CISCRP

2023

Perceptions & Insights Study

Global trends in public and patient attitudes about, and experience with, clinical research.

DECIDING TO PARTICIPATE

Introduction

General willingness to participate in a clinical research study among the public has increased overall compared to prior studies, with respondents from North America and Europe more willing than those from other regions.

In this report, CISCRP explores the decision-making process for those considering clinical research participation — specifically, sources of information about participation opportunities, drivers vs. barriers to enrollment, information needed, and other factors considered from the patient's perspective. Learnings from this report can help guide communication and recruitment strategies.

About **half of respondents** reported being **asked to join a study** — email, telephone, and through a doctor were cited as the primary means of recruitment.

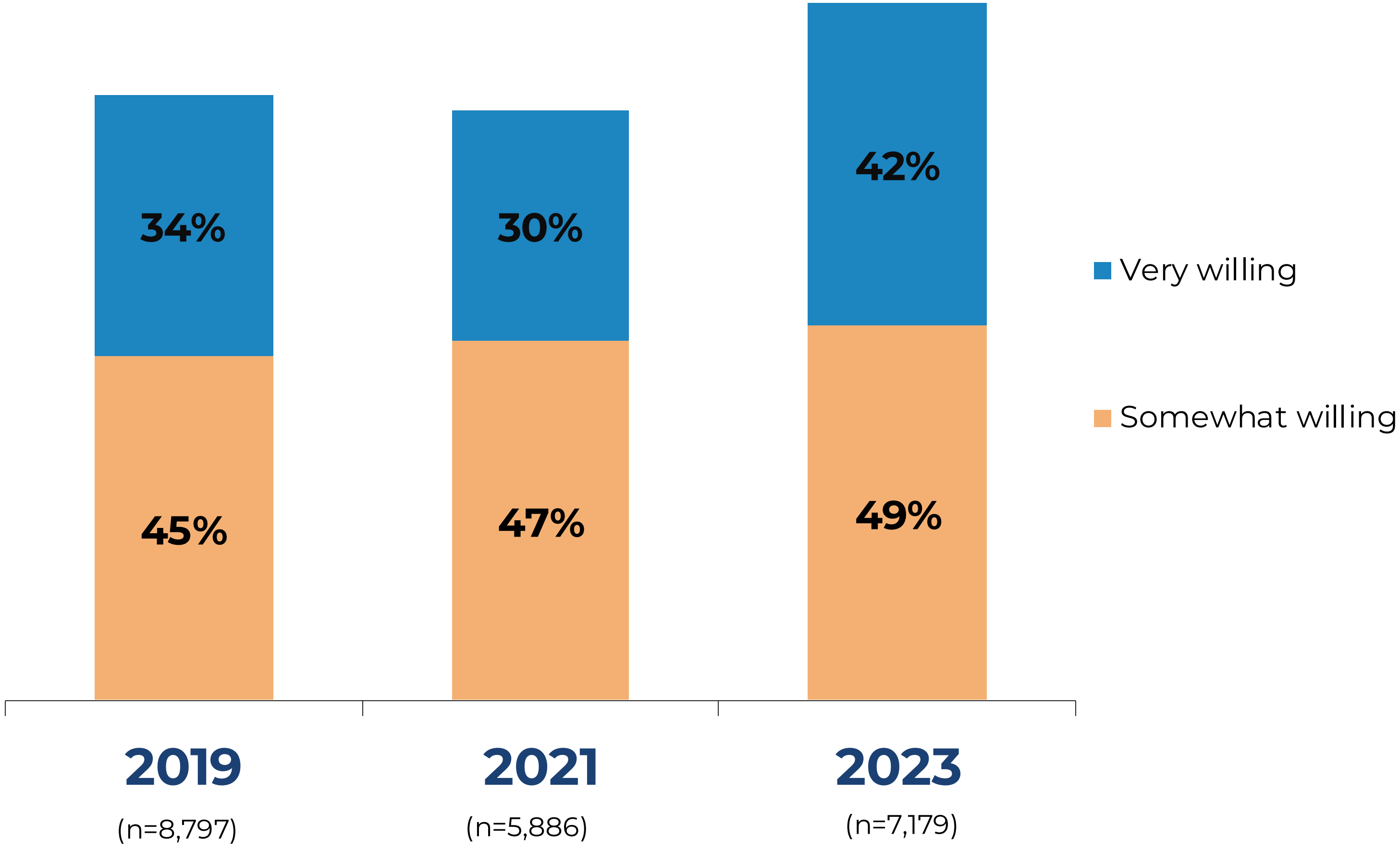
Knowing that the **study staff and other clinical trial participants are diverse** was cited as **very important** to deciding whether to participate among **Black and/or Hispanic respondents**.

Information critical to participant decision-making includes **knowing potential risks and benefits**, **study purpose**, how the investigational **treatment is believed to work**, as well as knowing involved **procedures**, potential **out-of-pocket costs**, physical **clinic location**, and **study duration**.

Willingness to Participate

Compared to 2021, there has been an increase in the willingness to participate in a clinical research study.

In general, how willing would you be to participate in a clinical research study?



Base: Those who have not participated in a clinical trial; excludes 'I am not sure'

Asian respondents were more likely to indicate being **'Not at all willing'** or **'Not very willing'** than all other races.

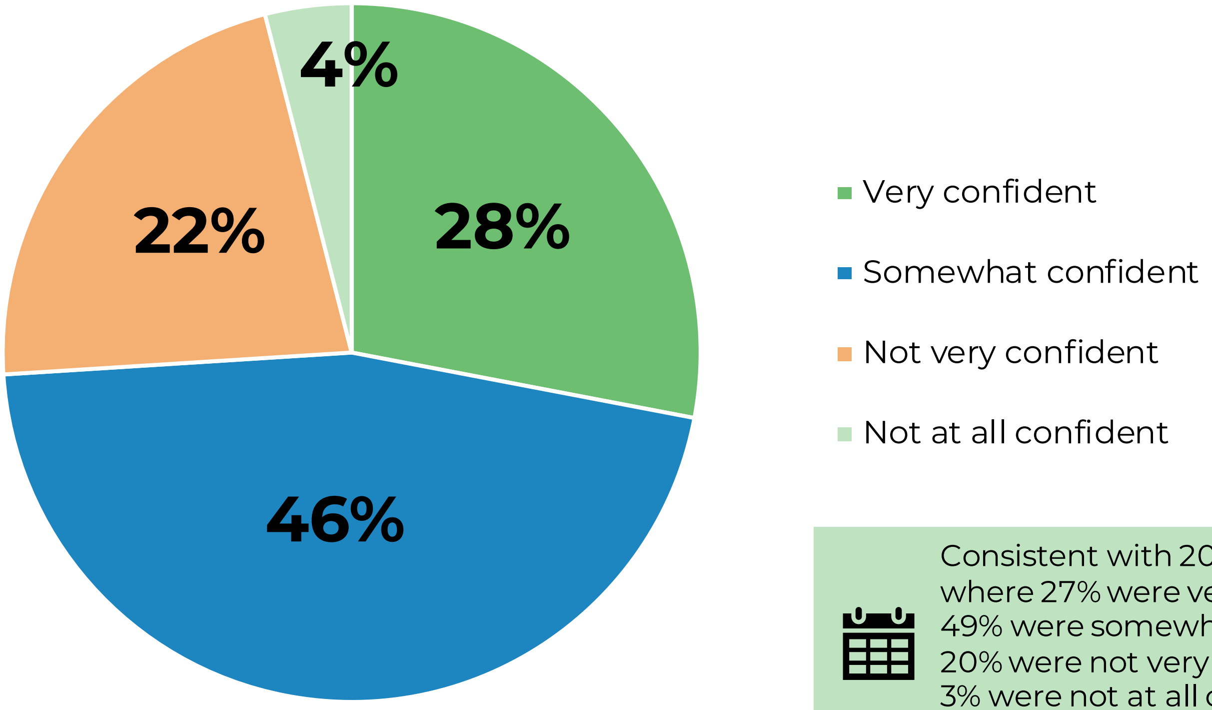
Overall, **North American** and **European respondents** were **more willing** than those from other regions.

- **North American respondents** were more likely to indicate **'Very willing' (46%)** than respondents from all other regions.
- **European respondents** were more likely to indicate **'Somewhat willing' (52%)** than respondents from all other regions.

Confidence in Identifying a Clinical Research Study

Most were confident that they could find a clinical research study that would be a good fit for them.

How confident are you that you could find a clinical research study that is right for you?



Sample Size = 12,017 | Base: All respondents

Consistent with 2021 findings, where 27% were very confident, 49% were somewhat confident, 20% were not very confident, and 3% were not at all confident.

Those in **North America (33%)** and **Africa (43%)** were more likely to report **'Very Confident'** compared to those in South America (24%), Europe (22%), and Asia-Pacific (25%).

Hispanic respondents (31%) were more likely to report **'Very Confident'** compared to Non-Hispanic respondents (27%).

Black respondents (44%) were more likely to report **'Very Confident'** compared to White (27%), Asian (24%), and All Other Races (29%) of respondents.

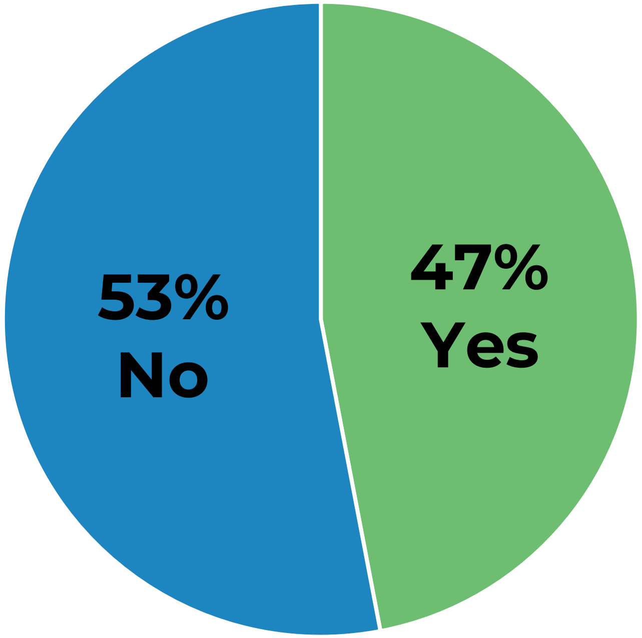
Those whose **household size is more than 5 people** were more likely to report **'Very Confident'** (36%) compared to those who live alone (26%), have a household size of 2 (27%), and have a household size of 3 (28%).

Recruitment Channels

About **half** reported being asked to participate in **2023**, a slightly **lower proportion** than in the **2021 study**. The primary means of recruitment were email or telephone communication from the research clinic or a patient recruitment company, or through their doctor.

Have you ever been asked to participate in a clinical research study?

% Responding



Sample Size = 12,017 | Base: All respondents

How were you asked to participate?

Top mentions:

- Through an email I received from a research study center or patient recruitment company (31%)
- Through my doctor (23%)
- Through a telephone call from a research study center or patient recruitment company (16%)
- Through social media (e.g., Facebook, Twitter, Instagram) (12%)
- Through my patient advocacy or patient support group (7%)

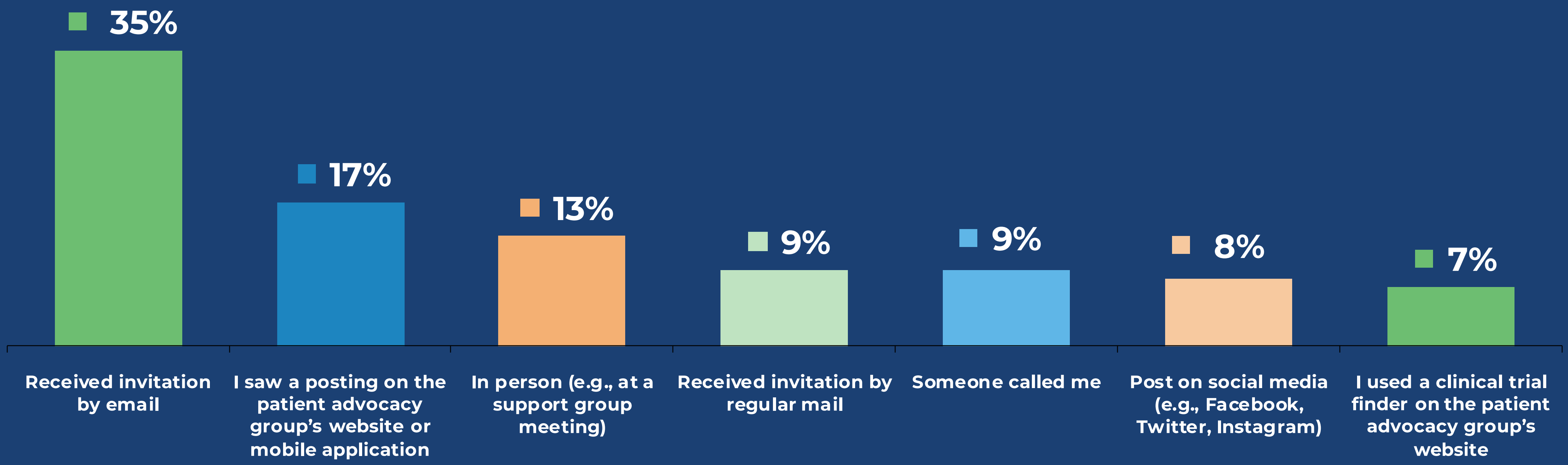
Sample Size = 5,692 | Base: Those asked to participate

In 2021, 55% of respondents had been asked to participate, as compared to 47% in 2023.

Most top mentions were the same in 2021 (email 30%, phone 17%, social media 16%, doctor 14%).

Advocacy Group or Patient Support Group Recruitment Channels

Receiving an invitation by email was the most common way of being asked to participate by a patient advocacy or support group.



Sample Size = 406 | Base: Those asked to participate by a patient advocacy or patient support group

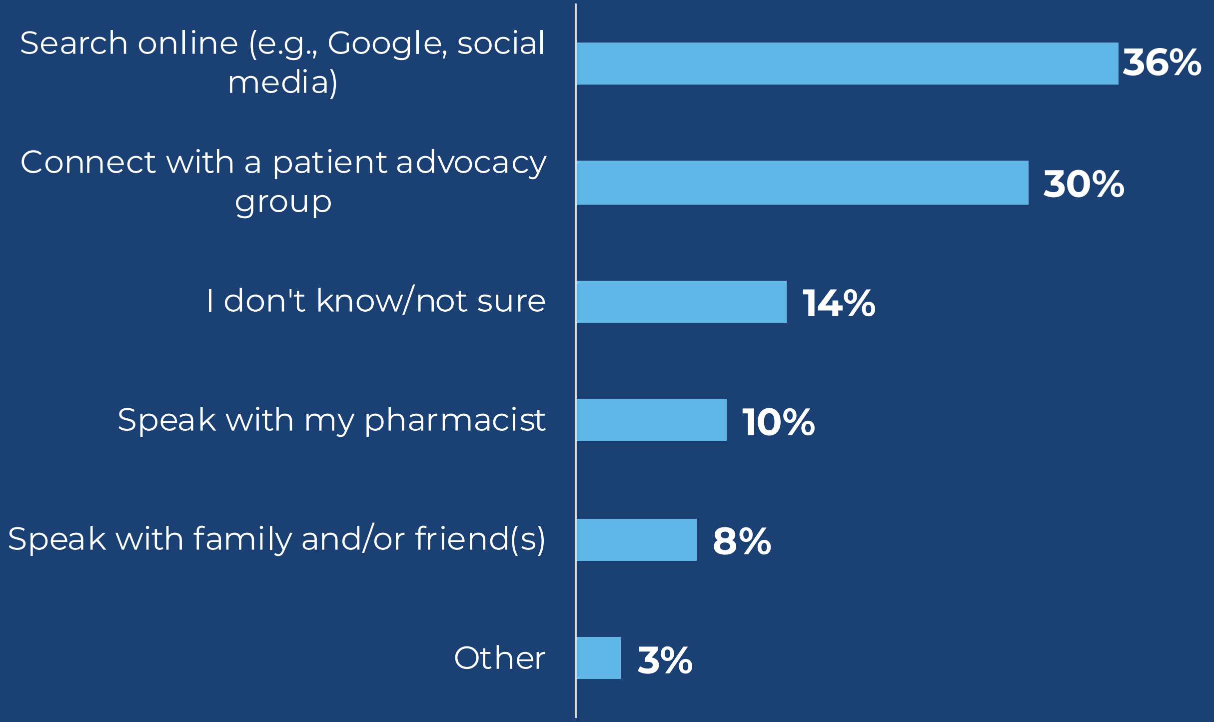
Black/African-American respondents were more likely to report having **been asked to participate by their patient advocacy** or **patient support group** than White respondents (12% vs. 6% respectively).

North Americans were more likely to report having **been asked to participate by their patient advocacy** or **patient support group** than European respondents (9% vs. 5% respectively).

First Step in Identifying Clinical Research Study

Outside of their doctor, many would turn to an **online source** or **patient advocacy group** first to identify a clinical study.

What would be your first step in finding a clinical research study that is right for you, other than speaking with your doctor?



Sample Size = 12,017 | Base: All respondents

After conducting your initial online search, which website would you go to next to find a clinical research study that is right for you?

% Mentioning

- The online clinical trial registry/database maintained by your government **(40%)**
- An online advertisement for a clinical research study (e.g., Google ad, YouTube ad) **(15%)**
- A patient advocacy group's website **(12%)**
- Social media **(11%)**
- A pharmaceutical company's website **(10%)**

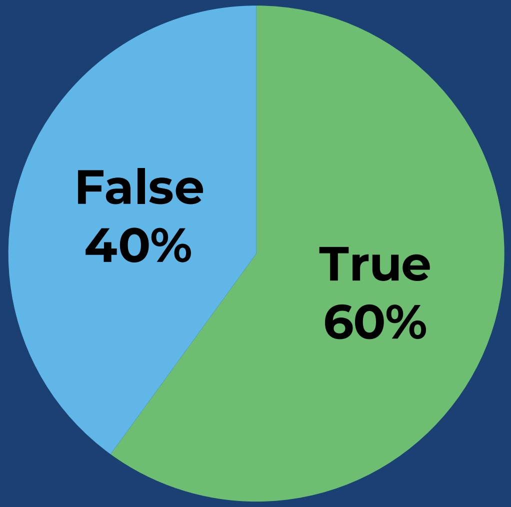
Sample Size = 4,335 | Base: Those who would search online as a first step to find a clinical research study

Perceptions of Expenses Associated With Clinical Research Participation

Confusion exists among some, regarding medical costs and out-of-pocket costs.

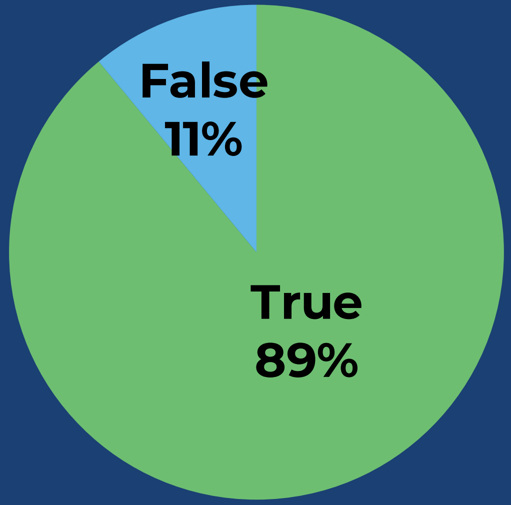
TRUE or FALSE?

All out-of-pocket expenses such as gas, parking, and/or meals are reimbursed by the clinical research study and the participant is not responsible for these costs.



TRUE or FALSE?

All medical costs will be covered by the clinical research study.



Sample Size = 12,017 | Base: All respondents

Information Desired Before Making Decision To Participate – Study Purpose and Design

Thinking about the purpose and design of a clinical research study, how important is it to you to know each of the following types of information before making the decision to participate in a clinical research study?

Higher Importance

Potential risks and benefits	**80%**
Purpose of the clinical research study	**71%**
Information about the study drug being researched (type of therapy, how it is believed to work, etc.)	**69%**
Results and information from earlier phase of studies on the study drug	**55%**
How my confidentiality (including contact information and medical results) would be protected	**53%**
If I would receive a summary of the study results after my participation ended	**52%**

Lower Importance

If I would have access to the study drug after my participation ended	**44%**
Hearing about the experiences of previous research participants	**44%**
Information about the company sponsoring (paying for) the study	**40%**
Knowing a group of patients and caregivers with my condition had provided feedback on the study design before beginning to enroll participants	**39%**
Knowing that other clinical trial participants are representative of diverse communities (e.g., mix of races, ethnicities, ages, genders, sexual orientations, etc.)	**25%**
Knowing that the staff conducting the study (doctors, coordinators, etc.) are representative of diverse communities (e.g., mix of races, ethnicities, ages, genders, sexual orientations, etc.)	**20%**

Never Participated (n=7,459) *% indicating 'Very important'*

Black respondents were more likely to report the following as being **'Very important'** compared to all other races:

- Info about the sponsor
- Knowing other clinical trial participants are diverse
- Knowing the staff conducting the study are diverse
- How confidentiality would be protected
- Knowing patients/caregivers had provided feedback on the study design

Information Desired Before Making Decision To Participate – Logistics

Thinking about the logistics of the clinical research study, how important is it to you to know each of the following types of information before making the decision to participate in a clinical research study?

Higher Importance

Types and number of medical procedures required	**58%**
Potential costs and reimbursements	**57%**
Physical location of the research study center (distance from home or work)	**55%**
Length of participation in the clinical research study (time commitment from start to end of study)	**53%**

Lower Importance

Number of study visits	**44%**
Duration of each study visit	**44%**
Flexible visit scheduling (e.g., weekends, after work)	**44%**
If time off from work is compensated (i.e., paid for)	**41%**
Clinical study medicine delivered to my home	**34%**
Some or all study visits conducted at my home or my office	**28%**

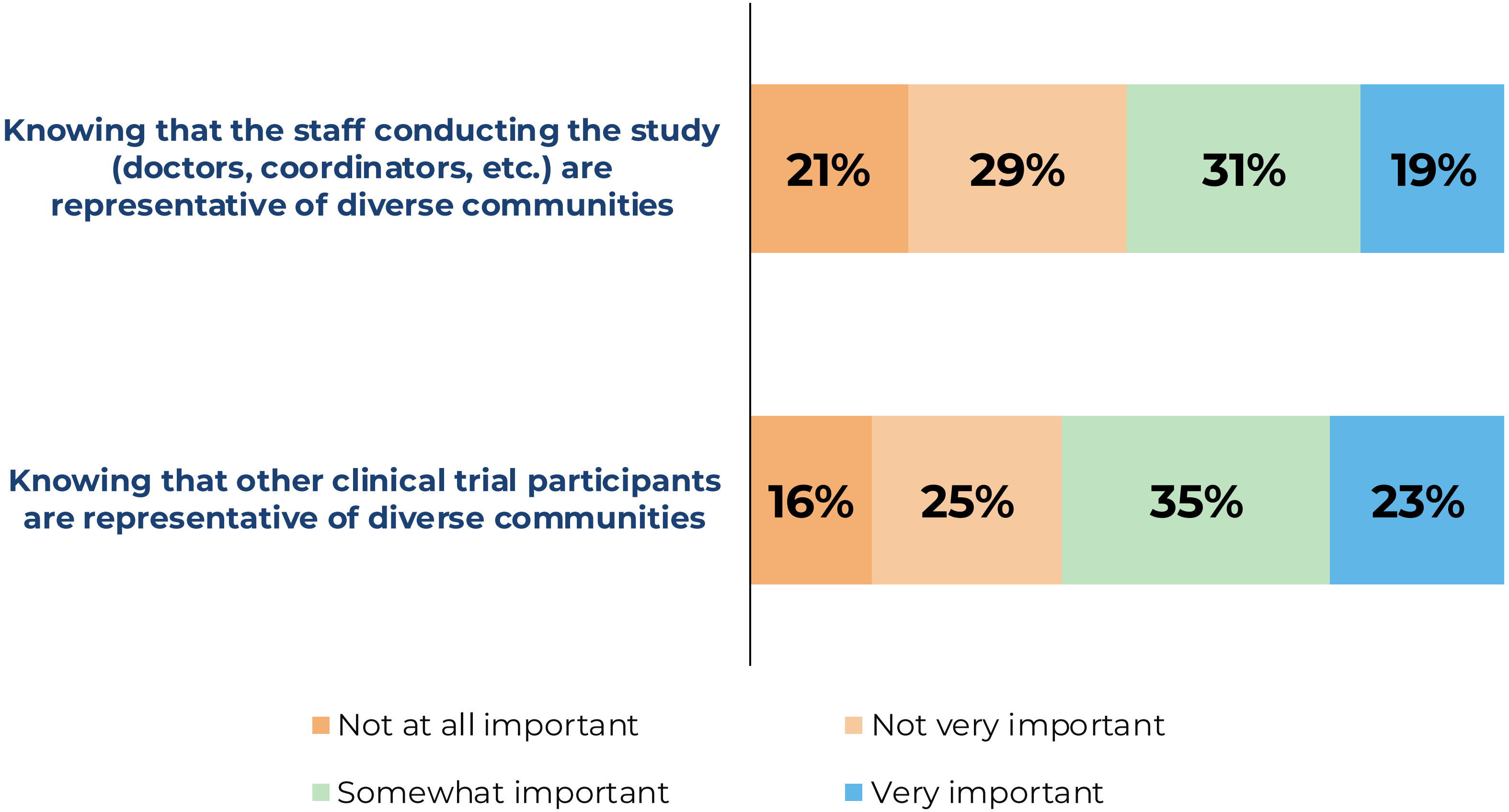
Never Participated (n=7,459) *% indicating 'Very important'*

North American respondents were more likely to report the following as being **'Very important'** compared to all other regions:

- Location of study center
- Length of participation
- Number and duration of study visits
- Medical procedures required
- Flexible scheduling for visits
- Remote visits
- Potential costs and reimbursements

Diversity of Study Staff and Clinical Trial Participants

Thinking about the purpose and design of a clinical research study, how important is it to you to know each of the following types of information before making the decision to participate in a clinical research study?



Sample Size = 12, 017 | Base: All respondents

European respondents were least likely to indicate **'Very important'** for having diverse staff and participants compared to other regions.

Hispanic and **Black/African-American respondents** were more likely to indicate **'Very important'** for having diverse staff and participants compared to other races/ethnicities.

About This Study

The objectives of this study are to establish routine global assessments of public and patient perceptions, motivations, and experiences with clinical research in order to monitor trends and identify opportunities to better inform and engage the public and patients as stakeholders and partners in the clinical research enterprise.

Between April and June 2023, CISCRP conducted an online international survey. The survey instrument was based in part on questions posed in past surveys. CISCRP received input and support from pharmaceutical, biotechnology, and contract research organizations; investigative sites; and patients. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, James Lind Care, Benchmark Research, and Rare Patient Voice to reach and engage respondents.

12,017
Survey Respondents

Respondent characteristics are as follows:

Gender	61% Female | 37% Male | 2% All other genders
Region	47% North America | 2% South America | 46% Europe | 4% Asia-Pacific | 1% Africa
Age	19% 18–34 years old | 18% 35–44 years old | 18% 45–54 years old | 21% 55–64 years old | 24% 65 or older
Race (top mentions)	81% White | 6% Black or African American | 6% Asian
Ethnicity	85% Non-Hispanic | 15% Hispanic
Incidence of participation in a clinical trial	62% have never participated | 38% have participated

Note: Percentages throughout this report may not total 100 due to rounding

About CISCRP

The Center for Information and Study on Clinical Research Participation (CISCRP) is an internationally recognized non-profit organization dedicated to educating and informing the public and patients about clinical research. CISCRP works to raise awareness, enhance experiences, and strengthen communication and relationships among participants, research professionals, and the public through various services and events.

RESEARCH SERVICES

Insights guiding public and patient engagement in clinical research

- Perceptions & Insights Study
- Patient Advisory Boards
- Patient Clinical Trial Journey Workshops
- Custom Research Projects

HEALTH COMMUNICATION SERVICES

Information in plain and easy-to-read language

- Trial Results Summaries
- Educational Brochures
- Review Panels

COMMUNITY ENGAGEMENT

Educational and engaging events held in local communities to build clinical research awareness and trust

- AWARE-for-All
- Medical Heroes Appreciation 5K
- Journey to Better Health Traveling Exhibit

INTERNATIONAL EDUCATION & AWARENESS

Helpful facts and information about clinical research

- Content Licensing
- Patient Diversity Campaign
- Website Content Development

CISCRP

Thank You

CISCRP thanks the following organizations for their support of the 2023 P&I Study:

abbvie
AMGEN
AstraZeneca
Benchmark™ Research
Raising the standard.™
Biogen
CLARINESS
Daiichi-Sankyo
EMD SERONO
greenphire®
janssen
PHARMACEUTICAL COMPANIES OF Johnson & Johnson
JLC JAMES LIND CARE.
Lilly
MERCK
Otsuka
RARE PATIENT Voice℠
Also Non-Rare!
sanofi

Connect With Us
ciscrp.org | info@ciscrp.org | (617) 725 2750