

Human Fertilisation and Embryology Authority

- Results from the Fertility Views online panel
 - November 2007

Presentation structure

- Overview
- Our approach
- Profile of respondents to this survey
- Main findings from 5th survey
- Conclusions and recommendations

Overview (1)

- Only one in five participants paying for their treatment received a personal costed treatment plan (20%). Most simply received a price list (79%)
- Over a quarter of recipients, having received cost information, were subsequently charged for additional, unexpected costs (27%).
 - Of these, only around 1 in 10 were alerted to these additional costs before treatment started and over a quarter of respondents were alerted to the additional costs after treatment.
 - Drug costs were cited as the most common source of unexpected, additional cost (61%), however there were a range of sources including supplementary treatments, additional blood tests or scans and freezing embryos
- Over 4 in 5 people who didn't receive a costed treatment plan would have liked one (88%)

Overview (2)

- Over half of the respondents believe that it is important to have printed HFEA information as well as being able to view and print from the HFEA website (58%)
- Over eight in ten respondents have read the HFEA Guide to infertility (88%)
 - Most of these people obtained it online - nearly half ordered the Guide from the HFEA website (48%) and a third read the Guide on the HFEA website (31%).
 - Most participants were quite positive about the Guide
 - 69% found general information about infertility useful
 - 64% said that the information on the different treatments available was useful
 - 63% felt the list of HFEA licensed clinics was useful
 - 50% felt that the information on finding the right clinic for you was useful

Overview (3)

- Most participants would be happy for researchers/ health experts to have access to their individual data for a follow up study with their child (80%)
 - The majority of these participants would be happy to allow researchers, for medical purposes, to have access to their individual data (89%), GPs (60%), or clinical experts (51%)
- Almost two thirds believe that if the HFEA found a problem at their clinic (that was not an immediate risk to patient safety) the HFEA should give the clinic no longer than 3 months to show improvements
 - 22% believe there should be a 1 month period to show improvements, and 42% believe there should be a 3 month period to show improvements
- Participants expressed much interest in the HFEA publishing information about clinics on their website
 - Priority information was when a clinic's license has been taken away (96%) and if the HFEA were taking regulatory action (94%)

Overview (4)

- Over four in five participants have used the HFEA 'find a clinic' search (81%) and most of them found it useful (70%)
- In terms of the information most useful in the 'Find a clinic' search, most thought that:
 - Information on a clinic's live birth rates would be useful (87%), comparing different success rates side by side would be useful (77%) and comparing a clinic's success rates with the national success rates would be useful (75%)
- Although nearly all respondents regard any live birth to be a desirable outcome, when asking about specific outcomes only 14% say triplets are desirable and 54% say twins are desirable
- There is an interest in seeing clinical success presented in various forms
 - 68% said they would like to see the chances of having a baby measured from when the embryos are transferred
 - 59% said they would like to see them presented from when the embryos implant

Overview (5)

- **Less than one in five of respondents have received blastocyst transfer (19%)**
 - Most had two blastocysts transferred (79%)
 - Half were successful (50%) in that a third had a singleton birth (38%) and just over one in ten had twins or more (12%)
- **When taking the increased success rate of blastocyst transfer into account, the majority of participants would consider having just one blastocyst transferred rather than one embryo transferred (62%)**
- **Most participants believe that the patient, in consultation with the clinician should make the decision on how many blastocysts to transfer (81%)**
 - Less than one in twenty participants believe that this should be decided by HFEA regulation (3%), or the clinician (2%) or professional guidelines (1%)

Our approach

- An online panel was set up in May 2005 through a microsite linked to the HFEA website
- Previously 1 recruitment questionnaire and 4 surveys have been completed
- The 5th survey was sent to panel members in September 2007
- This survey focussed on a number of issues including costs of treatment, clinic success rates, regulation and treatment methods
- 426 panel members completed this survey

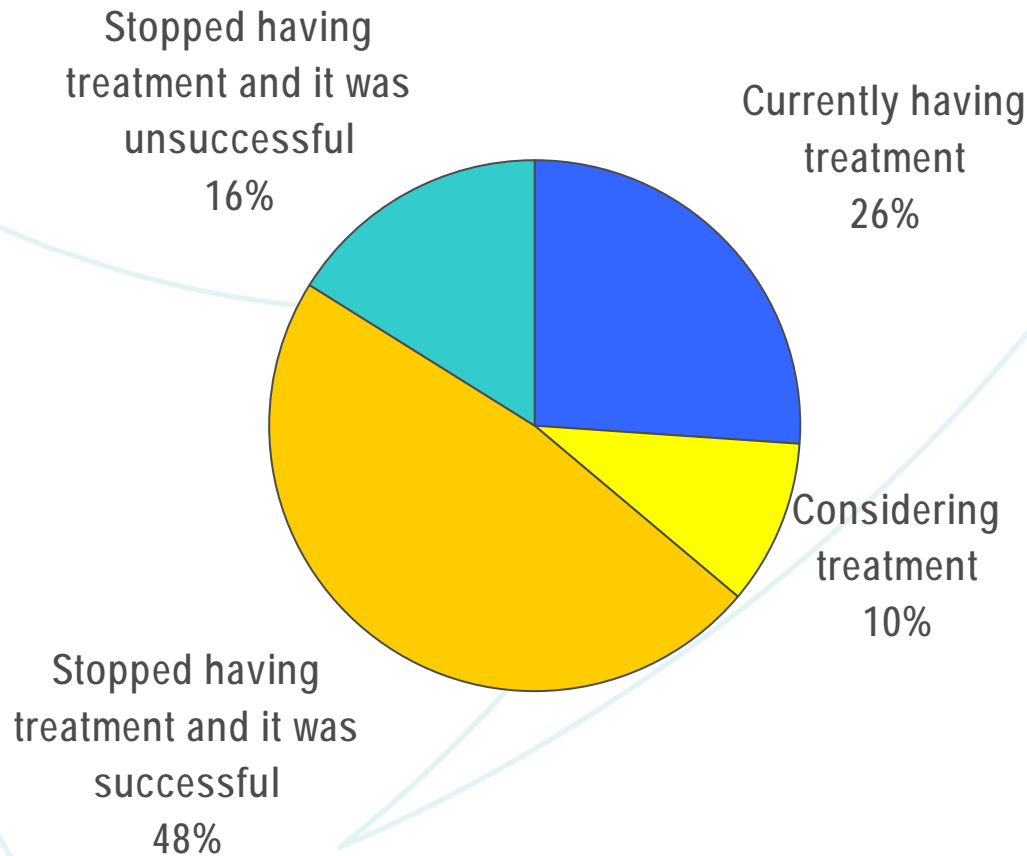


Profile of respondents

Summary of demographic profile

- 96% of those who responded are female
- 1% of those who responded are under 25, 34% are aged between 25-34, 62% are between 35-44, 4% are over 44
- 91% of those who responded are White (British, Irish or other), all other ethnic groups are 9%

What is your current status regarding fertility treatment?



Base 426: All respondents

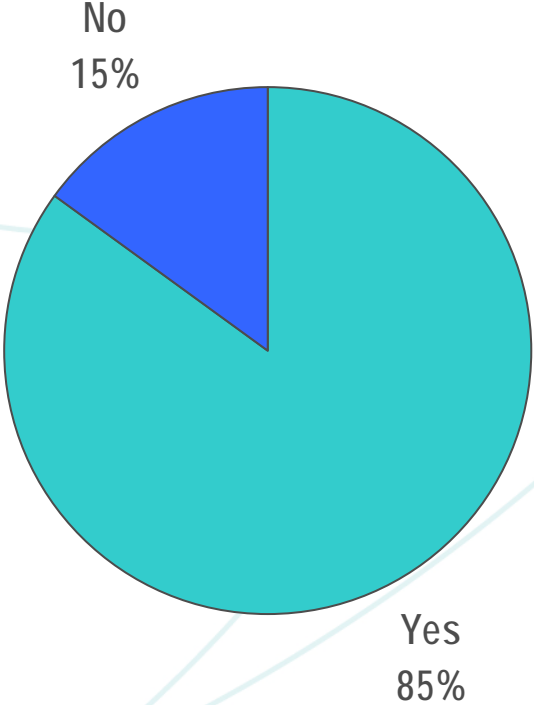


Responses to survey



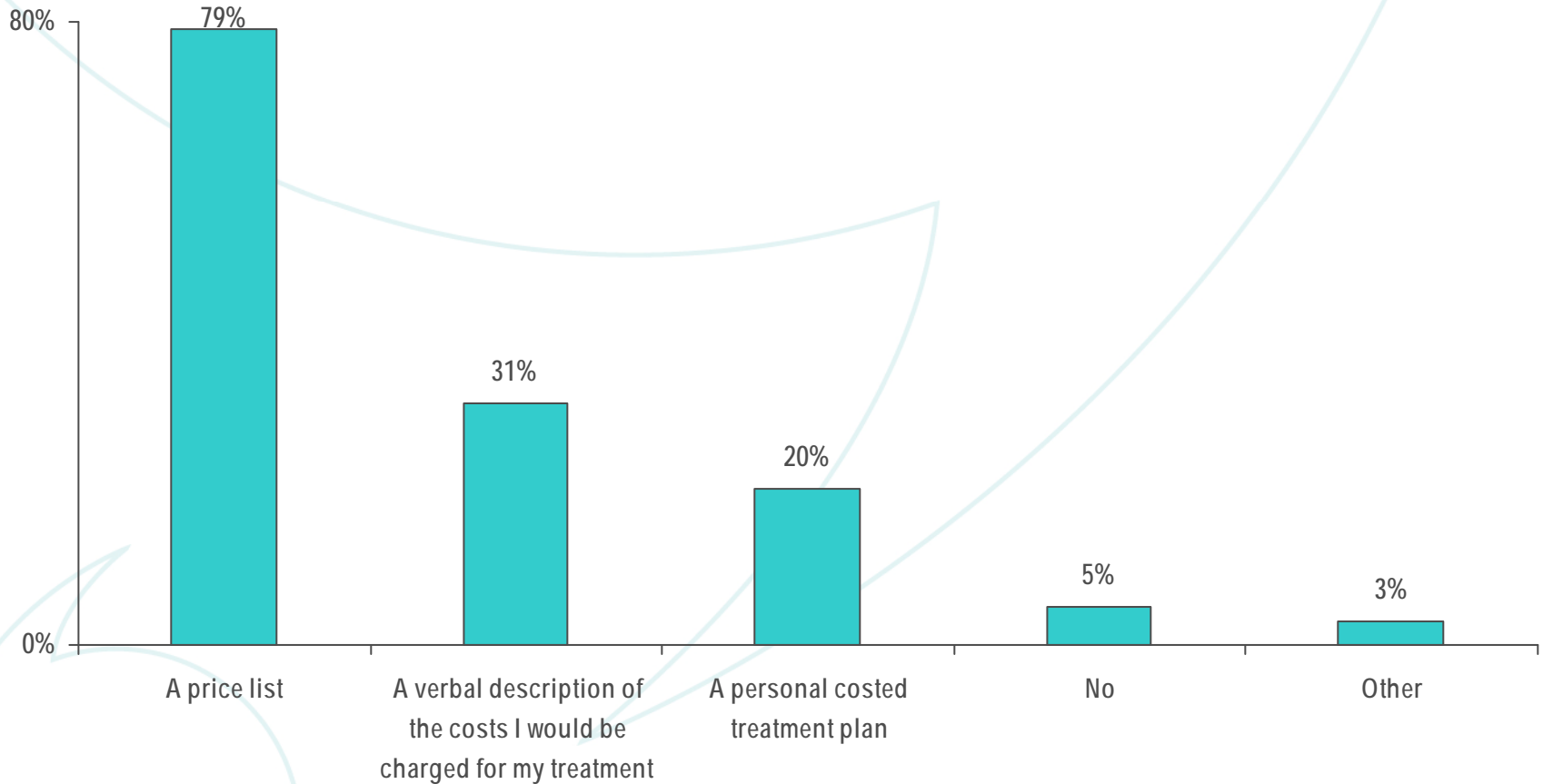
Costed treatment plans

Have you, will you be or are you currently paying for fertility treatments?



Base 426: All respondents

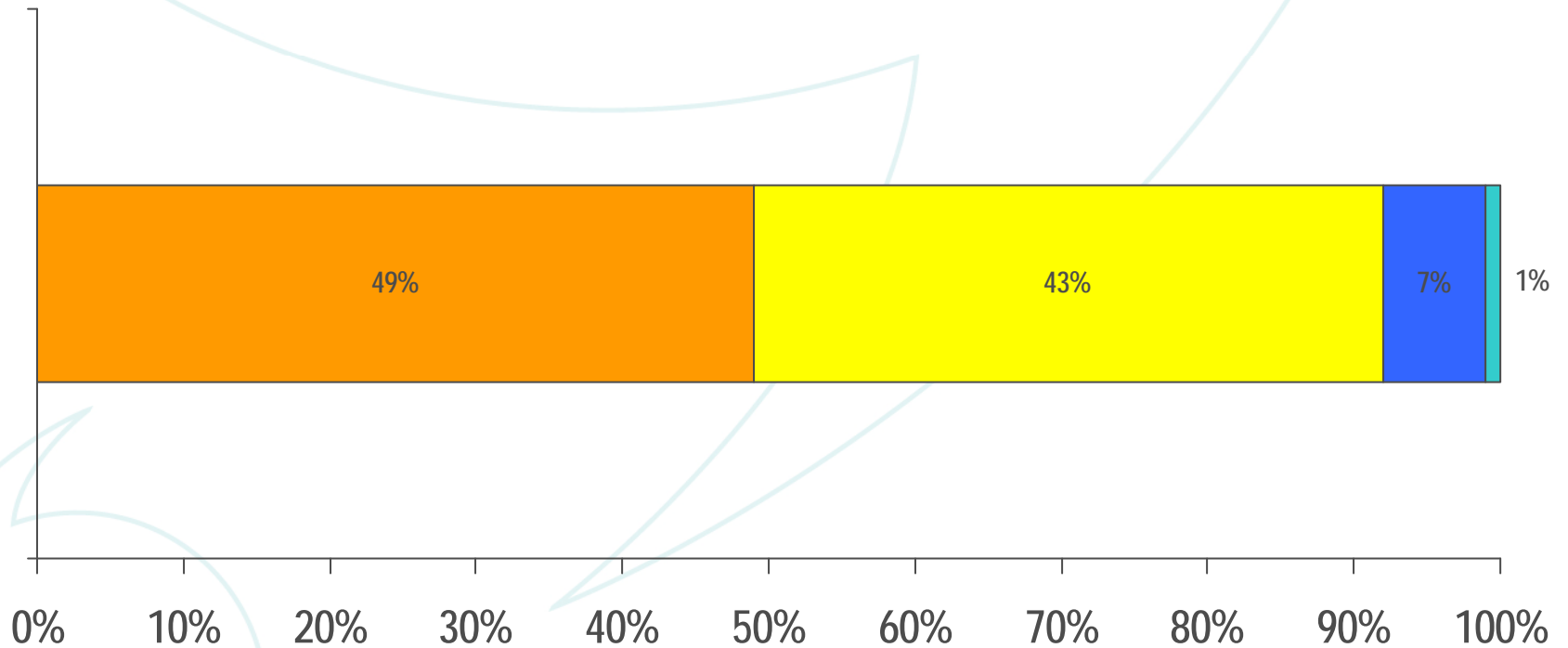
Have you received any of the following information about the cost of your treatment? (multiple response)



Base: 362 Those who are paying for fertility treatment

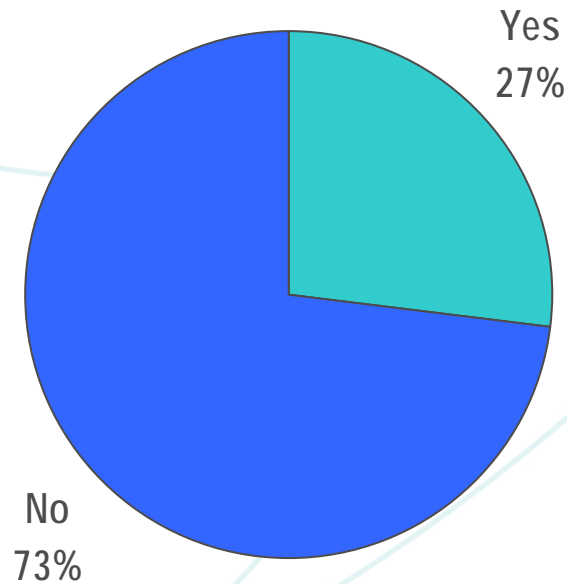
When did you receive this information?

At the first consultation Before I started treatment Other On the day of treatment



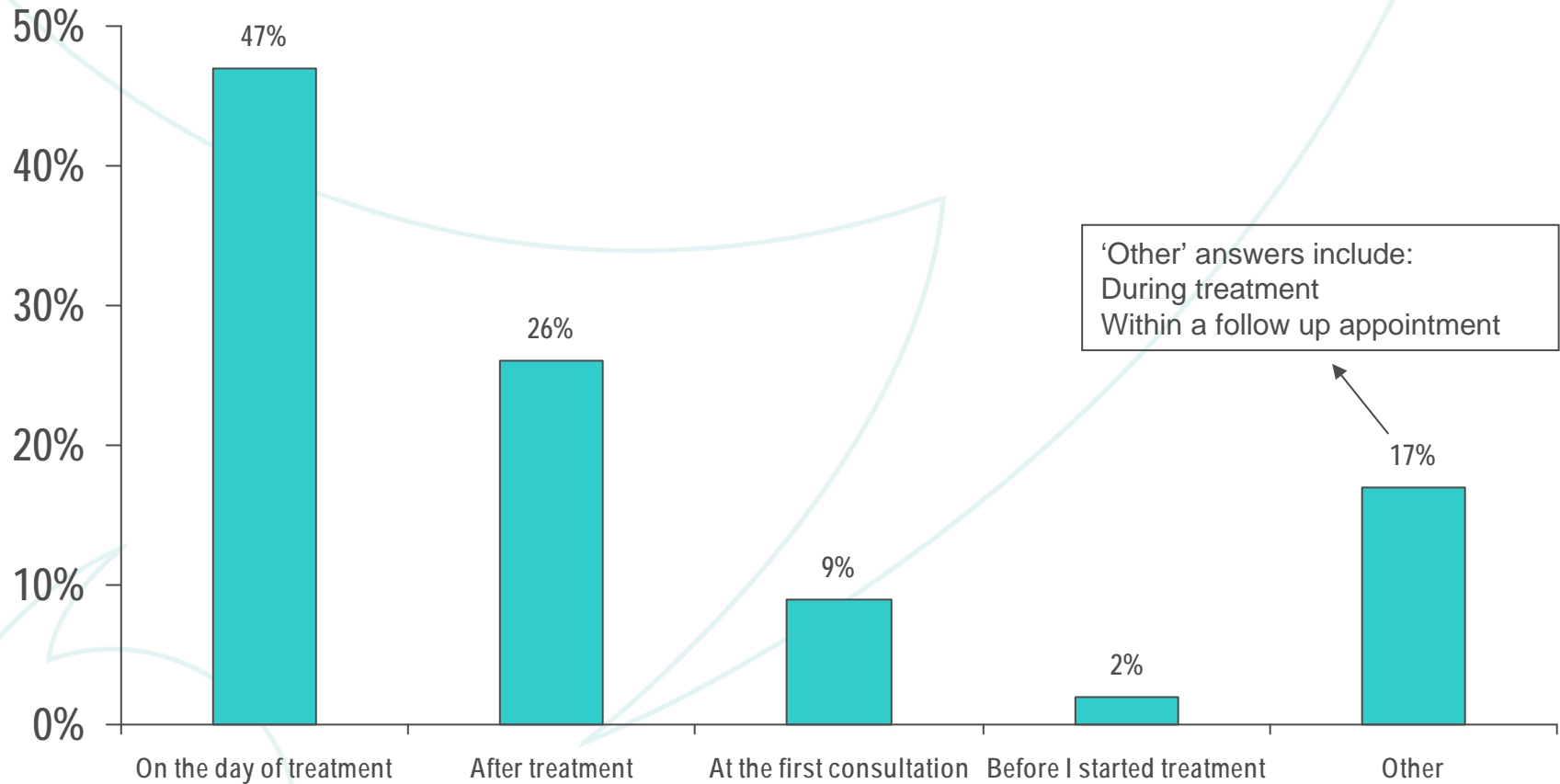
Base: 344 Those who have received information about the cost of their treatment

Having received this information, were you subsequently charged for any additional costs you were not expecting?



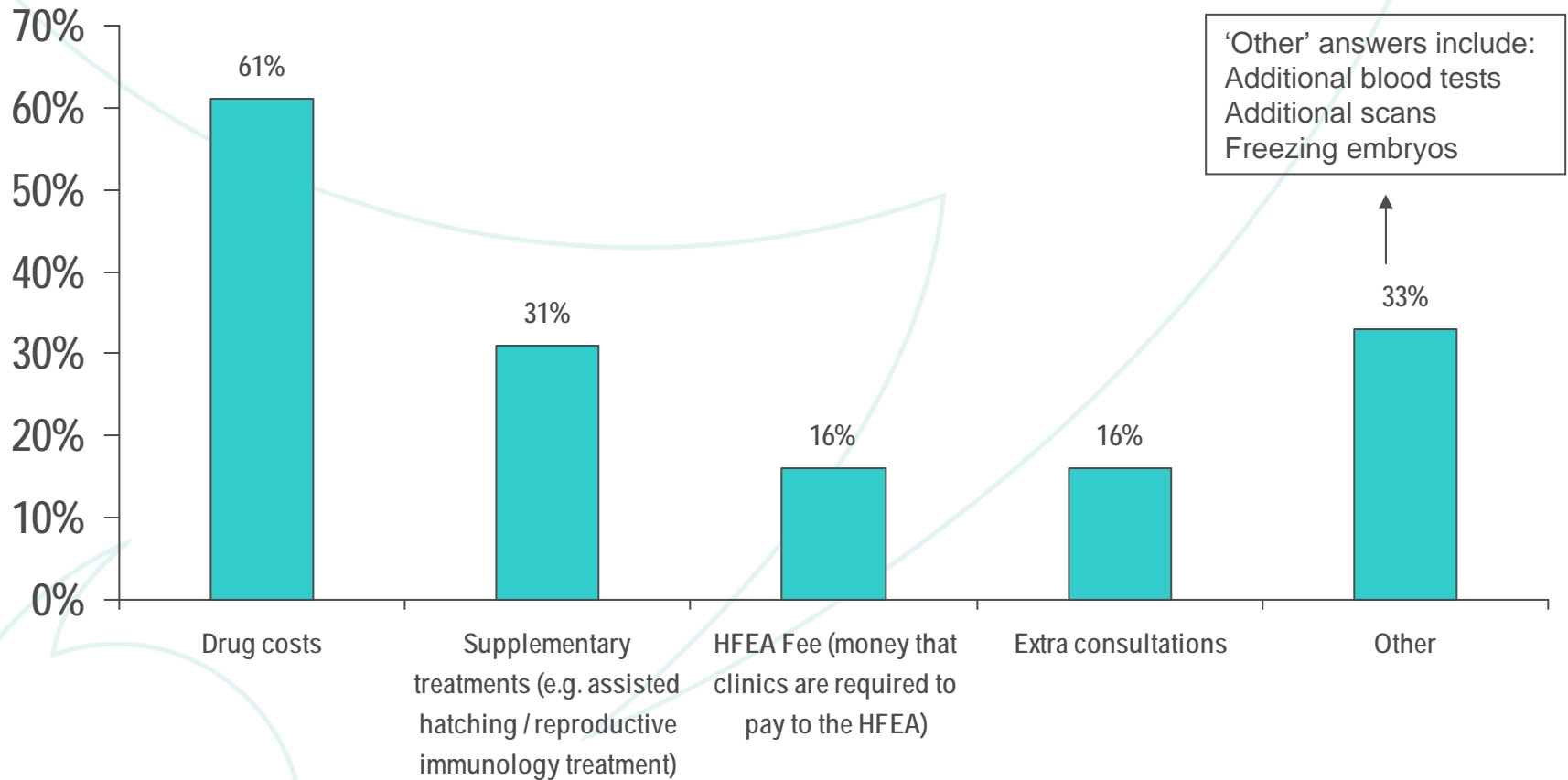
Base 344: Those who have received information about the cost of their treatment

At what point were you alerted to these additional costs?



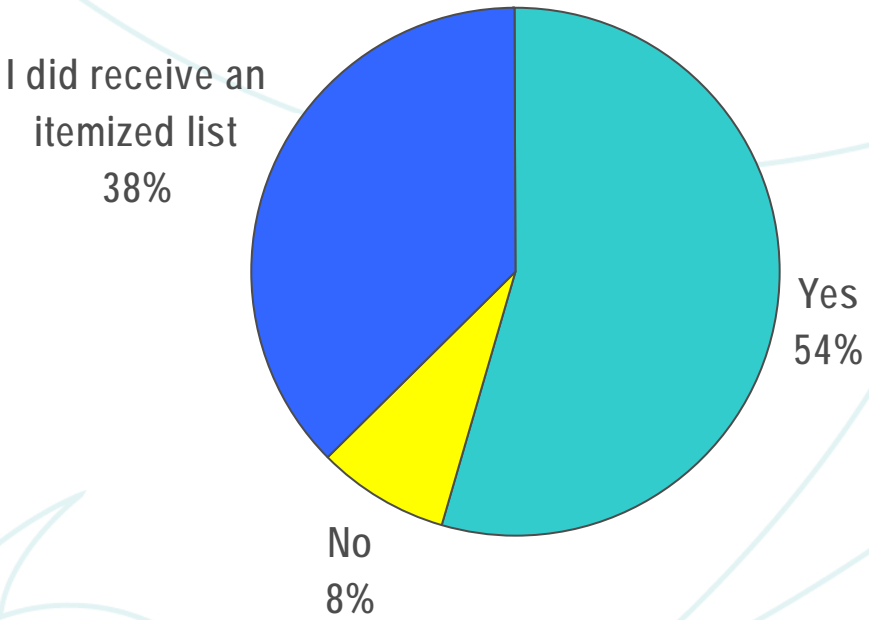
Base: 94 Those who were charged additional costs

What were these costs for?



Base: 94 Those who were charged additional costs

If you didn't receive one, would you have liked a costed treatment plan, detailing the costs involved in your treatment?



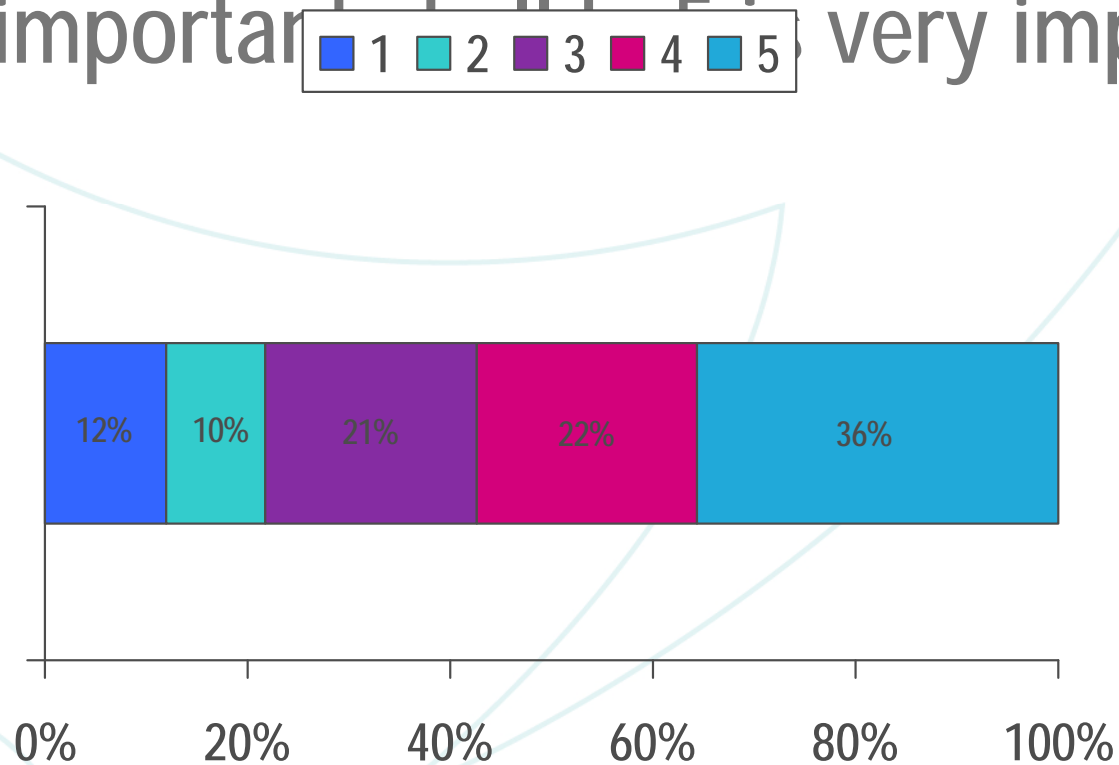
88% of people who didn't receive an itemized list would have liked a costed treatment plan

Base: 344 Those who are paying for their fertility treatment



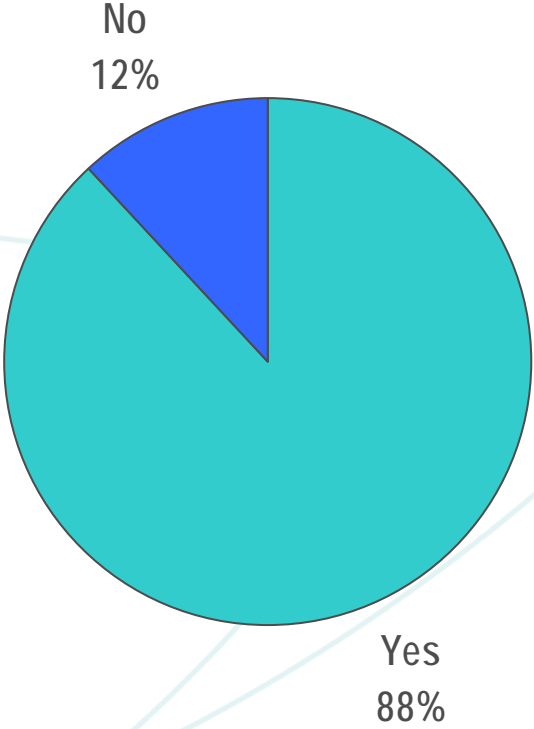
HFEA information

information from the HFEA as well as being able to view and print from the HFEA website? Answer on a scale of 1 to 5 where 1 is not important and 5 is very important



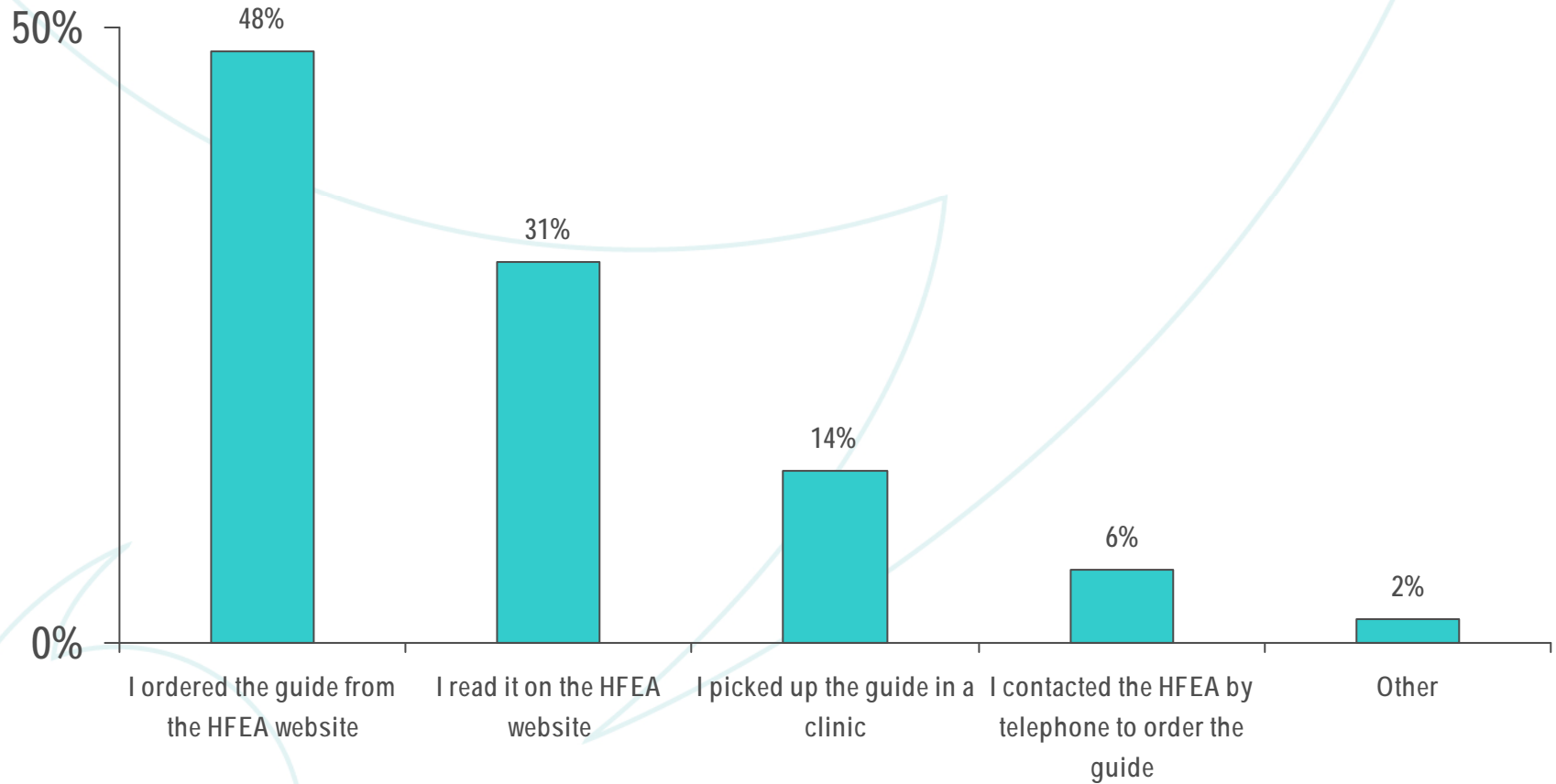
Base 426: All respondents

Have you read the HFEA Guide to Infertility?



Base 426: All respondents

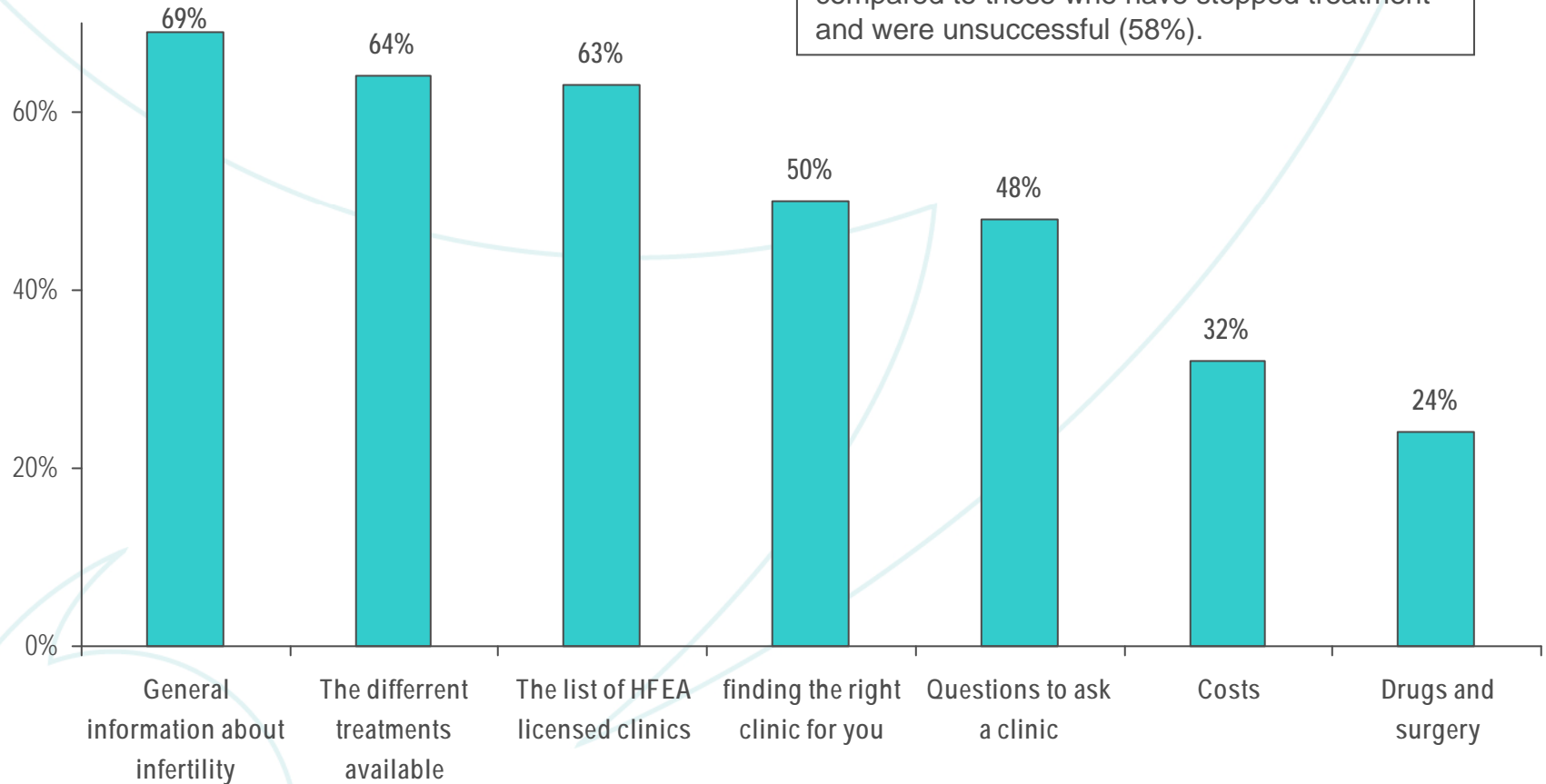
If yes, how did you read the Guide?



Base: 374 Those who have read the Guide

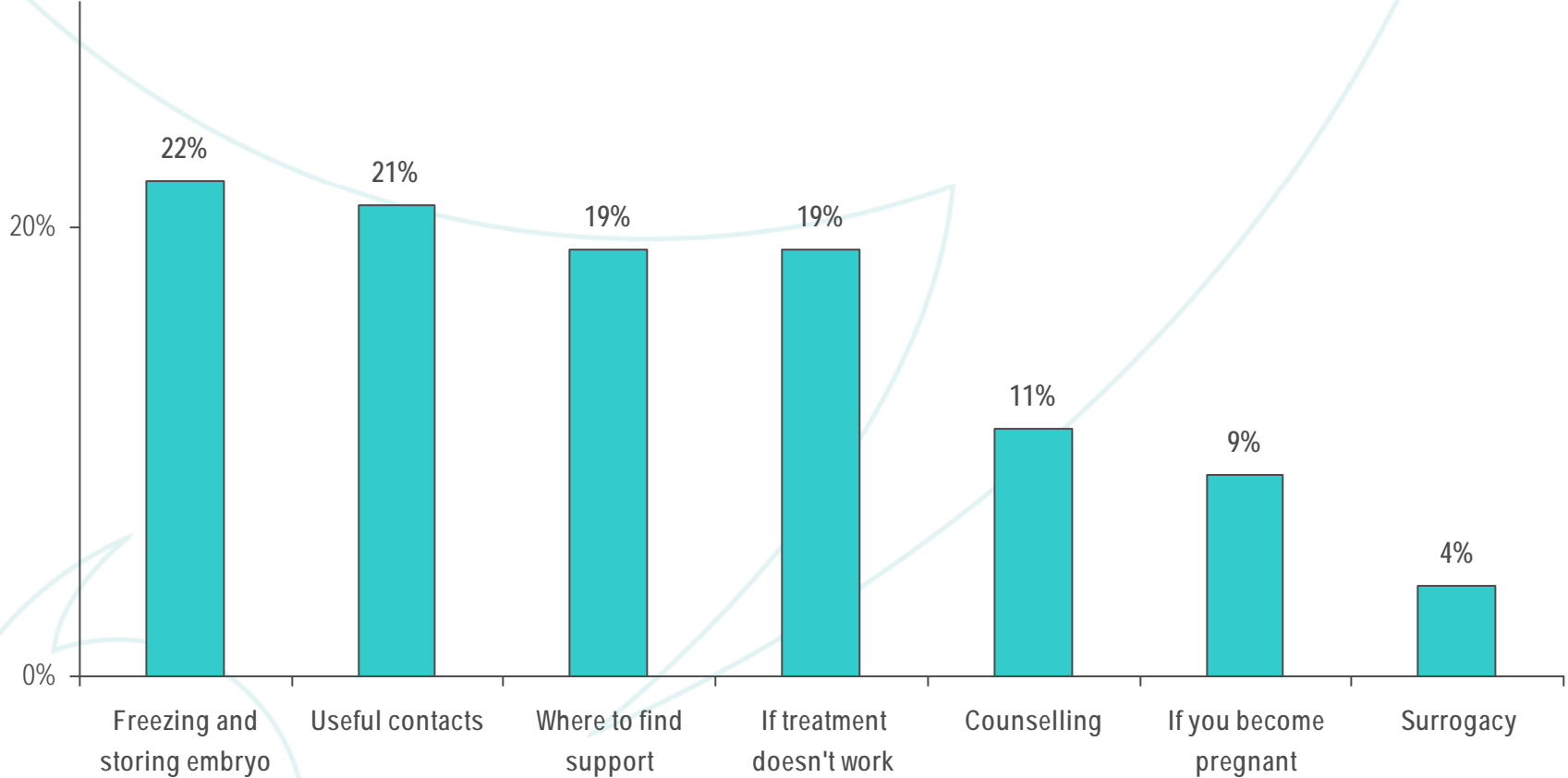
What information did you find useful in the Guide? (1)

Significantly more people who have stopped receiving treatment and were successful (76%) found general information about infertility useful, compared to those who have stopped treatment and were unsuccessful (58%).



Base: 374 Those who have read the Guide

What information did you find useful in the Guide? (2)



Base: 374 Those who have read the Guide

What else should be included in the Guide?

- Although people expressed contentment with the information provided by the Guide, people often identified gaps in information covering success rates and costs
- For success rates respondents believe the Guide should include:
 - The most recent success rates published as well as retrospective rates in order to compare
 - More detail to the published success rates, e.g. a break down of success rates dependent on area/ cause of infertility, or method of treatment

Quotes on success rates

- 'I found everything I wanted in the guide, although I used clinic websites for previous years success rates and more up to date success rates. Quite a few clinics also provided more detailed data'
- 'Would like to see stats for satellite clinics as I just had an NHS cycle at [my clinic] which ended up being cancelled and there are no stats available for them as the ET takes place at [another centre]. This is important for people considering going private there as I was not impressed with their service yet no-one really knows how effective they are as their stats get amalgamated with the [bigger centre].'
- 'Possibly more information on clinics performance rather than having to go to a separate section on the website - but this would mean a lot of data to publish - perhaps as a separate reference guide'
- 'Success rates of infertility treatment but not as a cumulative number for a clinic. I would like to see success rates dependent upon the cause of infertility.'

What else should be included in the Guide?

- For costs respondents believe the Guide should include:
 - Detailed breakdown of costs including the variation between treatments and different clinics
 - More information on the reasons for certain fees and costs within treatment
 - Detail on the NICE guidelines and the policies of local PCTs on funding

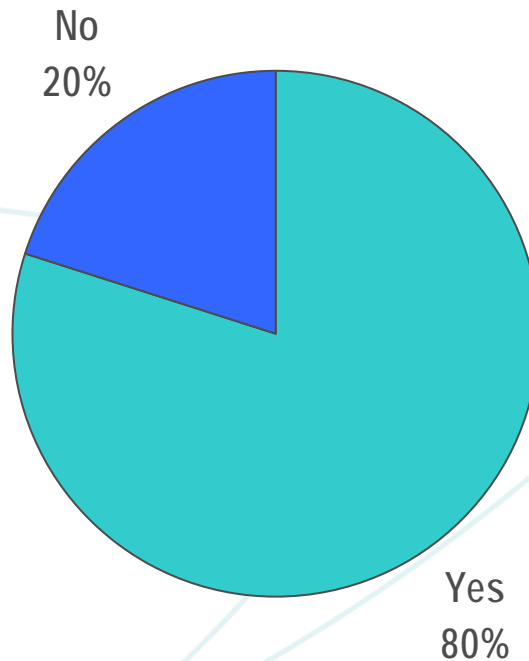
Quotes on cost

- 'Also must emphasise the need to get costs up front, I feel I was totally taken advantage of at [my centre] where the costs were never clear and was charged for unnecessary blood tests and the drug bill was over £5,000 which was not even mentioned until after my transfer.'
- 'Advice about NHS funding and why the NICE guidelines are widely ignored'
- 'Information on multiples. Also what happens to the £105 that we pay you for every cycle we do - so far I've paid you over £400 - what do I get for this?'
- 'More information about the NICE guidelines for NHS funding for treatments and why such funding still differs according to the area you live in. Many people find it frustrating that in some parts of the country patients receive 3 NHS funded attempts while in other areas no NHS funding is available. Also what type of treatment is funded differs.'



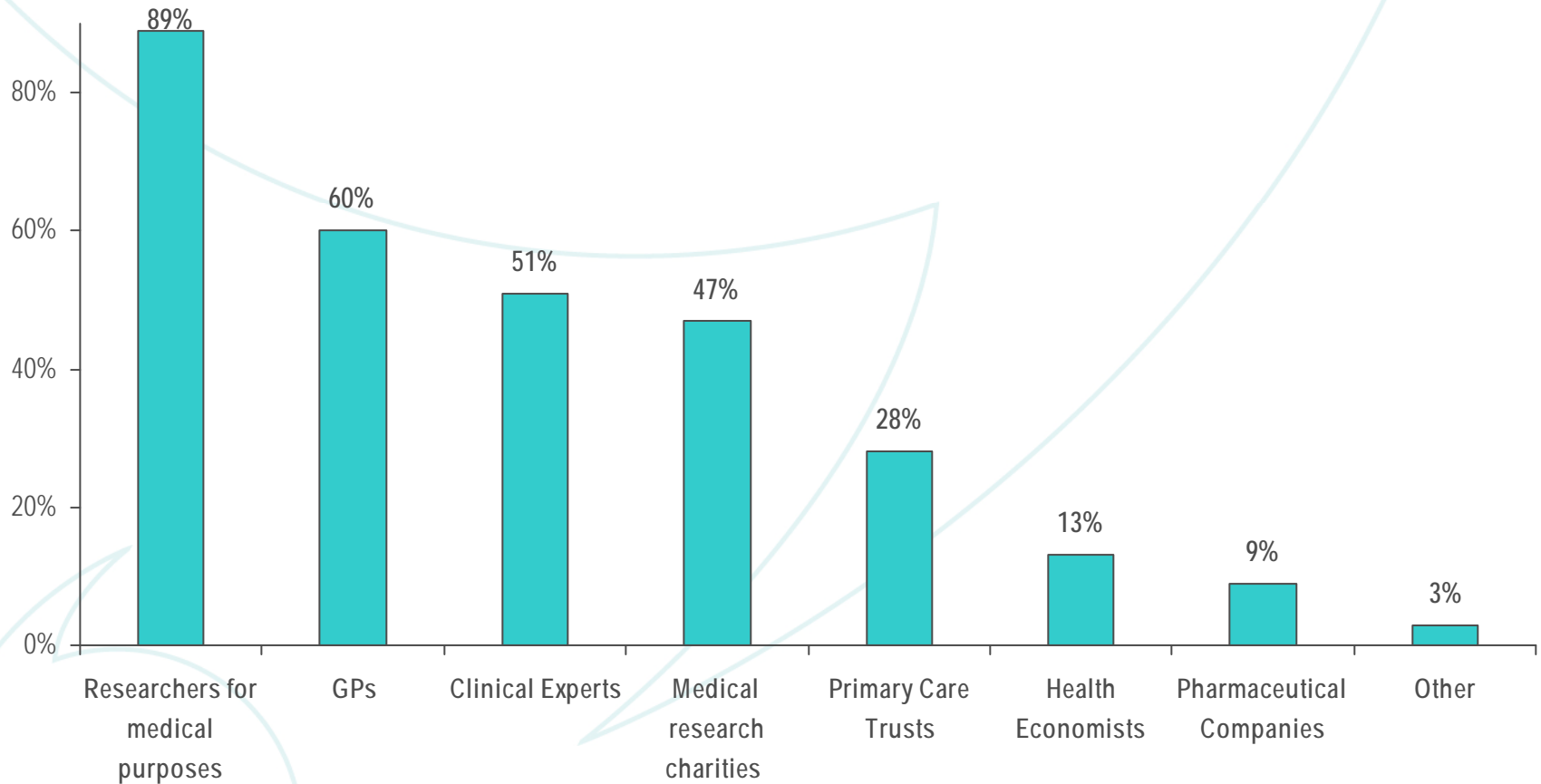
Access to your treatment information

If it would help others going through treatment in the future, would you be happy for researchers/ health experts to have access to your individual treatment data for a follow up study with your child?



Base 426: All respondents

Who should be allowed access to your individual treatment data?

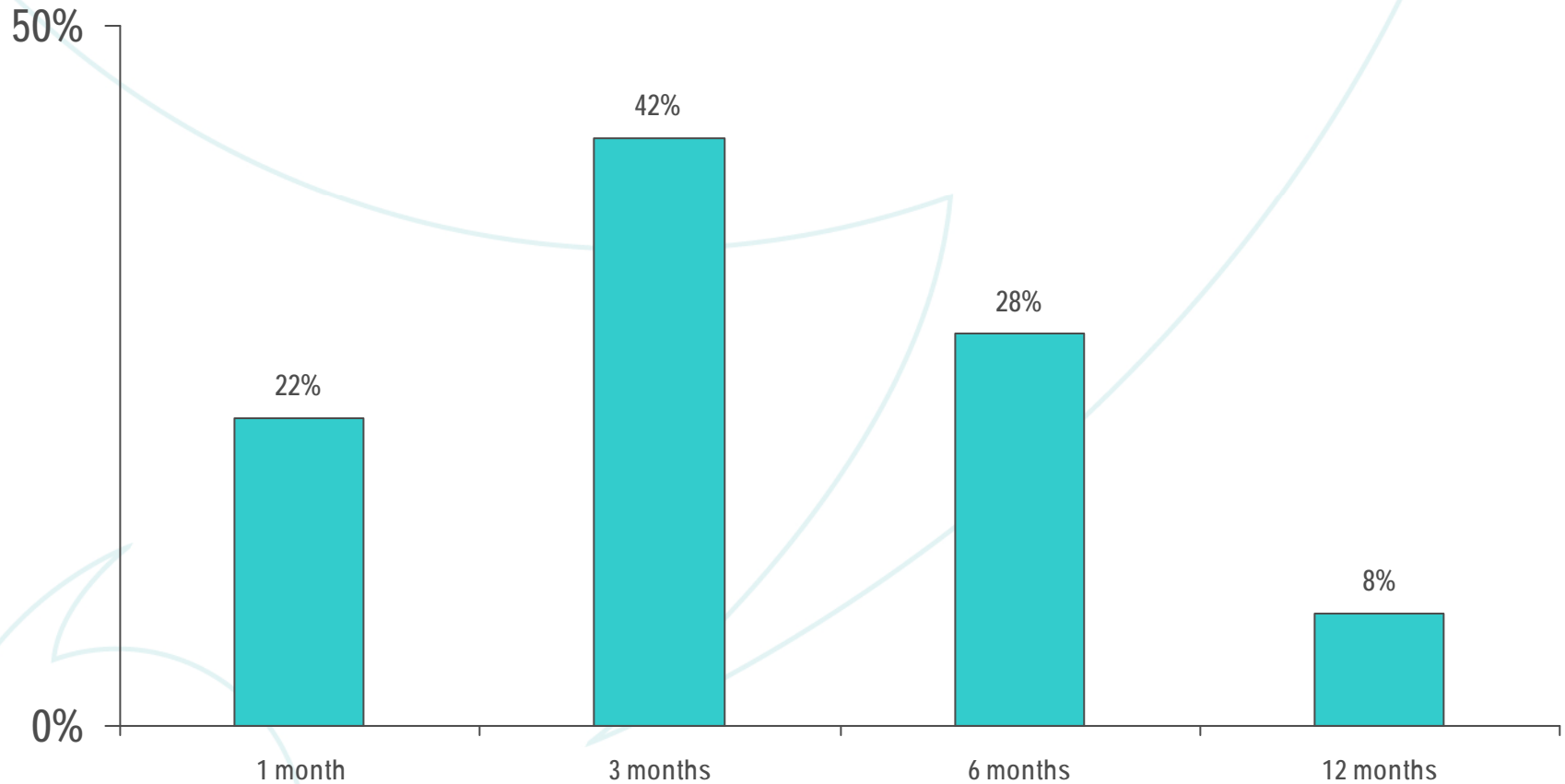


Base: 342 Those who would be happy to grant access to their treatment data



Regulation

If the HFEA found a problem at your clinic that was not an immediate risk to patient safety how long should the HFEA give your clinic to show improvements?



Base 426: All recipients

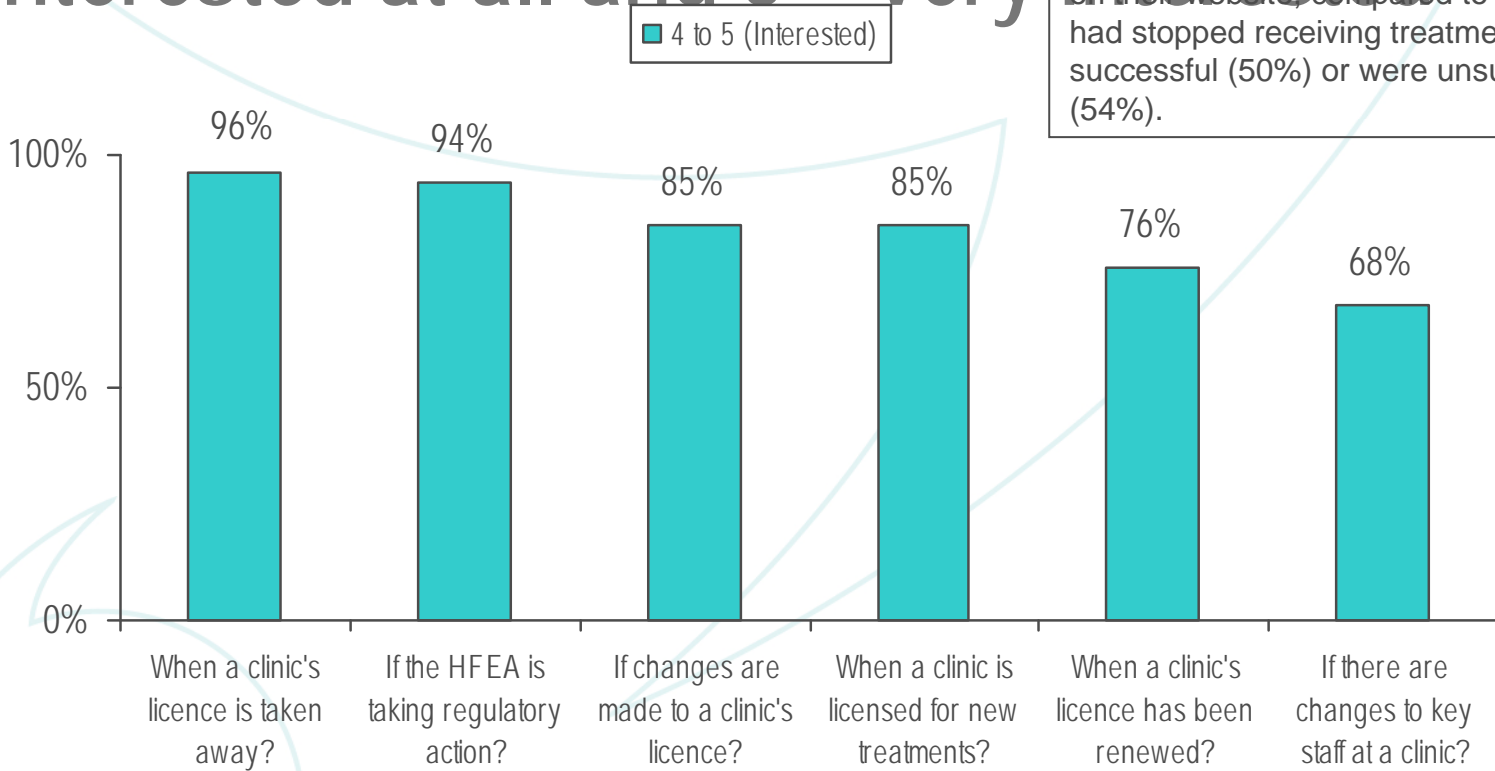


makes a range of decisions about clinics.

How interested would you be in the HFEA publishing this information on their website?

Answer on a 5 point scale where 1 = not interested at all and 5 = very interested

74% of those considering treatment were **very** interested in the HFEA publishing when a clinic's license has been renewed on their website, compared to those who had stopped receiving treatment and were successful (50%) or were unsuccessful (54%).

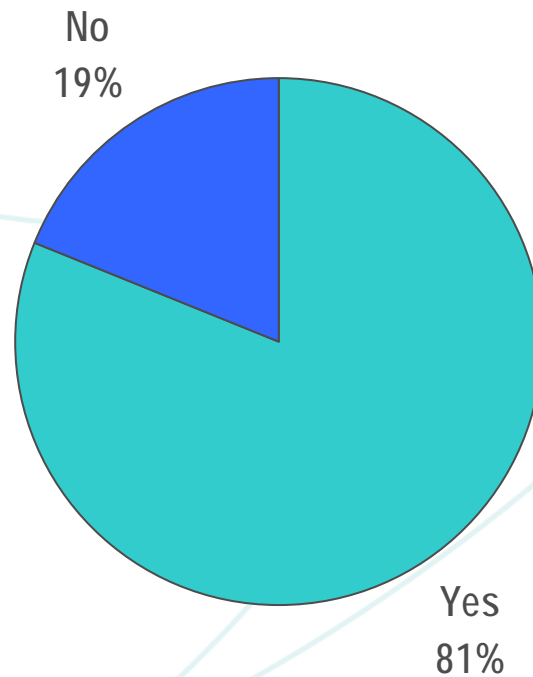


Base 426: All recipients



Clinic success rates

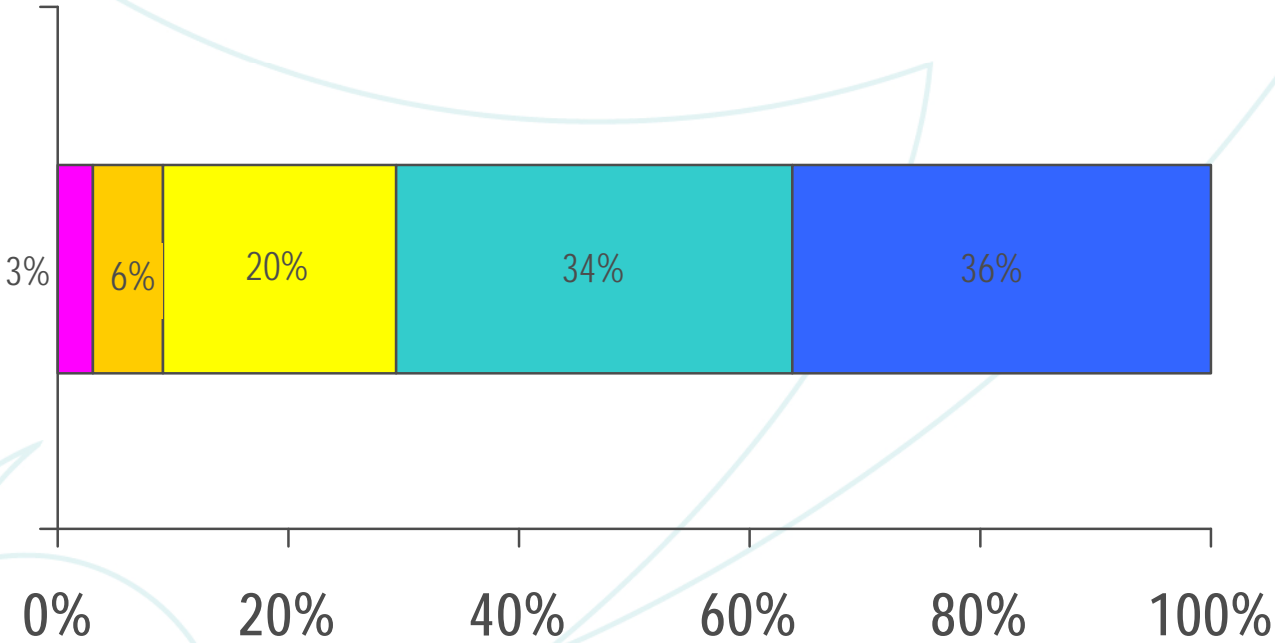
Have you used the HFEA 'find a clinic' search to look at clinic success rates?



Base 426: All respondents

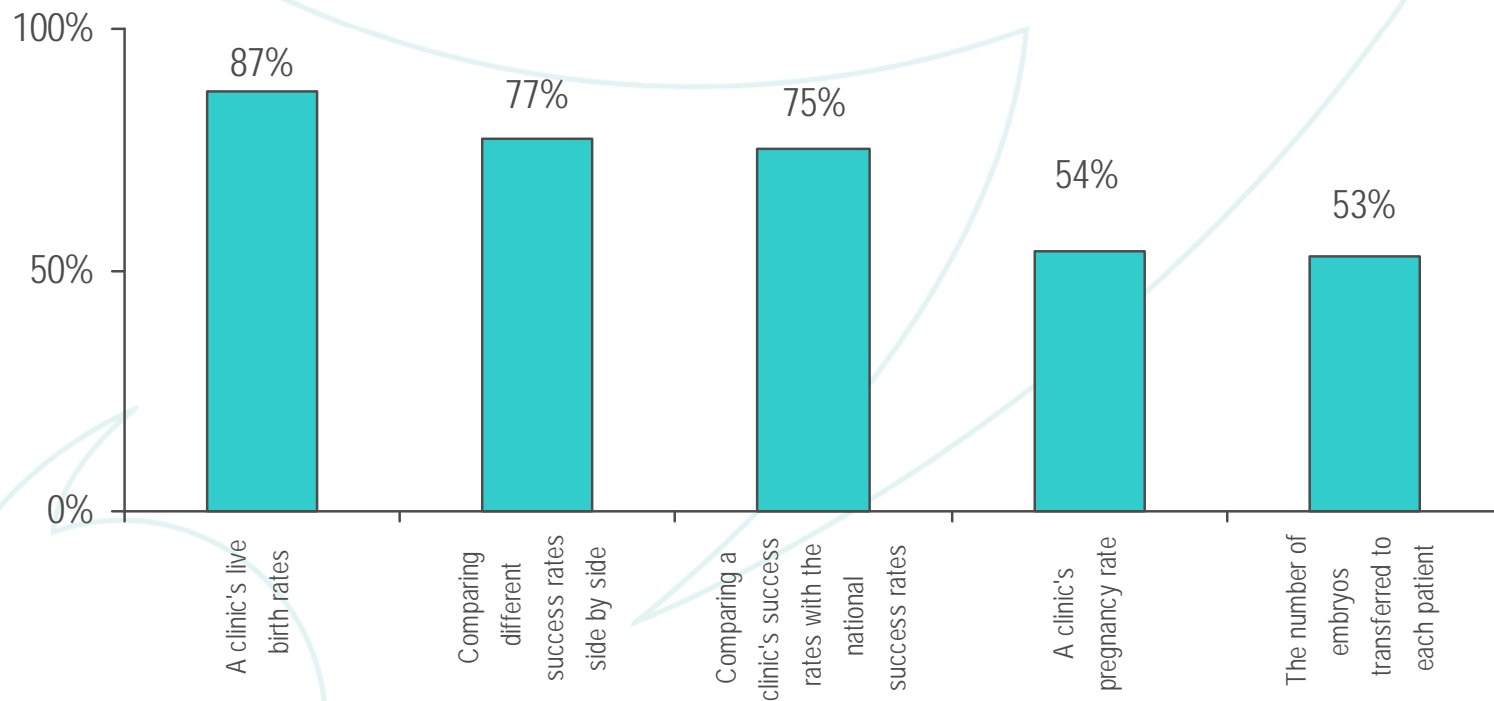
How useful did you find the success rate information on our 'find a clinic' search. Answered on a scale of 1-5 where 1 = not very useful at all to 5 = very useful

1 (Not very useful) 2 3 4 5 (Very useful)



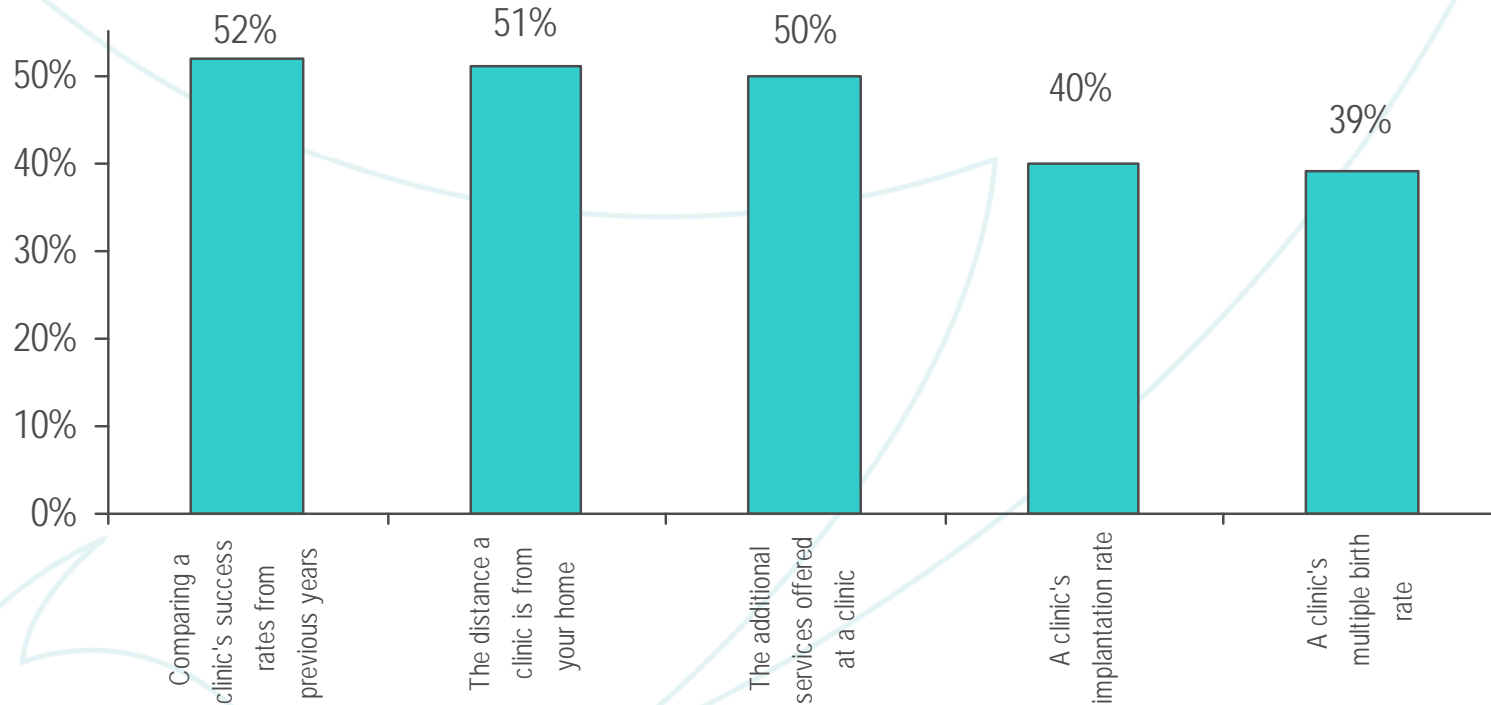
Base: 343 Those who have used the find a clinic search

What information did you find or would you find useful in the 'find a clinic' search?



Base: 415 All respondents

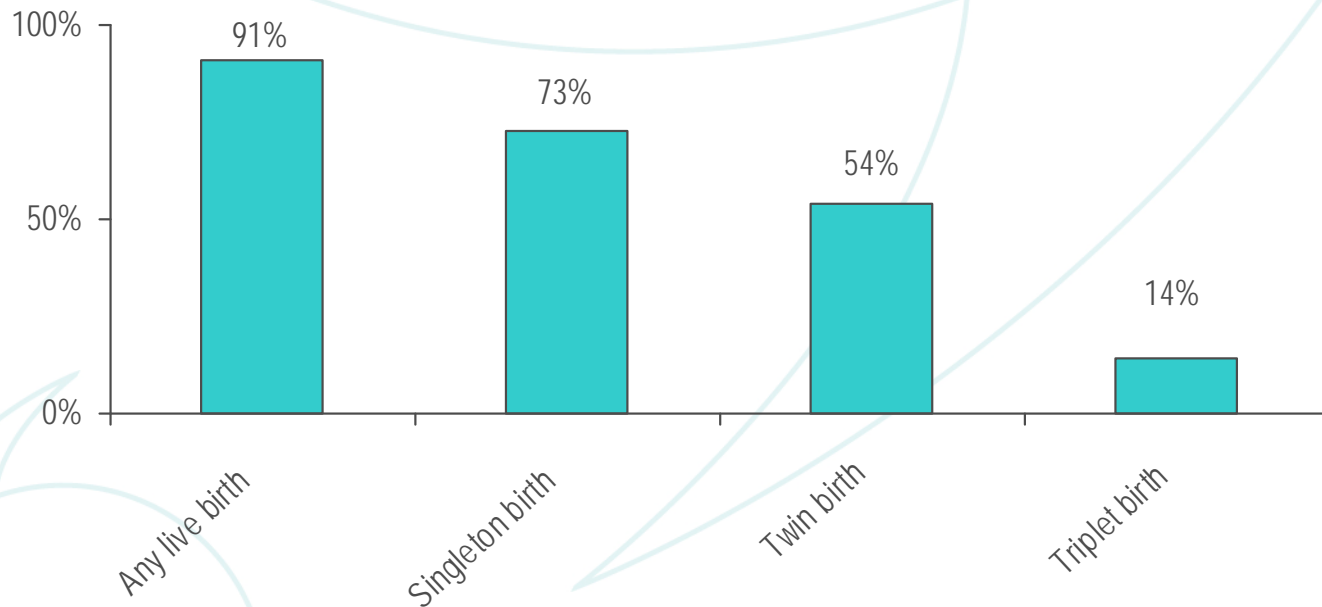
What information did you find or would you find useful in the 'find a clinic' search? Answered on a scale of 1-5 where 1 = not useful at all and 5 = very useful (2)



Base: 415 All respondents

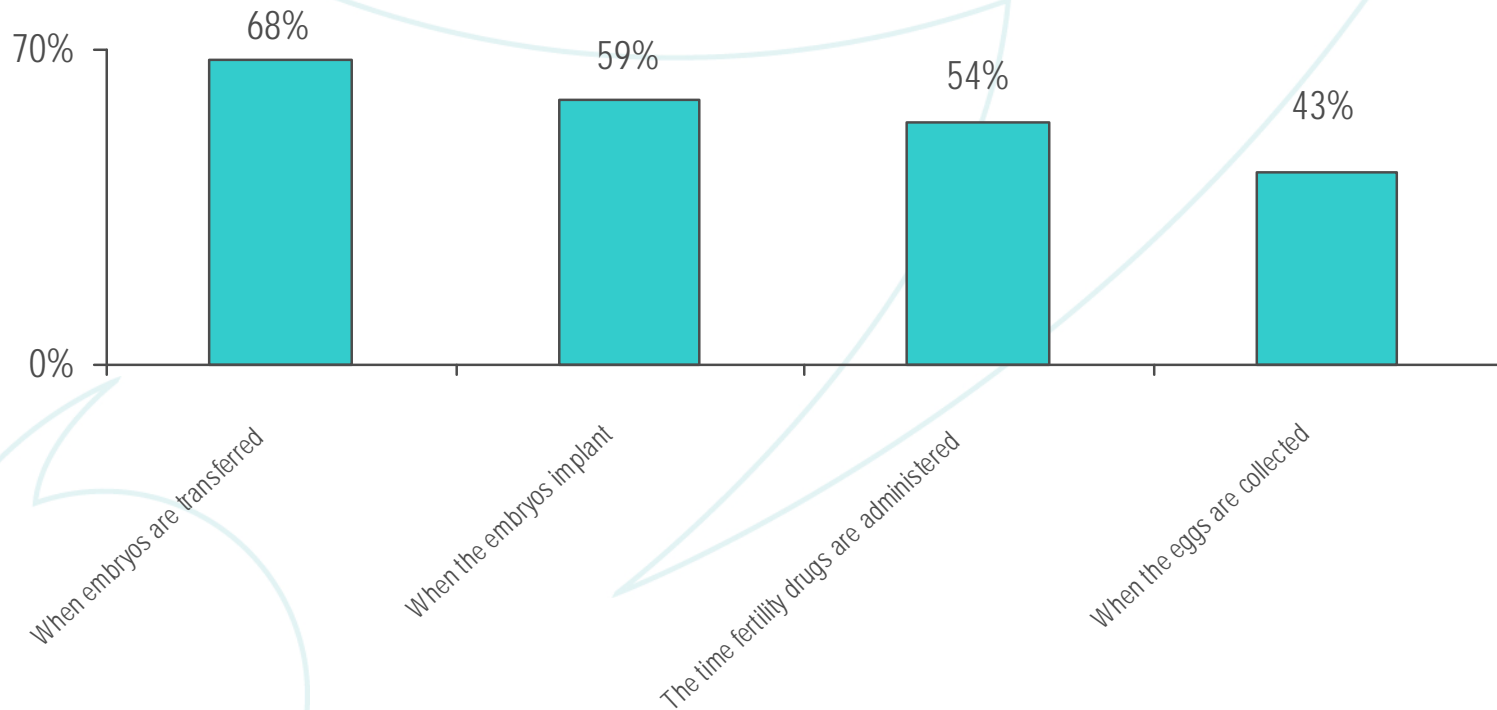
Please indicate how desirable you think the following outcomes of fertility treatment are for you personally. Answer on a scale of 1-5 where 1= not desirable at all and 5= very desirable

Percentage answering desirable and very desirable



Base 426: All respondents

There are a number of different ways of presenting clinical success rates. Do you want to know the chances of having a baby measured from:



Base 426: All respondents

What other information would you like to see on this clinic search?

- When respondents are searching for a clinic they say they would like access to detailed clinic ratings
 - Information on clinic's success by age of patients
 - Satisfaction rating from patients
 - Number of cycles patients undertake for success
 - Up to date information/statistics
- Other information respondents would like to see included information on a clinic's specialism/area of expertise
- As well as comments/ personal histories from patients (especially people who have been unsuccessful)
- People who are considering treatment would like information on costs of treatment/ways of paying

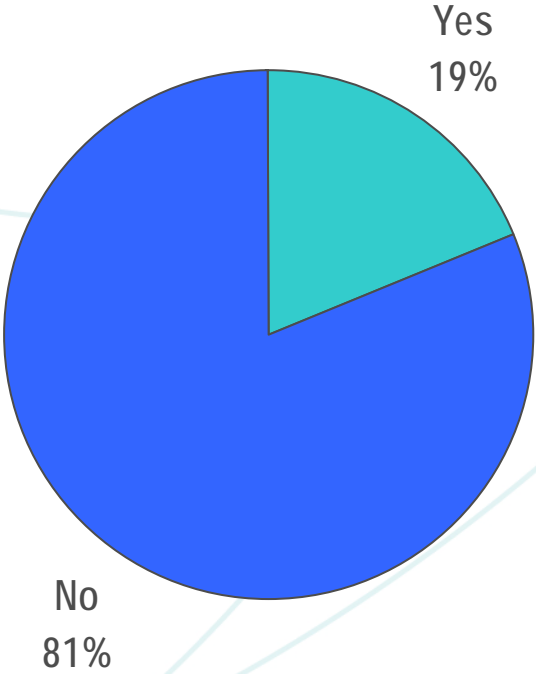
Quotes on 'What other information would you like to see on this clinic search?' ...

- 'Patient's ages, as this affects the meaning of every other statistic, and also older women need to know what clinics will accept them to avoid wasting time searching / being rebuffed'
- 'Statistics on the type of family situations they are experienced working with e.g.: single mothers, lesbian couples, heterosexual couples etc'
- 'More about the types of treatment offered. For example are more tests available than just the standard ones you can get on the NHS (i.e. cervical mucous testing, monitored cycle...)? Does the clinic offer counseling? Does the clinic offer any complementary therapies (e.g. acupuncture) or recommend practitioners for patients interested in exploring these options?'
- 'I think maybe some case studies or some info of people willing to be contacted so you can talk to someone going through the same situation'



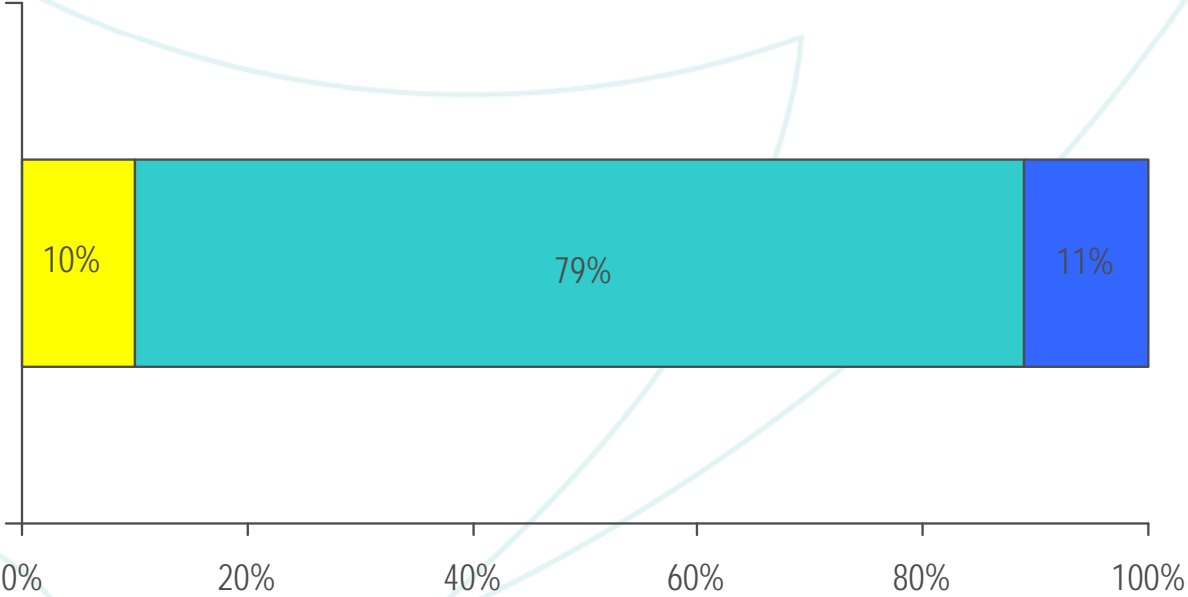
Blastocyst transfer

Have you ever received IVF treatment with blastocyst transfer (5 to 6 day embryo)?



Base 426: All respondents

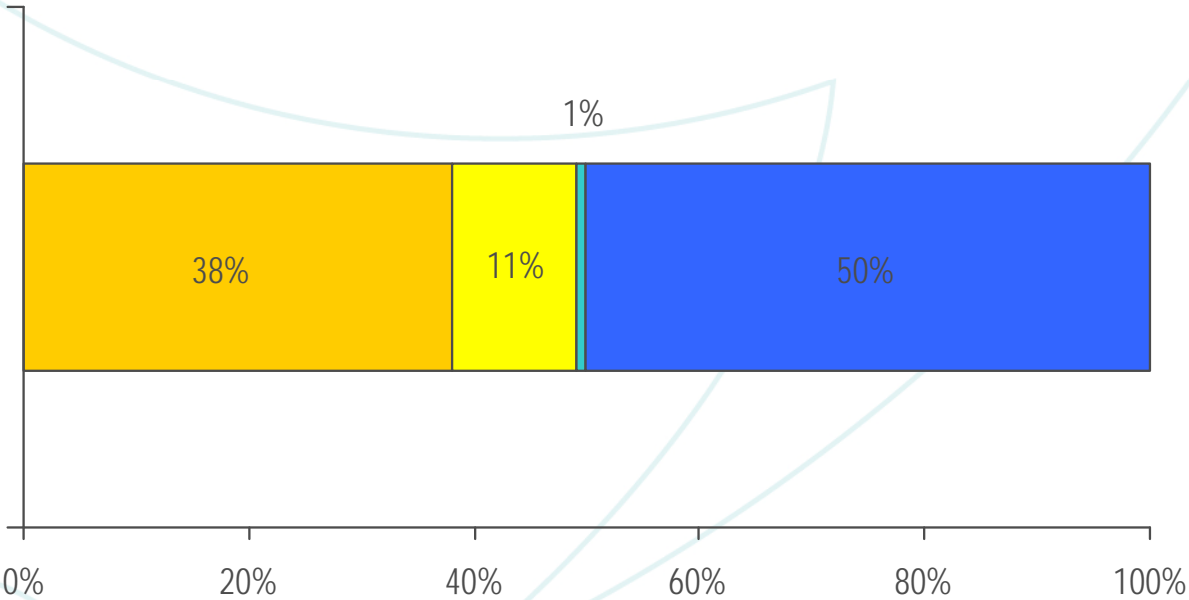
How many blastocysts did you have transferred in your most recent cycle?



Base: 82 Those who have received blastocyst transfer

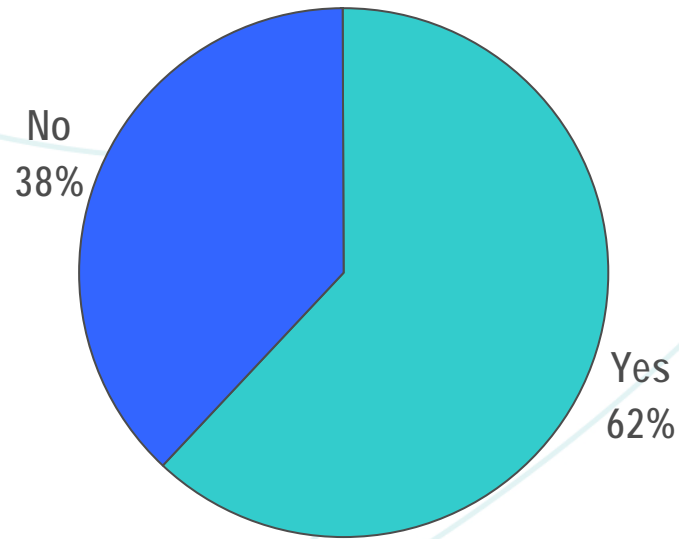
What was the outcome?

■ I had a singleton birth ■ I had twins ■ I had triplets or higher ■ The treatment was unsuccessful



Base: 82 Those who have received blastocyst transfer

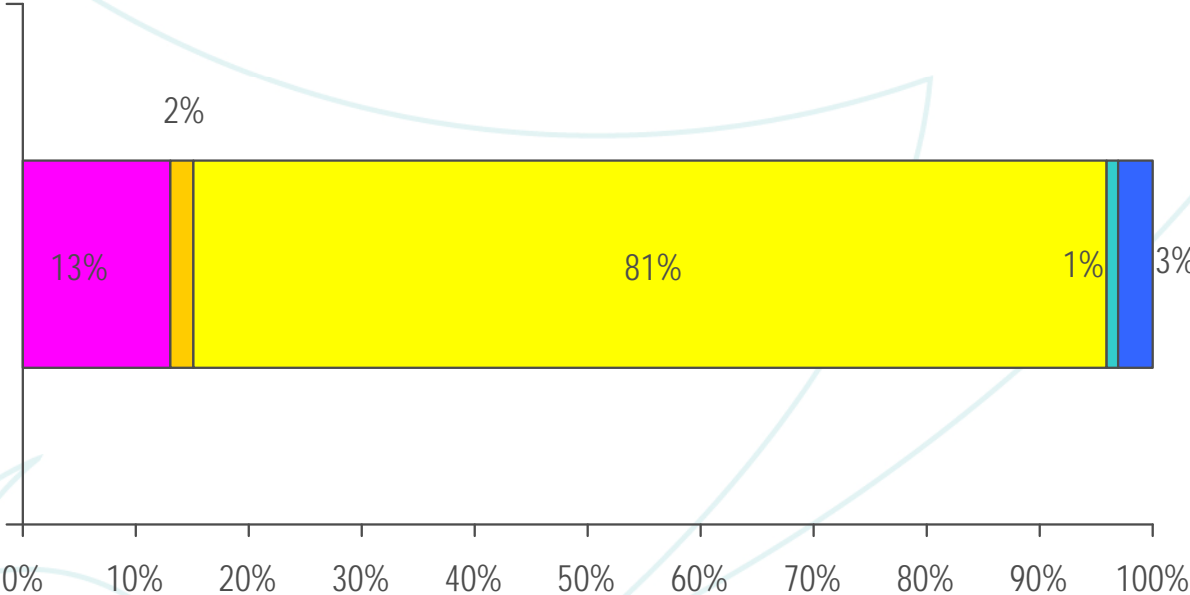
Taking the increased success rate into account, would you be more likely to consider having just one blastocyst transferred rather than one embryo transferred?



Base 426: All respondents

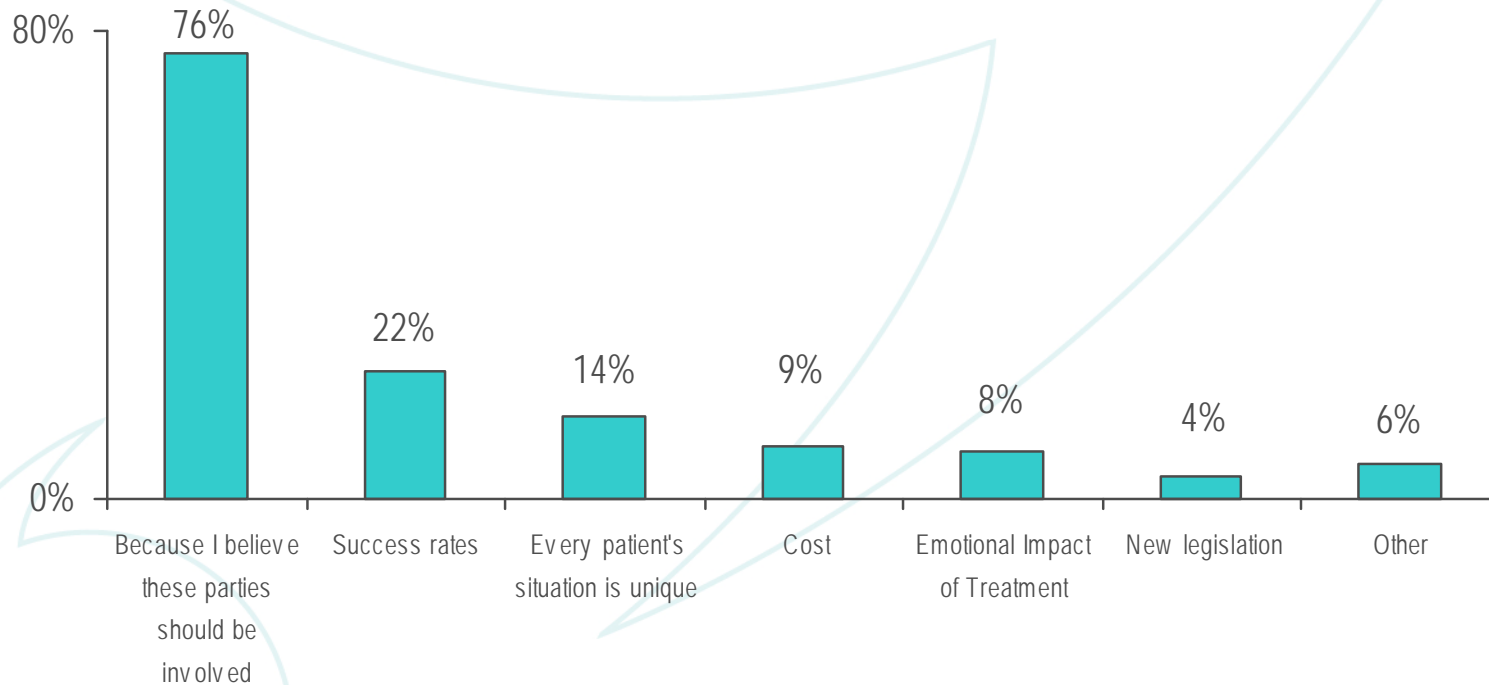
Who do you think should make the decision about how many blastocysts to transfer?

■ The patient(s) ■ The clinician ■ The patient(s) in consultation with the clinician ■ Professional guidelines ■ HFEA regulation



Base 426: All respondents

Reasons for deciding who should make the decision about how many blastocysts to transfer



Base 426: All respondents

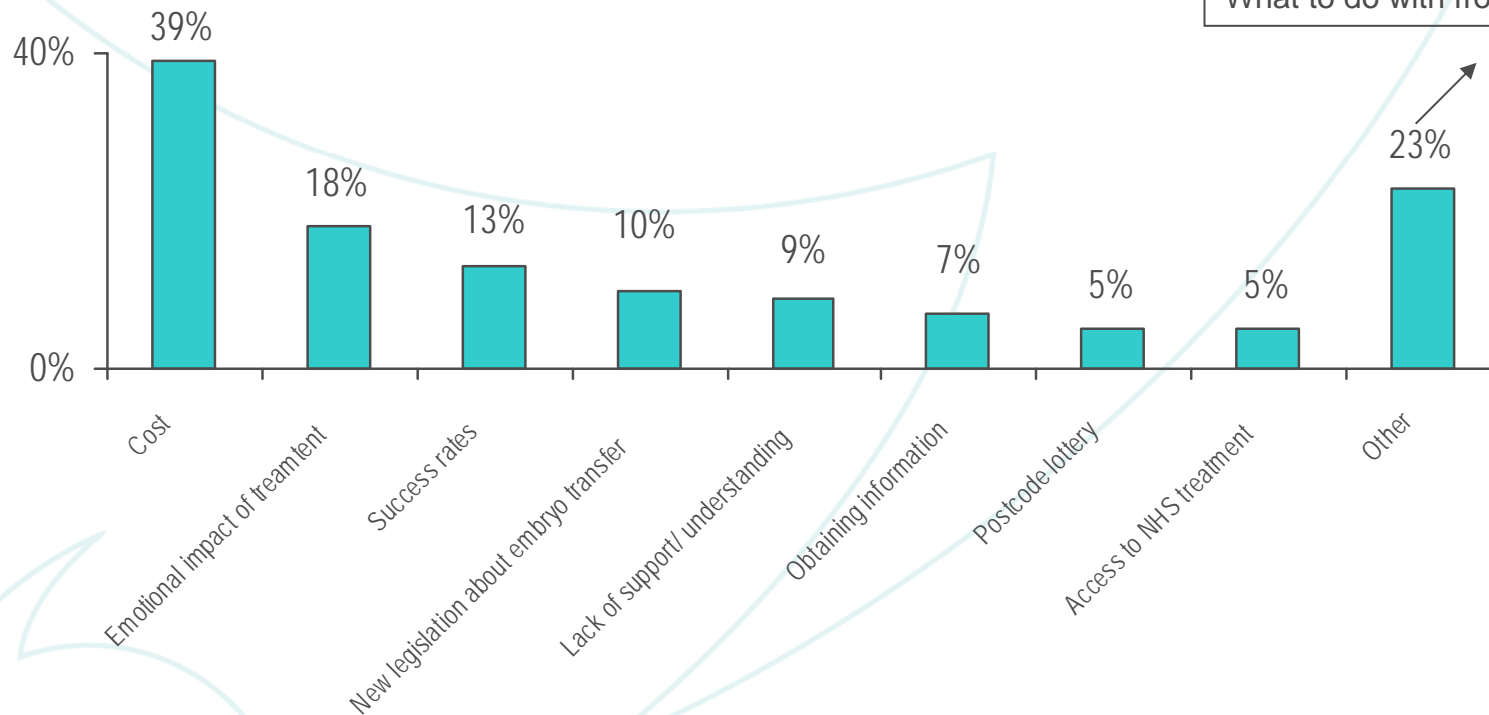
Quotes...

- 'The parent would have to deal with the outcome, but rarely has all the information needed to make an informed decision without the clinicians input'
- 'I believe you should be allowed to have two embryo's transferred when paying for a treatment cycle based primarily on the individual's wishes assuming they are a healthy weight and have a healthy lifestyle and have taken all considerations of the impacts of twin births for babies and Mother into account and considered what preventative measures they could take to reduce any of the risk factors'
- 'Observation of the embryos after 5 days enables the experts to provide an honest opinion of the quality (based on past experience) and can help prepare the way for success or disappointment without building too high an expectation'
- 'Some people do not want to have multiple pregnancy and should have the chance to say so, while others like myself would be more than happy with a multiple pregnancy'

What are the most important issues currently facing you regarding fertility treatment

Most of these issues are considered more important by people considering or currently going through treatment

Other responses include:
Availability of donor eggs/sperm
Having a healthy baby
What to do with frozen embryos



Base 426: All respondents

Conclusions and recommendations (1)

- Most people who didn't receive a costed treatment plan would like to receive one, so HFEA should encourage clinics to do this
- Clinics should be encouraged to provide information on any additional costs before treatment is started
 - Currently only around 1 in 10 were alerted to these additional costs before treatment
- HFEA should carry on publishing the Guide to infertility in printed format
 - 58% think this is important and most order it rather than reading online
- Most people are happy to be involved in future research on fertility treatment so are happy for researchers to have access to their individual data
 - 80% are happy with this

Conclusions and recommendations (2)

- People say that the HFEA should give clinics 3 months to show improvements if there is a problem found (that is not an immediate risk to patient safety)
- There is strong support for the HFEA publishing information about clinics on its website
 - This is seen as being most important when a clinic's licence has been taken away and when the HFEA are taking regulatory action
- The HFEA should further promote the risks of multiple births as over half think that twins is a desirable outcome of fertility treatment, and 14% think triplets is a desirable outcome

Conclusions and recommendations (3)

- There is no clear view on how success rates should be presented so the HFEA should present them in a number of different ways
 - Most would like them presented from when the embryos are transferred, when the embryos implant and when the fertility drugs are administered
- Although blastocyst transfer was only received by a minority of respondents, there were higher success rates with blastocyst transfer supporting other data (50% were successful)
- When considering SET HFEA should be aware that respondents would be happier to have a single blastocyst transferred than a single embryo due to the higher success rates
- Supporting earlier work for the HFEA on single embryo transfer, respondents would like the decision on how many blastocysts to transfer to be made by the patient in consultation with the clinician, rejecting stricter regulation