?	
<ul> <li>Where were you living at the time? And how did you feel about living here/ did you feel about living there?</li> <li>What were you doing at the time (e.g., caring, studying, training, working, something else)? How did you find that?</li> <li>If you try and think back, what other things of significance - if any - were happening in your life at this time?</li> </ul>	
How would you describe how you were feeling about life in general around the time of considering whether to pay for fertility treatment?	
<ul> <li>How would you describe your frame of mind and emotions during this time?</li> <li>If a paired depth, moderator to explore both partners' feelings.</li> </ul>	
I'm aware this is a very personal question, but please could I ask about how you funded your treatment? For example, did you receive any financial support from family members or someone else, or did you use savings / a loan / an overdraft to fund your treatment(s)? We're asking this because it's helpful for us to build a picture of how big of an investment this treatment was for you.	
<ul> <li>Can you remember whether there were any specific issues you faced when paying for your treatment?</li> <li>Can you remember whether there were any things you did differently around the time of paying for treatment in order to ensure you would be able to fund it?</li> </ul>	
At the stage you were thinking about whether to pay for treatment, where to have treatment and which treatment(s) to have, what were your main considerations? If participant is unsure, moderator to explain: I'm thinking here about things like different treatment options, number of clinics in your local area, where these clinics were relative to you, the price of treatment etc.	
<ul> <li>How did these considerations compare to one another in terms of importance?         <ul> <li>Which was most important? Why?</li> <li>Which was least important? Why?</li> </ul> </li> <li>To what extent did you make trade-offs between the different things that were important to you as you got closer to making a decision about which treatment(s) to have and where to have these treatment(s)? <i>If participant is unsure, moderator</i></li> </ul>	

	<ul> <li>to clarify using considerations relevant to the participant e.g.: Between the location of the clinic and the treatment options available? Between the price of treatment and the location of the clinic? Between the price of treatment and the range of treatment options?</li> <li>Finally, before we move on, please could you tell me: <ul> <li>At the point you started to think about paying for fertility treatment, how sure were you (on balance) that paying for treatment was something you were going to do? Why do you say that? Moderator to clarify where participants were in their thinking, e.g., "it was only a matter of when not if" / "we were determined to pay for treatment," "it was still completely up in the air" / "could have gone either way" / "depended on what we found out once we started looking into it", etc.</li> <li>And thinking that you would definitely/would probably/might pay for fertility treatment, which of these would you say came first for you: choosing where to have treatment (which clinic you would use) or choosing which treatment(s) to have?</li> </ul> </li> </ul>		
Role of success rate information	<ul> <li>I'd like to continue by talking about a couple of different <i>types</i> of information and how important these were in the decisions you made.</li> <li>Around the time that you were deciding where to have treatment and which treatment(s) to have, to what extent did you look for information specifically regarding the <u>success rates</u> of treatment at particular clinics?</li> <li>[IF NONE ACCESSED]: What were your reasons for not looking for information about success rates of treatment at the clinic where you had your treatment, if any?</li> <li>[IF ACCESSED]: How did you look for information about success rates? Moderator to probe on clinic websites, HFEA website, other websites, open days/evenings etc. Moderator to listen out for any suggestion the patient does not trust success rate information - If spontaneously raised, probe on what it is about success rates of this information.</li> <li>When throughout this process did you look for this information? Only at the beginning? Or at other points too?</li> <li>To what extent did information about success rates influence the decisions you made about where to have treatment or which treatment(s) to have? Why/ why not?</li> </ul>	10 (40)	15 (50)

Role of pricing information	To what extent did you look for information specifically regarding the <u>price</u> of treatment?		
	<ul> <li>[IF PATIENT IMPLIES THEY <i>DE</i>PRIORITISED PRICE INFORMATION]: To what extent was the price of treatment important to you? Why / why not?         <ul> <li>What, if any, were your reasons for not looking for information about the price of treatment?</li> <li>[IF PATIENT IMPLIES THEY PRIORITISED PRICE INFORMATION]: How did you look for information about the price of treatment? <i>Moderator to probe on clinic websites</i>, <i>HFEA website, other websites, open days/evenings etc.</i></li> <li>When exactly did you look for information about the price of treatment? Only at the beginning? Or at other points too?</li> <li>To what extent did information about the price of treatment influence the decisions you made about where to have treatment or which treatment(s) to have? Why/ why not?</li> <li>If you can remember, when you were told what the price of your treatment would be, was this the same, more or less expensive than what was advertised on the clinic website?</li> <li>How did the cost of different treatment options, at that clinic, impact on the choices you made, if at all?</li> </ul> </li> </ul>		
Deep dive on different sources of information	Moderator instructions: If participant paid for treatment in the same clinic as their NHS-funded treatment and didn't consider any other clinics, moderator to frame the discussion solely in terms of understanding why they did not consider other clinics and understanding their research process about which treatment(s) to have. I'd like to talk in a bit more detail about <i>how</i> you accessed information when deciding whether to pay for treatment, which treatment(s) to have and where to have fertility treatment. <b>At the time you were considering whether to pay for fertility</b>	15 (30)	15 (35)
	<ul> <li>treatment, to what extent did you search for other information about <u>which</u> treatment(s) to have and <u>where</u> to have treatment?</li> <li>What types of information in particular were you looking for? Moderator to listen out for references to information about success rates or price or treatment options, probe lightly to understand their experiences of this information at this stage.</li> </ul>		

	What were the different ways that you gathered information?	
	Moderator to note down <u>all</u> different methods of information-gathering used by the patient, e.g., clinic websites, online forums, review websites, other healthcare websites, social media, clinic information packs, clinic apps, attending open days/other events, clinic social media activities, speaking to friends/family, any other ways of collecting information.	
	<ul> <li>What types of information did you come across when using each of these methods? Moderator to understand for each different source of information that the patient looked at, what types of information they were accessing, e.g., to what extent was this about success rates / price / treatment options? We are particularly interested in clinic websites and what role this played in patient's decision-making.</li> <li>If applicable: When using social media platforms and/or review websites, which specific websites / platforms have you used, and which specific type of information are you accessing in this way?</li> <li>What impact (if any) did this information have on the decisions you made?</li> </ul>	
Shortlisting	To what extent did you create a shortlist of different clinics at the point you were looking into treatment options and where to have treatment?	
	<ul> <li>IF YES: <ul> <li>Why did you do this?</li> <li>How many did you shortlist?</li> <li>What information did you gather from the different clinics you shortlisted?</li> <li>How did you gather this information?</li> <li>What were the key factors that made you shortlist these particular clinics?</li> </ul> </li> <li>IF NO: <ul> <li>What, if any, were your reasons for not forming a shortlist of sorts?</li> </ul> </li> </ul> <li>[If participant paid for their treatment in the same clinic as where</li>	
	they had their <b><u>NHS-funded treatment</u></b> , moderator to probe on the extent to which they considered other clinics, if at all? Why/ why not?]	
Role of clinic websites	Thinking specifically about the information you looked at on <u>clinic websites</u> - what role did this play, if any, in how you felt about whether to pay for fertility treatment, where to have treatment or which treatment(s) to have?	

	<ul> <li>[IF NONE ACCESSED]: What, if any, were your reasons for not looking at clinic websites?</li> <li>[IF ACCESSED]: If you can remember, how many clinic websites did you look at overall?         <ul> <li>At what point(s) did you look at information on clinic websites?</li> <li>What information, if any, were you particularly looking at on clinic websites? Why was this? <i>Moderator to listen out for any references to success rates or price information.</i></li> <li>To what extent was information on clinic websites influential in the decisions you made about whether to pay for treatment, where to have treatment (inc. if applicable which clinics to shortlist) or which treatment(s) to have? Why/ why not? <i>If necessary, moderator to provide examples of single cycles of treatment versus a multicycle package, donor IVF or to egg share, natural/ mild versus standard ICSI versus IVF, or add-on treatments such as PGT-A or endometrial scratch.</i></li> <li>If you can remember, what information was most influential?</li> <li>How influential was this?</li> </ul> </li> </ul>	
Role of open days/evenings	treatment versus a multicycle package, donor IVF or to egg share, natural/ mild versus standard ICSI versus IVF, or add-on treatments such as PGT-A or endometrial scratch. If you can remember, what information was	
	<ul> <li>[IF NONE ATTENDED]: What, if any, were your reasons for not attending any clinic open days or open evenings?</li> <li>[IF ATTENDED]: How many open days or open evenings did you attend? Why was this?</li> </ul>	

	<ul> <li>Were these from the same clinic / different clinics?</li> <li>Were these online virtual events or in person?</li> <li>What were these open day(s) or open evening(s) like?</li> <li>To what extent were you able to access advice that was personalised to you at these events, if at all?</li> <li>To what extent were you provided with information that you could take away from these events? If so, what was this?</li> <li>Thinking about the information you accessed at this/these event(s), to what extent was this influential in the final decisions you made about where to have treatment or which treatment(s) to have? Why/ why not?</li> <li>If you can remember, what information was most influential?</li> <li>How influential was it?</li> <li>What happened after you had gathered this information?</li> <li>What steps did you take?</li> </ul>
Role of any other contact with clinics, for example, telephone calls, e-mails, social media, visits to clinics on a 1-2-1 level, i.e., not an open day/ evening event	<ul> <li>Did you have any other contact with the clinic/ any of the clinics that you were looking into?</li> <li>[IF NO] Moderator to move onto next question bank.</li> <li>[IF YES] What type(s) of contact and what role did this contact have, if any, in your decision about whether to pay for fertility treatment, where to have treatment and which treatment(s) to have?</li> <li>At what point(s) did you have the contact? <ul> <li>How many points of contact did you have with the clinic?</li> <li>If you can remember, who did you talk with at the clinic? (What was their role/job title? Were they medically qualified?)</li> <li>What information, if any, did you get from the clinic?</li> <li>Did you receive any information that was personalised to your own situation?</li> <li>To what extent did you gather information from more than one clinic?</li> <li>How did the information vary that you collected?</li> <li>To what extent was this contact influential in the final decisions you made about where to have?</li> </ul> </li> </ul>

Role of consultations	I'd like to talk about <u>consultations</u> at clinics, and what role these played, if any, in your decisions about where to have treatment and which treatment(s) to have.		
	<ul> <li>First of all, please can I ask how many clinics you had a consultation with?         <ul> <li>IF SEVERAL: What were your reasons for choosing to have consultations with multiple clinics?</li> <li>How did this affect your overall process of deciding where to have your treatment?</li> <li>IF ONLY ONE: What were your reasons for choosing to have a consultation with one clinic?</li> <li>To what extent were you sure that you would pay for treatment at that clinic at the point of going for your consultation? Why was this?                 <ul> <li>[IF SURE PRE-CONSULTATION]: Did anything happen during the consultation that made you reconsider this? If so, what?</li> </ul> </li> </ul> </li> <li>Prior to going for your consultation, to what extent had you already thought about which treatment(s) or treatment packages you might buy? If you had given this some thought, what treatment(s) or treatment packages did you think you might buy?</li> <ul> <li>What had influenced your thinking about which treatment(s) or treatment packages you might buy?</li> <li>Did anything happen during the consultation which treatment(s) or treatment packages you might buy?</li> <li>What had influenced your thinking about which treatment(s) or treatment packages you might buy?</li> <ul> <li>Did anything happen during the consultation which made you consider different treatment options? If so, what?</li> </ul> </ul></ul>		
	Thinking about all the different ways that you accessed information (e.g., looking at clinic websites, looking at other websites, looking on social media, attending clinic open days or evenings, attending consultation(s) with clinics etc.), <u>which</u> for you, if any, were most important in leading you to your final <u>decisions</u> about <i>where</i> to have treatment and <i>which</i> treatment(s) to have? • Why was this?		
	Moderator to offer break/pause		
In-depth exploration of choosing (and staying with) a particular clinic	We've already touched on some questions regarding how you made the decision about where to have treatment and which treatment(s) to buy. To ensure I'm understanding this correctly, I'd like to spend a couple of minutes confirming what I think you've told me as it is particularly important that we understand this.	5 (45)	10 (60)

and treatment	Firstly, please can you tell me, if you remember, at what point		
options	you decided <i>which</i> clinic to have treatment at?		
	<ul> <li>Once you'd had your initial consultation with the clinic you eventually paid for treatment, to what extent did you do more research about other clinics or consider having consultations with other clinics, if at all? Why/ why not?</li> <li>What would have needed to happen for you to change your clinic after you felt you had decided on a specific clinic? Why is this?</li> </ul>		
	(FOR THOSE THAT PAID FOR TREATMENT AT MORE THAN ONE CLINIC) What factors led you to pay for treatment at two different clinics?		
	At what point did you make the decision to change clinics?		
	If you can remember, please can you also confirm at what point exactly you made a final decision about which treatment(s) you would have? <i>If participant seems unsure, moderator to explain:</i> Here we're talking about whether you opted for a single cycle of treatment versus one of the various types of multicycle package, donor IVF or to egg share, natural/ mild versus standard ISCI versus IVF, or whether you chose any potential add-on treatments such as PGT-A or endometrial scratch.		
	<ul> <li>Moderator probe to understand whether this was before/after a consultation</li> </ul>		
	(FOR THOSE THAT CHANGED TREATMENT(S)) What factors led you to change treatment(s)?		
	• At what specific point in the process did you make this decision?		
In-depth exploration of raising an issue/	I'd like to finish up by discussing your overall experience of the clinic and its staff, and what – if anything – you would have liked to have happened differently regarding your interactions with the clinic and its staff.	10 (55)	15 (85)
complaint	Firstly, if you had to use 3 words to describe your overall experience with your most recent clinic and its staff, what words would you choose?		
	<ul><li>Why did you choose these words?</li><li>What were the key factors influencing your experience?</li></ul>		
	Was there anything that you would have liked the clinic to do differently? I'm thinking here about things that you may think of as small niggles all the way through to much larger issues. <i>If patient unsure, moderator to explain:</i> For example, things to do with:		

<ul> <li>Contact between you and your clinic</li> <li>The costs of treatment(s) and/or medication</li> <li>Information about treatment(s) and/or changes to treatment</li> <li>Invoicing</li> </ul>	
If participant experienced issues which is causing upset during the interview, moderator to reassure: Please know that you do not need to go into detail about what happened. We are asking these questions to understand whether you felt able to raise these issues with the clinic or make a complaint about what happened.	
<ul><li>What were these things that you would have liked to happen differently?</li><li>At what point did they occur during the process?</li></ul>	
Moderator to ensure patient has shared all of the things they wished had happened differently before moving on.	
[IF PATIENT <u>DID HAVE</u> THINGS THEY WANTED TO HAPPEN DIFFERENTLY]	
Thinking about the issues you just described, how comfortable did you feel discussing them with your clinic or raising a complaint about them?	
<ul> <li>What factors made you feel more or less able to discuss these issues or raise a complaint?</li> <li>To what extent do you feel there are barriers to discussing issues or raising complaints in this circumstance? <ul> <li>What influences this?</li> </ul> </li> <li>To what extent did you discuss any of these issue(s) with anyone at your clinic / raise a complaint?</li> <li>IF NO: Why do you think you didn't? Moderator to understand in full detail why the participant did not raise a complaint or discuss their issue with someone.</li> <li>Did you do anything else other than discuss your issue with someone at the clinic or raise a complaint?</li> <li>If so, what was this?</li> <li>If not, why do you think you didn't take this/these issue(s) any further?</li> <li>IF YES: How comfortable did you feel doing this?</li> <li>What was the process of discussing your issue or raising a complaint like?</li> <li>What was the outcome of this?</li> </ul>	

<ul> <li>If not, did you do anything else following on from this? Why/ why not?</li> <li>To what extent do you feel that discussing a concern or raising a complaint when you are buying fertility treatment is different to doing the same thing in other sectors/ when you pay for other types of product or service?</li> <li>If so, how is it different?</li> </ul>
[IF PATIENT DID <u>NOT</u> HAVE THINGS THEY WISHED HAPPENED DIFFERENTLY]
Moderator to probe on the following areas to ensure there was nothing they would like to have happened differently:
<ul> <li>Information they came across during their research phase either from clinics or other sources</li> <li>Information they saw about price or success rates</li> <li>The clinic they chose</li> <li>What the communication with clinic was like</li> <li>The staff they interacted with during the process</li> <li>Their consultation or other appointments they had with the clinic.</li> </ul>
In the event that something had happened during the process that you were less comfortable with, what - if anything - do you think you might have done?
<ul> <li>To what extent would you have felt able to discuss your concern and/or raise a complaint? <ul> <li>Why / why not?</li> </ul> </li> <li>To what extent do you feel there are barriers for people going through this process to discuss concerns or raise a complaint? <ul> <li>What are these barriers?</li> <li>Why do they exist?</li> <li>How do you think someone would go about discussing a concern or raising a complaint? <ul> <li>How easy do you think someone would find it to do this?</li> </ul> </li> </ul></li></ul>
<ul> <li>To what extent do you feel that discussing a concern or raising a complaint when you are buying fertility treatment is different to doing the same thing in other sectors/ when you pay for other types pf product or service?         <ul> <li>If so, how is it different?</li> </ul> </li> </ul>

Complaint- raising – case study testing	[IF MODERATOR IS STILL UNCLEAR ABOUT THE EXTENT TO WHICH THE PATIENT WOULD HAVE FELT COMFORTABLE WITH RAISING A COMPLAINT, CASE STUDY SCENARIOS TO BE TESTED AS BELOW]	5 (If needed)	5 (If needed)
	I'd like to describe a couple of fictional scenarios where something went less well than expected in order to find out what you think you might do in this kind of situation.		
	Case study scenario 1:		
	A patient attends their consultation and agrees a price for their treatment package which they are told includes everything. As they get further through the process, and as treatment begins, they are asked to pay additional costs for aspects of their treatment that the clinic did not tell them about before they agreed to treatment.		
	<ul> <li>In this situation, and remembering what it was like when you were going through treatment, what do you think you would have done?</li> <li>What kind of things might have made you feel able to raise a complaint? Why?</li> <li>What kind of things might have held you back from raising a complaint? Why?</li> <li>Ultimately, in this scenario, do you think you would raise a complaint with the clinic? <ul> <li>Why or why not?</li> </ul> </li> </ul>		
	Case study scenario 2:		
	Prior to agreeing treatment, the clinic had been very communicative and responsive. Imagine a scenario where you have already agreed on your treatment package, have paid some of the cost and are given a date when your treatment will begin. When you have had time to reflect, you have a few things that you would like clarified, for example why some of the medication is necessary or why you are having ICSI. The clinic is not responding to your calls or e-mails, and you start the treatment without answers to your questions. In this situation, what do you think you would do?		
	<ul> <li>What kind of things might have made you feel able to raise a complaint? Why?</li> <li>What kind of things might have held you back from raising a complaint? Why?</li> <li>Ultimately, in this scenario, do you think you would raise a complaint with the clinic? <ul> <li>Why or why not?</li> </ul> </li> </ul>		

Reflecting on the journey + thank and close	Thank you so much for sharing everything that you have with me today: understanding your experience has been incredibly helpful as part of this piece of research for the CMA. I'd like to finish our discussion with a couple of questions that relate	5 (60)	5 (90)
	to the time since you started having fertility treatment (i.e., including all previous rounds, if there are any).		
	<ul> <li>What, if anything, do you think you would do differently knowing what you now know?         <ul> <li>Why would you do this?</li> <li>To what extent are there things you already did differently as a result of previous experiences? What were these things?</li> </ul> </li> <li>What advice would you offer another person who is about to start looking for clinics and looking at treatment options?</li> <li>Thank participant(s), inform them of follow-up email with sources of support and close.</li> </ul>		

## **Post-interview support**

This information was provided to all participants via email following their interview as part of the safeguarding process. This was to thank participants for taking part, and reiterate what we would do with the information they had shared with us. The BritainThinks and CMA teams respectively were aware that these interviews had the potential to be emotionally challenging for the participants we heard from, and with that in mind used this document to provide links to organisations that could provide support.

Thank you very much for taking part in our research.

As a reminder:

- This research was conducted by BritainThinks, an independent research organisation, on behalf of the CMA (Competition and Markets Authority), an independent government department and the UK's lead competition and consumer authority.
- No personal data (including your name(s)) will appear in any reports.
- Your data will be stored securely with us at BritainThinks and will be deleted no later than October 2022.

We understand that participating in research of this nature can bring up upsetting memories for some, and we would like to provide you with a range of options for further support around some of the issues that we discussed, in case you have need of them.

Several services are available to support individuals struggling with fertility-related issues. Please see a list of some of these organisations below:

- <u>Fertility Network UK</u> is a charity that provides free and impartial support, advice, information and understanding for anyone affected by fertility issues.
- <u>HFEA</u> (The Human Fertilisation and Embryology Authority) is an executive nondepartmental public body of the Department of Health and Social Care in the UK and provides advice on how to raise a complaint about a fertility treatment clinic, which can be found <u>here</u>. They also provide <u>a list of organisations</u> where patients can get emotional support.
- If you are interested in paying for counselling, then the <u>British Infertility Counselling</u> <u>Association (BICA)</u> has an accredited list of counsellors. BICA is a professional counselling association for infertility counsellors and counselling in the UK which seeks to promote the highest standards of counselling for those considering or undergoing fertility investigations and treatment."

If you have any questions about the research or would like to raise an issue regarding the research process, please contact Sophie from the BritainThinks team on 020 8142 3889 / <u>sgiles@britainthinks.com</u>. We are always looking for ways to improve the way we work, and would very much welcome your thoughts.