



Clinical trial awareness and participation

Survey research results

January 2023

PAN Foundation

What is a clinical trial?

According to clinicaltrials.org, **clinical trials** are research studies performed on people aimed at evaluating a medical, surgical, or behavioral intervention. They are the primary way that researchers determine if a new treatment, drug, diet, or medical device is safe and effective in people.

- **Observational studies** observe people in normal settings. Researchers gather information, group volunteers according to broad characteristics, and compare changes over time.
- **Interventional clinical trials** are a type of clinical study in which participants are assigned to groups that receive one or more interventions or treatments (or no intervention) so that researchers can evaluate the effects of the interventions on biomedical or health-related outcomes.

Key findings

- 1. A majority of adults with chronic illnesses are interested in participating in clinical trials and see value in participation.** Three-fourths (75%) of adults with chronic illnesses say they are interested in finding more information on participating in clinical trials, especially Black and Hispanic adults. *(see slides 11-12)*
- 2. However, many adults with chronic illnesses face obstacles to learning about clinical trials.** Nearly 40% of adults with chronic illnesses who have looked for information about clinical trials said they did not know where to look for information or who to speak with. *(see slides 15-16)*
- 3. One of the largest barriers to participating in clinical trials is a lack of information.** A majority of adults with chronic illnesses who have not participated in clinical trials before report that they don't know what trials they are eligible for (58%) or how to apply (49%). *(see slide 27)*
- 4. While most adults with chronic illnesses trust their doctors to share information about clinical trials, few have discussed them.** Only 22% of adults with chronic illnesses have discussed the option of participating in a clinical trial with a healthcare professional. *(see slide 19)*

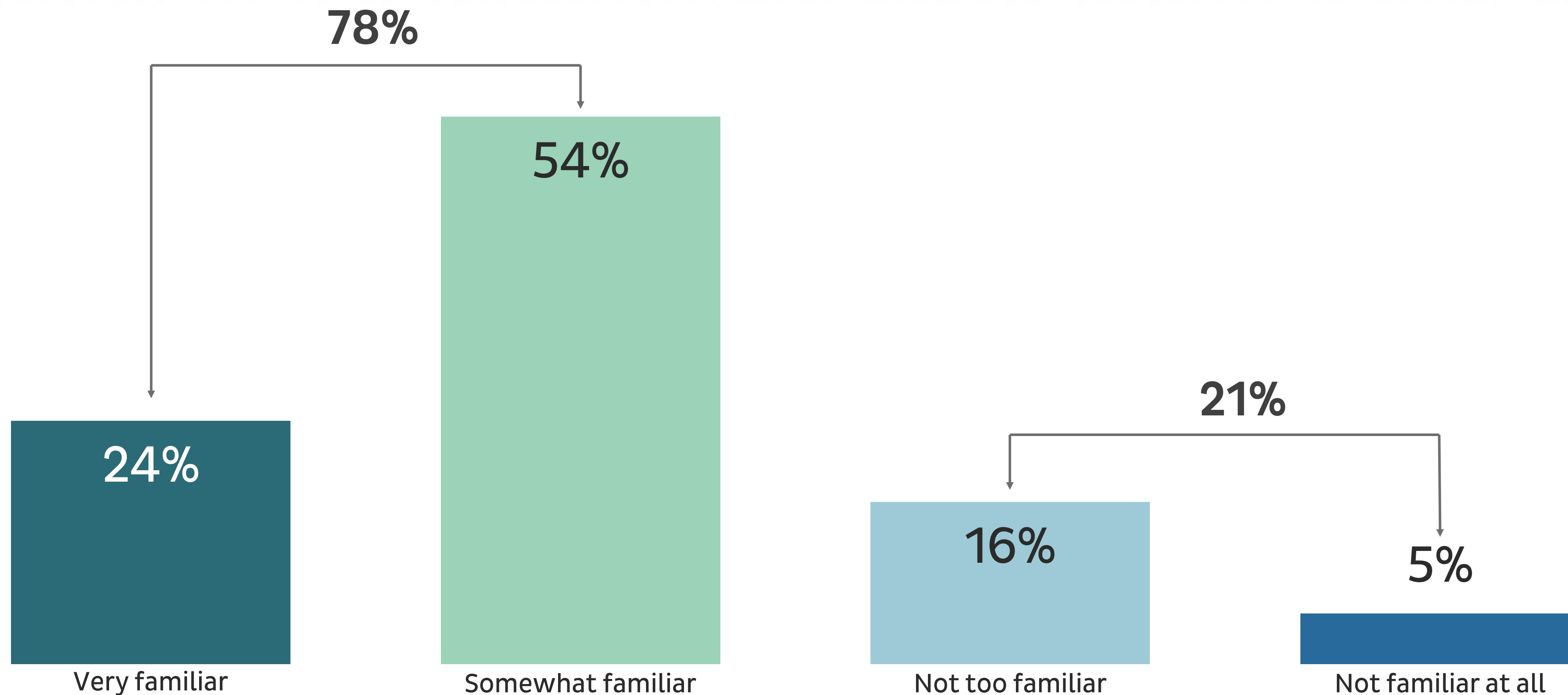
The following audiences are examined throughout this analysis:

| Audience | Sample Size | Margin of Error (+/-) |
|---------------------------------|-------------|-----------------------|
| Adults with Chronic Illnesses | 1,503 | 3% |
| Gender: Male | 697 | 4% |
| Gender: Female | 806 | 3% |
| Age: 18-34 | 278 | 6% |
| Age: 35-44 | 203 | 7% |
| Age: 45-64 | 547 | 4% |
| Age: 65+ | 475 | 4% |
| Ethnicity: White (Non-Hispanic) | 1,126 | 3% |
| Ethnicity: Hispanic | 138 | 8% |
| Ethnicity: Black (Non-Hispanic) | 165 | 8% |
| Ethnicity: Other (Non-Hispanic) | 74 | 11% |

Awareness of clinical trials

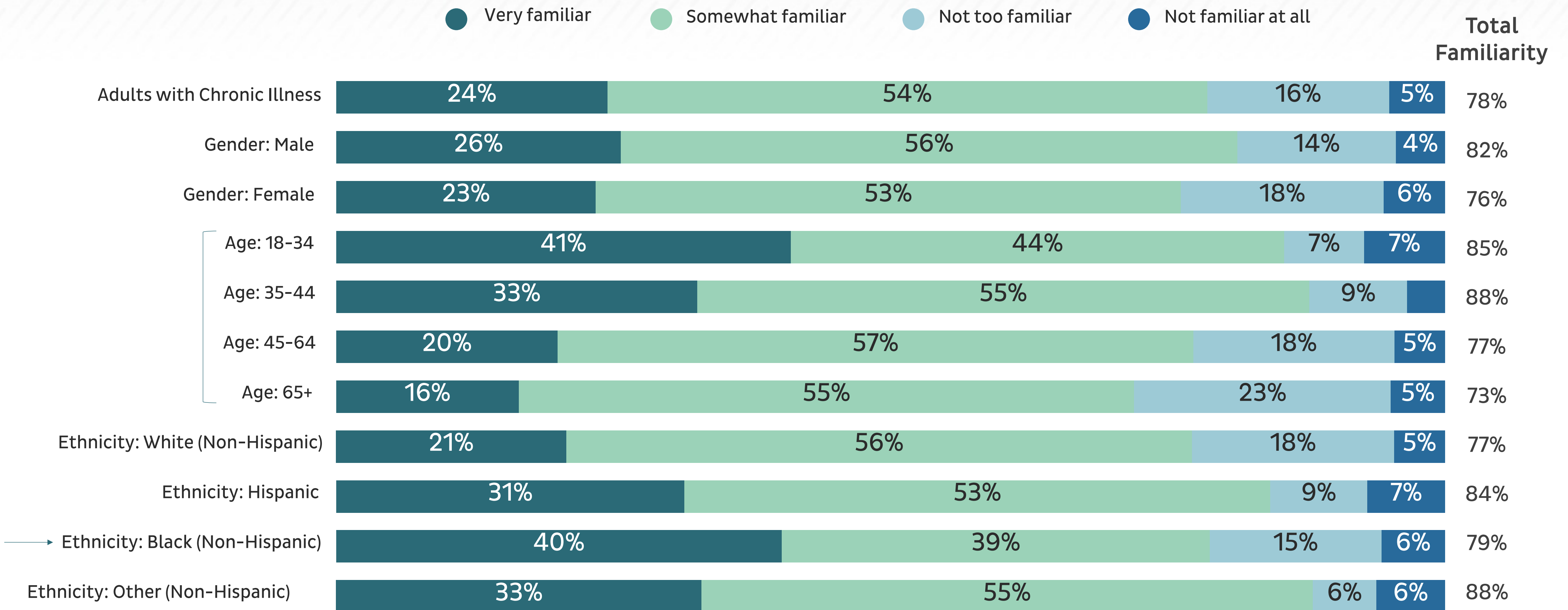
About four-in-five (78%) adults with chronic illnesses say they are familiar with the general purpose and overall process of clinical trials, including 24% who say they are very familiar.

How familiar are you, if at all, with the general purpose and overall process of clinical trials?



Adults with chronic illnesses below the age of 45 are more likely than those above those ages 45+ to say they are very familiar with the general purpose and overall process of clinical trials.

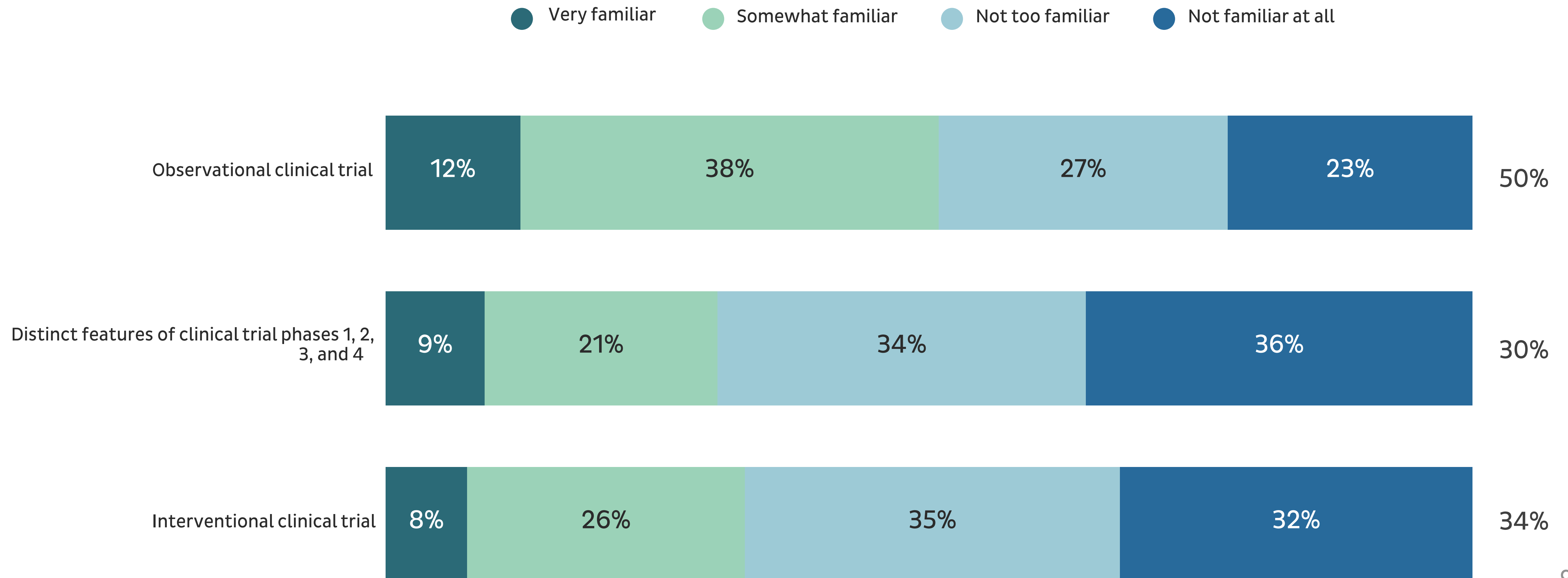
How familiar are you, if at all, with the general purpose and overall process of clinical trials?



Additionally, four-in-ten Black adults with chronic illnesses say they are very familiar with the general purpose and overall process of clinical trials.

Half (50%) of adults with chronic illnesses say they are familiar with observational clinical trials.

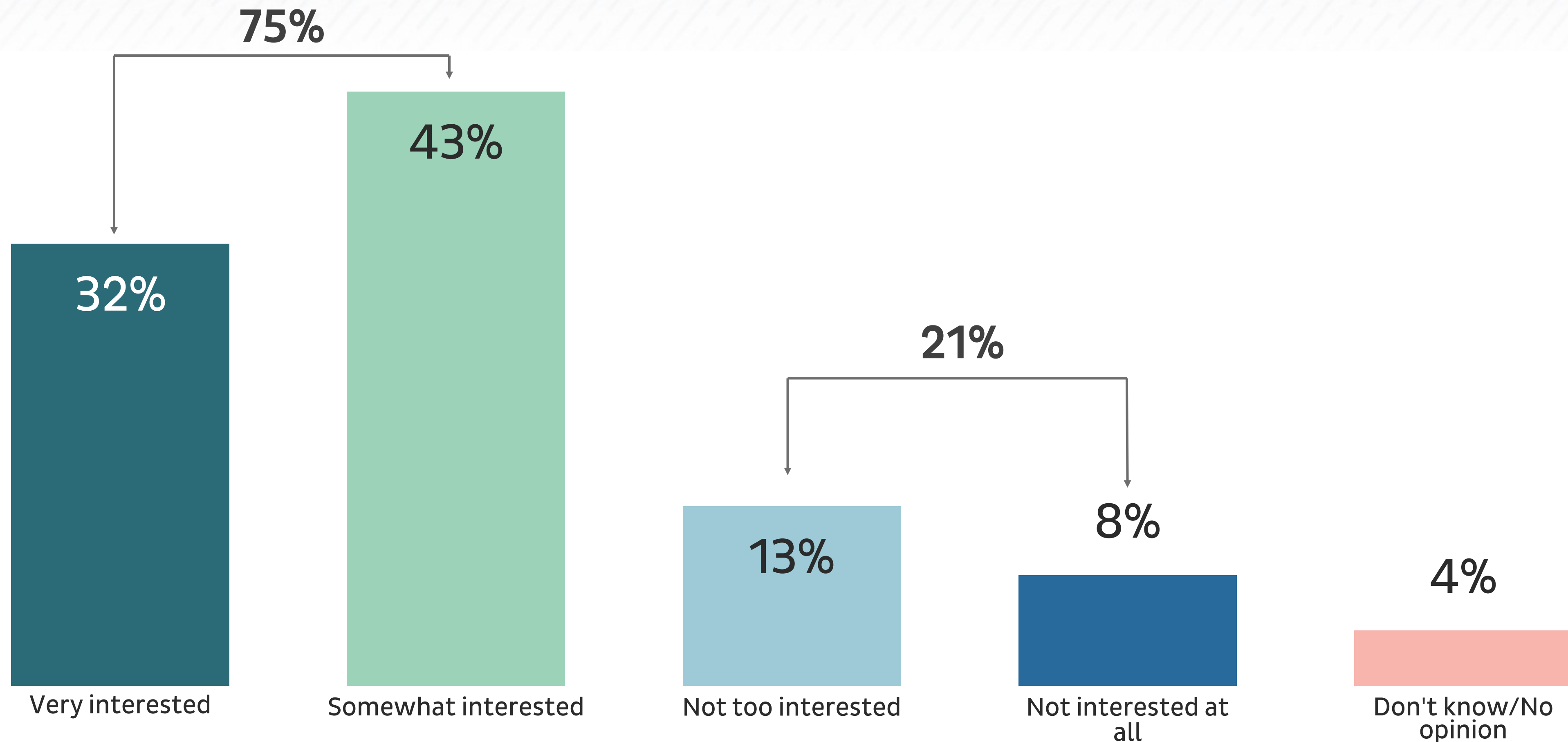
As you may know, a clinical trial is a type of research study that examines new tests and treatments and evaluates their effects on human outcomes. People volunteer to take part in clinical trials to find out if a new treatment, such as a drug or medical device, is safe and effective in people. How familiar are you, if at all with each of the following features and types of clinical trials?



Access to information on clinical trials

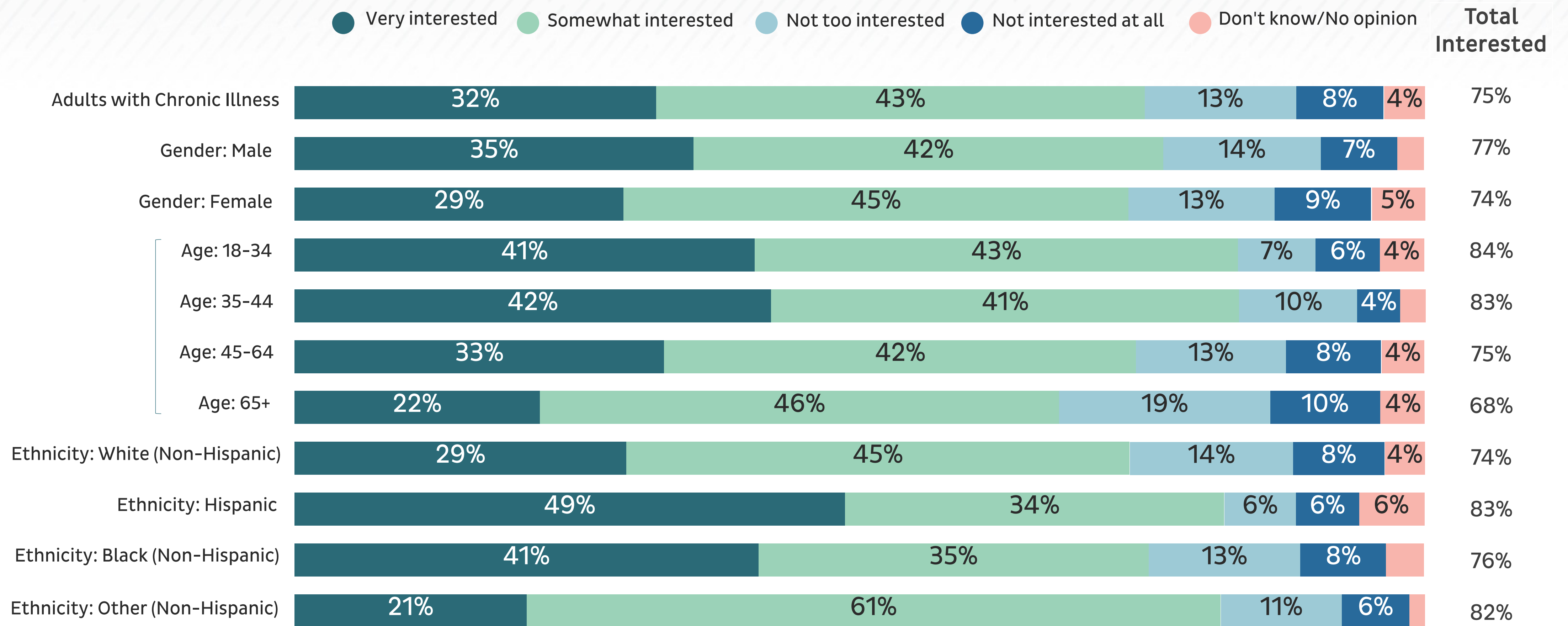
Three-in-four (75%) adults with chronic illnesses say they are interested in finding more information on participating in clinical trials, including 32% who say they are *very interested*.

How interested are you, if at all, in finding more information on participating in clinical trials?



Among adults with chronic illnesses, adults below the age of 45, Black adults and Hispanic adults are especially likely to say they are very interested in finding more information about clinical trials.

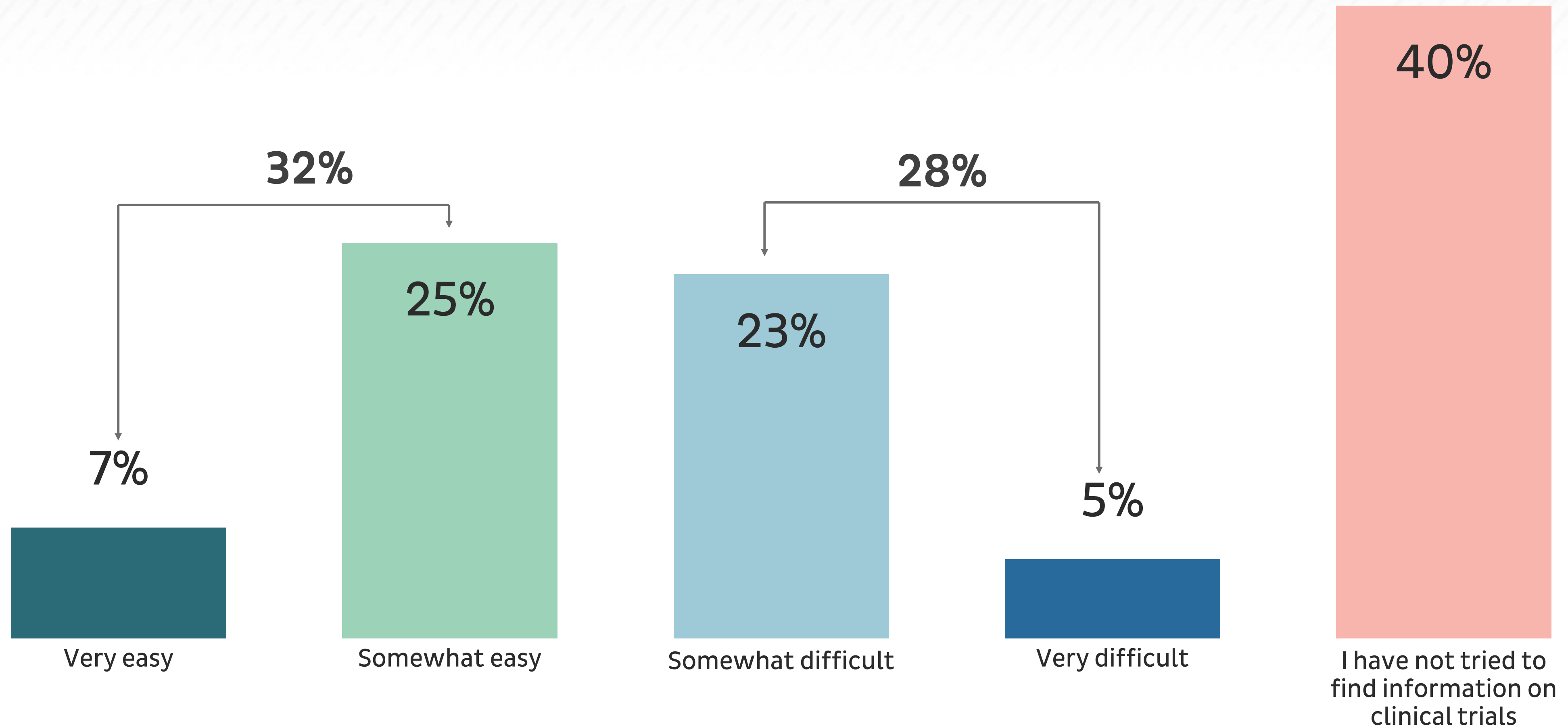
How interested are you, if at all, in finding more information on participating in clinical trials?



Black (41%) and Hispanic (49%) adults with chronic illnesses are more likely than white (29%) adults and adults of other ethnicities (21%) to say they are very interested in finding more information on participating in clinical trials.

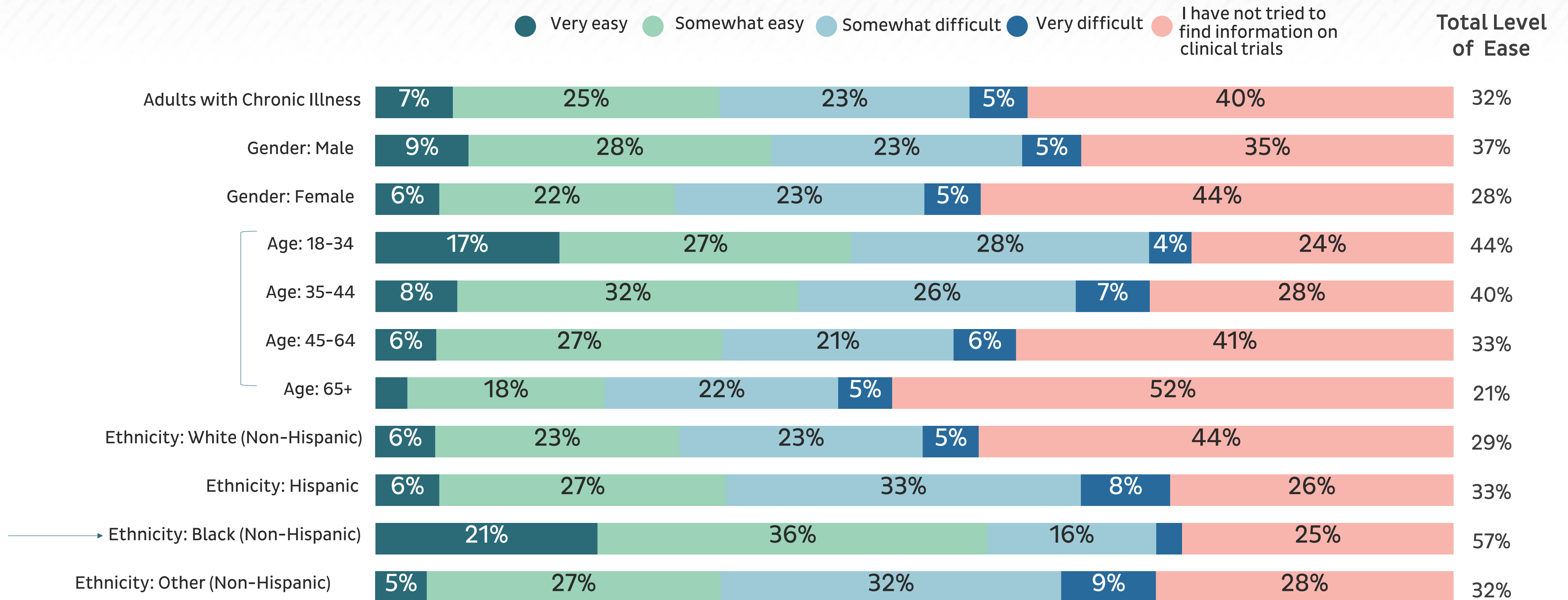
Four-in-ten adults (40%) with chronic illnesses have not tried to find information on clinical trials in the past. The adults who have sought out information are divided on whether it is easy (32%) or difficult (28%) to find information.

In your opinion, how easy or difficult is it for you to find information on clinical trials? If you have not tried to find information in the past, please indicate that below.



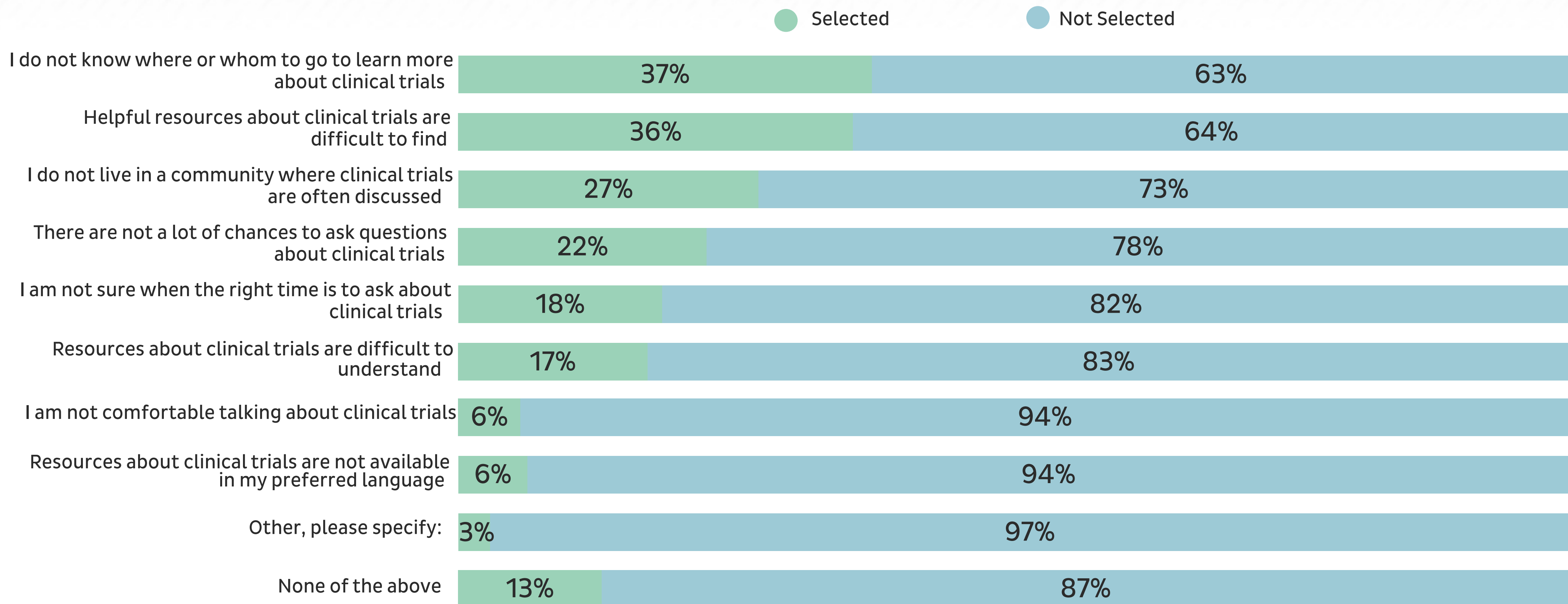
Among adults with chronic illnesses, those below the age of 45 are more likely than those ages 45+ to say it is easy to find information on clinical trials.

In your opinion, how easy or difficult is it for you to find information on clinical trials? If you have not tried to find information in the past, please indicate that below.



Adults with chronic illnesses who have looked for information on clinical trials before say not knowing where or whom to go to learn more (37%) and helpful resources being difficult to find (36%) are barriers to learning more about clinical trials.

As a reminder, a clinical trial is a type of research study that examines new tests and treatments and evaluates their effects on human outcomes. People volunteer to take part in clinical trials to find out if a new treatment, such as a drug or medical device, is safe and effective in people. In your opinion, which of the following if any, are barriers to learning more about clinical trials? Please select all that apply.



Across income levels, ethnicities, and age groups, adults with chronic illnesses say they do not know where or whom to go to learn more about clinical trials and that helpful resources about clinical trials are difficult to find.

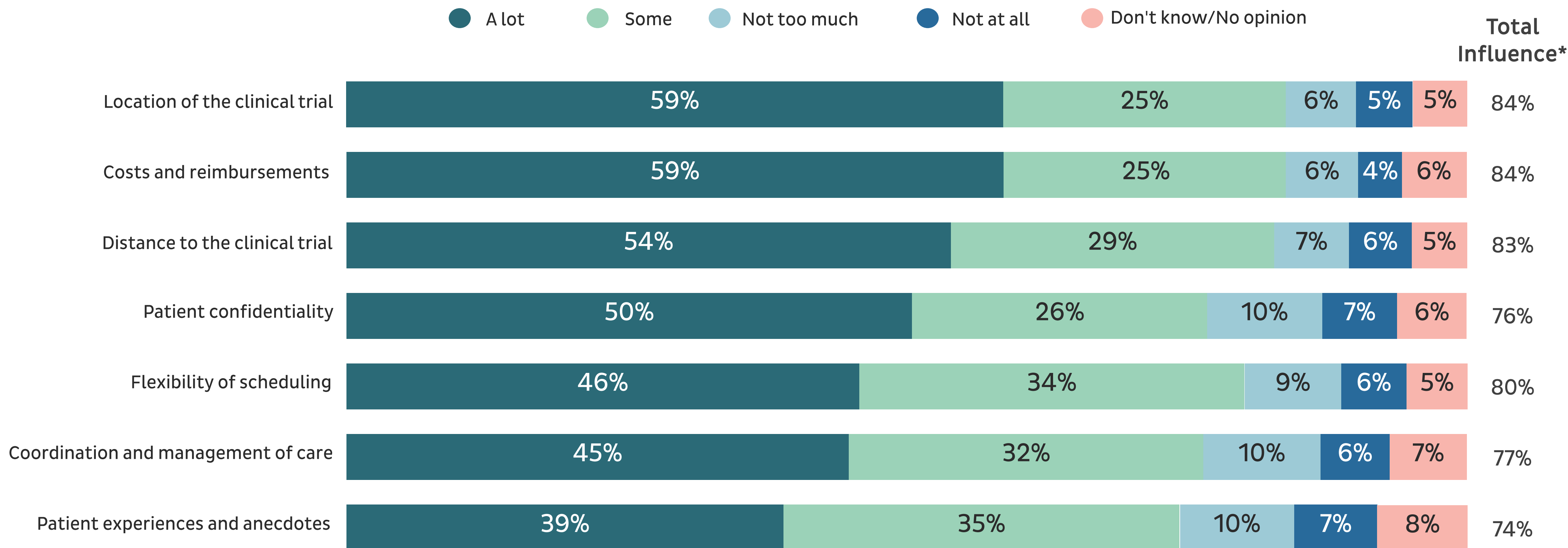
As a reminder, a clinical trial is a type of research study that examines new tests and treatments and evaluates their effects on human outcomes. People volunteer to take part in clinical trials to find out if a new treatment, such as a drug or medical device, is safe and effective in people. In your opinion, which of the following if any, are barriers to learning more about clinical trials? Please select all that apply.

| % SELECTED | Adults with Chronic Illness | Income: Under 50k | Income: 50k-100k | Income: 100k+ | Ethnicity: White (NH) | Ethnicity: Hispanic | Ethnicity: Black (NH) | Ethnicity: Other (NH) | Age: 18-34 | Age: 35-44 | Age: 45-64 | Age: 65+ |
|--|-----------------------------|-------------------|------------------|---------------|-----------------------|---------------------|-----------------------|-----------------------|------------|------------|------------|----------|
| I am not sure when the right time is to ask about clinical trials | 18% | 20% | 18% | 13% | 19% | 18% | 19% | 17% | 22% | 20% | 17% | 15% |
| I do not know where or whom to go to learn more about clinical trials | 37% | 35% | 41% | 36% | 40% | 31% | 29% | 33% | 29% | 42% | 36% | 43% |
| Helpful resources about clinical trials are difficult to find | 36% | 31% | 41% | 40% | 37% | 39% | 27% | 31% | 30% | 38% | 35% | 40% |
| Resources about clinical trials are difficult to understand | 17% | 13% | 23% | 18% | 17% | 18% | 13% | 26% | 13% | 18% | 16% | 21% |
| There are not a lot of chances to ask questions about clinical trials | 22% | 21% | 22% | 29% | 23% | 21% | 20% | 18% | 17% | 20% | 23% | 28% |
| Resources about clinical trials are not available in my preferred language | 6% | 7% | 5% | 5% | 3% | 8% | 20% | 5% | 11% | 10% | 4% | 3% |
| I do not live in a community where clinical trials are often discussed | 27% | 30% | 26% | 19% | 28% | 20% | 30% | 24% | 27% | 27% | 29% | 24% |
| I am not comfortable talking about clinical trials | 6% | 6% | 4% | 7% | 6% | 2% | 6% | 6% | 6% | 5% | 5% | 7% |
| Other, please specify: | 3% | 4% | 1% | 3% | 4% | 1% | 0% | 3% | 1% | 2% | 3% | 5% |
| None of the above | 13% | 13% | 13% | 14% | 12% | 16% | 13% | 17% | 14% | 11% | 12% | 15% |

Among adults with chronic illnesses, adults below the age of 45 are also more likely than those ages 45+ to say there are not a lot of chances to ask about clinical trials. ¹⁶

Compared to other options tested, adults with chronic illnesses said location (84%), cost (84%), and distance to the clinical trial (83%) would most influence whether or not they would participate in a clinical trial in the future.

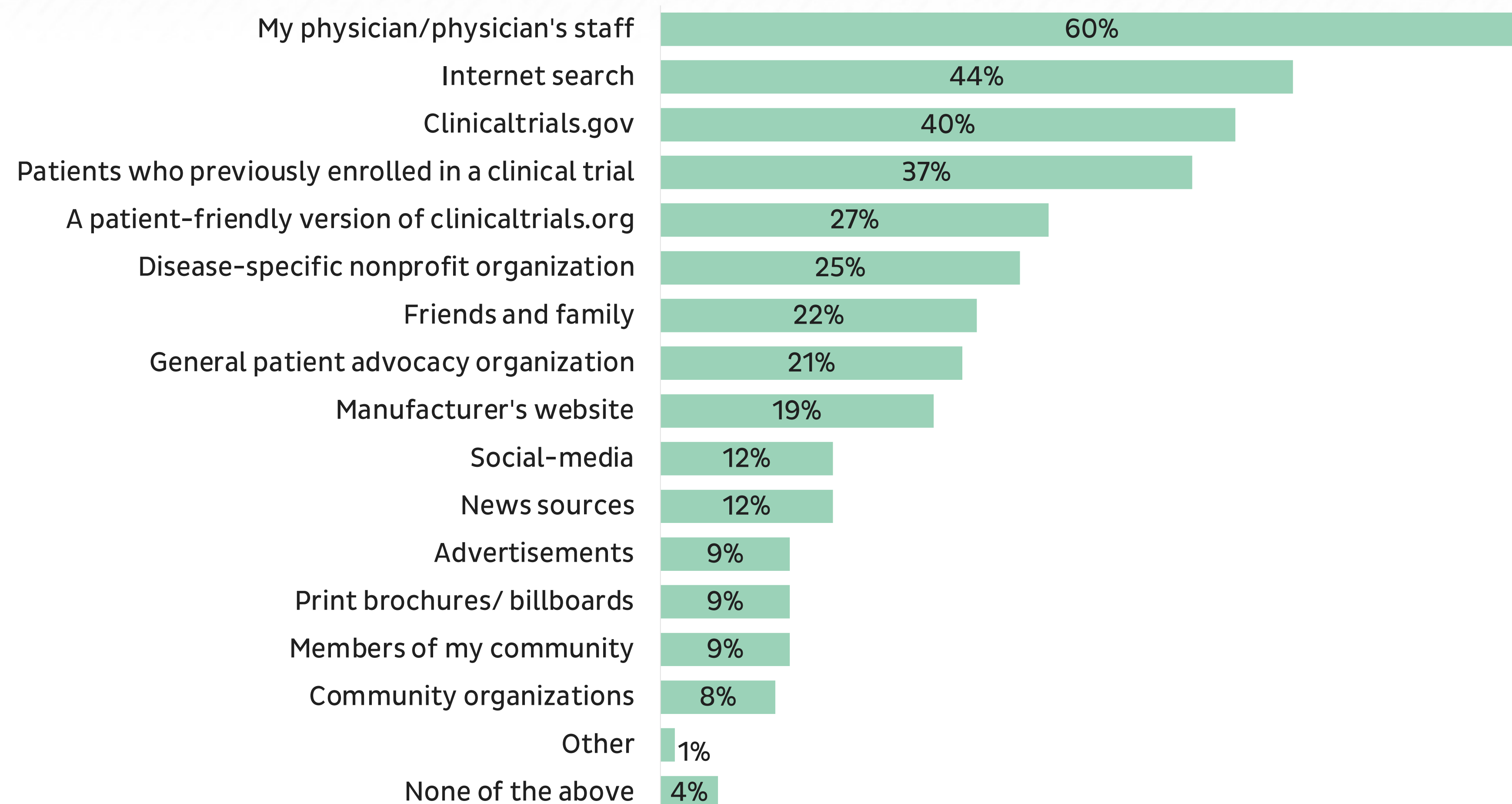
As a reminder, a clinical trial is a type of research study that examines new tests and treatments and evaluates their effects on human outcomes. People volunteer to take part in clinical trials to find out if a new treatment, such as a drug or medical device, is safe and effective in people. How much would information on each of the following features of a clinical trial influence your willingness to participate in the future?



*Total Influence = A lot + Some

Three-in-five (60%) adults with chronic illnesses say they would consider their physician/physician's staff a trusted source to go to for questions about participating in a clinical trial.

If you had questions about participating in a clinical trial, which of the following would you consider a trusted source to go to for obtaining information? Please select all that apply.



About three-in-four (78%) adults with chronic illnesses say they they have never discussed the option of participating in a clinical trial with a health care provider.

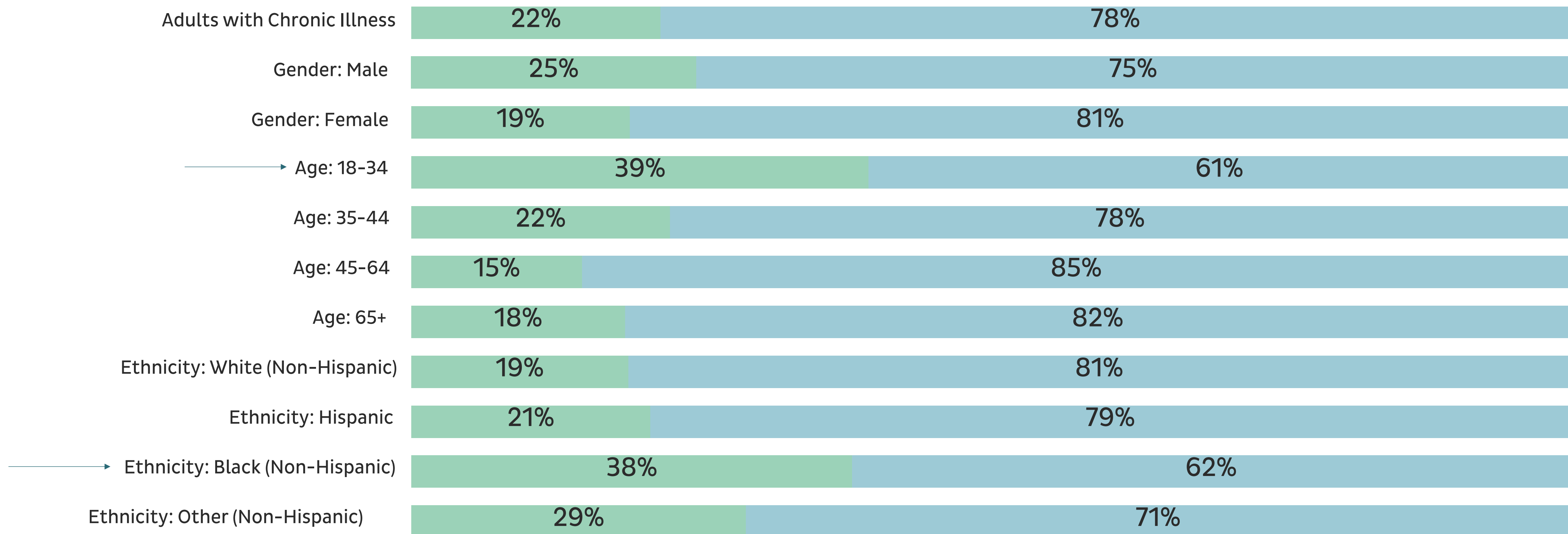
As a reminder, a clinical trial is a type of research study that examines new tests and treatments and evaluates their effects on human outcomes. People volunteer to take part in clinical trials to find out if a new treatment, such as a drug or medical device, is safe and effective in people. Has a healthcare provider or professional ever discussed the option of participating in a clinical trial with you?



Among adults with chronic illnesses, those ages 18-34 (39%) and Black adults (33%) were especially likely to have discussed clinical trials with a healthcare provider.

As a reminder, a clinical trial is a type of research study that examines new tests and treatments and evaluates their effects on human outcomes. People volunteer to take part in clinical trials to find out if a new treatment, such as a drug or medical device, is safe and effective in people. Has a healthcare provider or professional ever discussed the option of participating in a clinical trial with you?

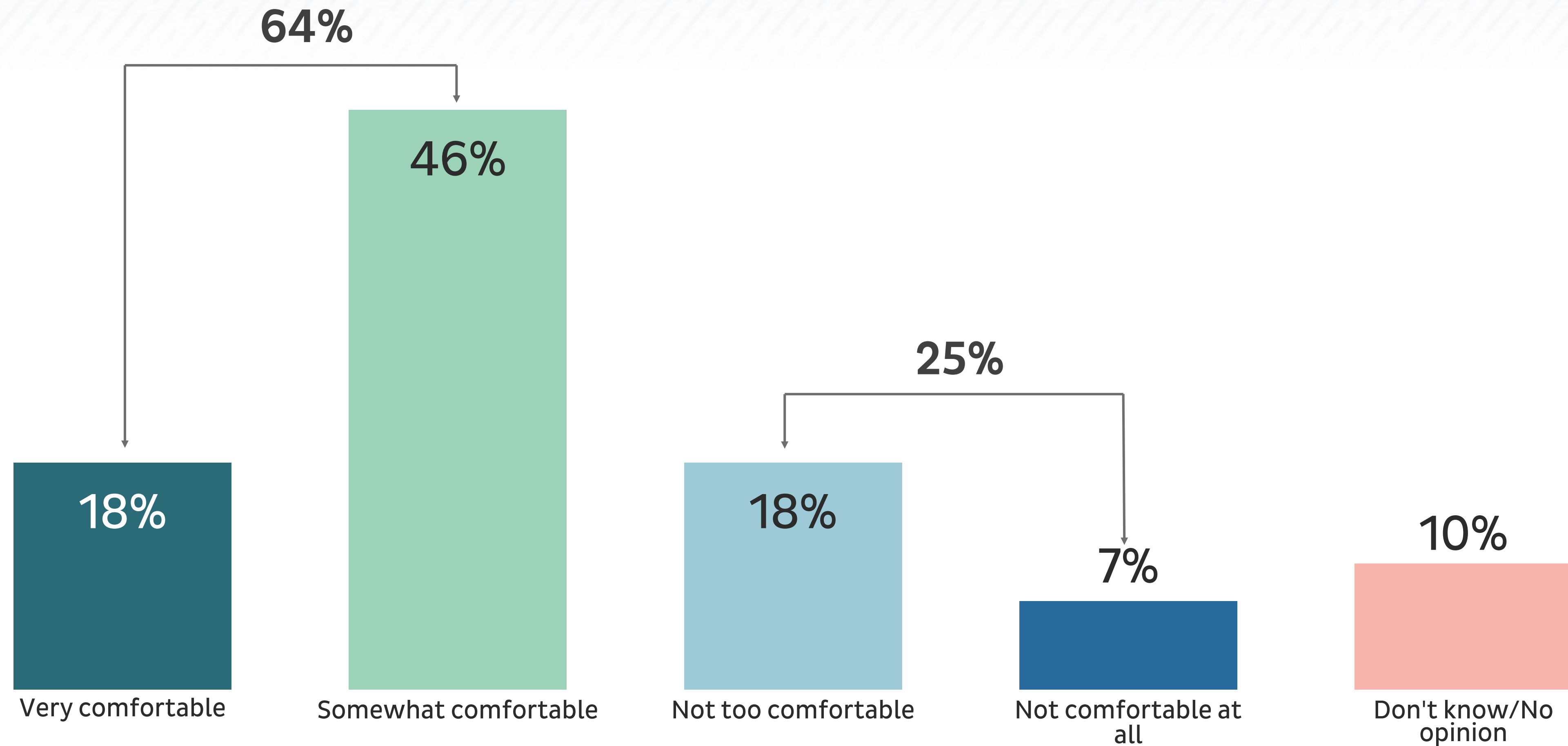
● Yes ● No



Clinical trial participation

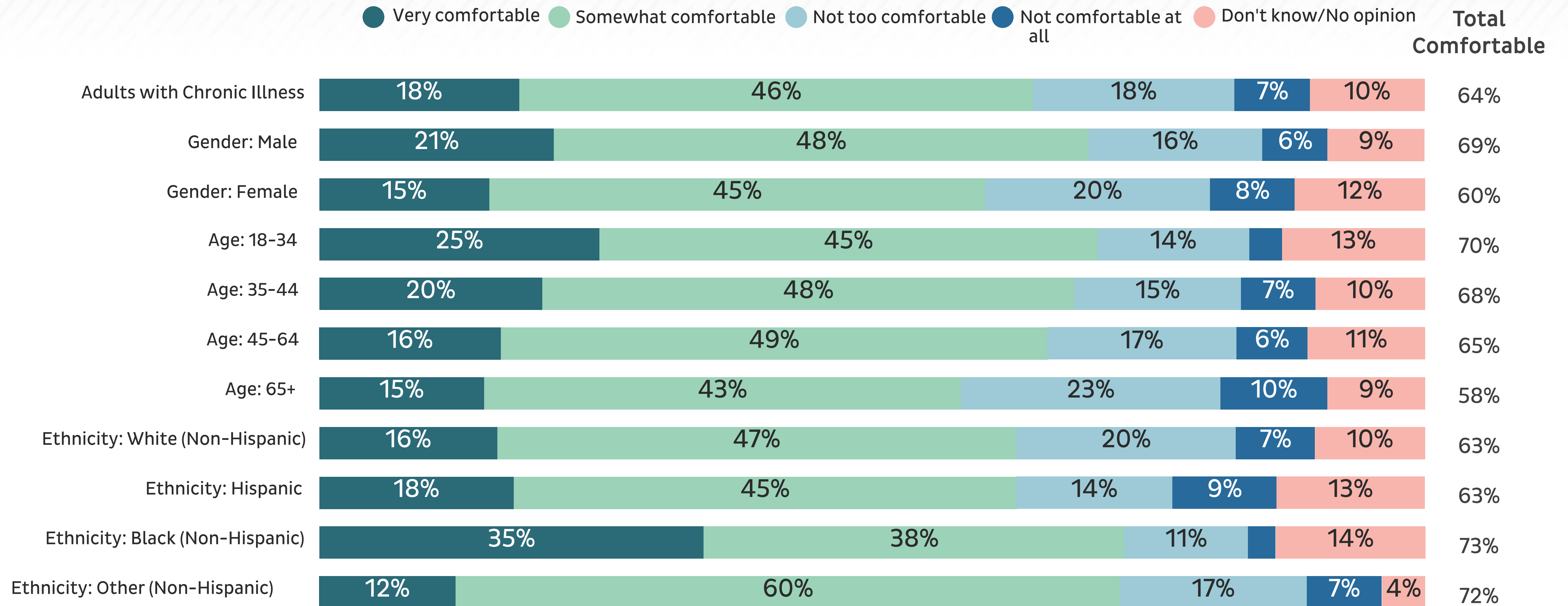
A majority of adults (64%) with chronic illnesses say they would feel comfortable navigating the clinical trial process.

How comfortable would you be, if at all, navigating the clinical trial process? Navigating the process can include finding a relevant trial or enrolling in a trial of interest.



A majority of adults across demographic groups say they would feel comfortable navigating the clinical trial process.

How comfortable would you be, if at all, navigating the clinical trial process? Navigating the process can include finding a relevant trial or enrolling in a trial of interest.



About 8-in-10 (83%) adults with chronic illnesses say they have not participated in a clinical trial before.

Have you ever done either of the following before?

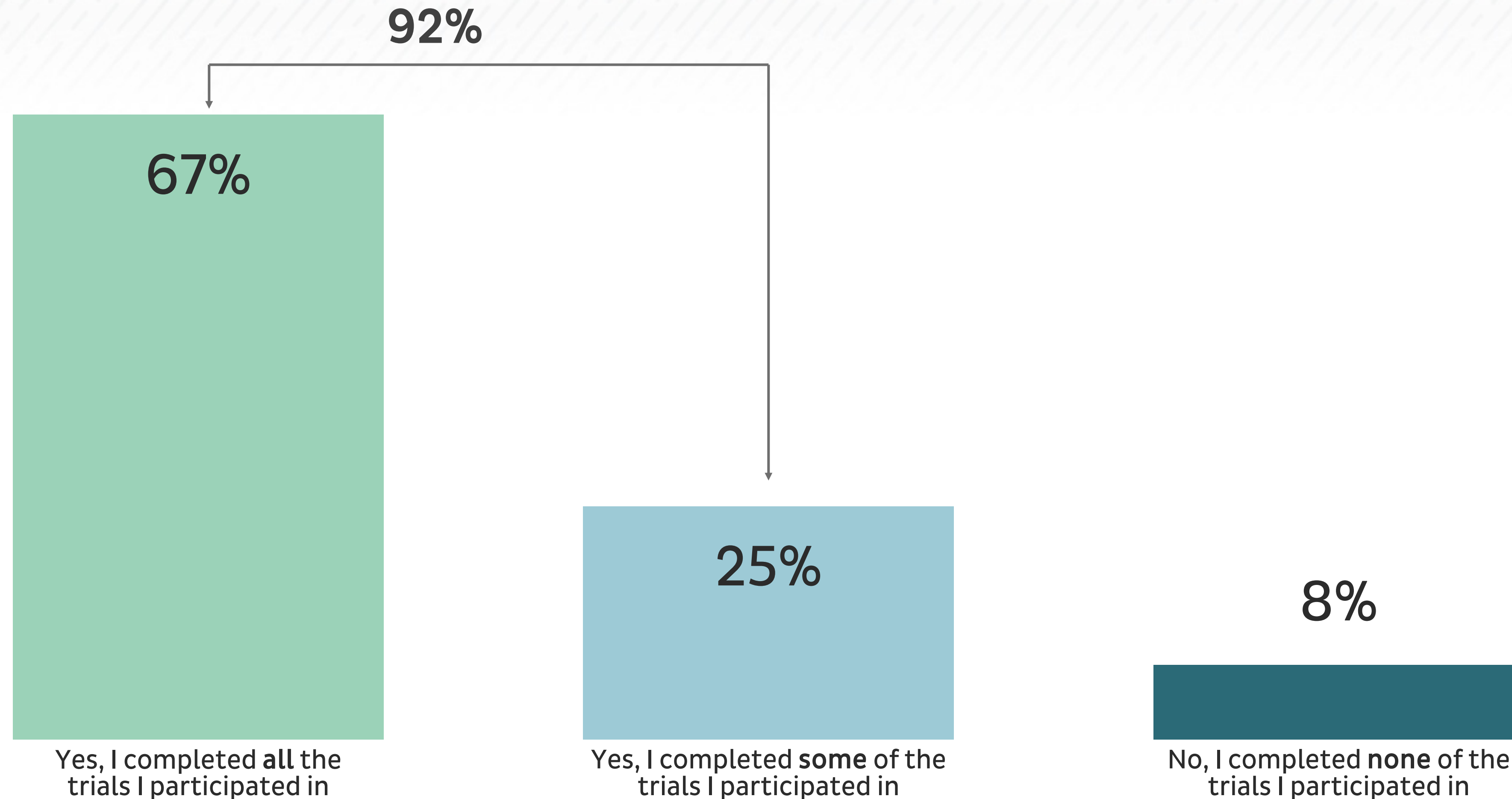
● Yes ● No



Three-in- ten adults with chronic illnesses ages 18-34 say they have participated in one or more clinical trial enrollment processes (31%) and in one or more clinical trials (30%) before.

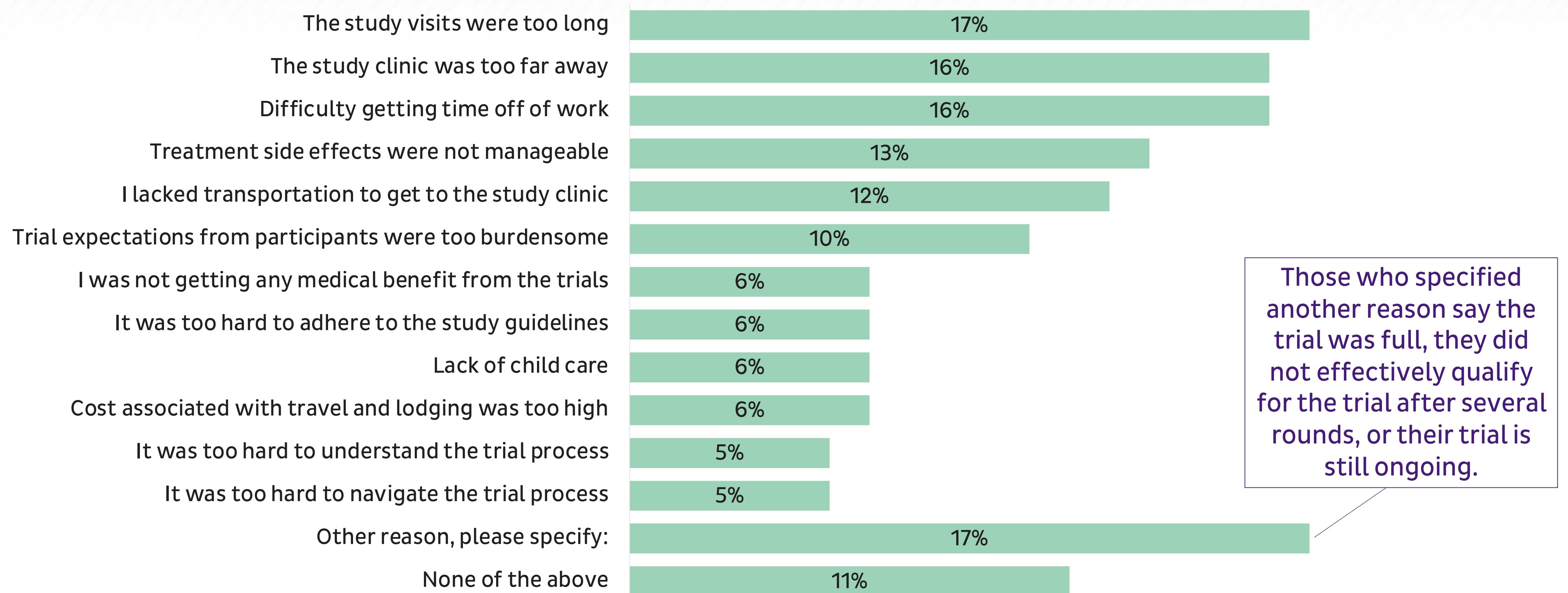
Nine-in-ten (92%) adults with chronic illnesses who have participated in one or more clinical trials have completed at least some of the trials they participated in.

Did you complete the trial(s) that you participated in?



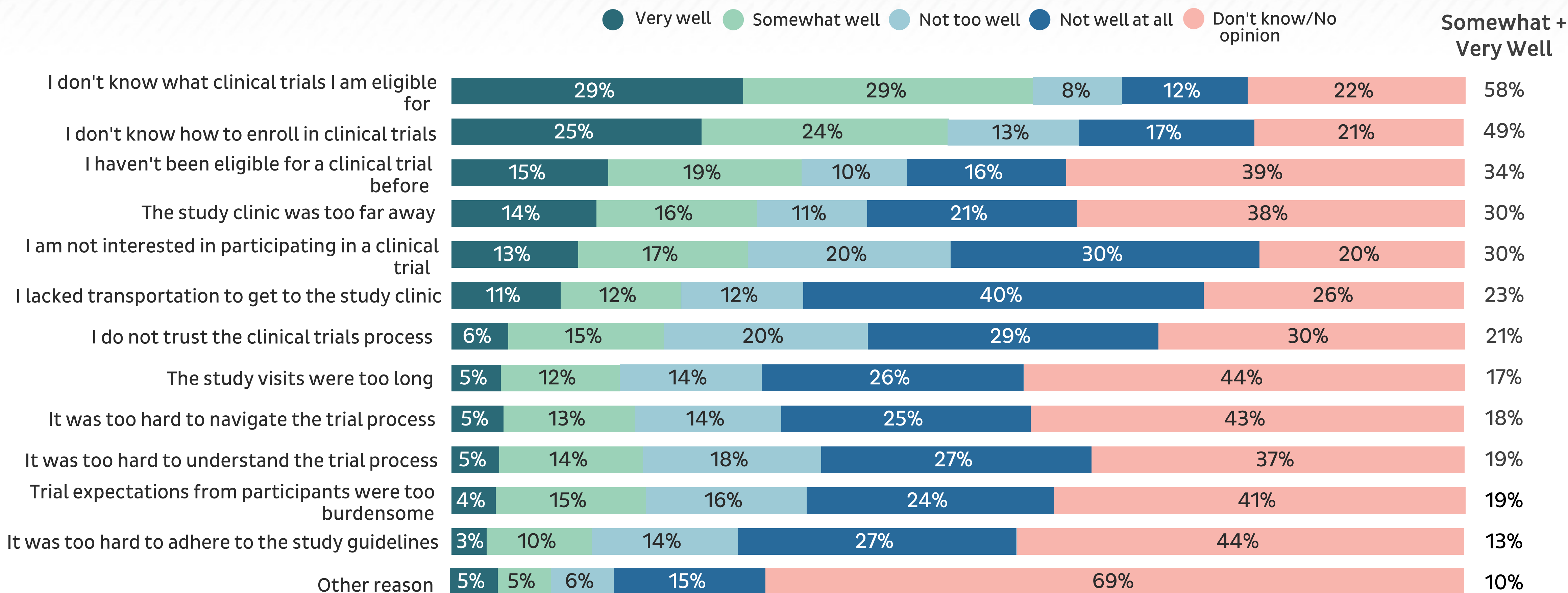
Adults with chronic illnesses who have participated in one or more clinical trials say they did not complete all of them because of long study visits (17%), difficulty getting time off work (16%), and study clinics being too far away (16%).

Which of the following reasons, if any, describe why you did not complete all the clinical trial(s) you participated in? Please select all that apply.



Adults with chronic illnesses who have not participated in a clinical trial before say they have not participated because they do not know what trials they are eligible for (58%) or how to enroll (49%).

How well, if at all, do the following reasons describe why you haven't participated in a clinical trial before?



AMONG ADULTS WITH CHRONIC ILLNESSES WHO HAVE NOT PARTICIPATED IN A CLINICAL TRIAL, n=1,241

Across demographic groups, adults with chronic illnesses who have not participated in a clinical trial say they do not know what clinical trials they are eligible for and that they do not know how to enroll in clinical trials.

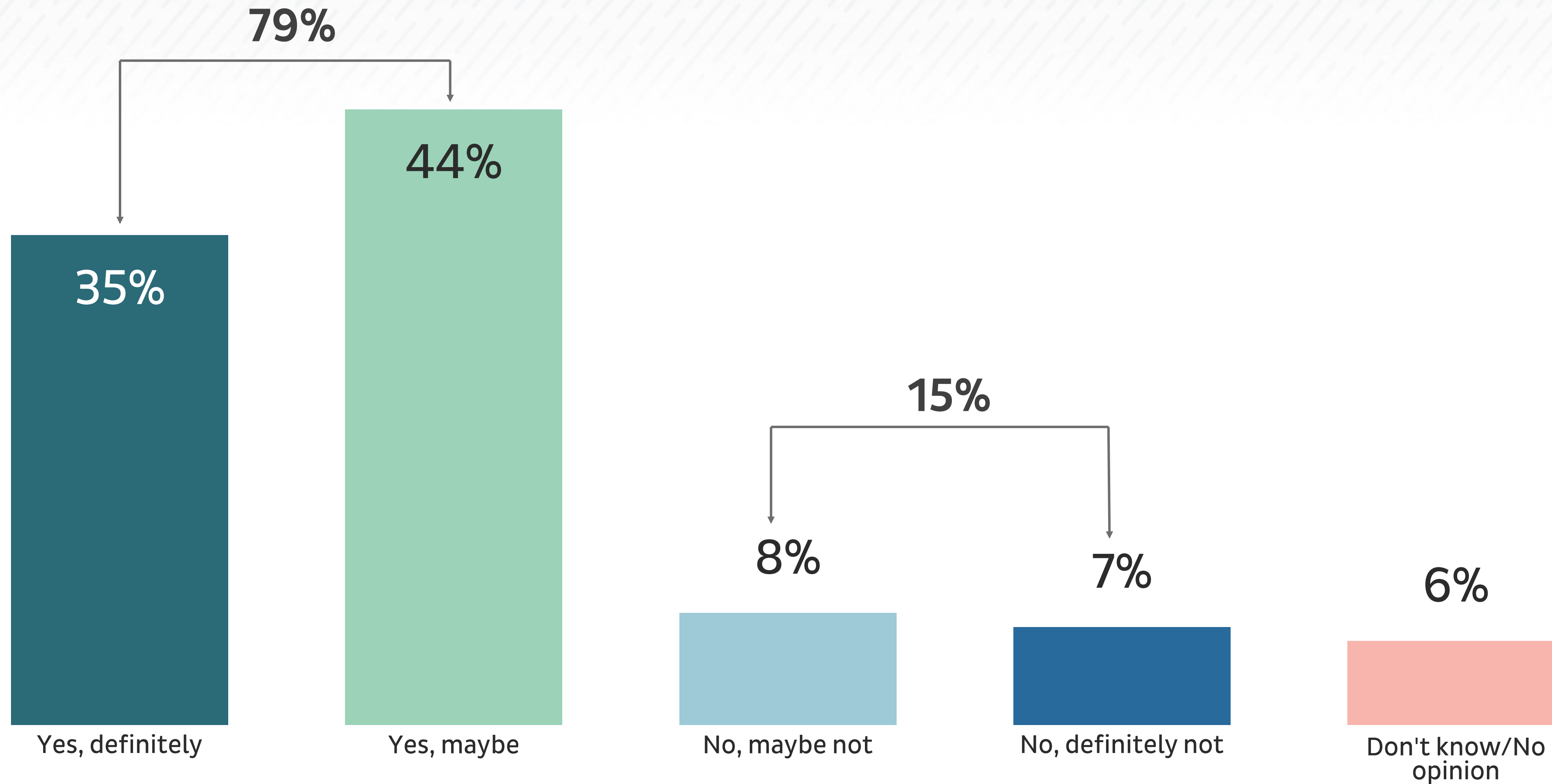
How well, if at all, do the following reasons describe why you haven't participated in a clinical trial before?

| % SOMEWHAT + VERY WELL | Adults with Chronic Illness | Income: Under 50k | Income: 50k-100k | Income: 100k+ | Ethnicity: White (NH) | Ethnicity: Hispanic | Ethnicity: Black (NH) | Ethnicity: Other (NH) |
|--|-----------------------------|-------------------|------------------|---------------|-----------------------|---------------------|-----------------------|-----------------------|
| I haven't been eligible for a clinical trial before | 34% | 33% | 39% | 31% | 36% | 23% | 34% | 46% |
| I don't know what clinical trials I am eligible for | 58% | 57% | 59% | 60% | 58% | 65% | 41% | 77% |
| I don't know how to enroll in clinical trials | 49% | 50% | 50% | 44% | 50% | 54% | 39% | 52% |
| I do not trust the clinical trials process | 21% | 21% | 23% | 17% | 20% | 18% | 31% | 30% |
| I am not interested in participating in a clinical trial | 30% | 29% | 27% | 33% | 30% | 27% | 28% | 31% |
| I lacked transportation to get to the study clinic | 23% | 27% | 20% | 11% | 21% | 26% | 25% | 27% |
| Trial expectations from participants were too burdensome | 19% | 18% | 23% | 19% | 18% | 21% | 20% | 25% |
| It was too hard to understand the trial process | 19% | 17% | 20% | 20% | 17% | 18% | 29% | 35% |
| It was too hard to navigate the trial process | 18% | 17% | 20% | 20% | 16% | 29% | 19% | 33% |
| The study clinic was too far away | 30% | 32% | 29% | 25% | 29% | 38% | 30% | 40% |
| The study visits were too long | 17% | 16% | 18% | 19% | 15% | 21% | 26% | 23% |
| It was too hard to adhere to the study guidelines | 13% | 12% | 17% | 14% | 13% | 14% | 19% | 24% |
| Other reason | 10% | 11% | 8% | 11% | 10% | 10% | 13% | 8% |

AMONG ADULTS WITH CHRONIC ILLNESSES WHO HAVE NOT PARTICIPATED IN A CLINICAL TRIAL, n=1,241

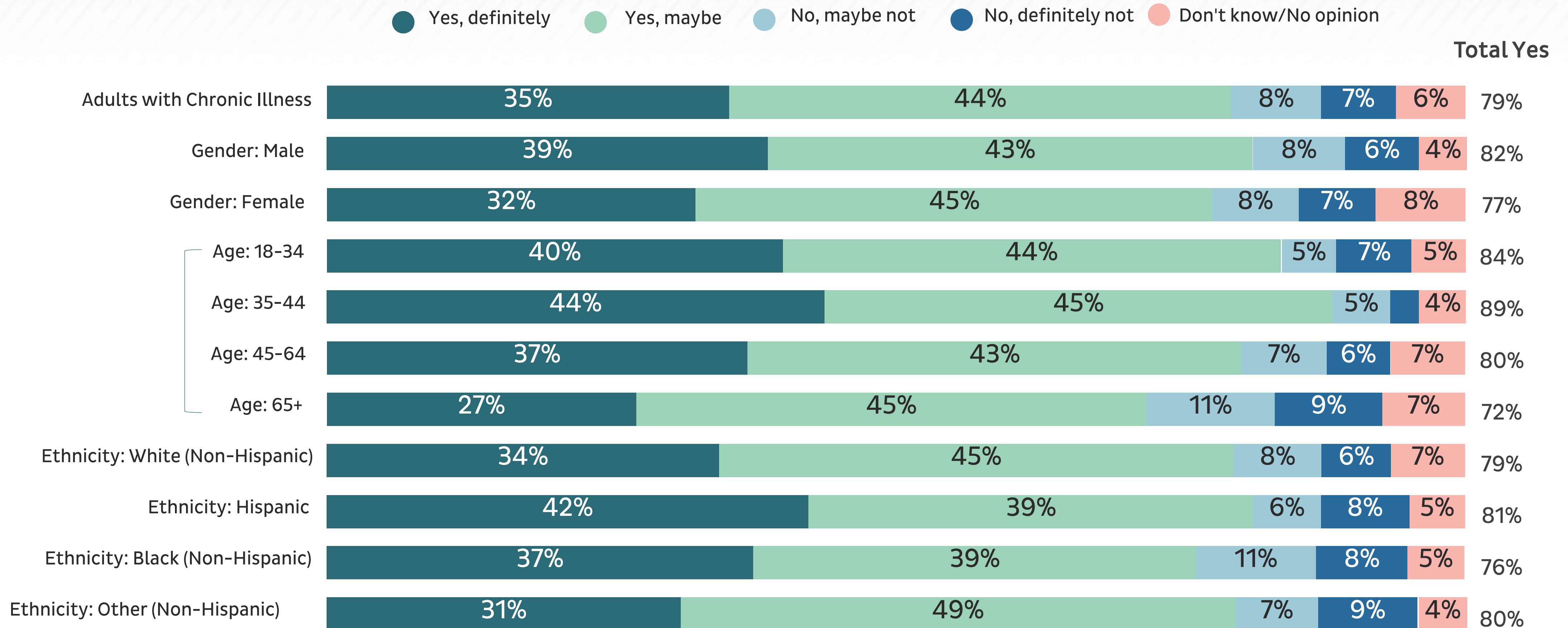
Four-in-five (79%) adults with chronic illnesses say they are open to participating in a clinical trial in the future, including nearly two-in-five (35%) who say they are definitely open to participating.

Are you open to participating in a clinical trial in the future?



Adults with chronic illnesses below the age of 45 are more likely than those ages 45+ to say they are open to participating in a clinical trial in the future, including 44% of adults with chronic illnesses ages 35-44 saying they are definitely open to participating.

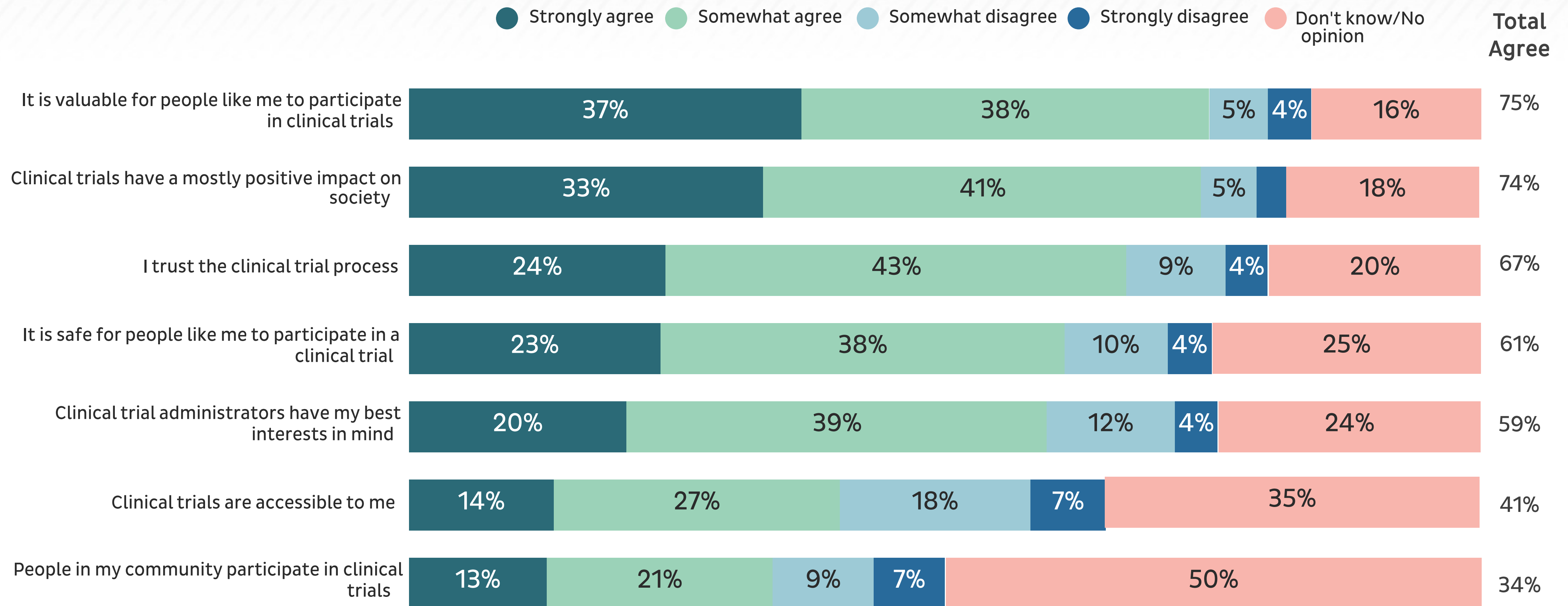
Are you open to participating in a clinical trial in the future?



Perceptions of clinical trials

Three-in-four adults with chronic illnesses agree that it is valuable for people like them to participate in clinical trials (75%) and that clinical trials have a mostly positive impact on society (74%).

How much do you agree or disagree with each of the following statements?



About two-in-five adults with chronic illnesses of other ethnicities (42%) say they disagree with the statement “clinical trials are accessible to me.”

How much do you agree or disagree with each of the following statements?

| % DISAGREE | Adults with Chronic Illness | Income: Under 50k | Income: 50k-100k | Income: 100k+ | Ethnicity: White (NH) | Ethnicity: Hispanic | Ethnicity: Black (NH) | Ethnicity: Other (NH) |
|---|-----------------------------|-------------------|------------------|---------------|-----------------------|---------------------|-----------------------|-----------------------|
| It is valuable for people like me to participate in clinical trials | 9% | 8% | 10% | 12% | 8% | 19% | 13% | 10% |
| Clinical trials have a mostly positive impact on society | 8% | 8% | 8% | 11% | 6% | 17% | 11% | 9% |
| I trust the clinical trial process | 13% | 13% | 12% | 16% | 12% | 17% | 15% | 18% |
| It is safe for people like me to participate in a clinical trial | 14% | 14% | 13% | 16% | 12% | 17% | 17% | 24% |
| Clinical trial administrators have my best interests in mind | 16% | 15% | 16% | 18% | 16% | 16% | 16% | 23% |
| Clinical trials are accessible to me | 25% | 25% | 25% | 26% | 23% | 24% | 29% | 42% |
| People in my community participate in clinical trials | 16% | 15% | 17% | 16% | 15% | 22% | 13% | 27% |

