



Human Fertilisation and Embryology Authority

Results from the Fertility Views online panel

December 2006

Presentation structure

- Overview
- Our approach
- Profile of respondents to this survey
- Main findings from 4th survey
- Conclusions and recommendations

Overview (1)

- This survey focussed on a number of issues including success rates, information, counselling and discrimination
- Many respondents were not given a percentage chance of success when discussing treatment (33% of people currently having or who have finished treatment were not given a figure)
- However, this figure is an important factor in the decision to pay for treatment
 - When asked if they would go ahead and pay for treatment with a 25% chance of success, nearly all say they would (94%)
 - Although the number drops as the percentage chance of success drops, many are willing to take the risk and would pay at much lower chances of success. Nearly 1 in 4 respondents would still go ahead and pay for treatment if there was less than a 5% chance of success (23%)

Overview (2)

- Related to this, when asked what the most important issues currently facing them are, many people mention the importance of good success rates due to the financial implications of treatment
- However, when choosing a clinic, factors other than costs and success rates have a bearing
 - Over a quarter said they had no choice and went to the clinic they were referred to (27%)
 - Almost a quarter chose a clinic near their home/work primarily (23%)
- In terms of the information most valued when deciding which clinic to go to live birth rates are most important (45% rated them top), ahead of information about costs and other information from the HFEA, the clinic or other sources

Overview (3)

- People visit multiple websites for information, the most popular one being fertility friends with almost two thirds having visited it (63%)
- Over half the people currently or considering going through fertility treatment have visited the HFEA website since June (56%)
- Most were quite positive about the site
 - 65% said it was easy to find the information they wanted
 - 57% said the website was well designed in terms of layout and presentation
 - 73% felt the information on the website was the right level of complexity

Overview (4)

- Over a third (39%) have had counselling before, during or after treatment with mixed feelings
 - Many said it was very helpful and they would strongly recommend it to others (34%)
 - However, almost half (46%) said that it didn't add much to their experience. Most still said it was worth doing (30%) but 16% said it wasn't worth doing
- Many who didn't have it wished they'd had counselling or said that with hindsight it might have been helpful (42%)
- Although clinics are supposed to suggest counselling, some said they didn't have it because the clinic didn't suggest it (21%)
- Very few people have encountered problems because of their race, religion, sexuality or disability (NB very small base sizes)

Our approach

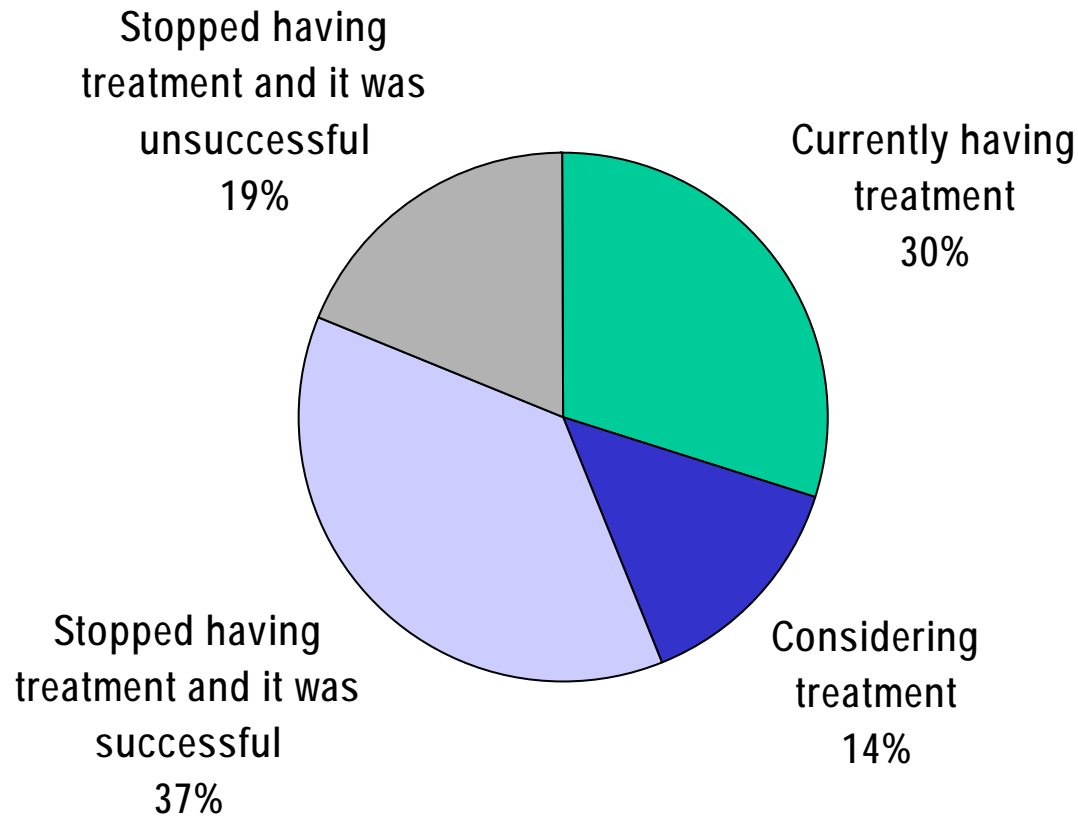
- An online panel was set up in May 2005 through a microsite linked to the HFEA website
- Previously 1 recruitment questionnaire and 3 surveys have been completed
- The 4th survey was sent to panel members in November 2006
- This survey focussed on success rates, information, counselling and discrimination
- 515 panel members completed this survey

Profile of respondents

Summary of demographic profile

- 97% of those who responded are female
- 8% of those who responded are under 30, 36% are between 30-34, 28% are between 35-37, 14% are 38-39, 14% are over 40
- 88% 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
- 55% say they are Christian
- Almost half are from Southern England (SE, SW and London)

What is your current status regarding fertility treatment?



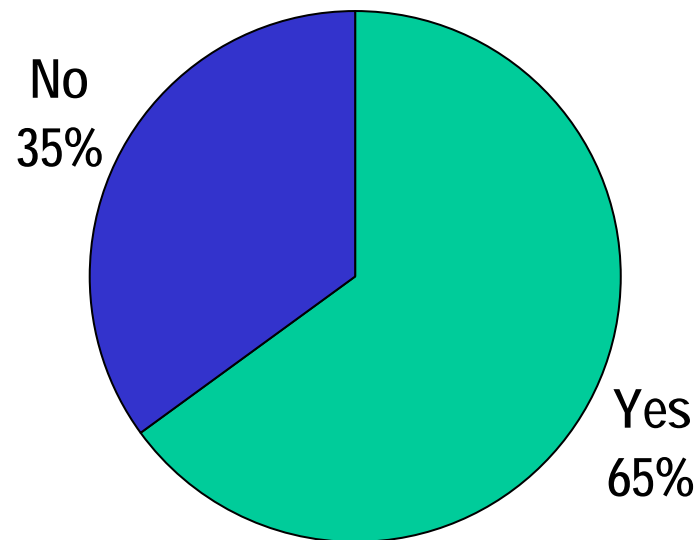
- Base 515: All respondents

Responses to survey

Key findings (1)

- Two thirds of respondents were given a figure, when discussing treatment, for how likely they were to have a baby (65%)
- Nearly all respondents would go ahead and pay for treatment if there was a 25% chance of success (94%)
 - Nearly 1 in 4 respondents would still go ahead and pay for treatment if there was less than a 5% chance of success (23%)
- When choosing a clinic, over a quarter said they had no choice and went to the clinic they were referred to (27%)
 - Almost a quarter chose a clinic near their home/work (if they had not heard anything negative about them) (23%)

Did your doctor give you a figure for how likely you were to have a baby (e.g. a percentage chance of success)?

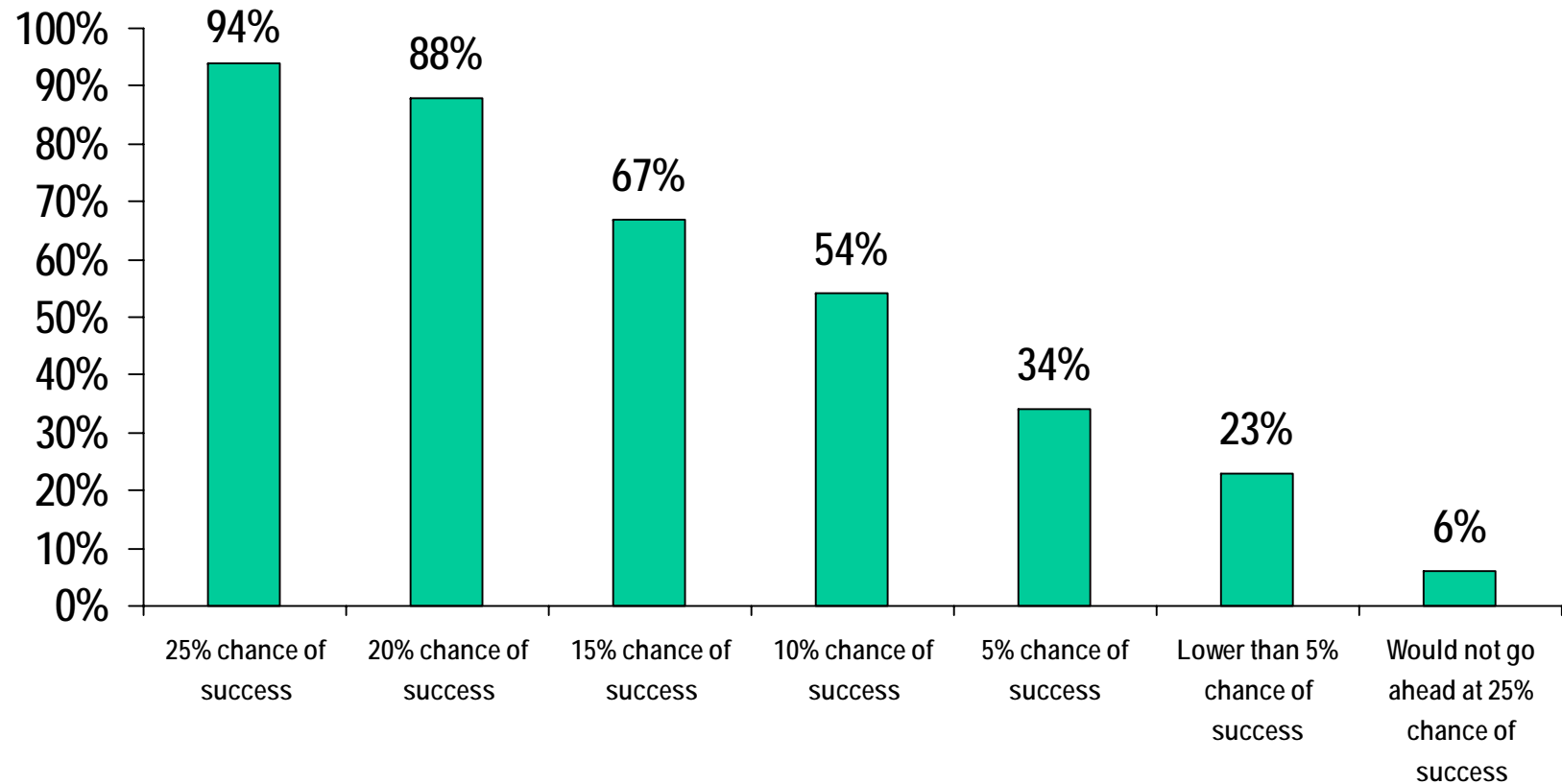


Significantly more people over 40 years old (79%) were given a figure compared to younger age groups (60% of aged 29 or under and 59% of 30-34 year olds)

When those considering treatment are removed, the percentage saying yes rises to 67%

- Base 515: All respondents

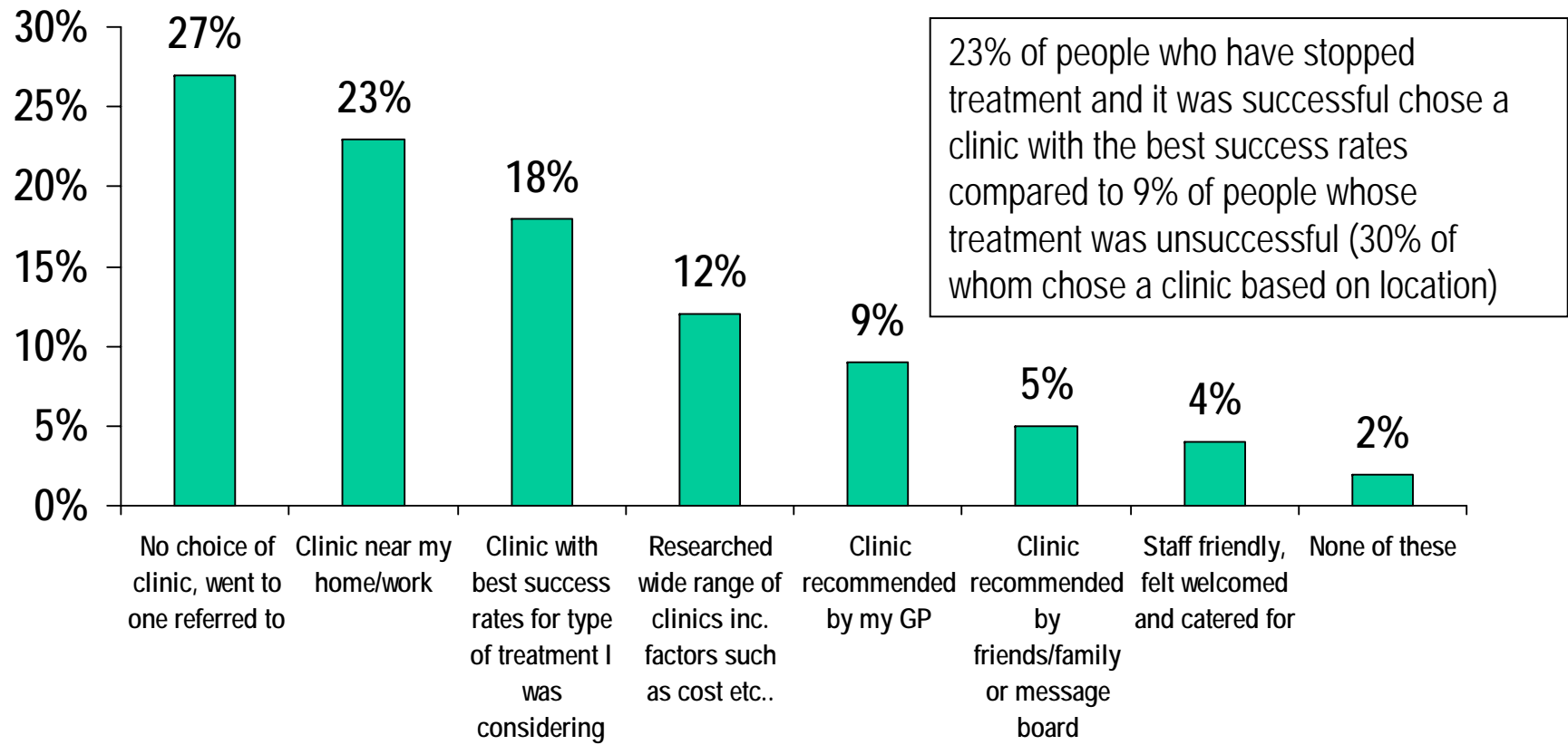
Imagine your doctor told you they would treat you no matter what your chances of having a baby were, providing you were willing to pay. Would you go ahead and pay if there was a...



•Base 515: All respondents



There are many different approaches to choosing a clinic. Which one of the following most closely describes your own approach?



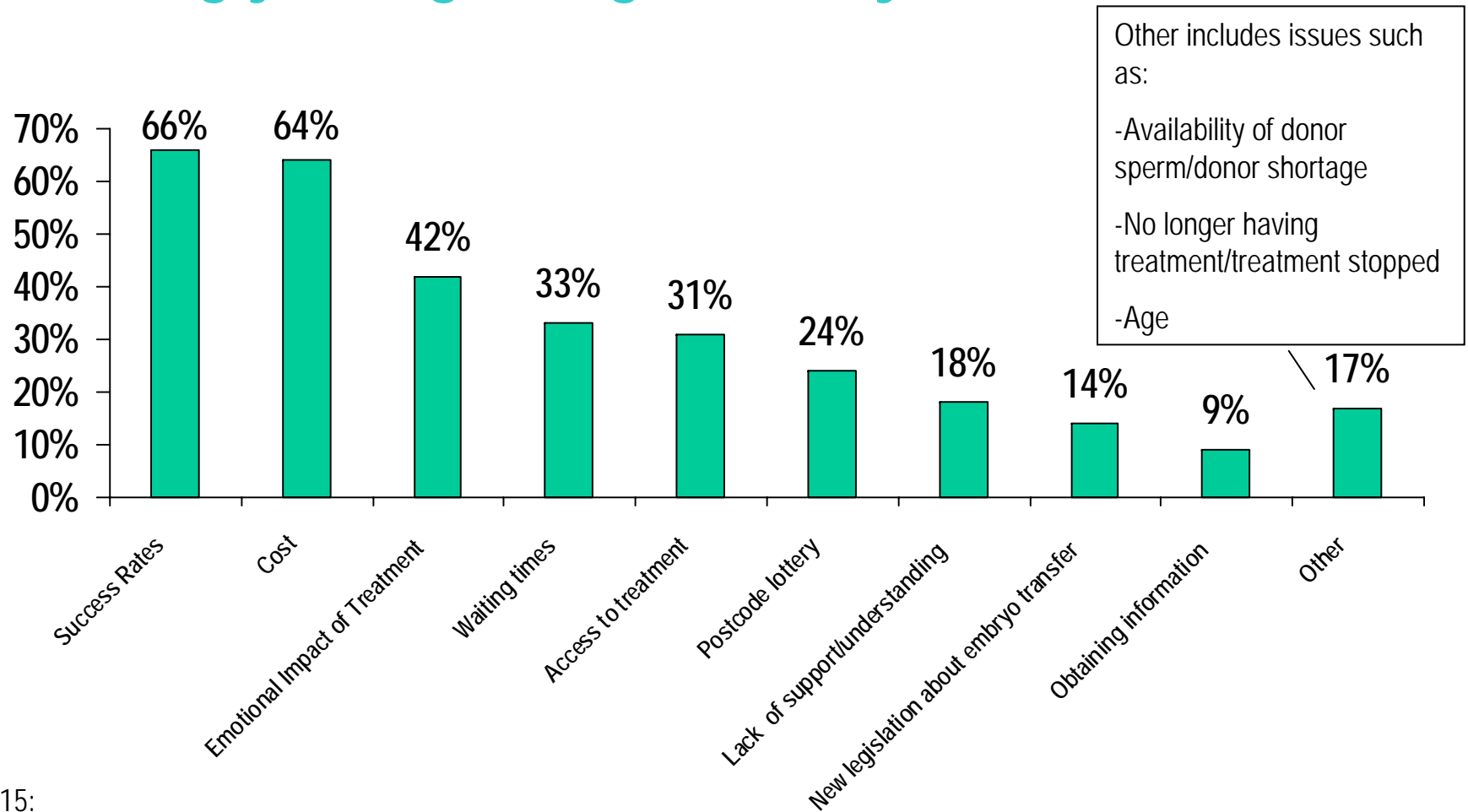
•Base 515: All respondents



Key findings (2)

- Success rates are one of the most important issues to 66% of respondents
 - Success rates are one of the most important issues to 72% of people currently going through treatment
- Cost is one of the most important issues to 64% of respondents
 - Cost was chosen by 75% of people considering having fertility treatment
- Emotional impact of treatment was one of the most important issues to 42% of respondents
 - Emotional impact of treatment was important to 51% of those currently having treatment, 47% of those considering having it and 47% of those who stopped it and it was unsuccessful

What are the most important issues currently facing you regarding infertility treatment? (1)



•Base 515:

Could you explain why these issues are particularly important to you?

- People often mentioned several issues together (especially costs and success rates)

For success rates the main issues were around:

- How important it is to have the greatest chance of success from each treatment due to the emotional and financial impacts of each treatment
- The importance of success rates rising with age

Quotes on success rates

“Success is important as we cannot afford to pay privately and have only one attempt at IVF. However, the stress of trying for a baby could seriously affect our chances of success in this one IVF attempt.”

“Treatment is very expensive, some clinics have long waiting times and its good to know statistics of clinics to check your chances of success.”

“Success rates are the most important thing for me bar none. I am ineligible for NHS treatment anyway due to the postcode lottery, costs are a significant issue, but I am willing to go into debt to give myself the best possible chance of success.”

“Success rates are important to me now as I feel that I am running out of time. I was 40 last month.”

Could you explain why these issues are particularly important to you?

For costs the main issues were around:

- The importance of success rates due to cost of treatment
- Treatment being too expensive/ a huge cost
- Financial impact/not being able to afford it
- The number of previous failed treatments making it very expensive to carry on
- Having to self-fund/paying for own treatment/postcode lottery of NHS treatment/wanting more NHS cycles for free

Quotes on cost

"I feel everyone should be given the same chance whereas we had to pay literally thousands of pounds for a truly special bundle after 5 attempts and cannot afford to try again privately for a sibling."

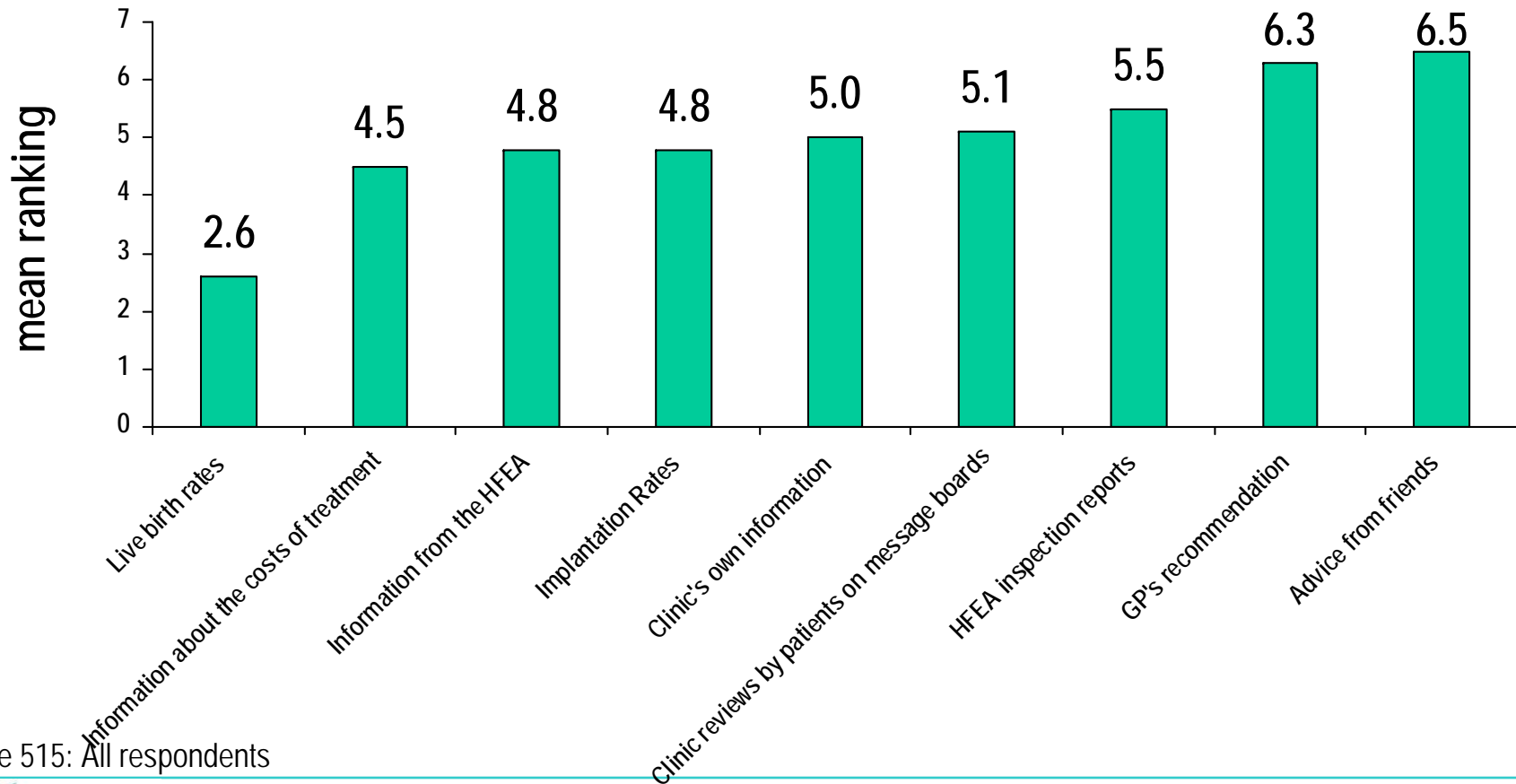
"In facing infertility treatment I need to accept that I may need several rounds and therefore the cost of all of those rounds needs to be considered. Success rates are key to me as I need to have something to rationalise what we are doing."

"After 5 failed IVF cycles , it's a LOT of money that we are paying out time after time, and there is also a strain on our marriage with the costs , what every normal person gets naturally and most of all for FREE, I have to pay for and my infertility is not my fault. It was from an operation i had when i was 13 years old that blocked both my tubes"

Key findings (3)

- Live birth rates are the most valued information when deciding where to go for treatment (45% rated it top)
- Fertility Friends is by far the most commonly visited fertility website with around two thirds having visited it (63%)
- Over half the people currently or considering going through fertility treatment have visited the HFEA website since June (56%)
- Most were quite positive about the site
 - 65% said it was easy to find the information they wanted
 - 57% said the website was well designed in terms of layout and presentation
 - 73% felt the information on the website was the right level of complexity

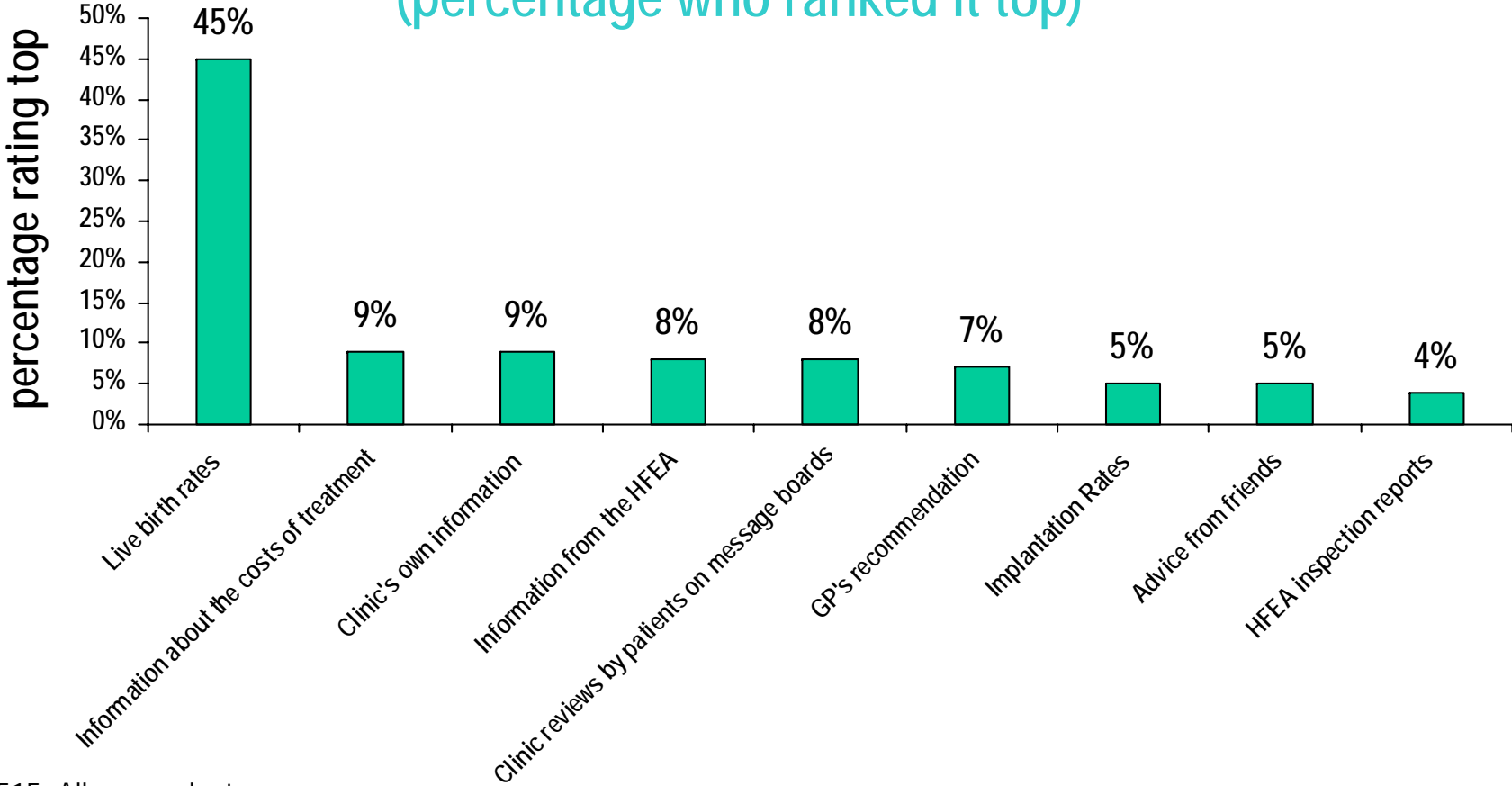
We are interested in finding out what kinds of information about clinics is most valued by patients when deciding where to go for treatment. Please rank them in order of their importance to you with 1 being most important and 9 least important



•Base 515: All respondents



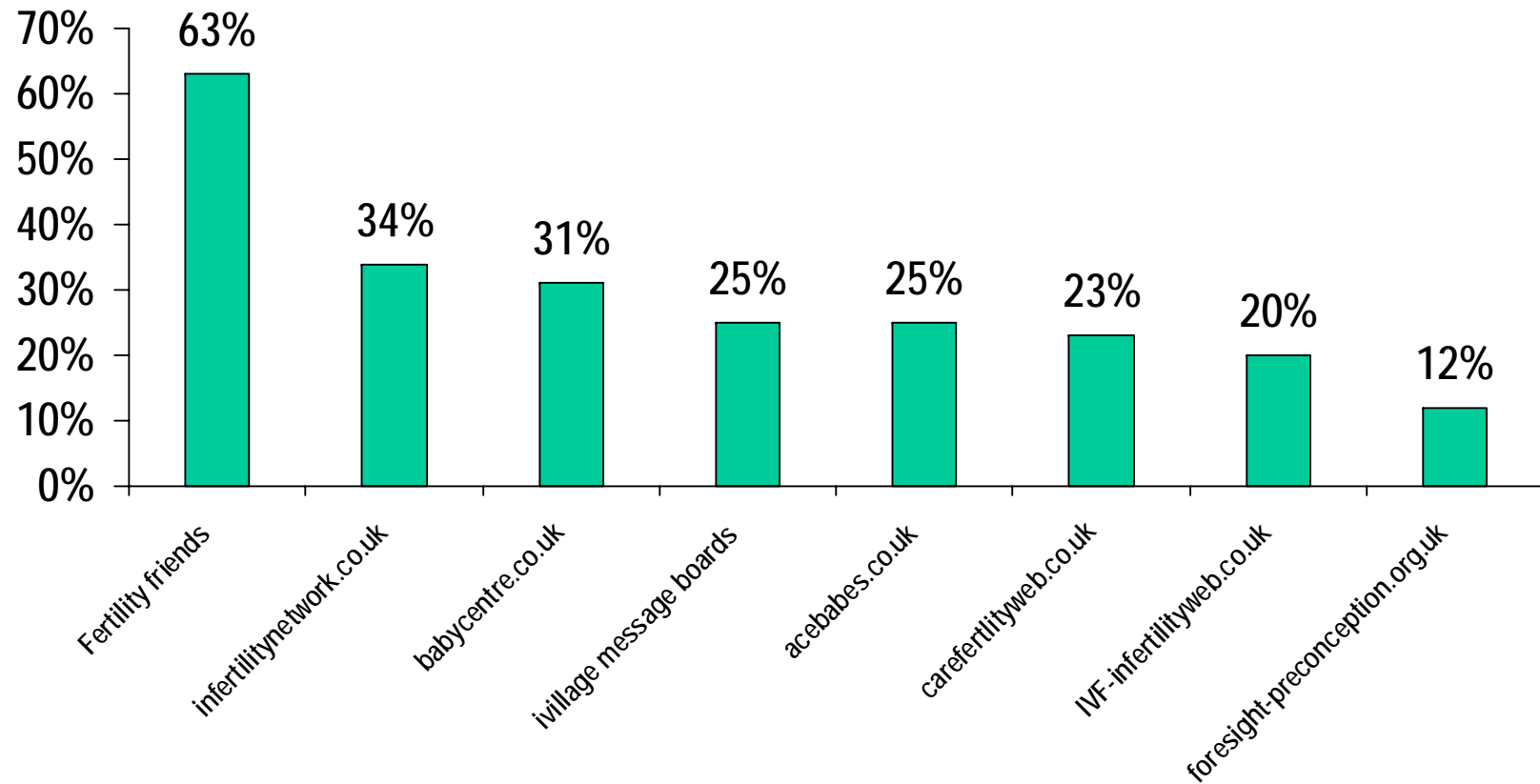
We are interested in finding out what kinds of information about clinics is most valued by patients when deciding where to go for treatment. Please rank them in order of their importance to you (percentage who ranked it top)



•Base 515: All respondents



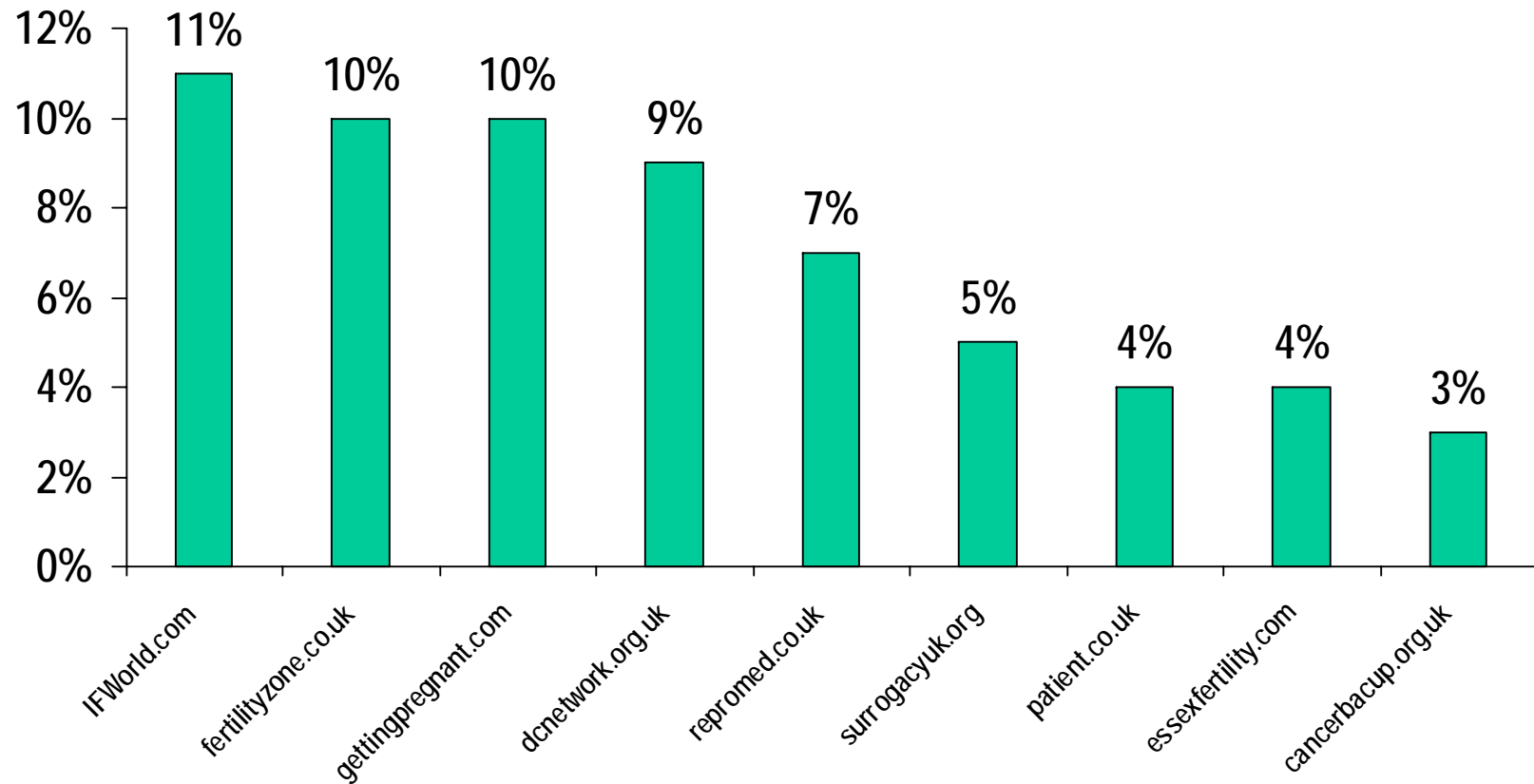
Have you ever visited any of the following websites for support or information? (1)



•Base 515: All respondents



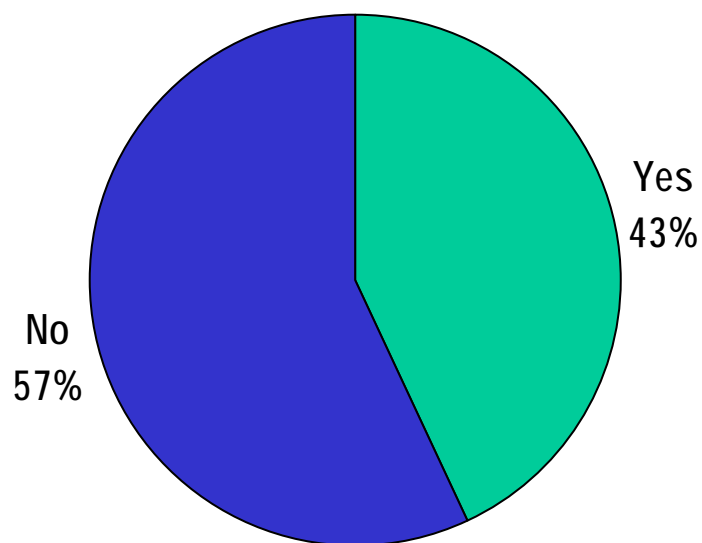
Have you ever visited any of the following websites for support or information? (2)



•Base 515: All respondents



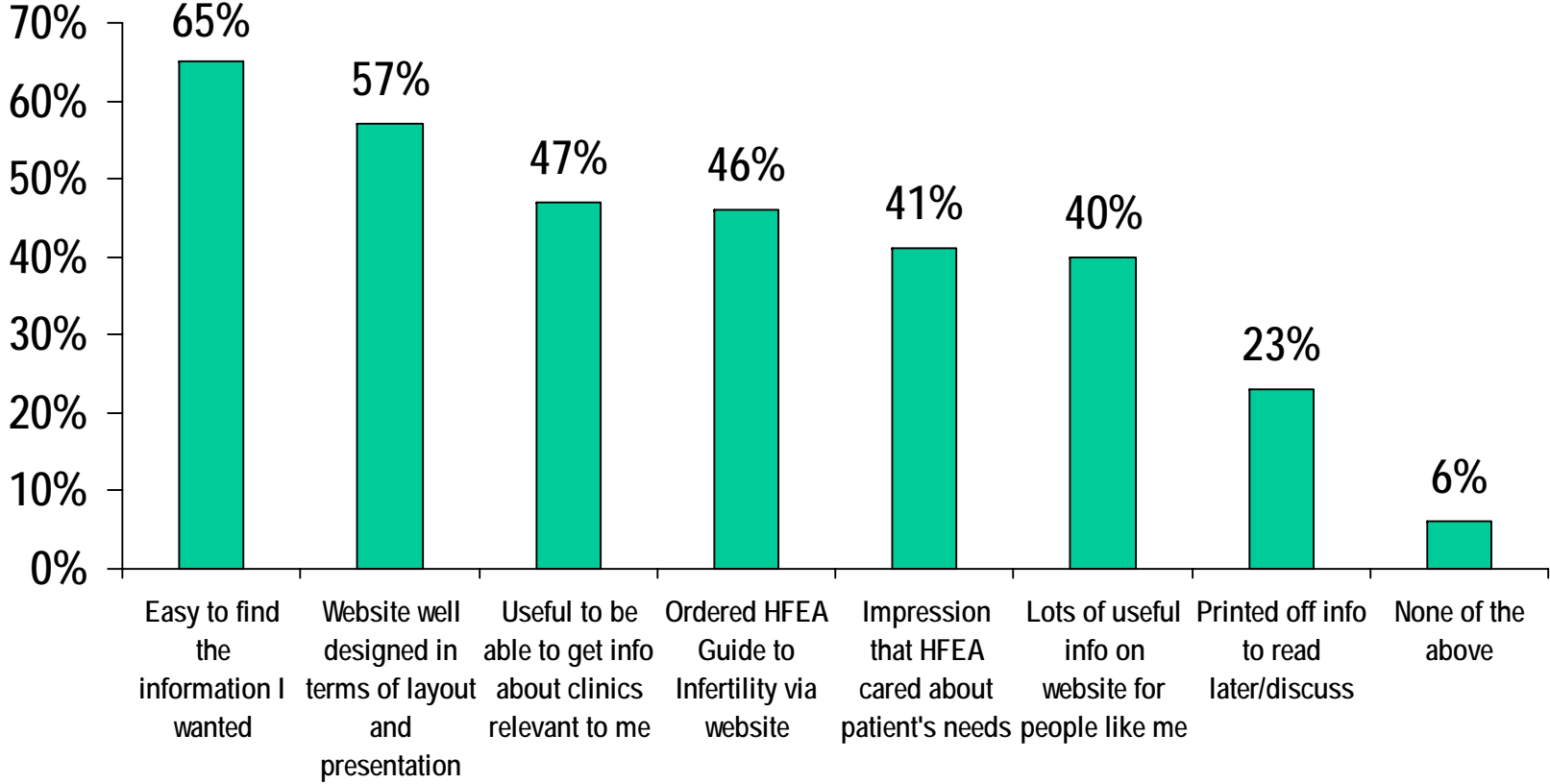
Have you visited the HFEA website since June this year?



60% of those considering having treatment and 55% of those currently having treatment have visited the HFEA site since June this year

- Base 515: All respondents

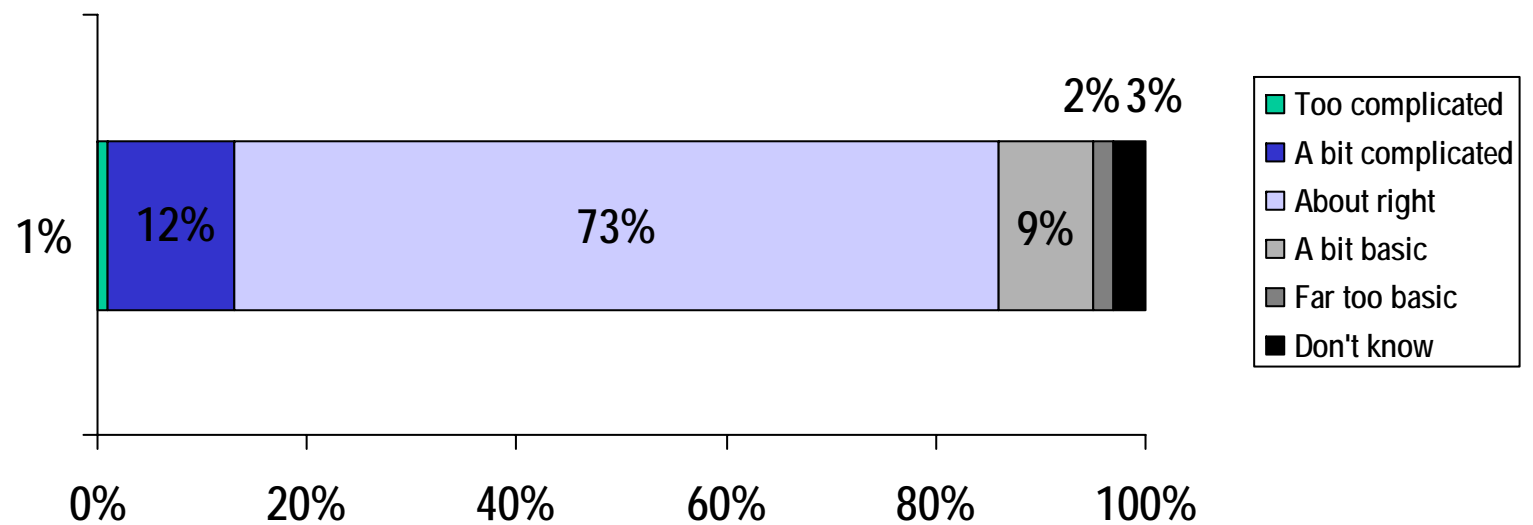
If 'yes', which of the following are true for you?



•Base 222: All respondents who visited the HFEA website since June 06



If 'yes', how would you rate the information provided in terms of its complexity?

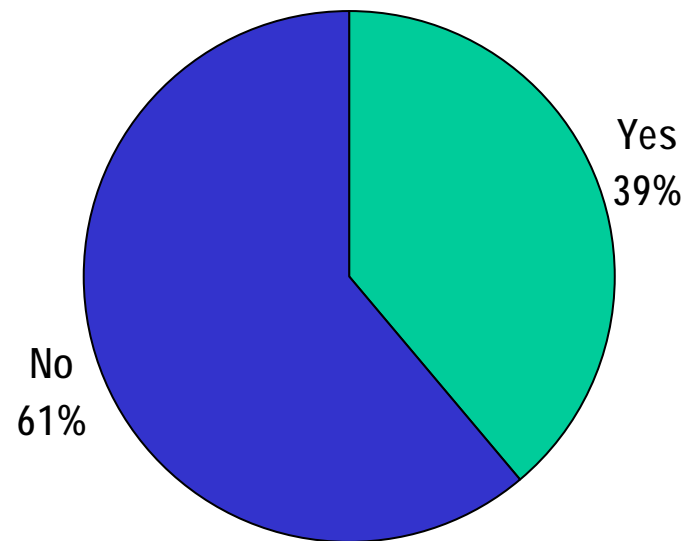


- Base 222: All respondents who visited the HFEA website since June 06

Key findings (4)

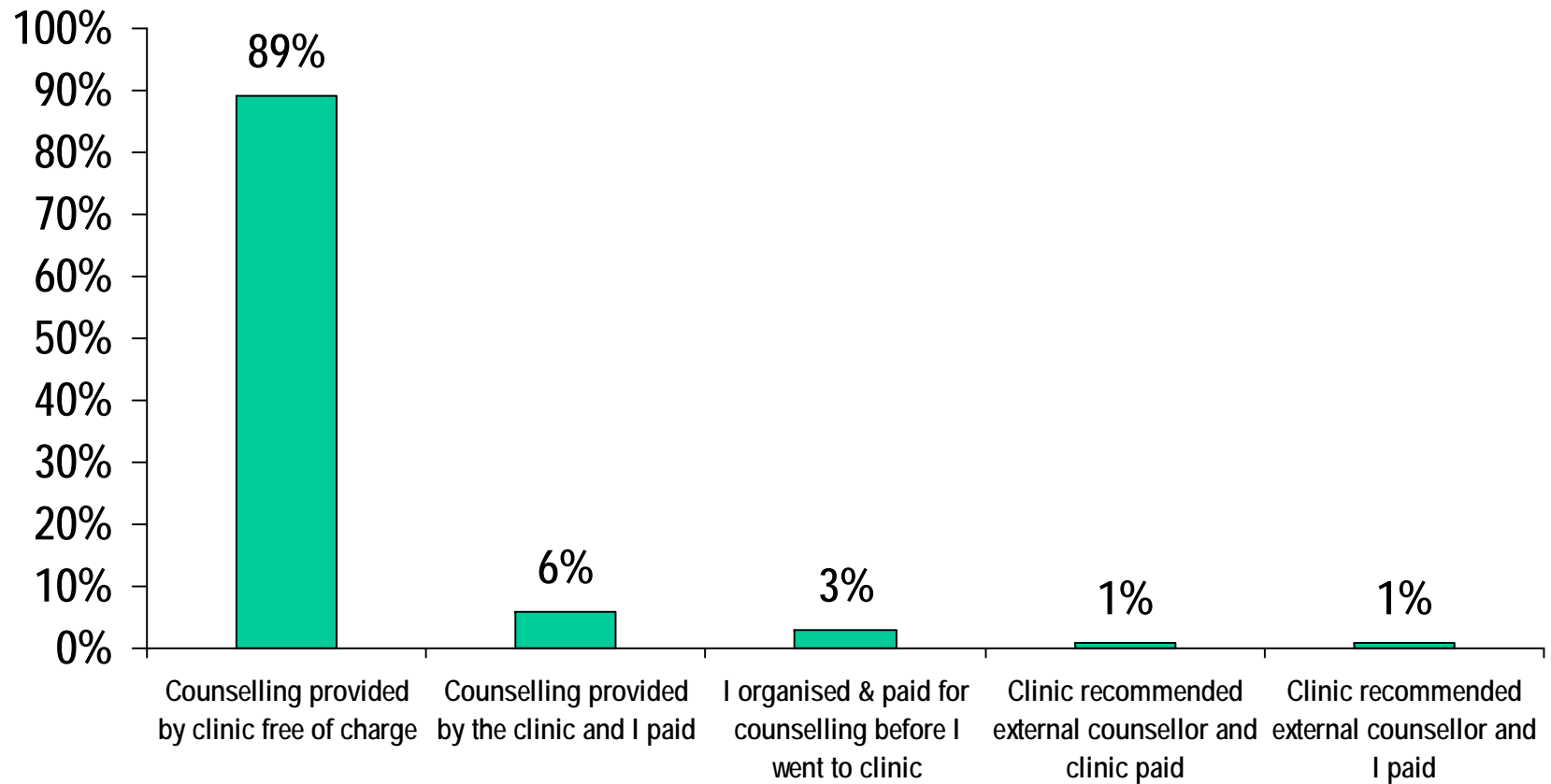
- Over a third (39%) have had counselling
 - An overwhelming majority said the counselling was provided by the clinic and it was free of charge (89%)
 - 1 in 10 paid for their own counselling (10%)
- One third (34%) of the people who had counselling said it was very helpful and they would strongly recommend it to others
 - However, almost half (46%) said that it didn't add much to their experience and 16% said it wasn't worth doing
- Of those that didn't have counselling, 21% said it was because the clinic didn't suggest it
- 42% who didn't have counselling said that with hindsight it might have been helpful or that they wish they'd had the chance to talk to a counsellor

Licensed clinics have to offer patients access to counselling before they begin treatment. Did you have any counselling before, or during, your treatment?



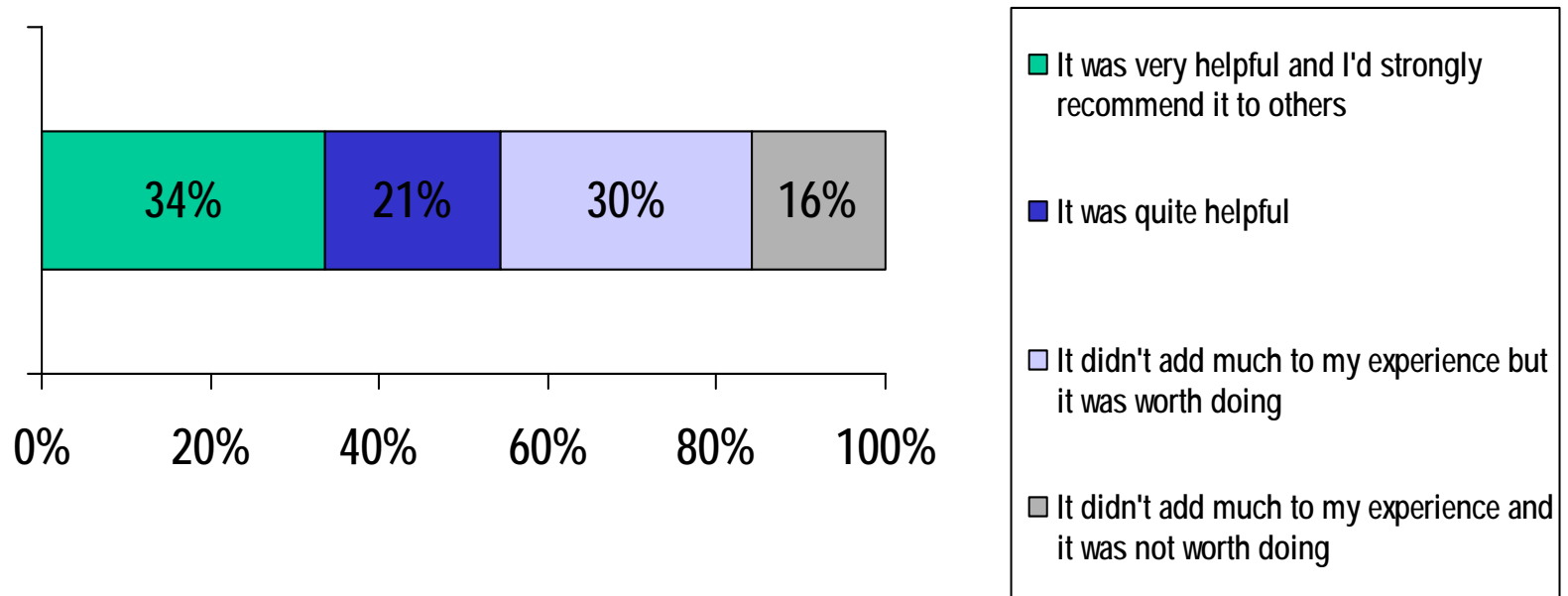
- Base 515: All respondents

If 'yes', which of the following occurred:



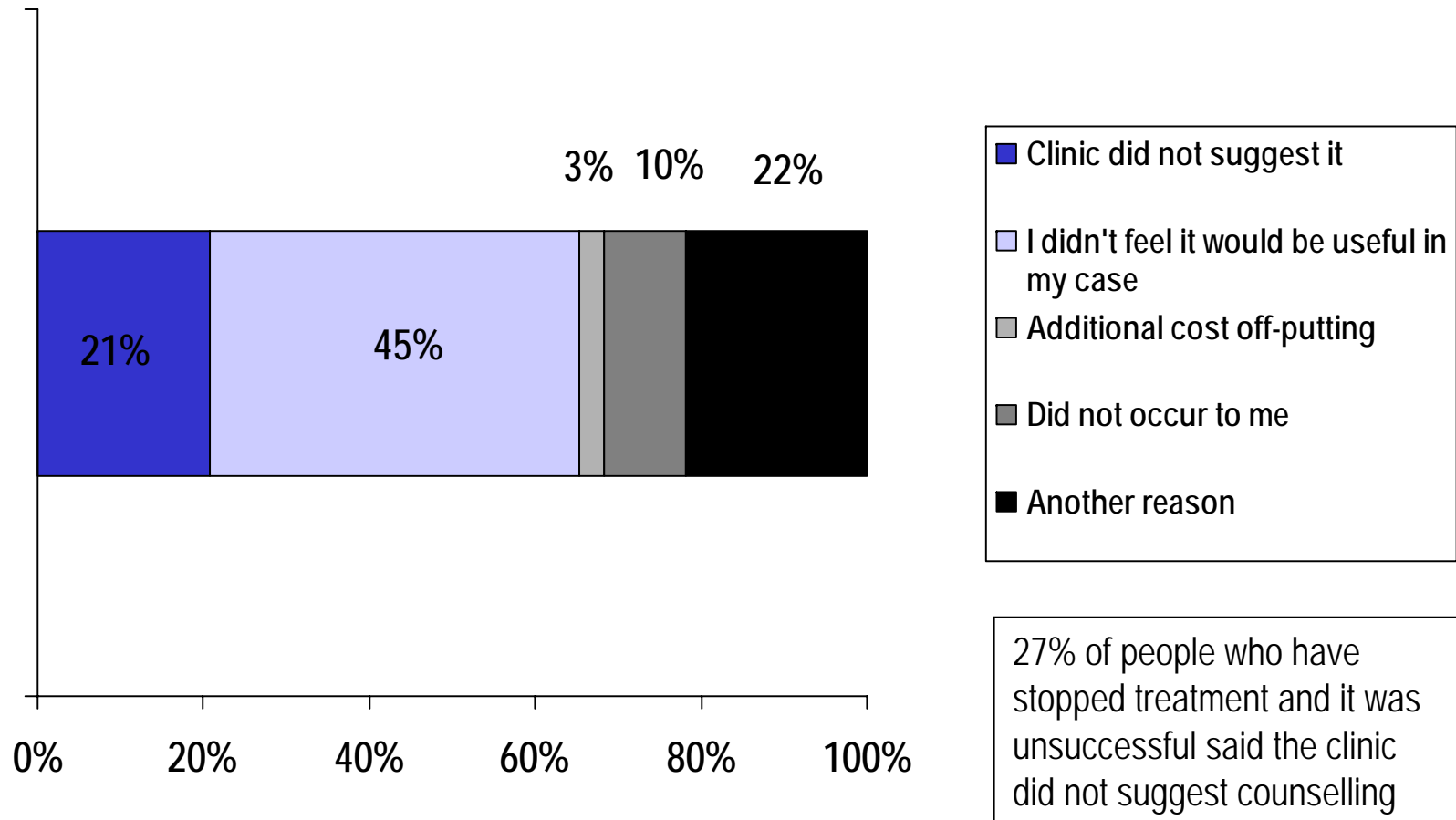
•Base 203: All those who had counselling

If 'yes', would you say that:



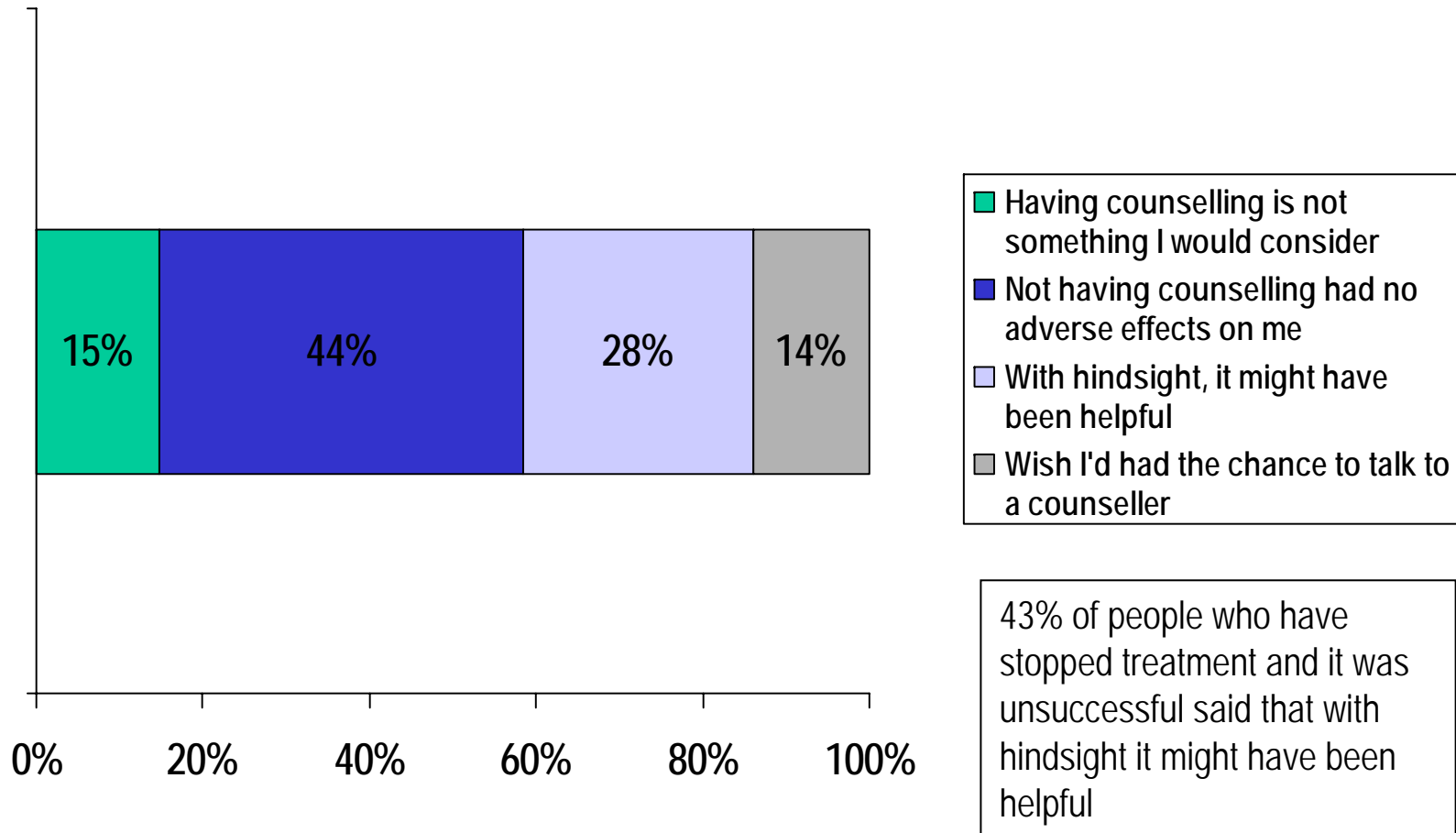
- Base 203: All those who had counselling

If 'no', was that because:



•Base 312: All those who didn't have counselling

If 'no', would you say that:



•Base 312: All those who didn't have counselling

Key findings (5)

- Very few people have encountered problems because of their race, religion, sexuality or disability (NB very small base sizes)
- People who had experienced problems wanted more flexibility, sensitivity and acceptance by clinics
- People said that the HFEA should monitor clinics for discrimination, do patient surveys/research, give guidelines to clinics, promote awareness and give patients route for complaining about these issues

In the course of your fertility treatment, do you feel you ever encountered problems because of:

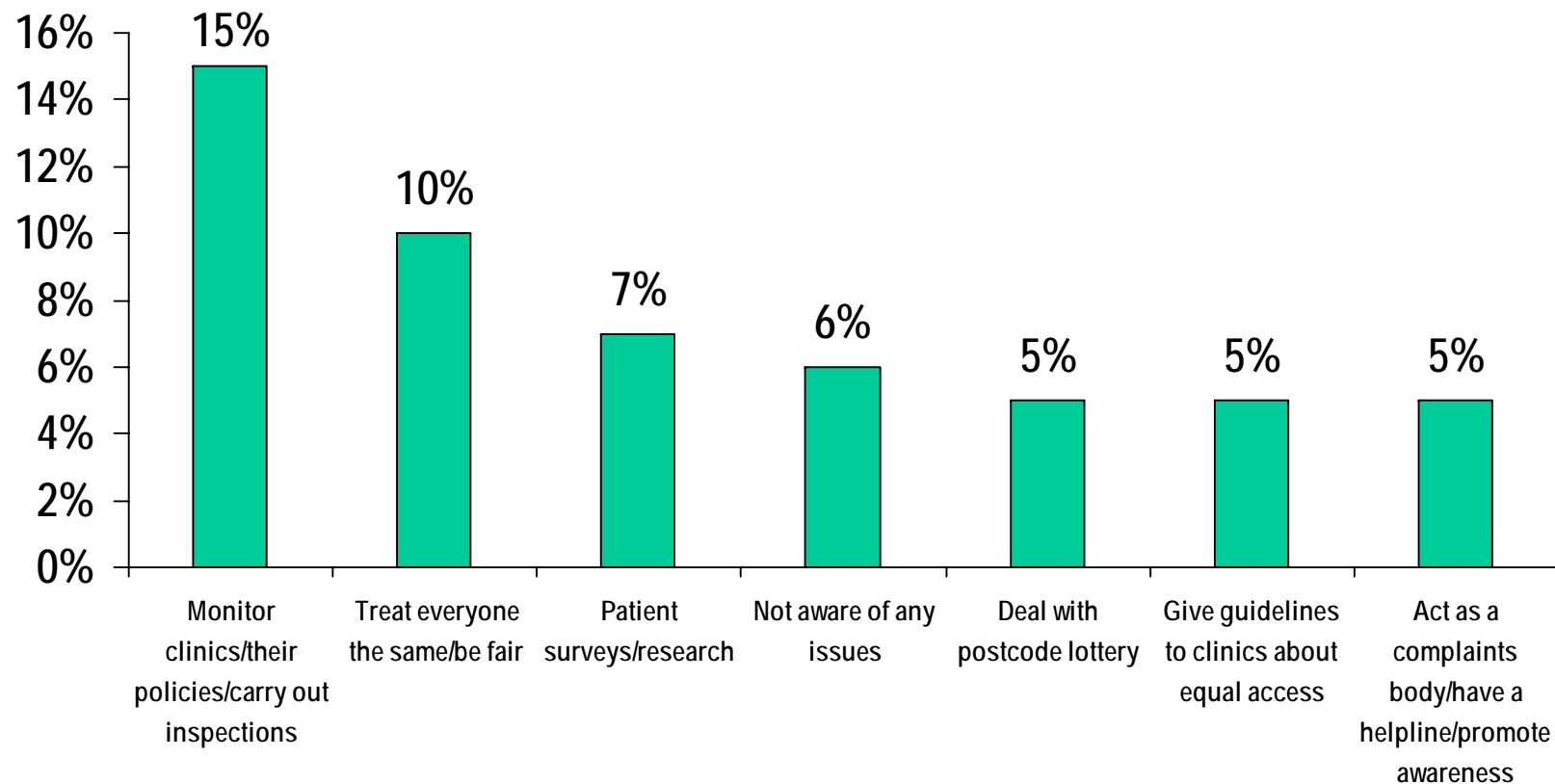
- Your race?
 - 7% of BME respondents said they had encountered problems (this was a very small base size of 29)
- Your religion?
 - 2% of people who say they have a faith or religion said they had encountered problems (base:334). 6 out of the 7 people who encountered problems were of Christian faith
- Your sexuality?
 - 40% of people who are living with a partner of the same sex said they had encountered problems (this was a **very** small base size of 5)
- Your disability?
 - 19% of people with a disability said they had encountered problems (this was a very small base size of 21)

If so, what was the nature of the problem – and what would you have wanted the clinic to do instead?

- People who had experienced problems wanted more flexibility, sensitivity and acceptance by clinics
 - Wanted to be offered treatments other than IVF that fitted with Christian beliefs
 - Wanted to be able to create one embryo at a time due to religious beliefs
 - Wanted more acceptance from the doctor regarding sexuality and single status
 - Wanted clinics to cater for gay men in their donating rooms
 - Wanted more sensitivity from clinic about disability e.g. not easy to access clinic and get appropriate treatments

•Base 24: Those who have had a problem with a clinic due to race, religion, sexuality or disability

What do you think the HFEA, in its role as regulator, should do to ensure patients are treated equally, regardless of race, sexuality, religion or disability?



•Base 515: All respondents

Quotes...

“Ensure that all are treated fairly and investigate and take action where this hasn't happened.”

“Clinics should be made to publish to the HFEA all records of patients they have turned down even at initial enquiry stage, and the reasons given for refusing treatment so that the HFEA can adequately gauge if there is a real problem with discrimination for these reasons. If clinics refuse to treat certain patients as policy (i.e. the ARGC will not treat single women or ladies with high FSH) then this information should be made available on the HFEA clinic site.”

“Monitor clinic's policies for who they will agree to treat. Ask them to provide a statement and clear information about this. Help patients to register complaints if they are discriminated against.”

“Ensure that all clinics have adequate policies in place and that they are actually followed.”

•Base 515: All respondents



Conclusions and recommendations (1)

- It is important for more clinics to give people a figure for how likely they are to have a baby, as this influences many people's decisions on paying for treatment and which clinic they might choose
 - Currently only two thirds say they were given this figure
- If the predicted success rate is 25% almost all respondents say they would pay for treatment. If the figure is under 5% almost 1 in 4 would still go ahead and pay for treatment
- Because of this weighing up process, success rates and the actual cost of treatment are the most important issues currently facing people
- Live birth rates is by far the most important information when deciding where to go for treatment, however some primarily go to a clinic near to where they work/live. It is important that this information is made accessible

Conclusions and recommendations (2)

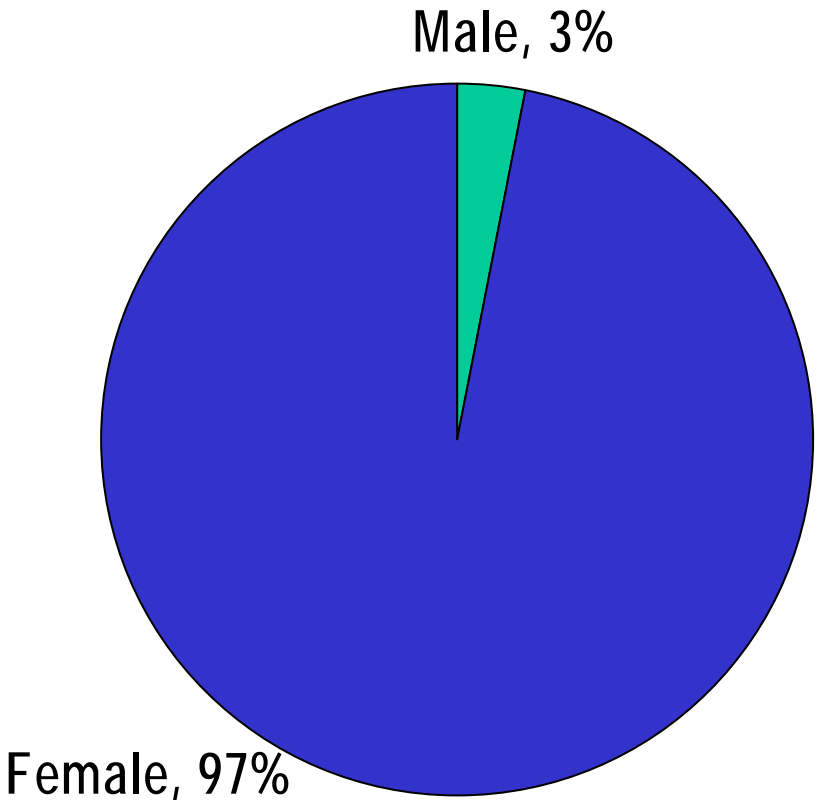
- 3 in 5 people considering treatment have visited the HFEA website in the last 6 months
- It is viewed quite positively in terms of the level of complexity of information
 - However, a third did **not** say the information was easy to find and over a third did **not** say they thought the site was well designed so there could be some improvements in these areas
- People use multiple sources of information and support online. The most popular site is fertility friends with almost two thirds of respondents having visited this website
 - HFEA guide to infertility is already available through fertility friends and there is a link to the HFEA website [here](#)
 - The HFEA, and the information it provides, could be more present on other popular websites

Conclusions and recommendations (3)

- 2 in 5 people had counselling, mostly provided free of charge by the clinic, with mixed feelings
 - Most people who had counselling said it was helpful but almost half said that it didn't add much, showing that perhaps some improvements could be made to the service. More research could be done on what makes a positive experience
- There are still a number of people who are not suggested counselling
 - This is perhaps particularly concerning for people who have had treatment and it was unsuccessful. It is important that counselling is suggested to everyone
- There appears to be few problems encountered with discrimination in most areas although more research should be carried out on this due to small base sizes

Appendix – profile questions

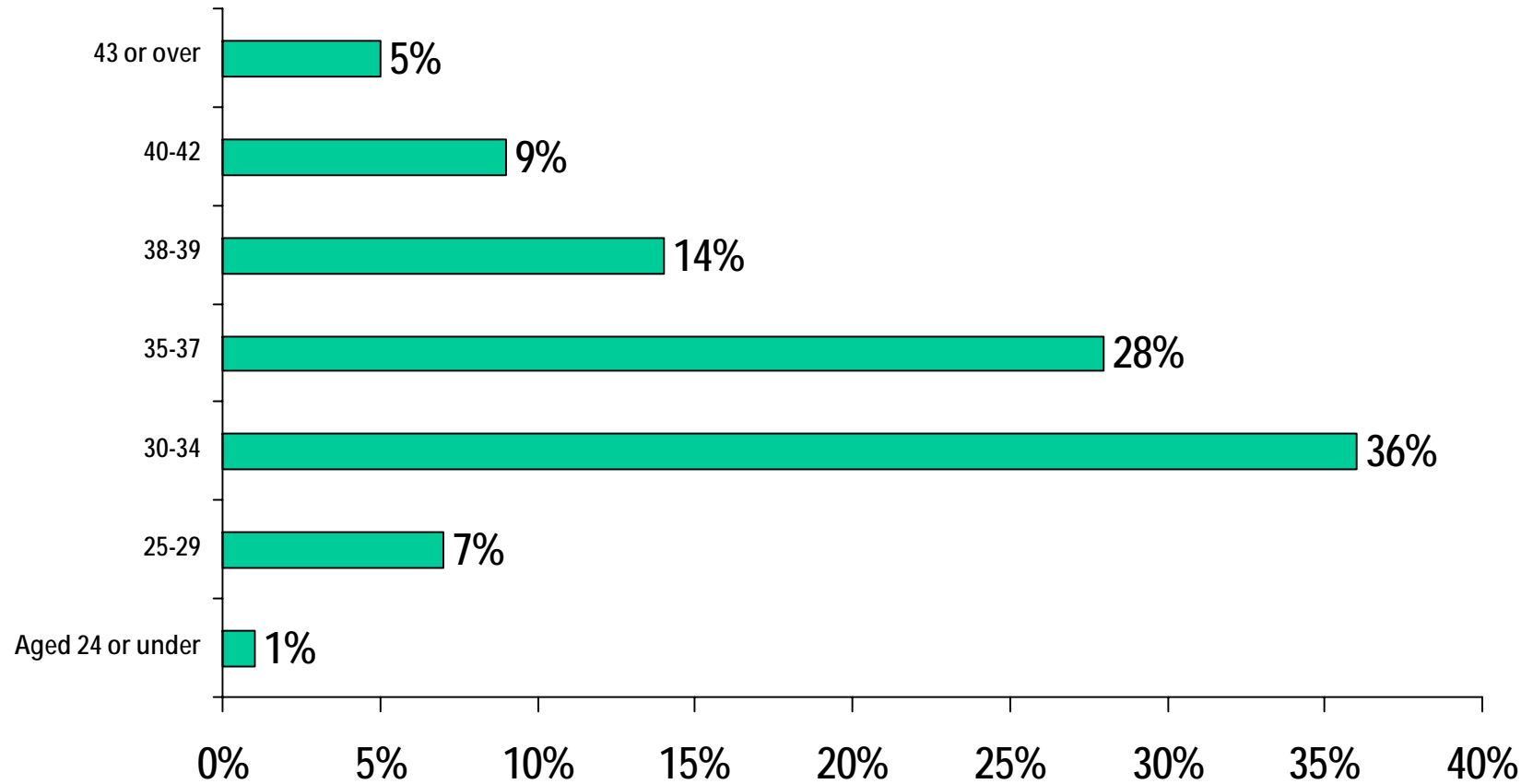
Gender



Base 515 All respondents



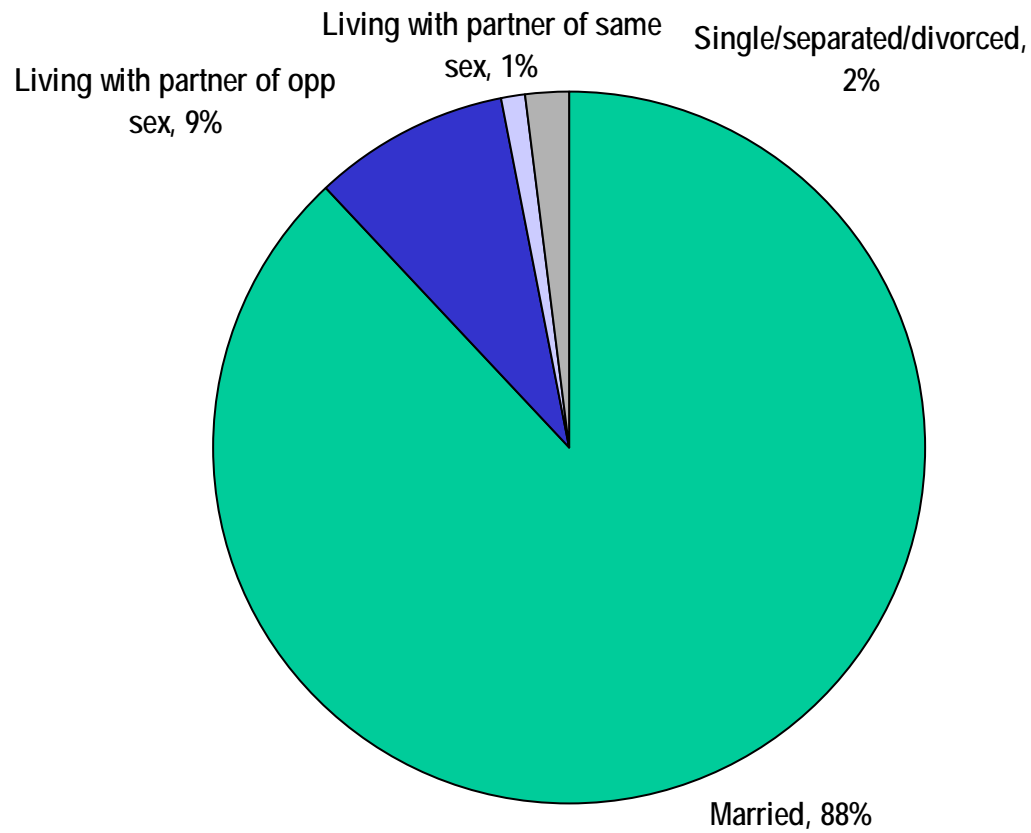
Age



•Base 515 All respondents



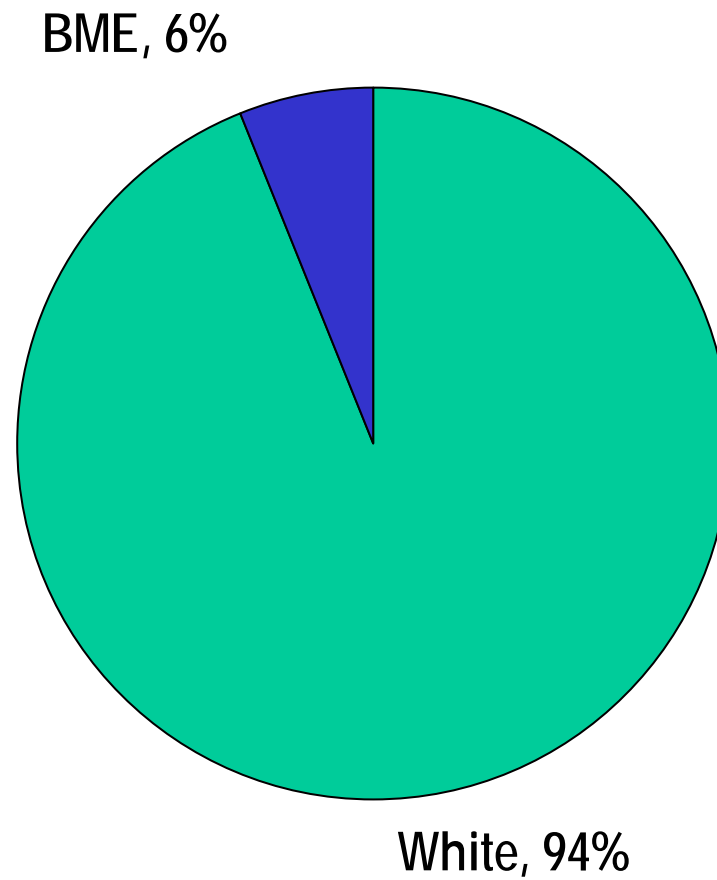
Marital Status



Base 515 All respondents

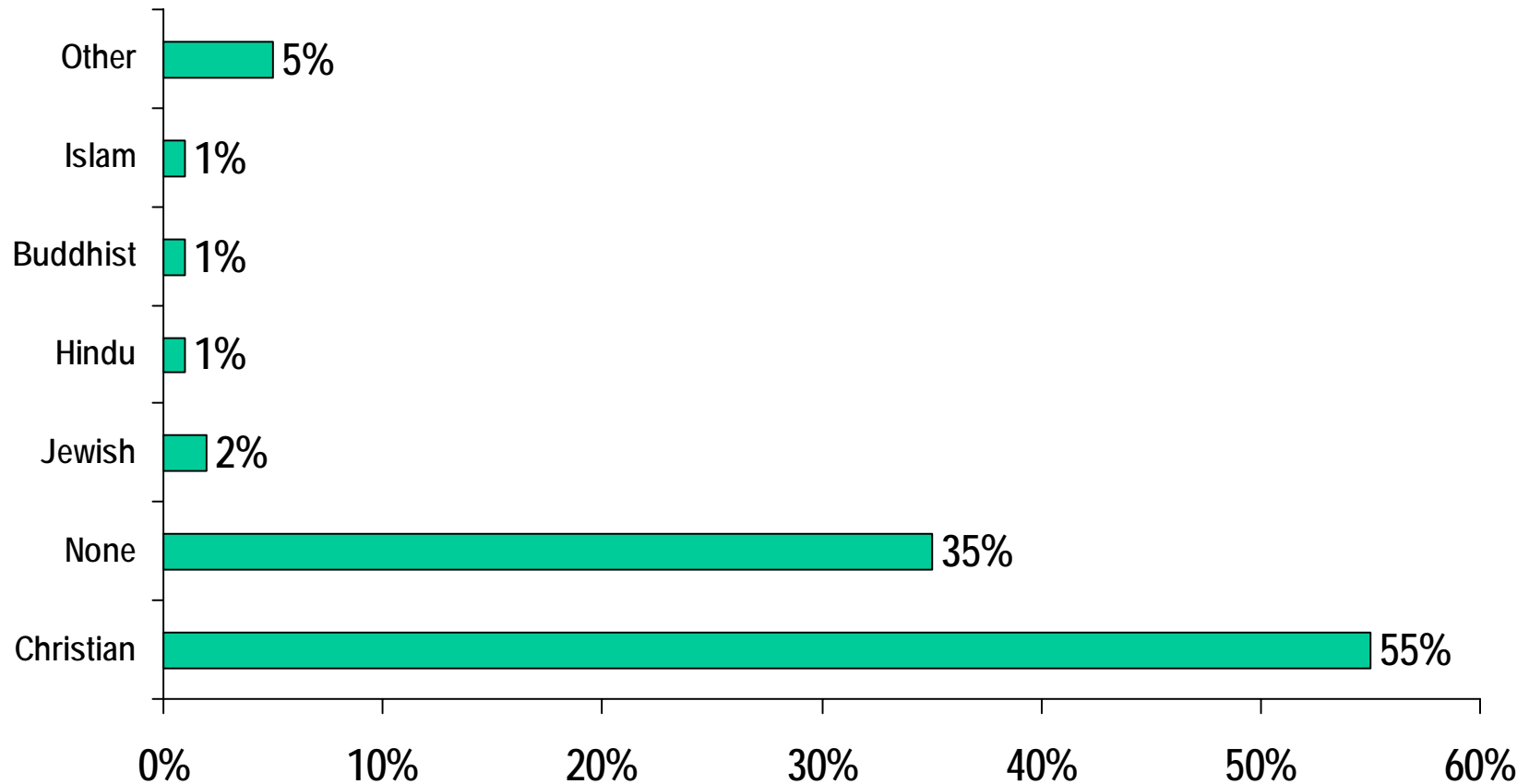


Ethnicity



Base 515 All respondents

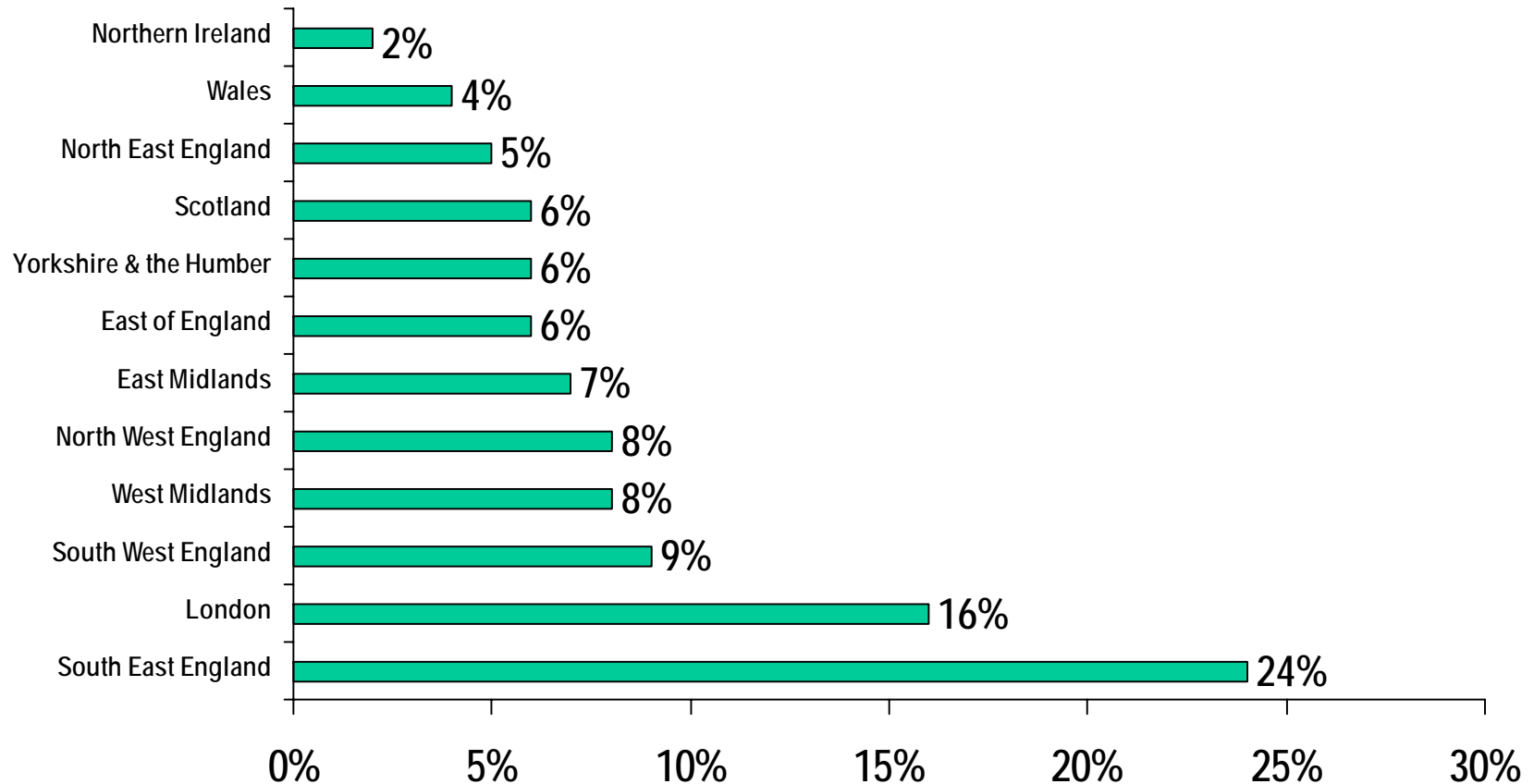
What, if any, would you describe as your faith or religion?



•Base 515 All respondents



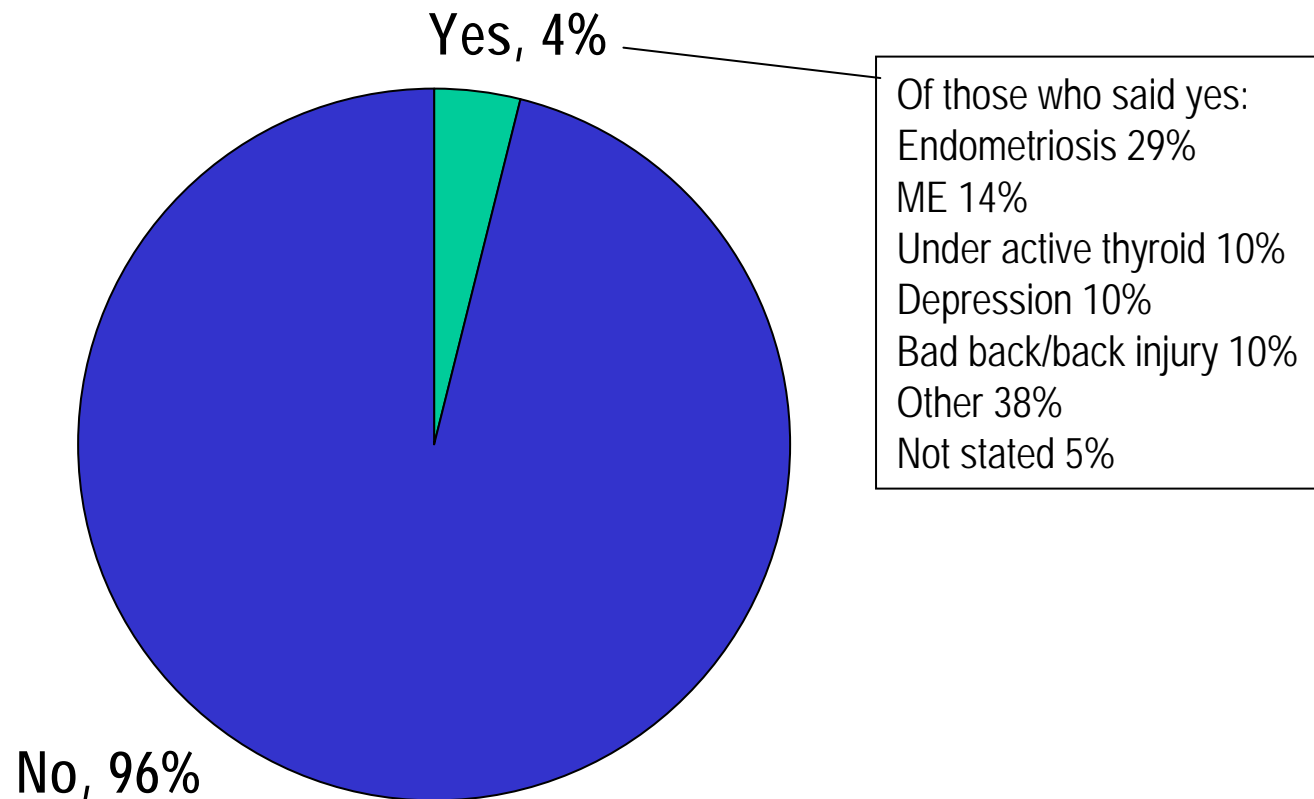
Which of the following UK regions best describes where you live?



•Base 515 All respondents



Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?



Base 515 All respondents