



Human Fertilisation and Embryology Authority

Results from the Fertility Views online panel

April 2006

Presentation structure

- Overview
- Our approach
- How the panel is made up
- Main findings from 3rd questionnaire

Overview (1)

- The 3rd Fertility Views survey focussed on embryology research, donation and embryo transfer, as well as complaints and the cost of IVF treatment
- Only one in three people (31%) have been given information about research involving sperm, eggs and embryos
- Almost half (45%) have been asked if they were willing to donate sperm, eggs or embryos to research
 - Of these, less than half (40%) had the opportunity to speak to an independent person about this
 - Almost half (47%) of those who were asked, have refused consent
 - People who had received information were more likely to give consent

Overview (2)

- Very few (6%) received feedback on whether their sperm, eggs or embryos were used in research
 - Many wanted feedback who did not receive it (39%)
- Most people (72%) were given information about the risks of multiple embryo transfer
 - However, this doesn't change their attitude towards it – only 9% changed their attitude
- But of the 57% who would refuse to have only 1 embryo transferred, 75% would be more likely to consider it if they could have 3 cycles on the NHS

Overview (3)

- The majority (81%) have encountered problems with the availability of donor sperm/eggs during treatment
 - Almost all were warned about this (91%), but only three quarters (76%) were warned about the problems with availability of sperm from the same donor
- Three in ten (30%) encountered a problem with the clinic
 - These problems were mainly associated with empathy and information
- Although only just over a third (39%) complained, nearly three quarters of those (70%) did not feel their complaint was successfully dealt with

Overview (4)

- Four in ten people (41%) had items on their bill that they did not expect but only a small number (7%) did not understand items
- Two thirds of people (66%) who have received one or more free cycles of IVF treatment on the NHS have received one cycle
- The most important issues facing them regarding infertility treatment are costs, access to NHS treatment and waiting times
- The top three places they would go to pick up the Guide to Infertility are an infertility clinic (65% chose this), GP surgery (56% chose this) and gym sports or leisure centre (56% chose this)

Our approach

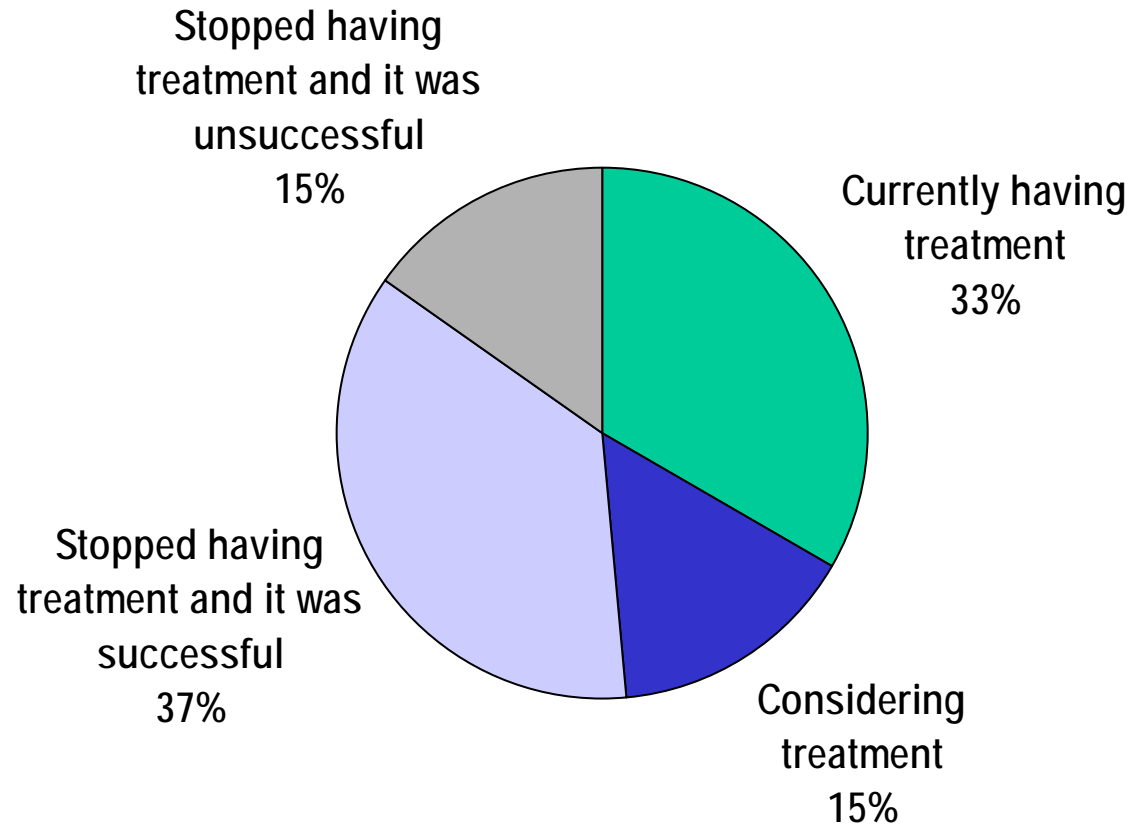
- An online panel was set up in May 2005 through a microsite linked to the HFEA website
- Previously 1 recruitment questionnaire and 2 attitudinal surveys have been completed
- The 3rd attitudinal survey was sent to panel members in March 2006
- The 3rd survey focussed on embryology research, donation and embryo transfer, but also complaints and the cost of IVF treatment
- This presentation shows the results of survey
 - 516 completed (out of 775 = 67% response rate)

How the panel is made up

Demographic profile

- 95% of those who responded are female
- 12% of those who responded are under 30, 42% are between 30-34, 27% are between 35-37, 10% are 38-39, 10% are over 40
- 87% of those who responded are married
- 94% of those who responded are White (British, Irish or other), all other ethnic groups are under 1% each

What is your current status regarding fertility treatment?



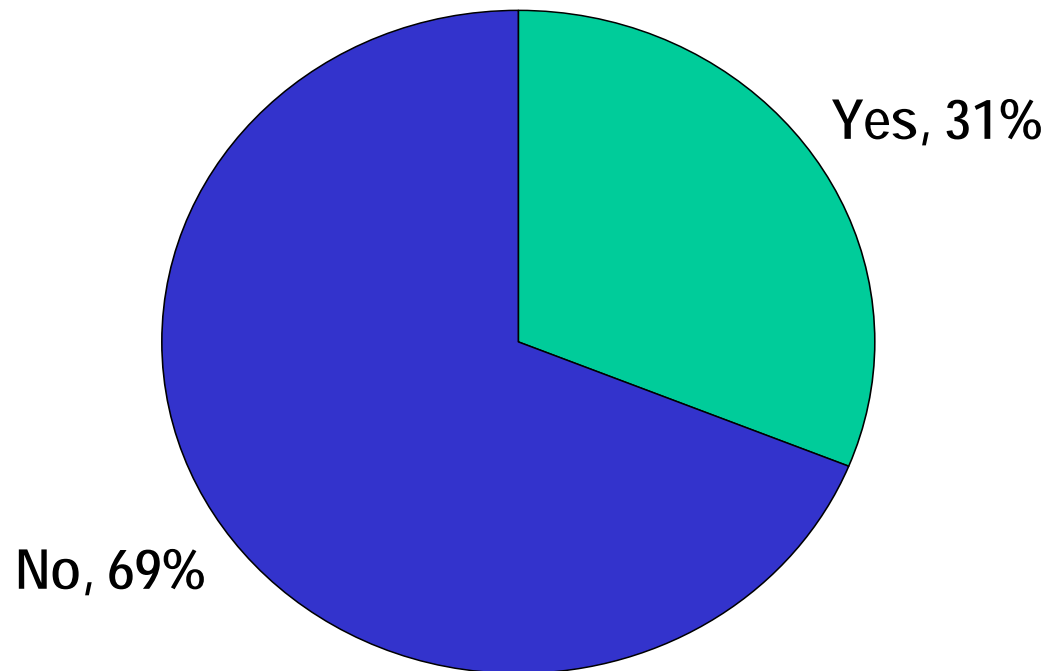
- Base 516: All respondents

Embryology research

Summary

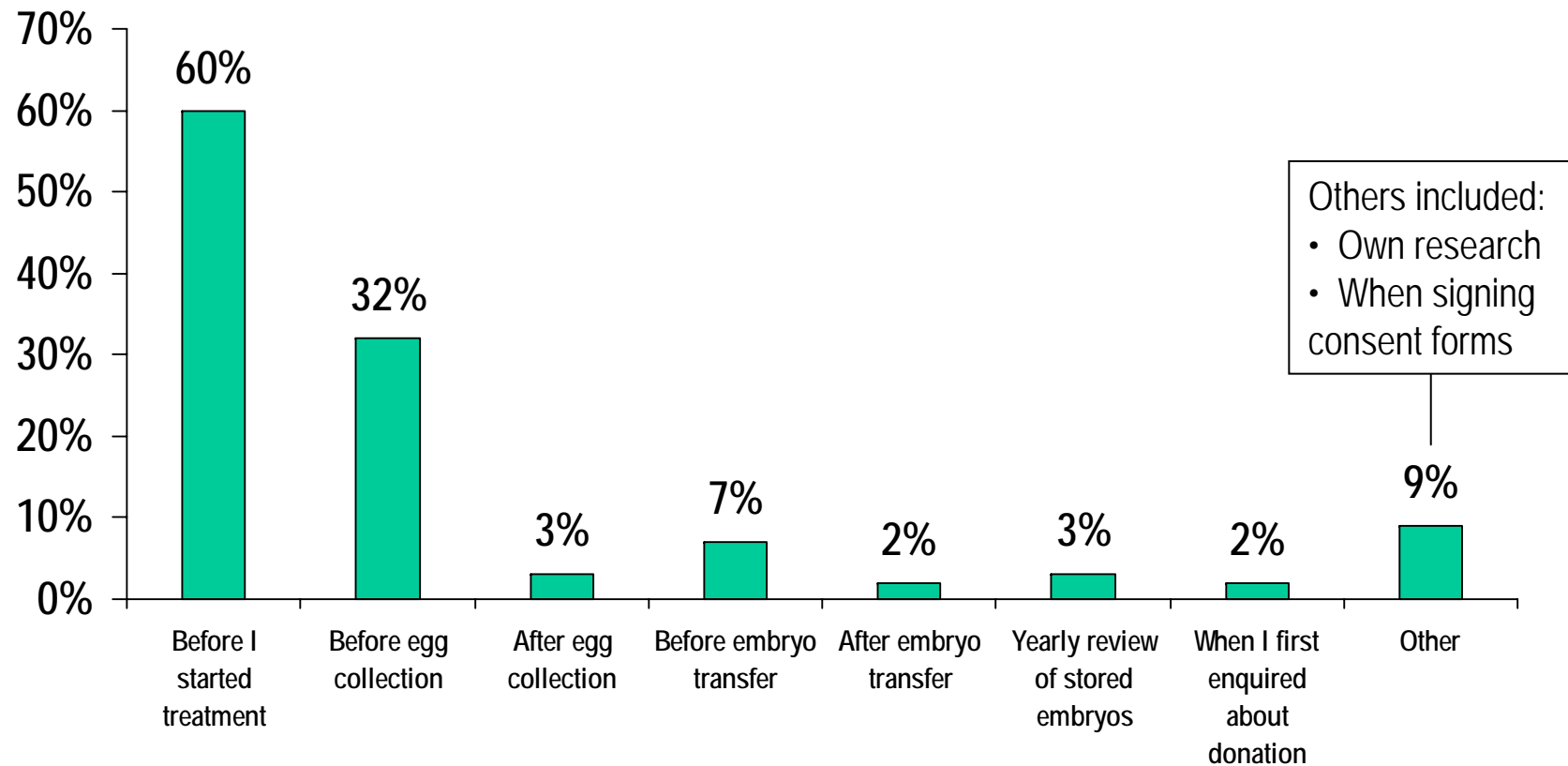
- Only one in three (31%) participants were given information about research involving sperm, eggs or embryos
 - The majority (60%) were given this information before they started treatment
 - Half (49%) were given this information by the nurse
- Almost half (45%) of participants have been asked if they were willing to donate sperm, eggs or embryos to research
 - Half (49%) were approached before starting treatment
 - Half (52%) were approached by the nurse

Have you ever been given any information about research involving sperm, eggs or embryos carried out at treatment centres?



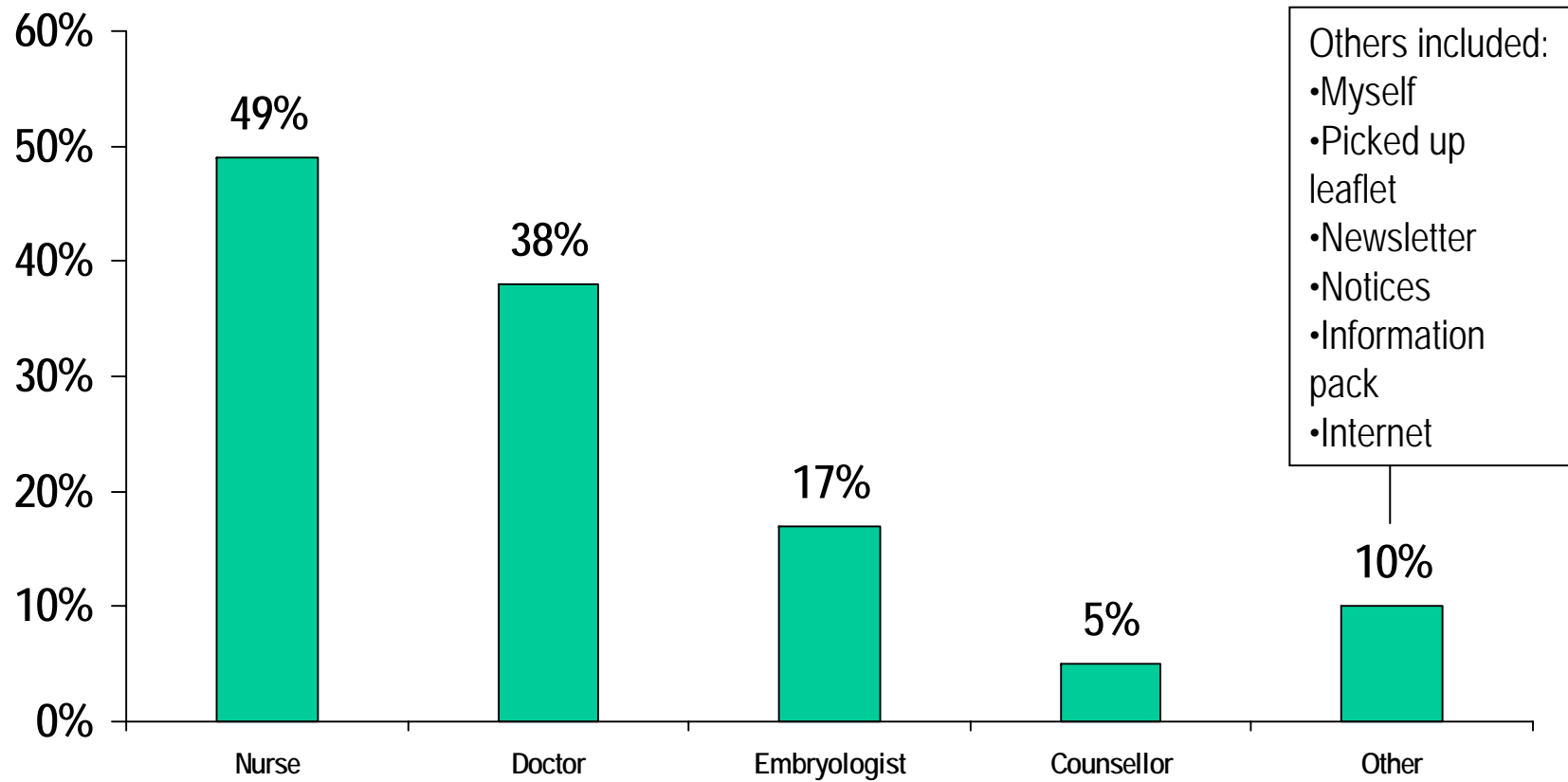
- Base 516: All respondents

When were you given the information?



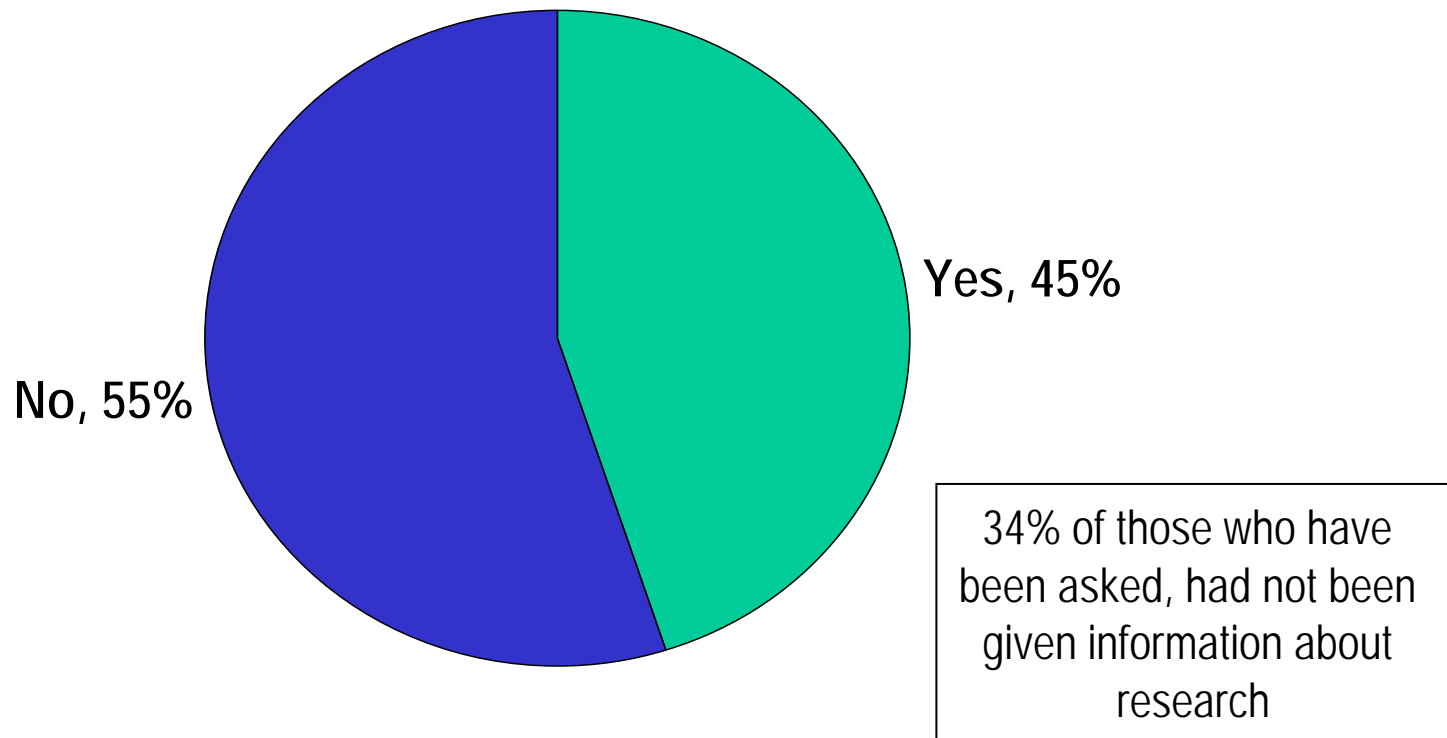
•Base 161: Those who have been given any information about research involving sperm, eggs or embryos

Who gave you the information?



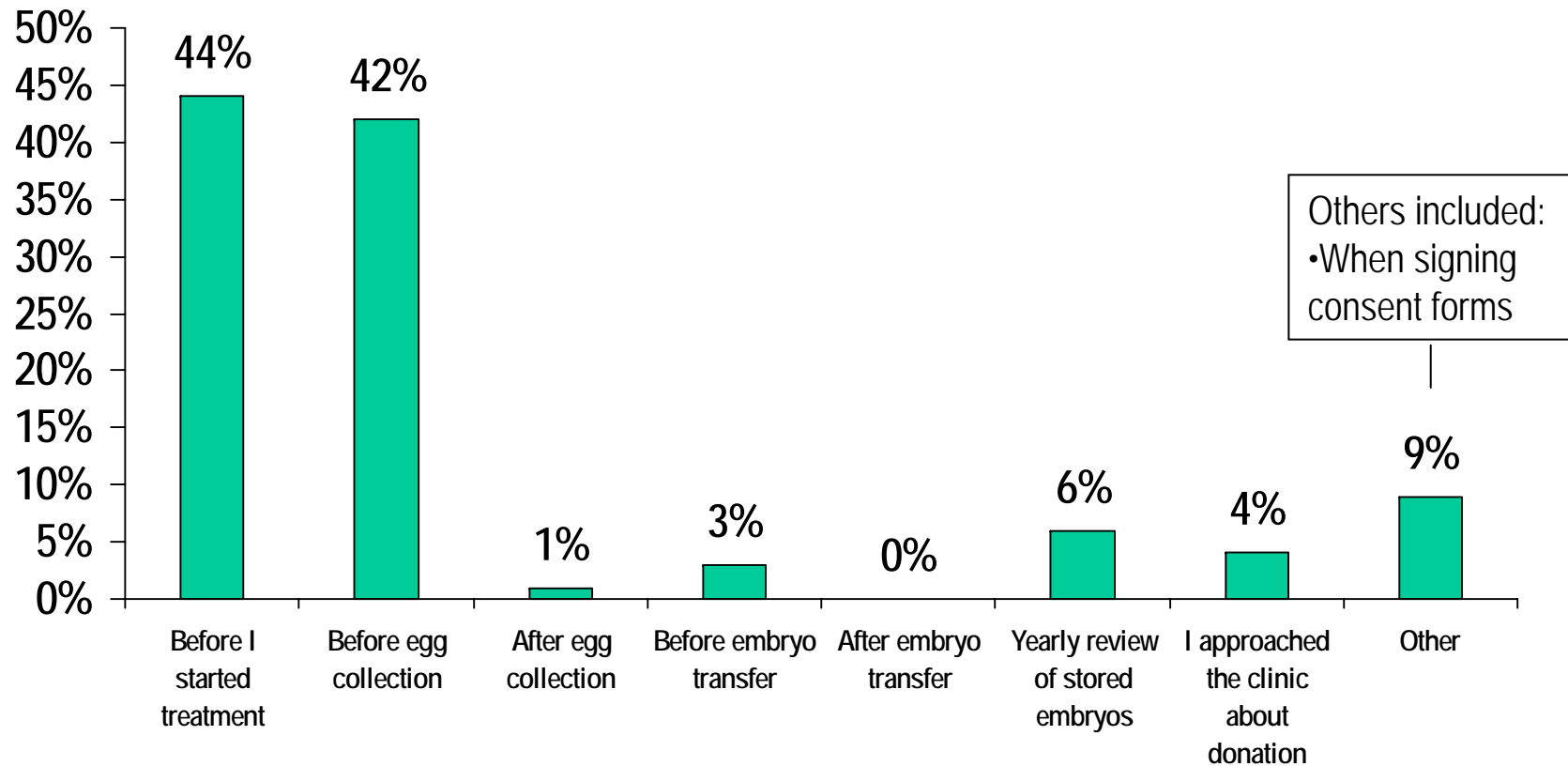
•Base 161: Those who have been given any information about research involving sperm, eggs or embryos

Have you ever been asked if you were willing to donate sperm, eggs or embryos to research?



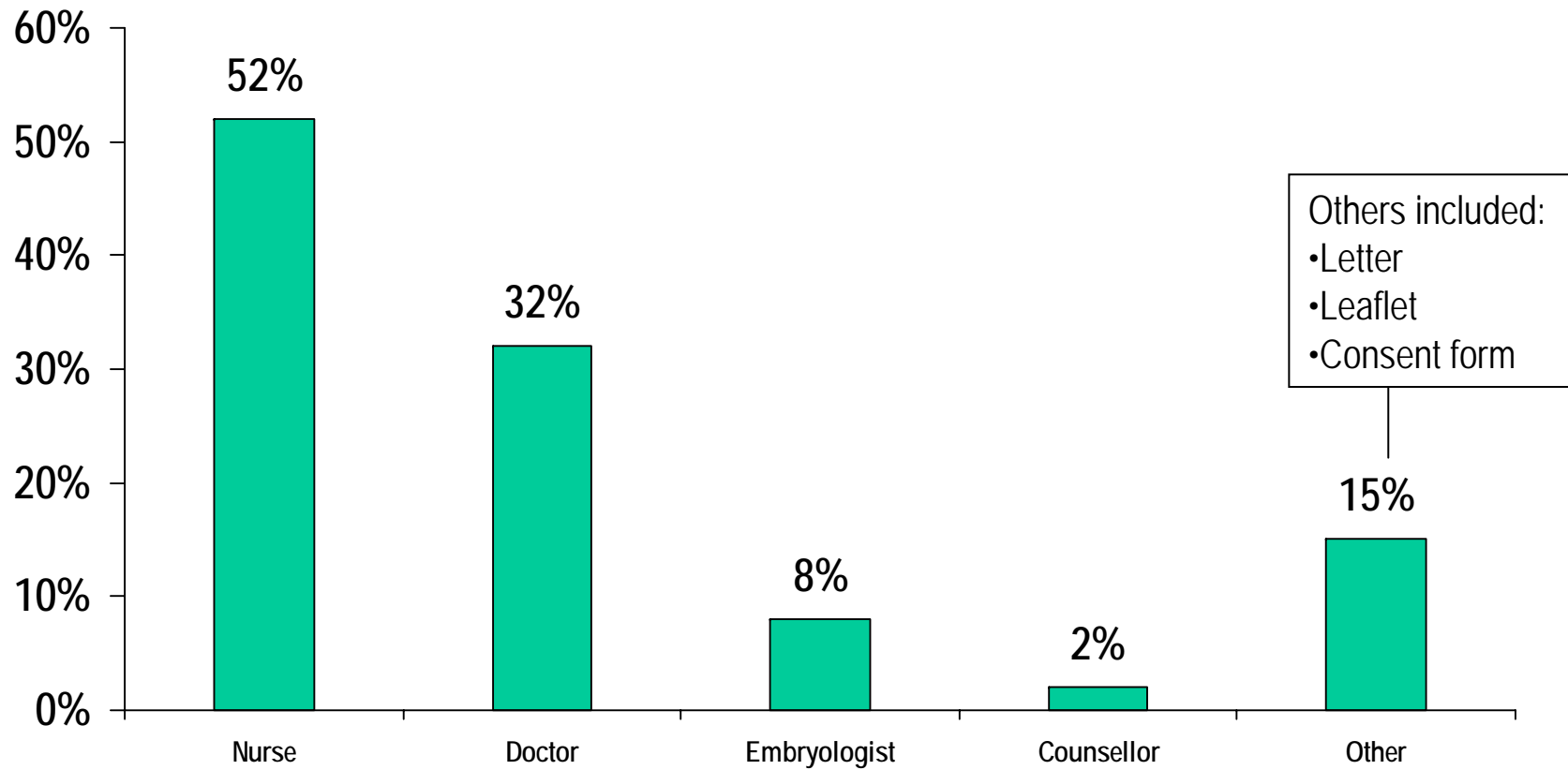
- Base 516: All respondents

When were you approached about donating sperm, eggs or embryos for research?



•Base 230: Those who have been asked if they were willing to donate sperm, eggs or embryos to research

Who approached you?

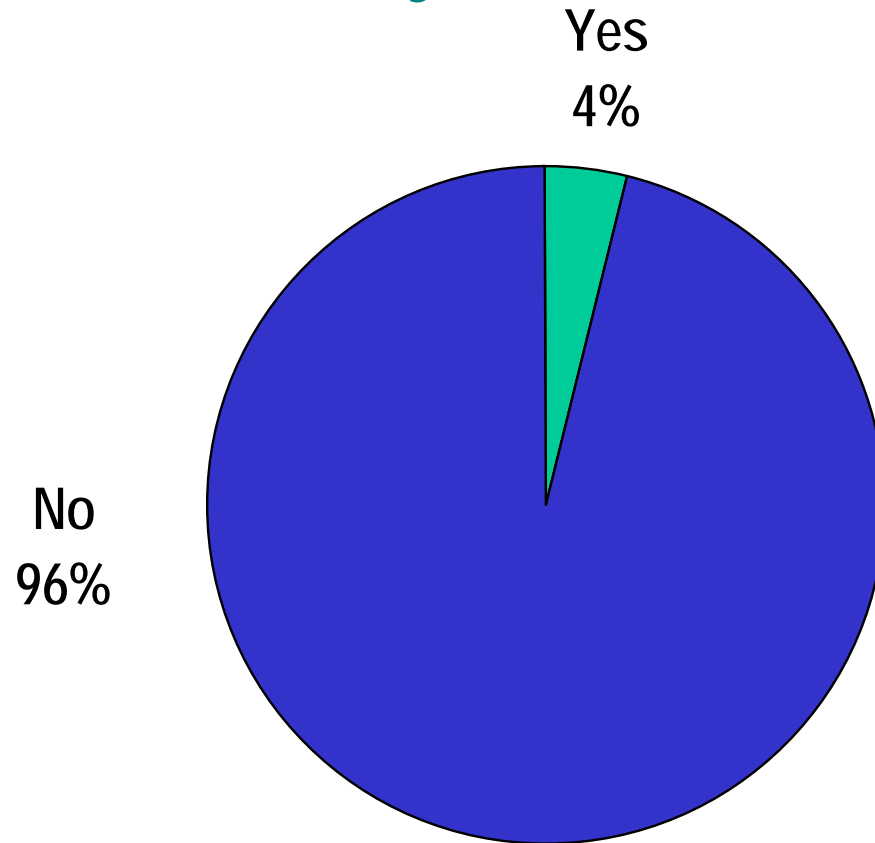


•Base 230: Those who have been asked if they were willing to donate sperm, eggs or embryos to research

Summary

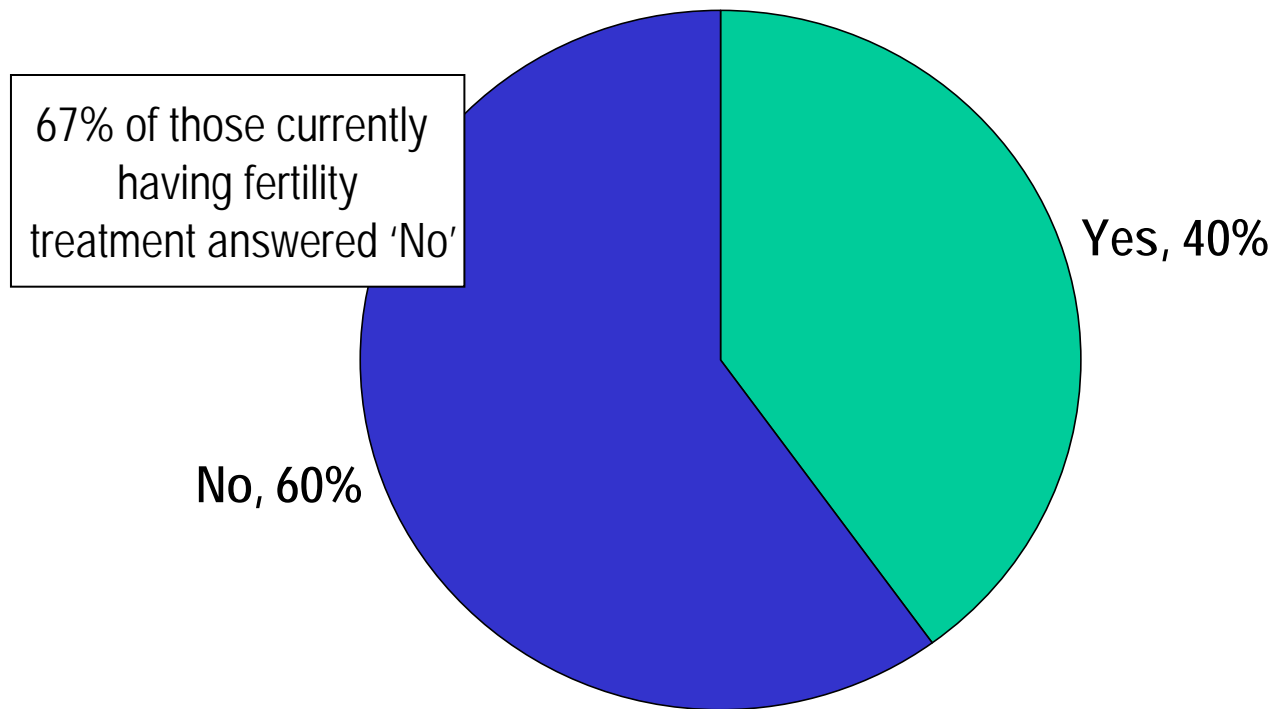
- Of the people who were asked if they were willing to donate sperm, eggs or embryos to research (45%);
 - A small minority (4%) felt pressure to donate
 - Less than half (40%) had the opportunity to ask questions and speak with an independent person regarding donating
 - Almost half (47%) have refused consent for their sperm, eggs or embryos to be used in research
 - People who had received information about research involving sperm, eggs or embryos were more likely to give consent than those who hadn't received information

Did you feel any pressure to donate sperm, eggs or embryos to research?



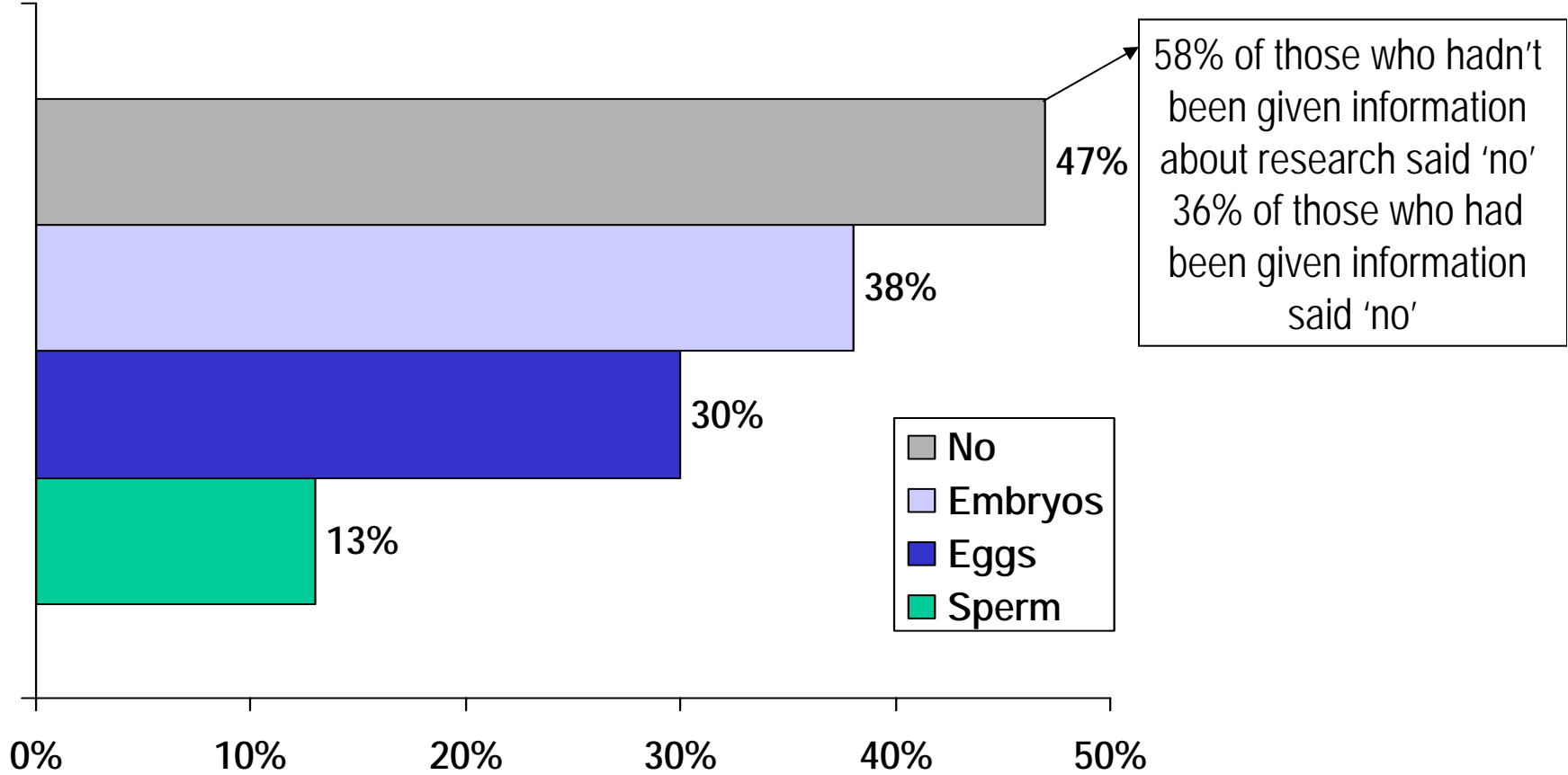
•Base 230: Those who have been asked if they were willing to donate sperm, eggs or embryos to research

Did you have an opportunity to ask questions and speak with an independent person regarding donating sperm, eggs or embryos to research?



•Base 230: Those who have been asked if they were willing to donate sperm, eggs or embryos to research

Have you given consent for your sperm, eggs or embryos to be used in research?



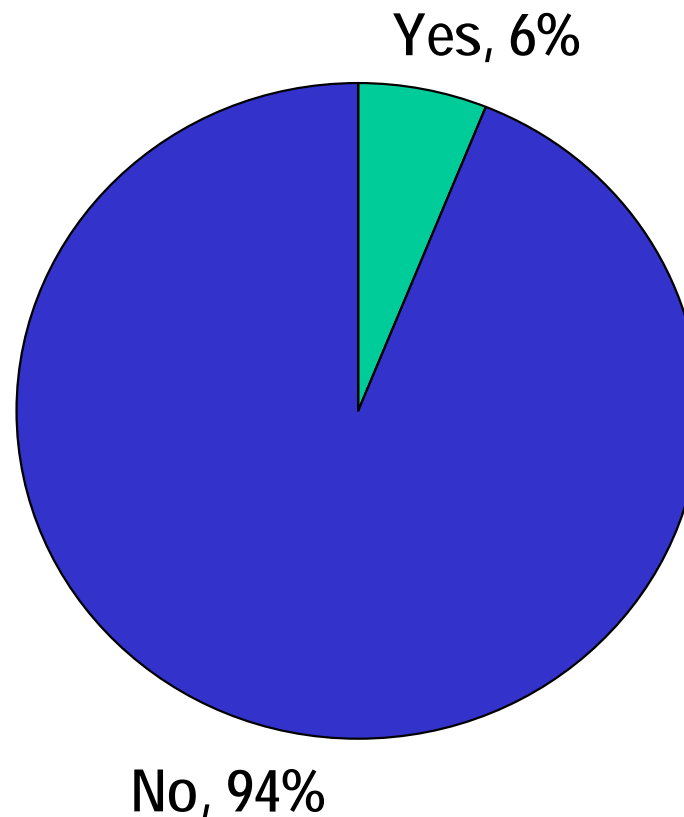
•Base 230: Those who have been asked if they were willing to donate sperm, eggs or embryos to research



Summary

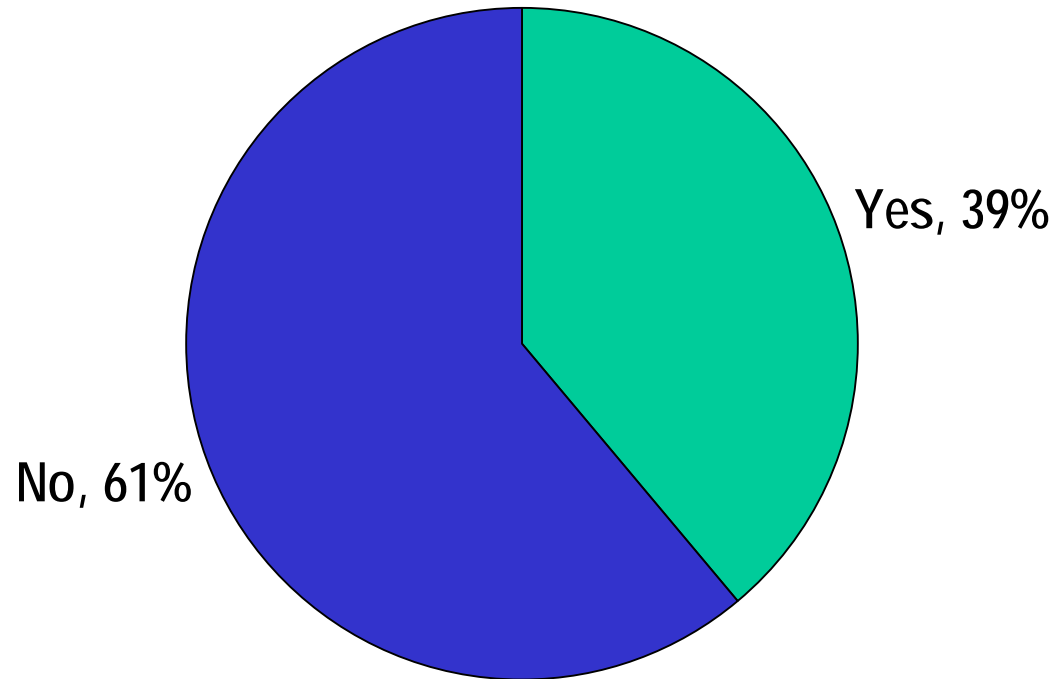
- Only a small number of people (6%) received feedback on whether their sperm, eggs or embryos were used in research
- Over a third (39%) of those who didn't receive feedback wanted to receive feedback

Did you receive feedback on whether your sperm, eggs or embryos were actually used in research?



•Base 121: Those that have given consent for their sperm, eggs or embryos to be used in research

Did you want to receive feedback on whether your sperm, eggs or embryos were actually used in research?



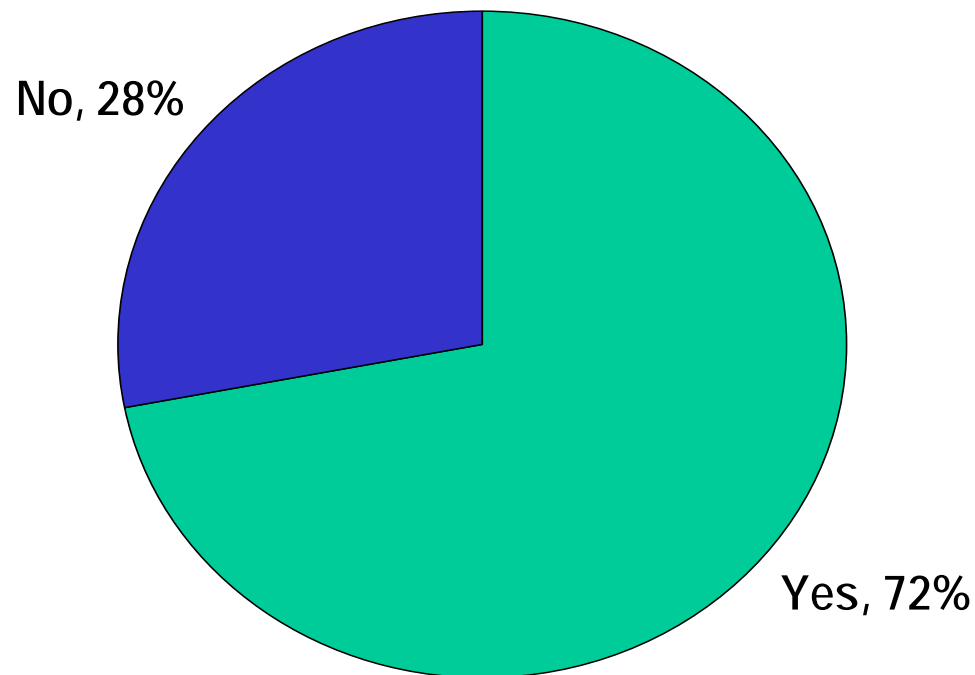
•Base 114: Those that have given consent for their sperm, eggs or embryos to be used in research, but have not received feedback on whether they were actually used

Multiple pregnancies

Summary

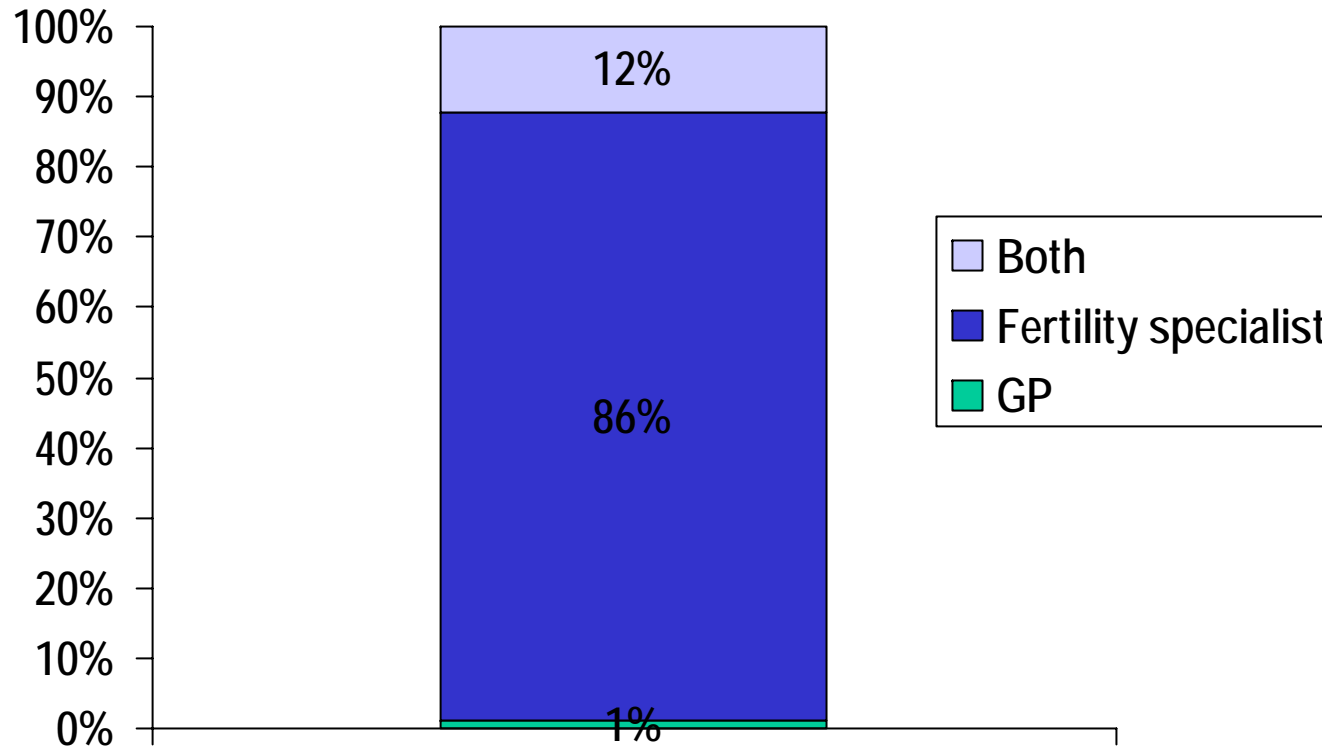
- Most participants (72%) were given information about the risks to mothers and babies resulting from multiple embryo transfer
- Almost all were given this information by a fertility specialist (86% solely, 12% along with information from the GP)
- However, only a minority (9%) changed their attitude towards multiple embryo transfer because of this information
- Over half (57%) would **not** agree to having one embryo transferred in order to minimise the chance of a multiple pregnancy even if medical staff felt it was appropriate for them
- However, three quarters (75%) of these people would be more likely to consider having one embryo transferred if NHS funding was routinely available for 3 cycles of treatment rather than the single cycle currently available in many areas

If you have seen a medical practitioner about problems conceiving, were you given information about the risks to mothers and babies of multiple pregnancies resulting from multiple embryo transfer?



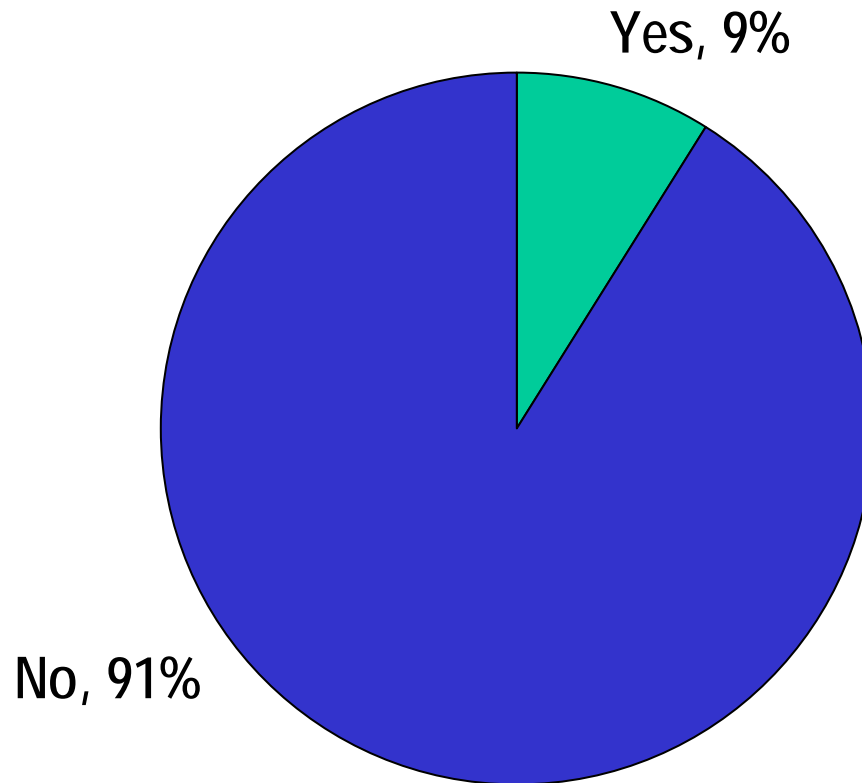
- Base 481: All respondents who have seen a medical practitioner

Was the medical practitioner who gave you information about the risks your GP, a fertility specialist or did you get information from both sources?



Base 346: Those that were given information about the risks to mothers and babies of multiple pregnancies resulting from multiple embryo transfer

Did the information change your attitude towards multiple embryo transfer?



Base 346: Those that were given information about the risks to mothers and babies of multiple pregnancies resulting from multiple embryo transfer

In what way?

- People who changed their attitudes did so because they realised the risks:

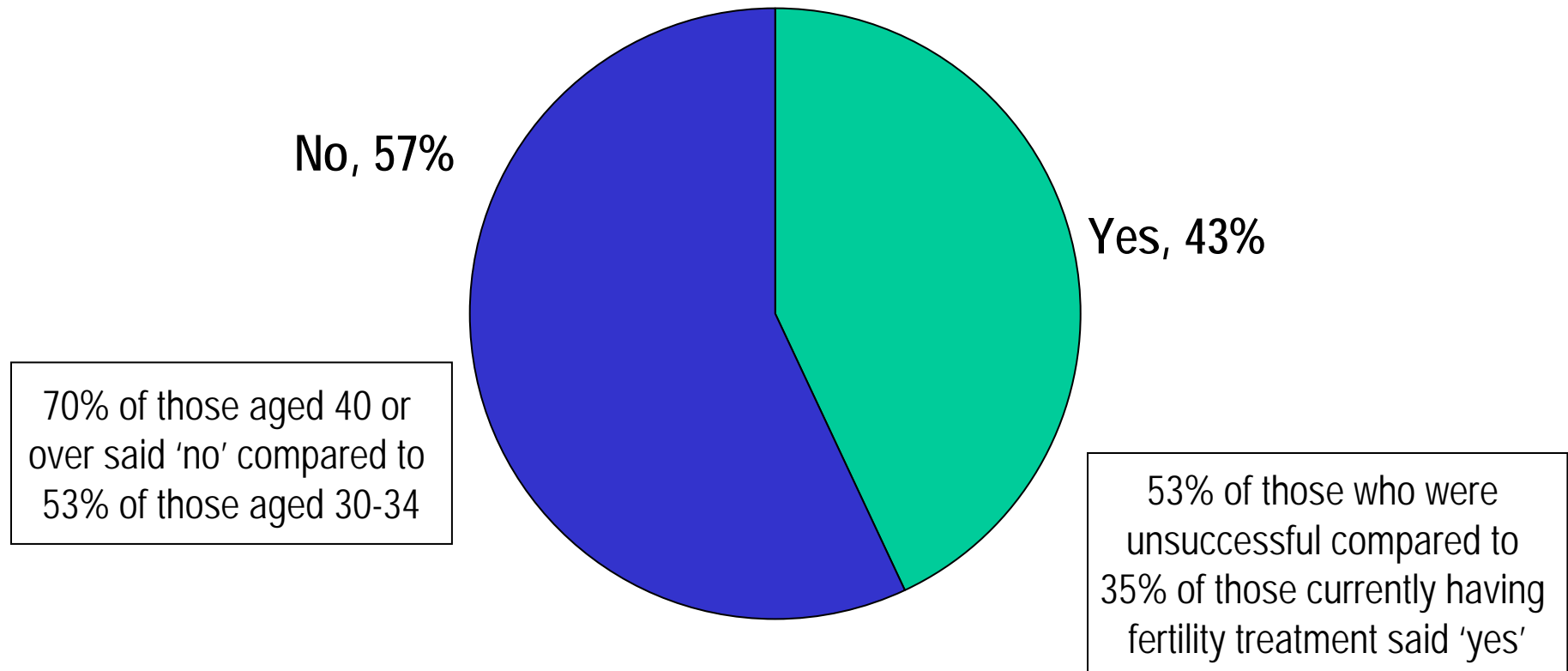
“Due to the risks explained we decided that implanting 2 rather than 3 embryos was the sensible option”

“Previously I would have wanted as many embryos transferred as possible to give best chance of success but now understand that any more than 2 can be risky”

“Realising the risks to mother & child/ren, decrease in live birth rates”

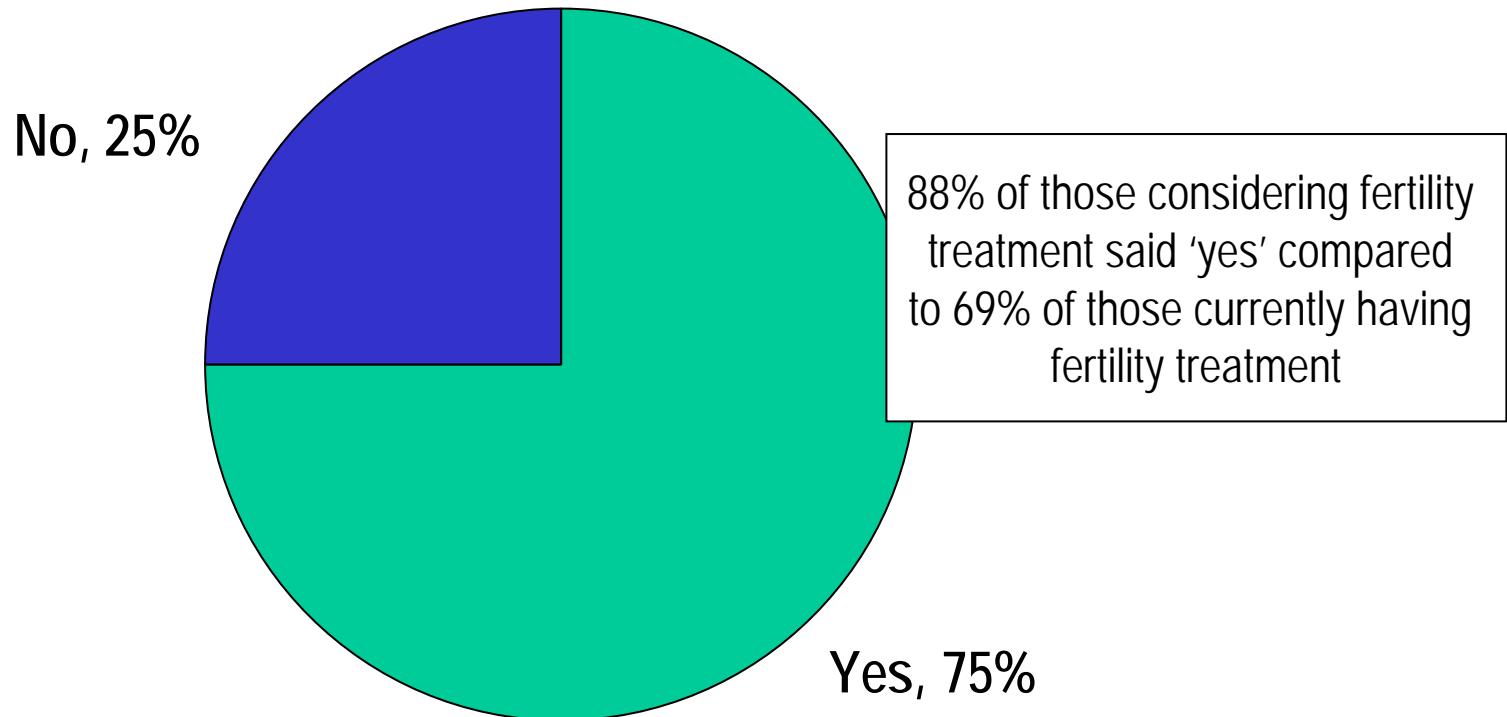
“I would prefer fewer embryos to avoid multiple pregnancy (had twin miscarriage at 13 + weeks)”

Would you agree to having just one embryo transferred in order to minimise the chance of multiple pregnancy if medical staff felt it was appropriate for you?



Base 516: All respondents

Would you be more likely to consider having one embryo transferred if NHS funding was routinely available for 3 cycles of treatment rather than the single cycle currently available in many areas?



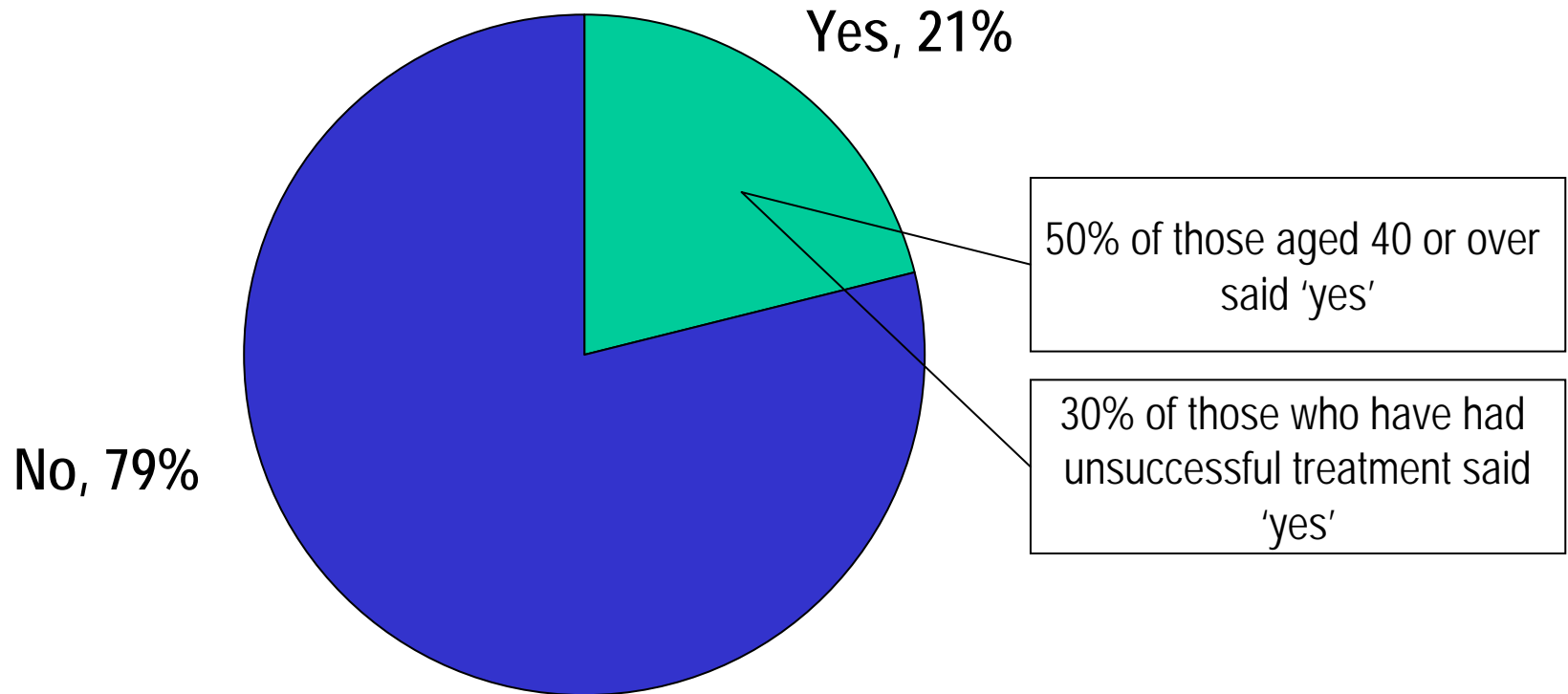
Base 294: Those not agreeing to have one embryo transferred in order to minimise the chance of multiple pregnancy

Availability of donor sperm/eggs

Summary

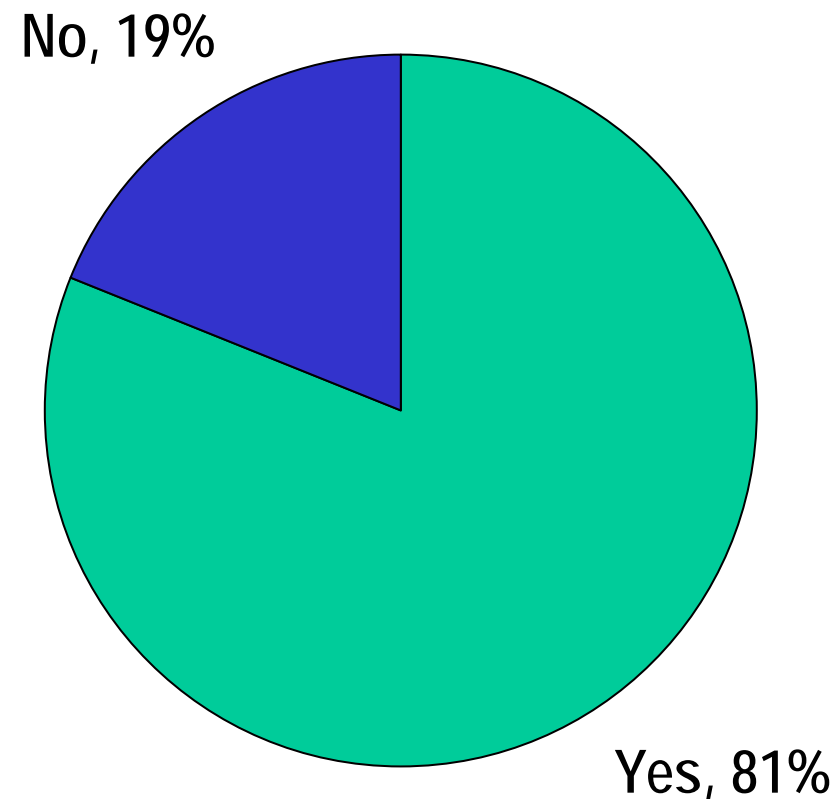
- Over four in ten (81%) of those who have started treatment involving donor sperm/eggs have encountered problems with their availability
 - One in ten (9%) of these were not warned prior to treatment that there might be a shortage
- A third (32%) wanted to use sperm from the same donor to produce siblings who are related on the paternal side
 - A quarter (24%) of these were not warned that sperm from the same donor may not be available

Have you received or been recommended fertility treatment that involves using donor sperm/eggs?



Base 516: All respondents

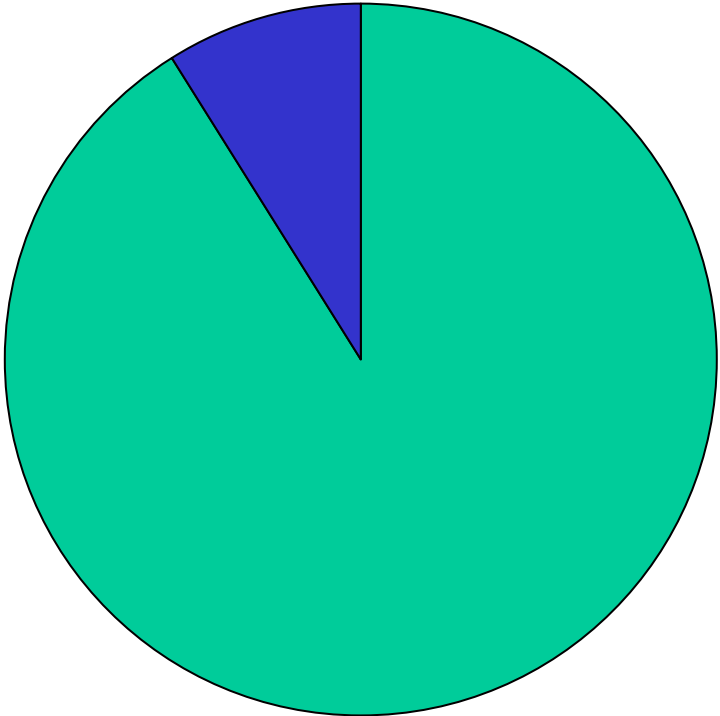
Have you encountered problems with the availability of sperm/eggs for your treatment?



Base 78: Those who have received/been recommended fertility treatment that involves using donor sperm/eggs and have started/had treatment

Were you warned prior to treatment that there might be a shortage of donated sperm/eggs?

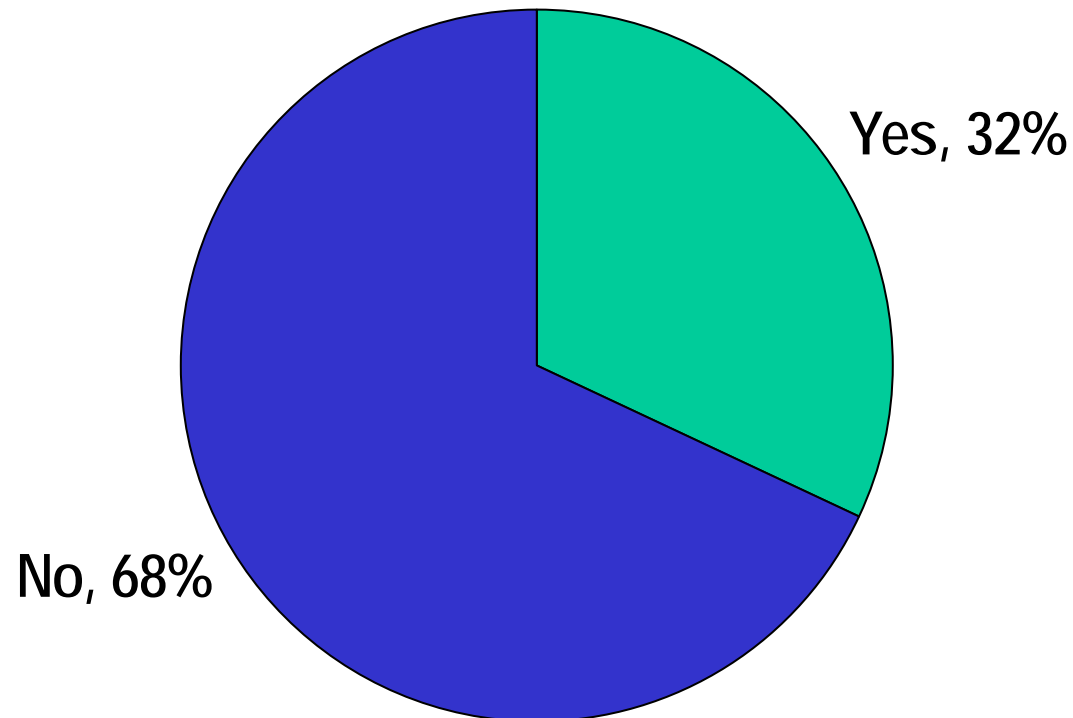
No, 9%



Yes, 91%

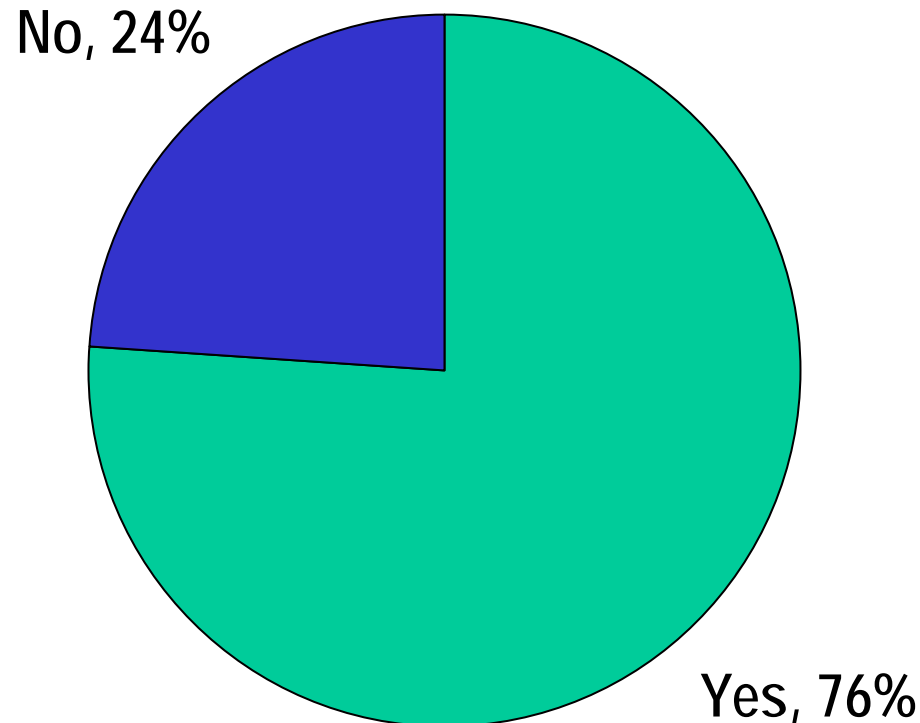
BASE 65: Those who have received or been recommended fertility treatment that involves using donor sperm/eggs and have encountered problems

Have you used or have you wanted to use sperm from the same donor to produce siblings who are related on the paternal side?



BASE 65: Those who have received or been recommended fertility treatment that involves using donor sperm/eggs and have encountered problems

Were you warned prior to treatment that sperm from the same donor may not be available to have siblings who are related on the paternal side?



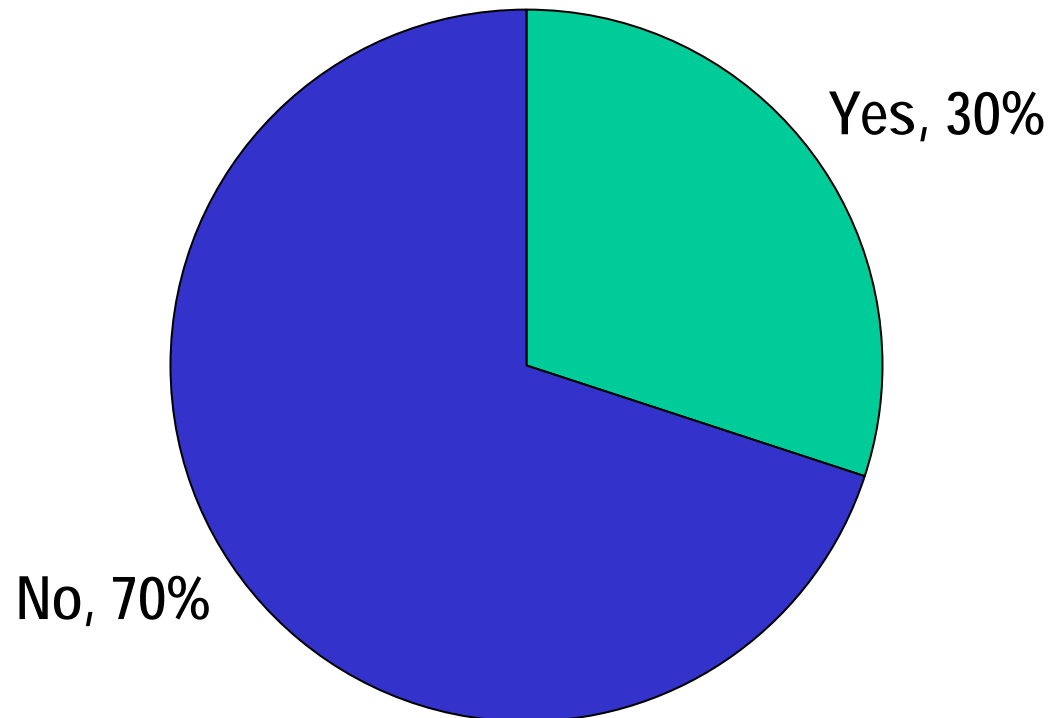
*SMALL BASE 21: Those who have received or been recommended fertility treatment that involves using donor sperm/eggs who have encountered problems, and wanted to use sperm from the same donor to produce siblings who are related on the paternal side

Complaints

Summary

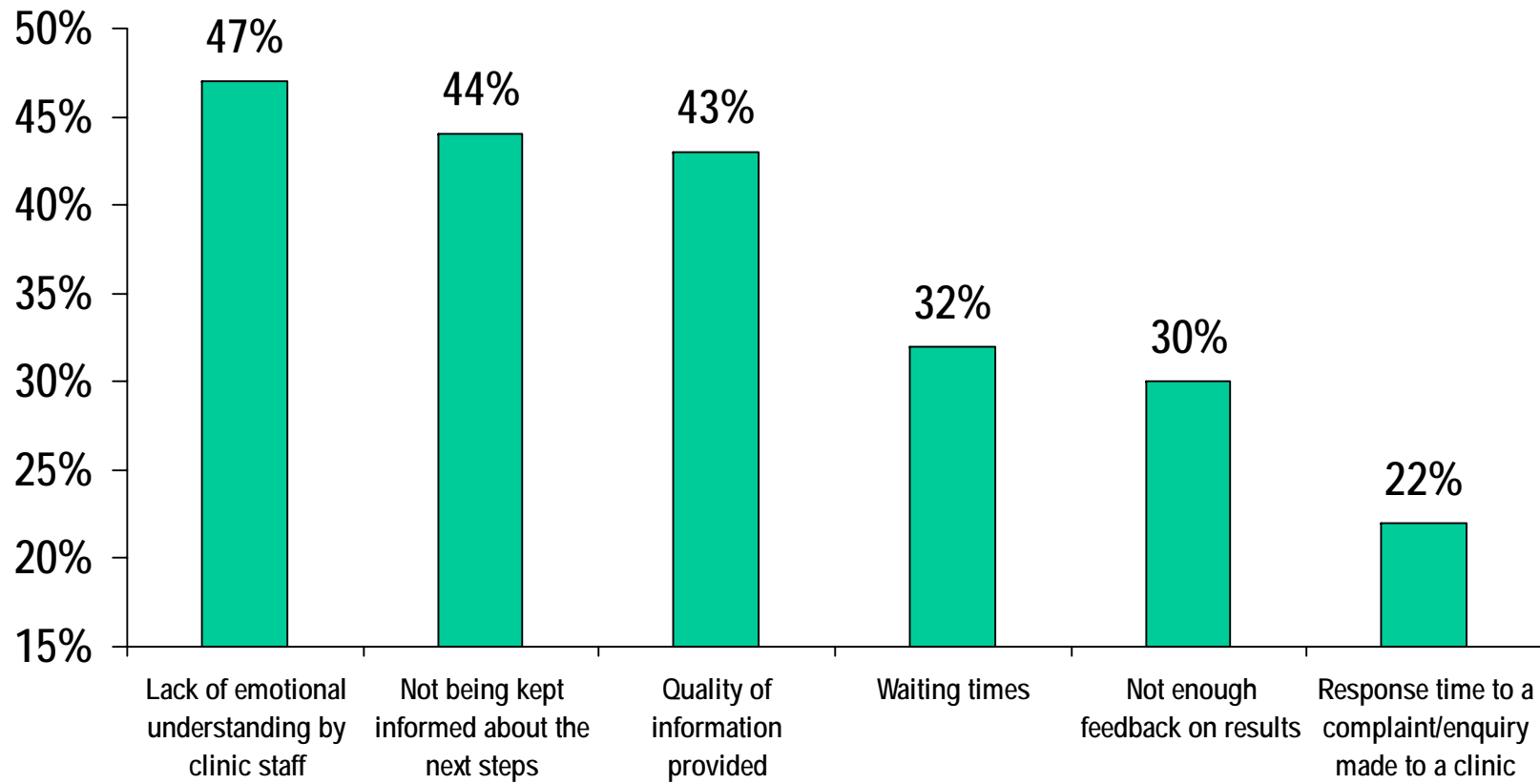
- Three out of ten (30%) of those who had used a clinic have had a problem with it
 - 47% had a problem concerning the lack of emotional understanding by clinic staff
 - 44% had a problem concerning not being kept informed about the next steps
 - 43% had a problem concerning the quality of information provided
- Four out of ten (39%) of people who had a problem complained
- Nearly all (94%) of complaints were not anonymous
- Seven out of ten (70%) of these people did not feel that their complaint was successfully dealt with

If you have used a clinic, have you ever had a problem with your clinic?



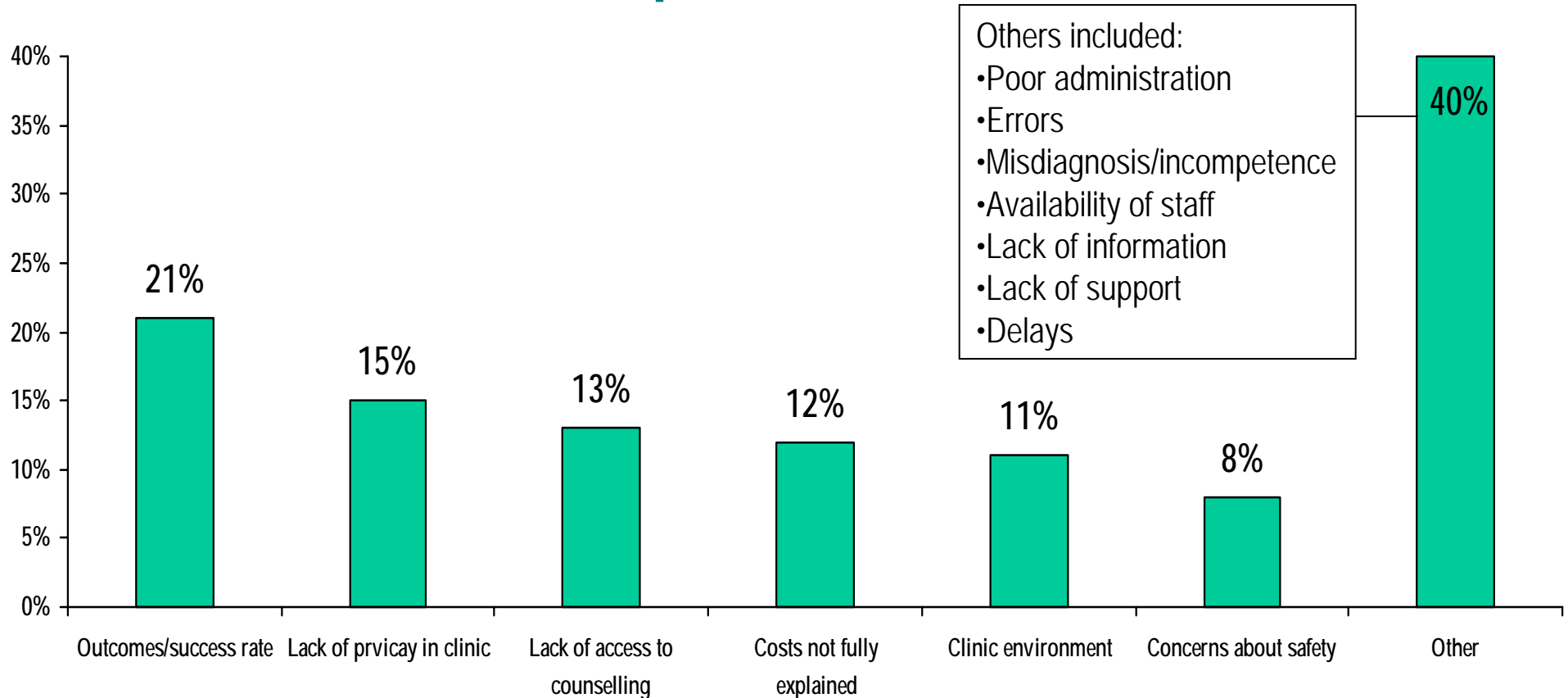
Base : 465: People who have used a clinic

What was the problem related to? (1)



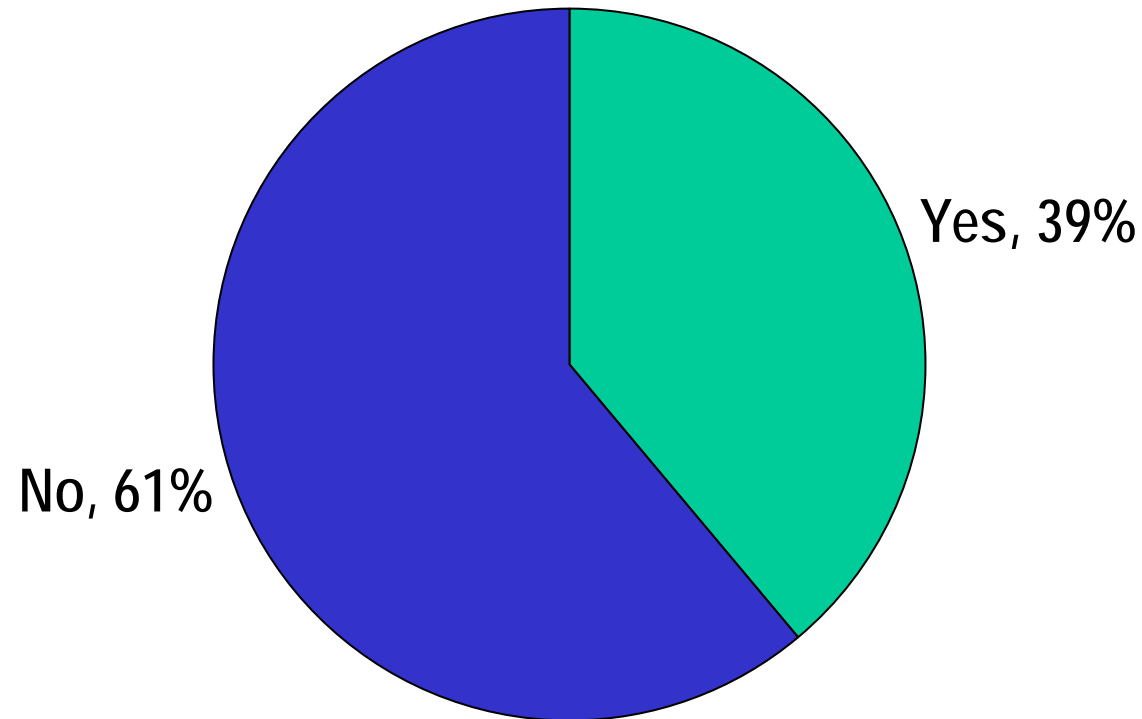
•Base 139: Those who have had a problem with the clinic

What was the problem related to? (2)



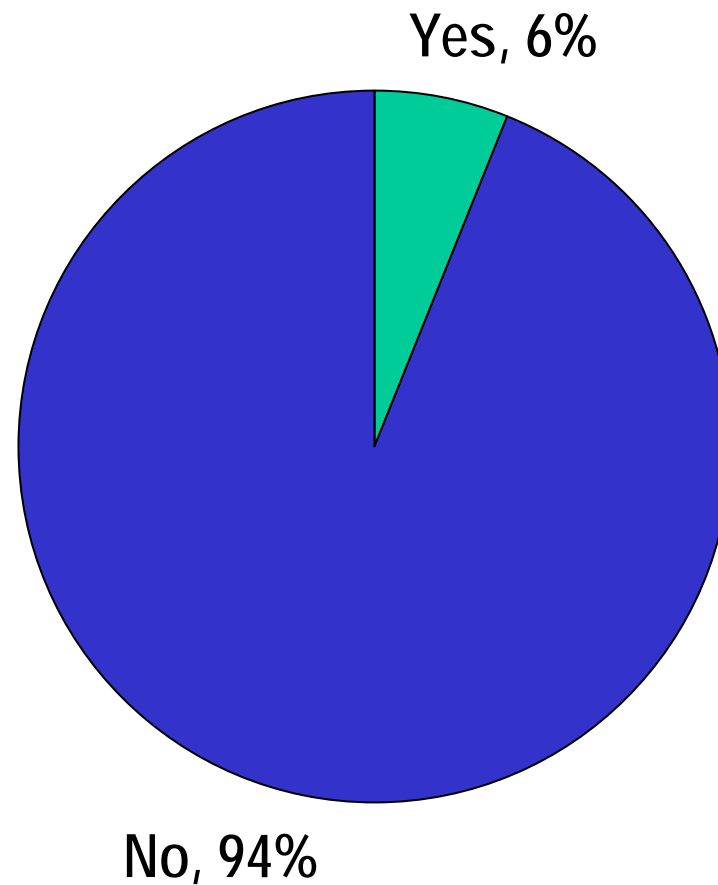
•Base 139: Those who have had a problem with the clinic

Did you complain?



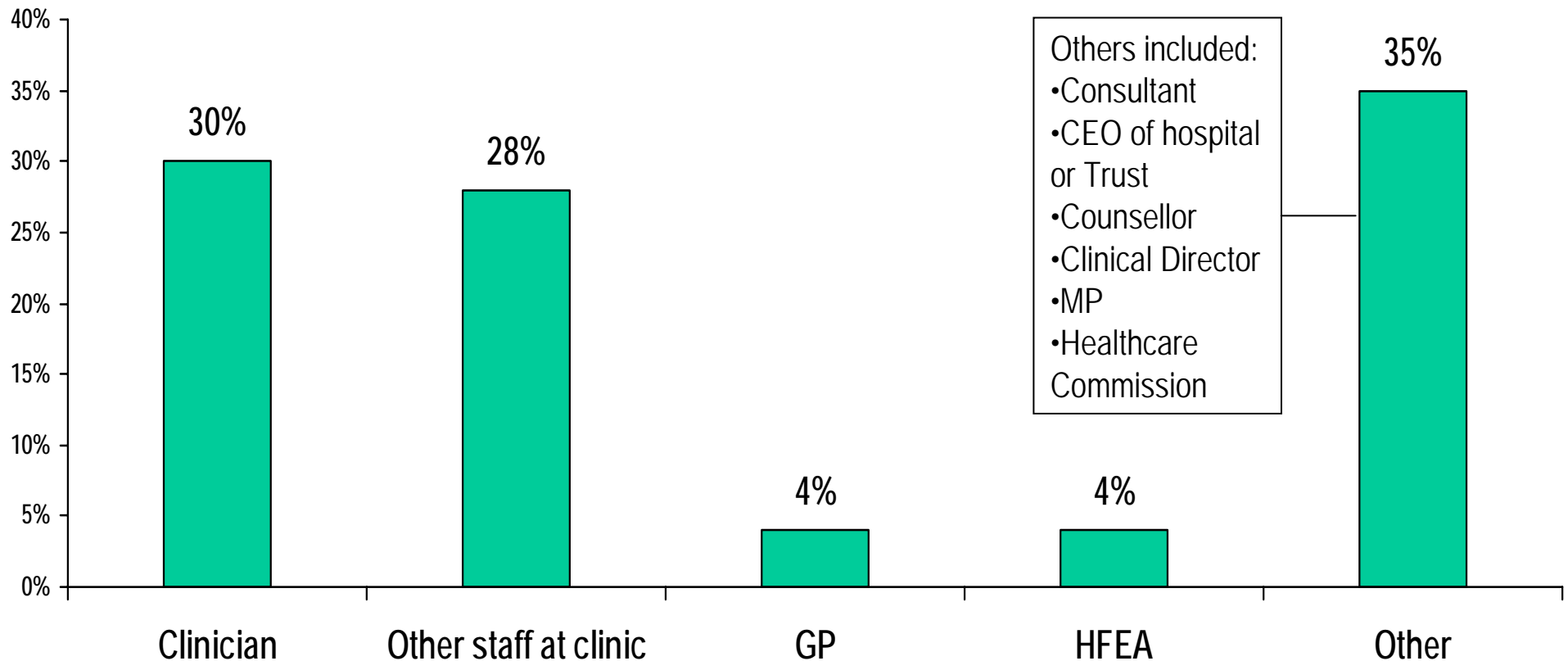
•Base 139: Those who have had a problem with the clinic

Was your complaint anonymous?



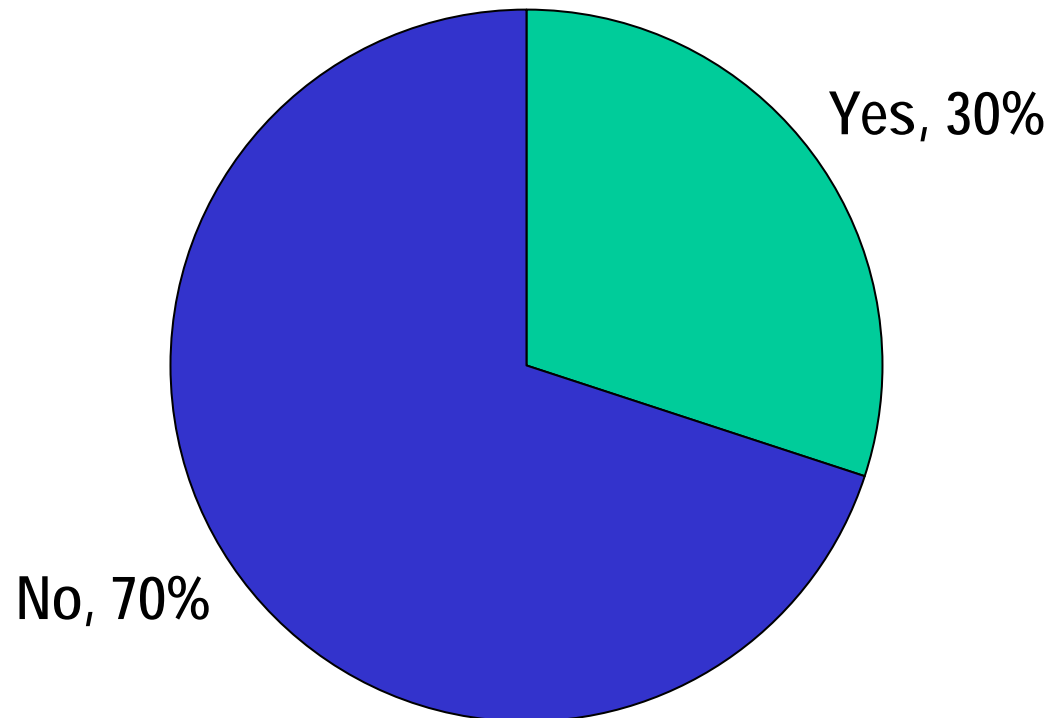
•BASE 54: Those who have had a problem with the clinic and made a complaint

Who did you complain to?



•BASE 54: Those who have had a problem with the clinic and made a complaint

Did you feel your complaint was successfully dealt with?



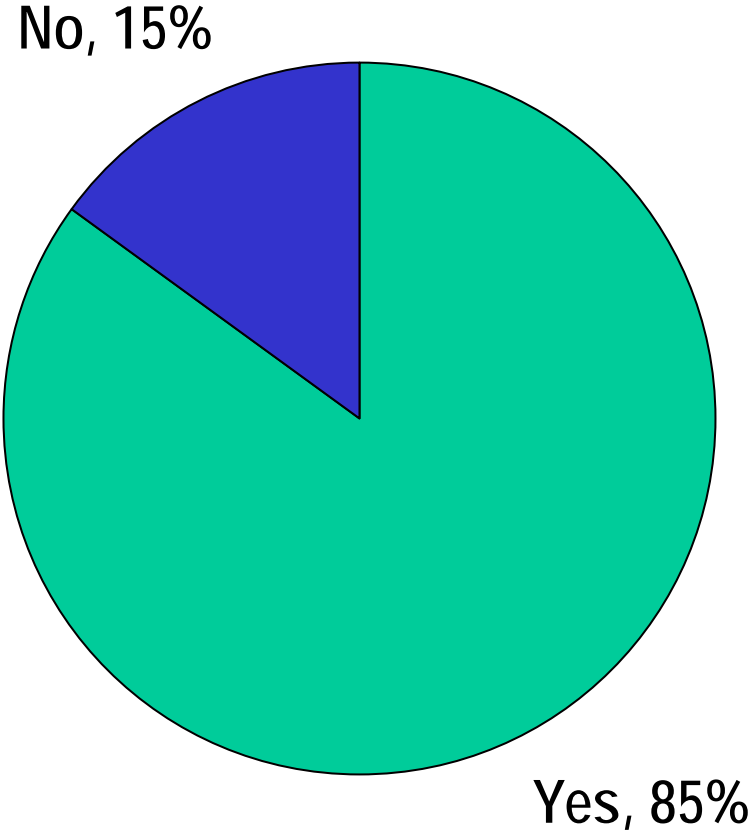
•BASE 54: Those who have had a problem with the clinic and made a complaint

Cost of IVF

Summary

- A significant minority (36%) of those having/or have had IVF treatment and are paying/paid for it themselves found that their bill was more than they expected it to be
- Four in ten people (41%) had items on their bill they did not expect
- However, only a small number (7%) did not understand items on their bill
- Two thirds (65%) of those having/or have had IVF treatment received one or more free cycles of IVF treatment on the NHS

Are you having or have you had IVF treatment?



•Base 437: Those currently having fertility treatment or have stopped having fertility treatment

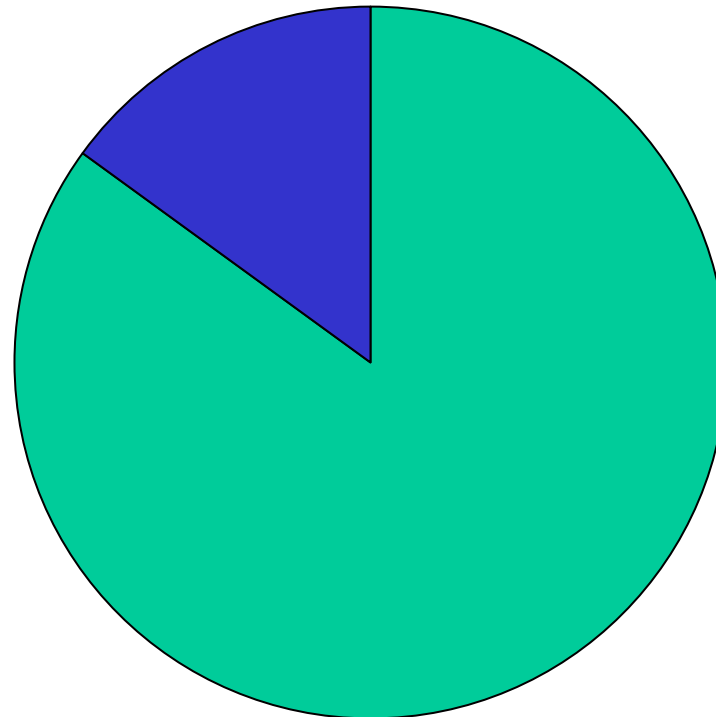


Opinion Leader Research, 5th Floor, Holborn Gate, 330 High Holborn, London, WC1V 7QG
Tel: 020 7861 3080 Fax: 020 7861 3081 Website: www.opinionleader.co.uk

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Did you pay or are you currently paying for IVF treatment?

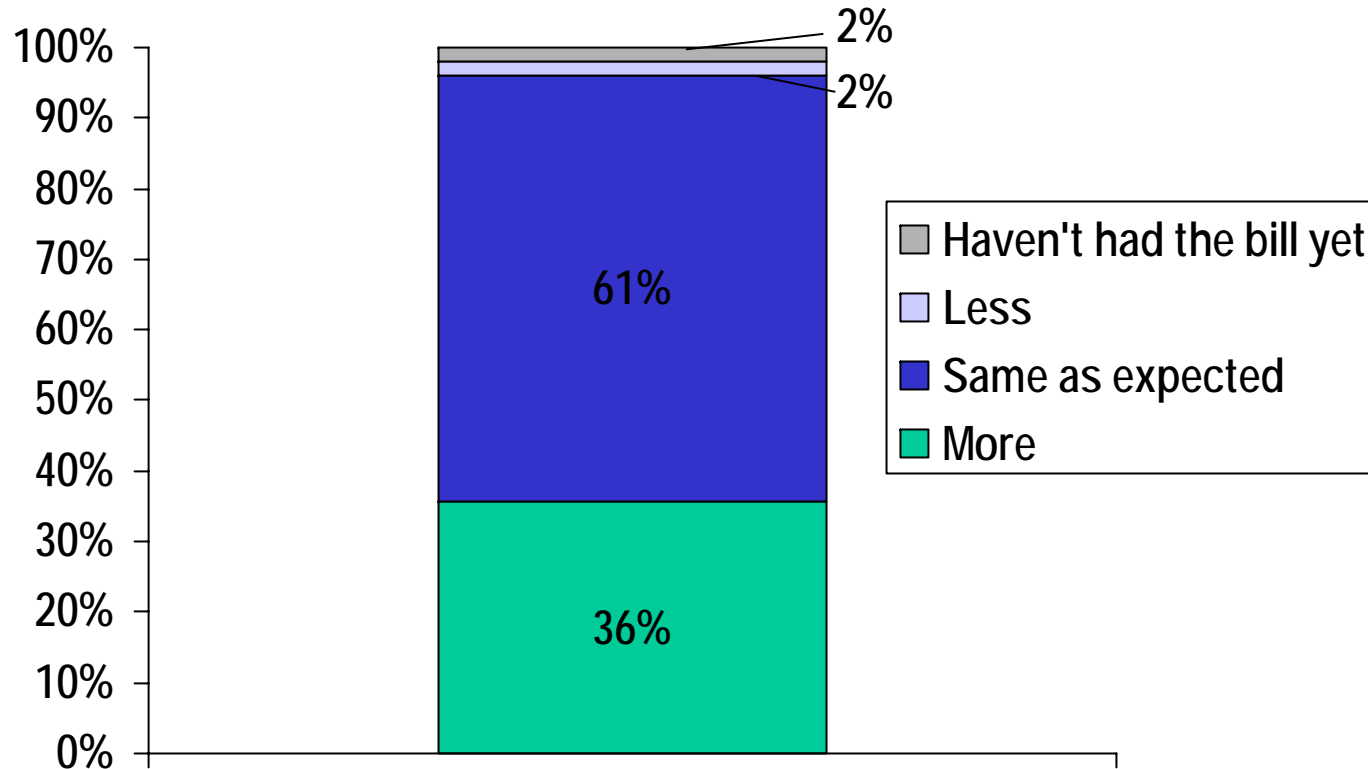
No, 15%



Yes, 85%

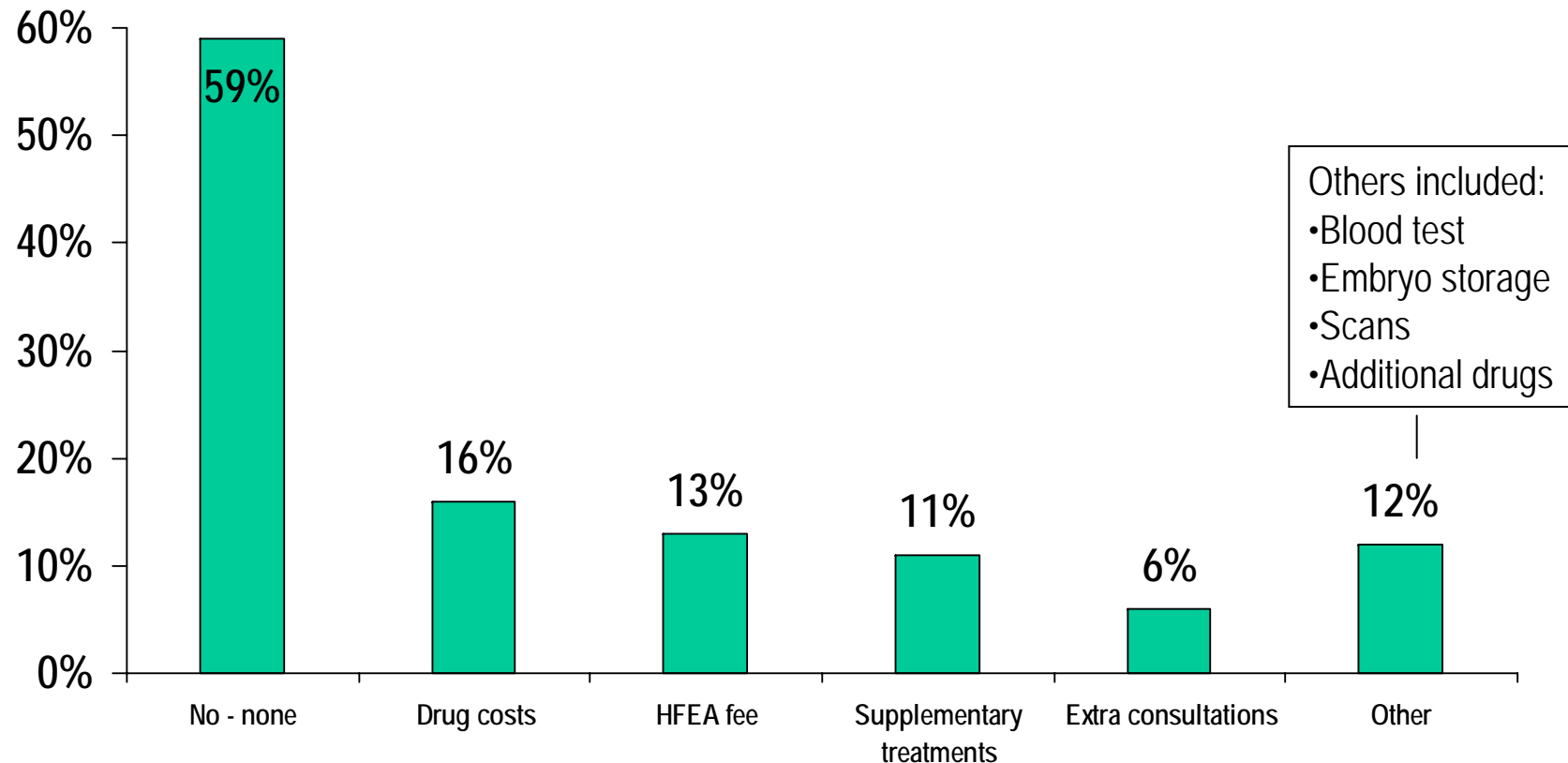
•Base 370: Those currently having or have had IVF treatment

Was the bill more, less or the same as you expected it to be?



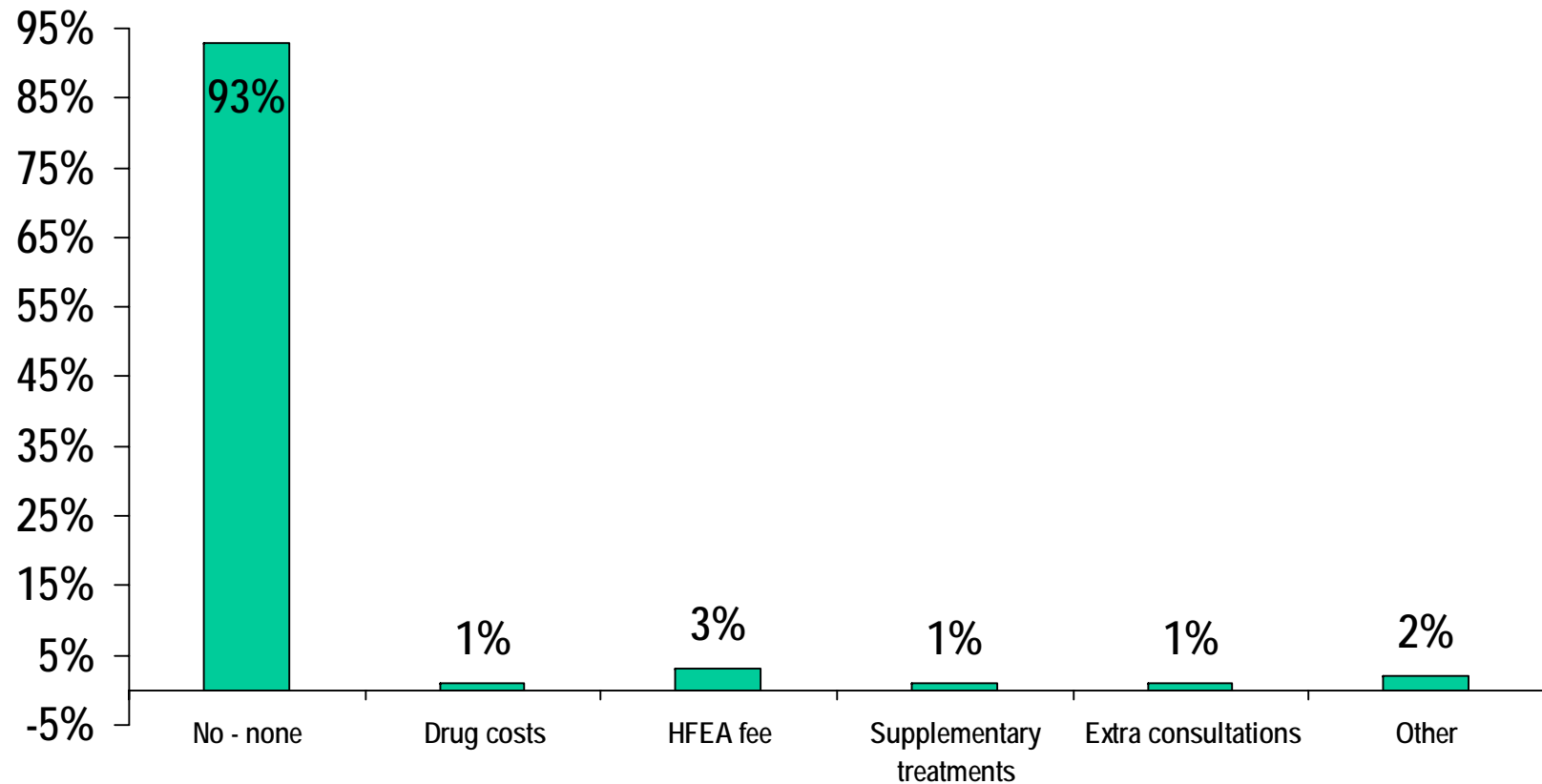
Base 313: Those currently having or have had IVF and are paying/paid for it themselves

Were there any items on your bill that you didn't expect?



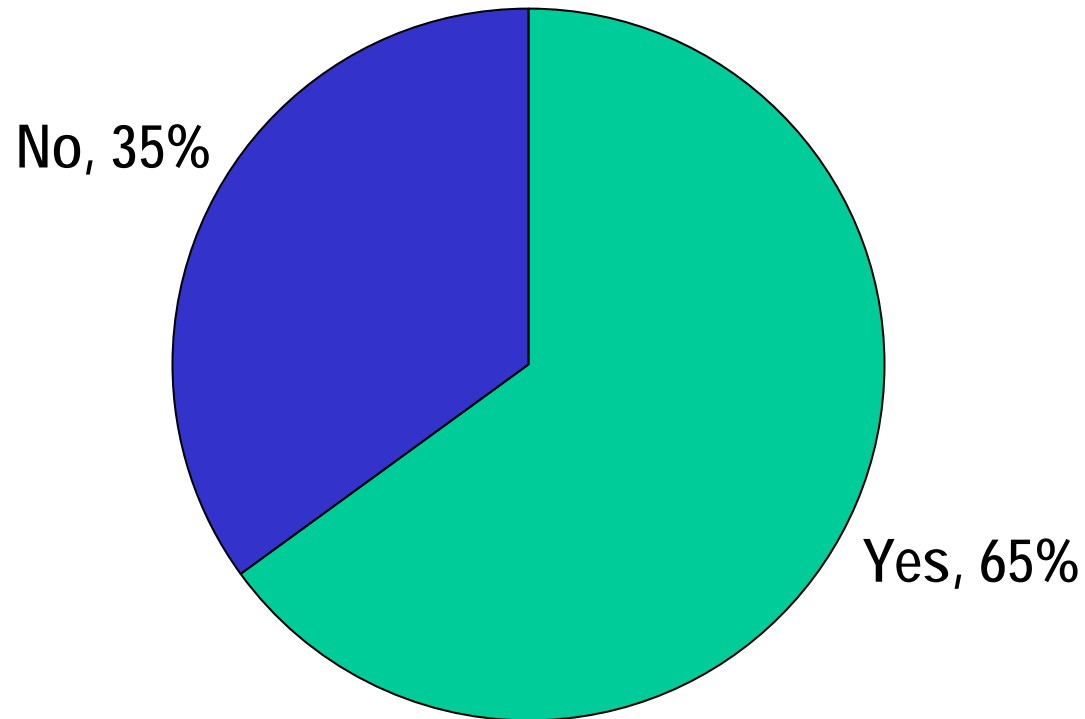
•Base 308: Those currently having or have had IVF and are paying/paid for it themselves and have had the bill

Were there any items on your bill that you didn't understand?



•Base 308: Those currently having or have had IVF and are paying/paid for it themselves and have had the bill

Have you received one or more free cycles of IVF treatment on the NHS?



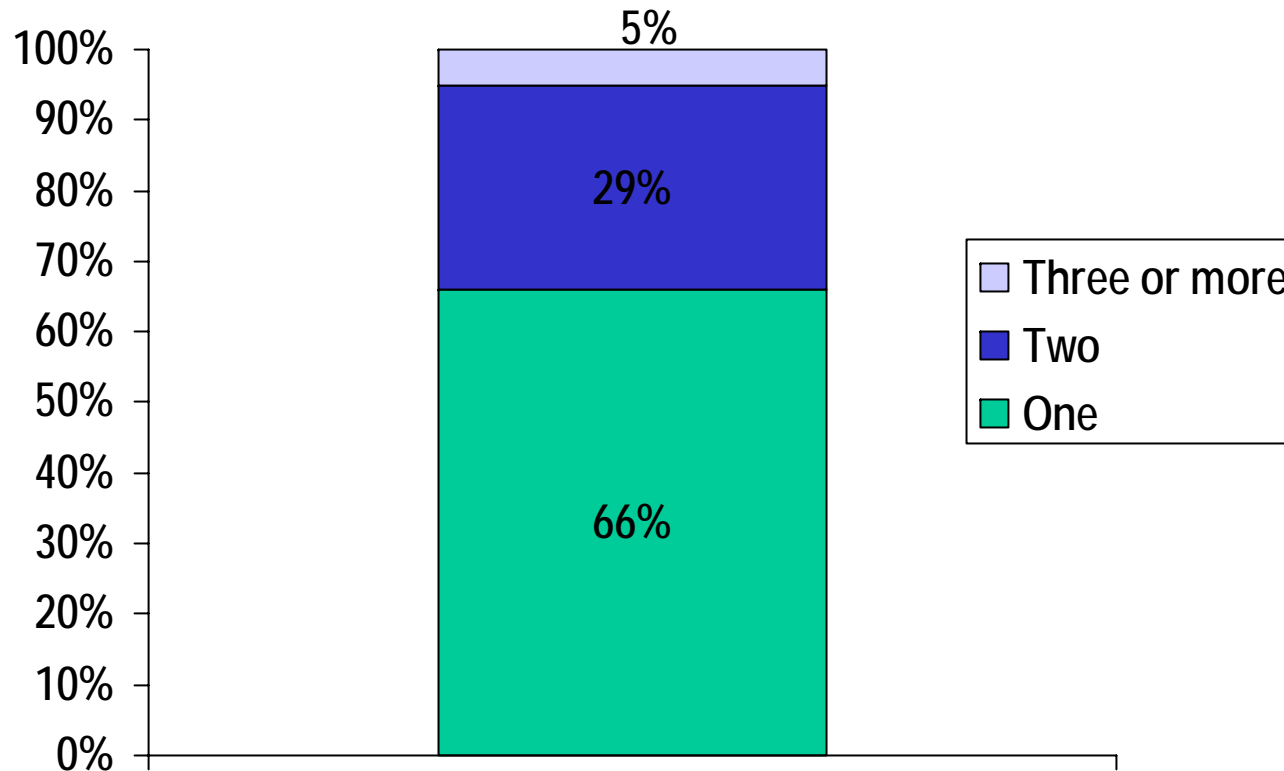
•Base 370: Those currently having or have had IVF treatment



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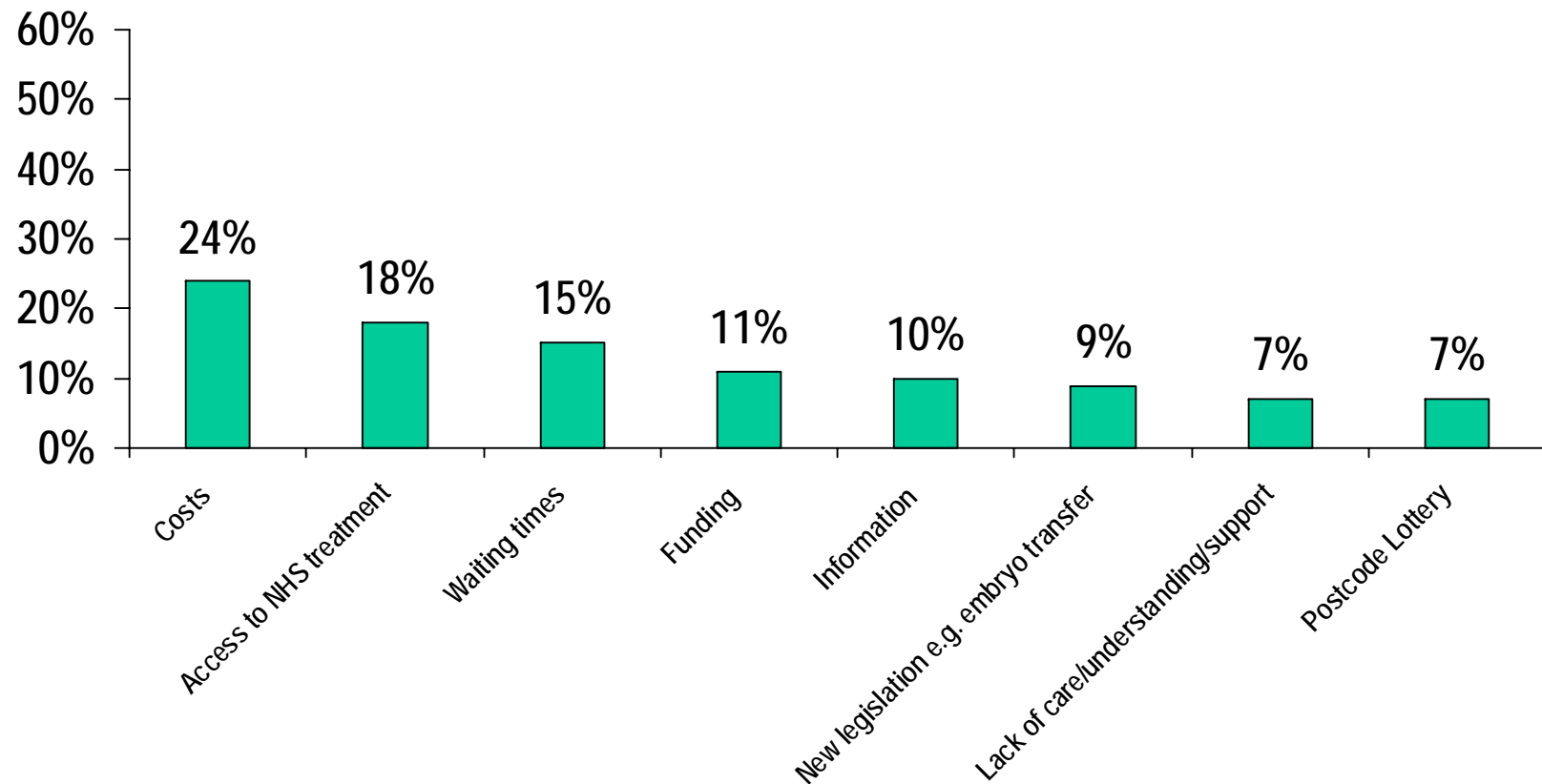
How many cycles of NHS IVF treatment did you receive?



Base 131: Those currently having or have had IVF who have received one or more free cycles on the NHS

Important issues in infertility treatment

What are the most important issues facing you regarding infertility treatment? (coded from open ended responses)



Quotes on costs

"The cost! When the government announced that from April last year every couple would be entitled to one free cycle of IVF, we presumed that, starting our cycle in June we would be entitled to a free cycle. However, funding had not been agreed and we had to pay £4000 ourselves."

"We had to pay fully for both cycles as my husband has children from a previous marriage (who live with their mum), this has left us in debt."

"Coming to terms with the fact that we have now stopped treatment and we may well never complete our family. This is mainly due to the emotional turmoil that we have experienced and also the financial costs."

"The increasing costs of IVF treatment worries and surprises me intensely. The annual and sometimes more than annual increases on price do not appear to be justified."

Quotes on access to NHS treatment

"I've come across many people who have been told they qualify for a cycle of NHS funded IVF but depending on where they live there still seems to be a 'lottery' on how long they have to wait to start their treatment."

"My partner and I were told we were ineligible for a free IVF cycle because we are a same sex couple. This seems grossly unfair."

"It is totally unfair to penalise childless couples who have both paid into the NHS for 20 years each and have had 1 self funded IVF and therefore not eligible for NHS treatment – disgusting."

"I was even put on hold mid-treatment when they had staffing problems that I later found out that they knew would arise."

Quotes on waiting times

"People need to be made aware of waiting times in their area for treatment. It's a complicated path simply ascertaining what the problem is and there needs to be more information as to the possible processes you may go through."

"I strongly feel that the clinic should give an honest estimate of waiting lists. I was told 18mths for IVF – it was actually 3.5 years."

"Allowing payment of donors may lead to a reduction in waiting lists as seen in other countries."

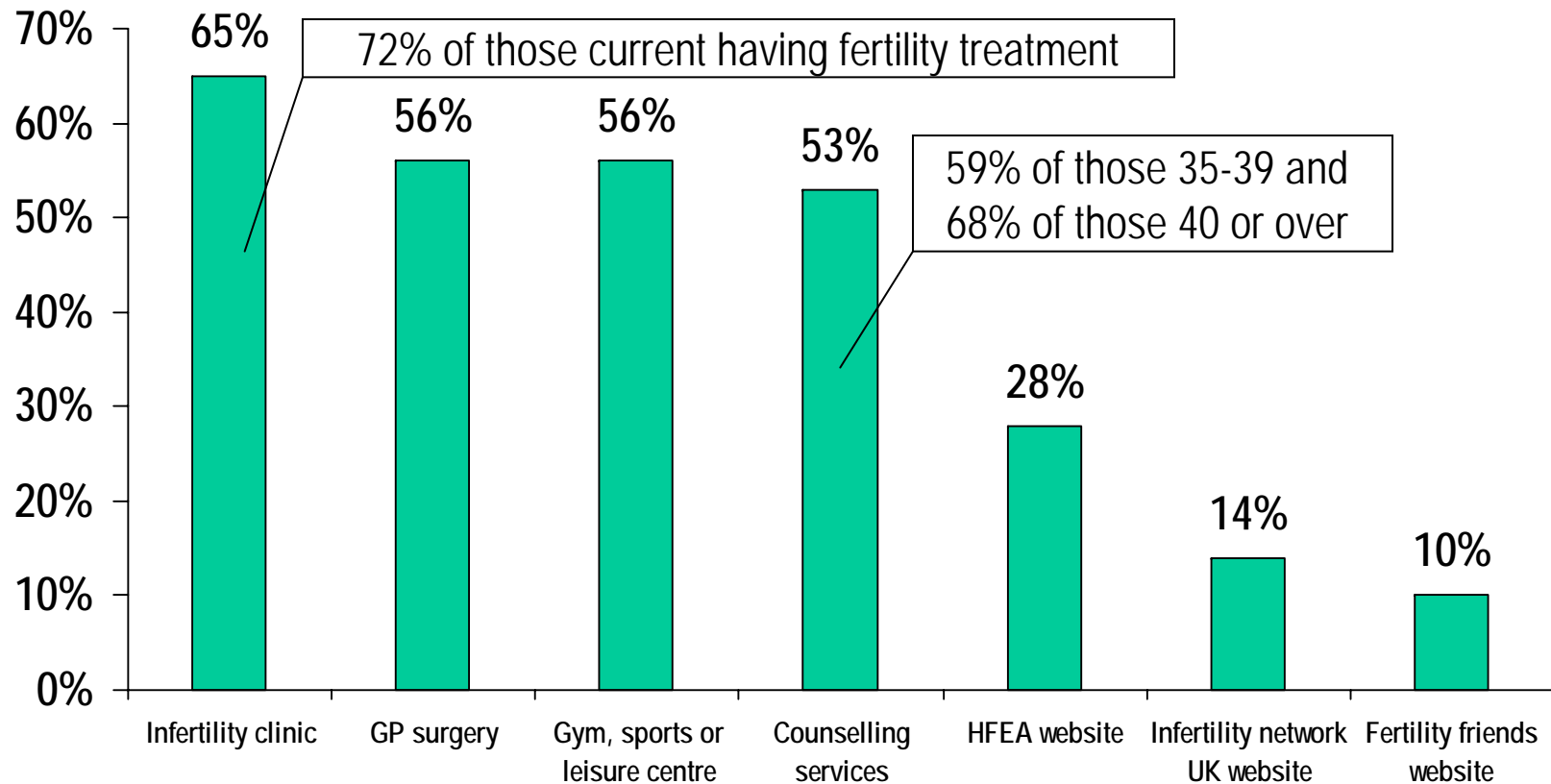
"The waiting list of 2 years to be matched for donor eggs."

"Waiting lists...the fact that couples who already have children appear to be on the same waiting list as those who don't"

"The fact that my one free cycle had a four year waiting list (Lambeth)."

Guide to infertility

Choose the top three places you would go to pick up the Guide to Infertility?



•Base 516 : All respondents

Conclusions and recommendations (1)

- Increasing the numbers of people being given information about research will increase the numbers giving consent for their sperm, eggs or embryos to be used
- Many people would like to receive feedback on whether their sperm, eggs or embryos were used in research
- Giving people information about the risks of multiple embryo transfer does not often change people's attitudes towards it
- However, giving people 3 free cycles on the NHS will increase the likelihood of people considering single embryo transfer

Conclusions and recommendations (2)

- Some people were not warned about the potential problems with availability of sperm from the same donor
- Although the numbers of complaints about problems were quite low, the levels of dissatisfaction with complaint handling was high
- There is an issue around the items expected on bills, although patients do generally understand what the items are on their bill
- The Guide to Infertility should be placed in gyms, sports or leisure centres as well as more conventional settings such as clinics and GP surgeries