CISCRP

PERCEPTIONS AND INSIGHTS STUDY 2021

DECIDING TO PARTICIPATE

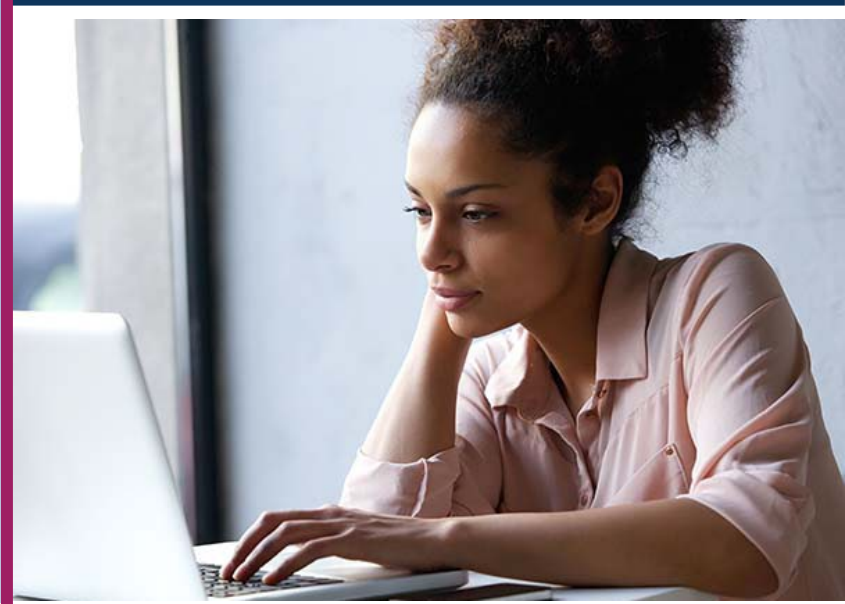
INTRODUCTION

While the COVID-19 pandemic appeared to increase willingness to participate among prior study participants, general willingness to participate among the general public has slightly decreased since 2019.

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 perspective. Learnings from this report can help guide communication and recruitment strategies.

HIGHLIGHTS

- A greater proportion of respondents reported being asked to join a study compared to the 2019 survey – email, telephone, and social media were cited as primary means of recruitment.
- Information about risks and benefits, study purpose, types of medical procedures required, confidentiality protection, as well as various logistical aspects continue to be critical to informed decision making.
- Notably, knowing the study staff and clinical trial participants were diverse was cited as critically important to deciding whether to participate among Black and/or Hispanic respondents.



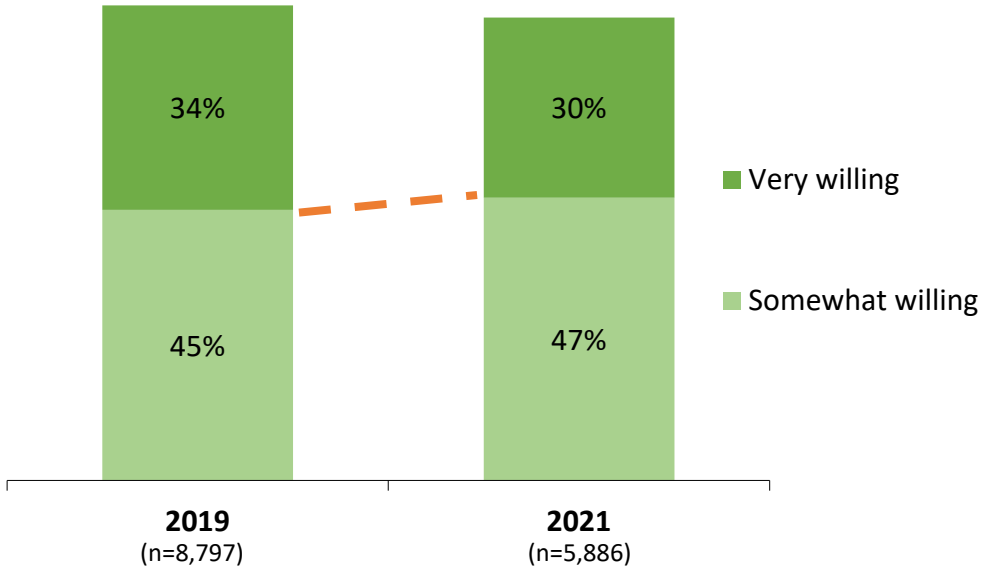
RESEARCH SERVICES

WILLINGNESS TO PARTICIPATE

Since 2019, general willingness to participate in clinical research has decreased slightly, with a notable impact on willingness to participate as a result of the COVID-19 pandemic.

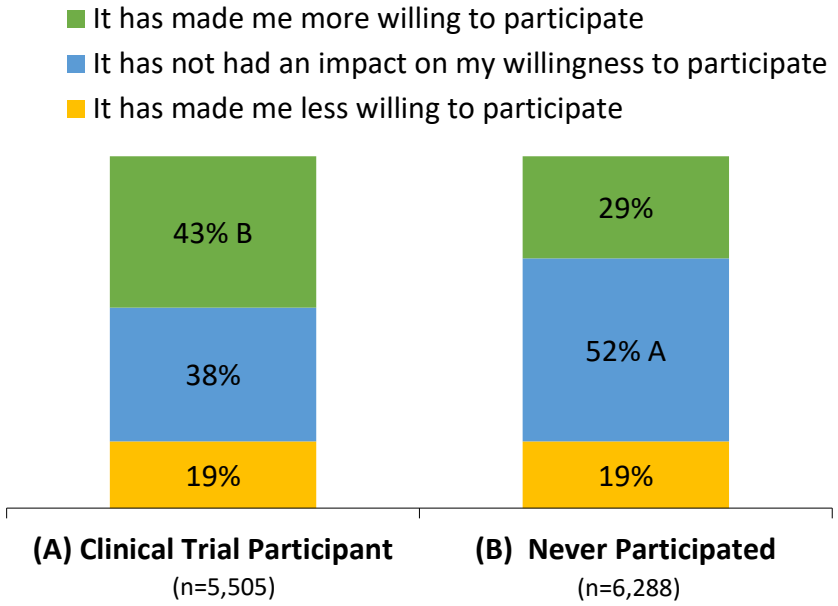
- Those who have participated in clinical research were more likely to report that the COVID-19 pandemic has made them more willing to take part in a clinical research study, whereas those who have not participated were more likely to report that the pandemic has not affected their willingness to participate.

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'

What impact, if any, has the COVID-19 pandemic had on your willingness to participate in a clinical research study?



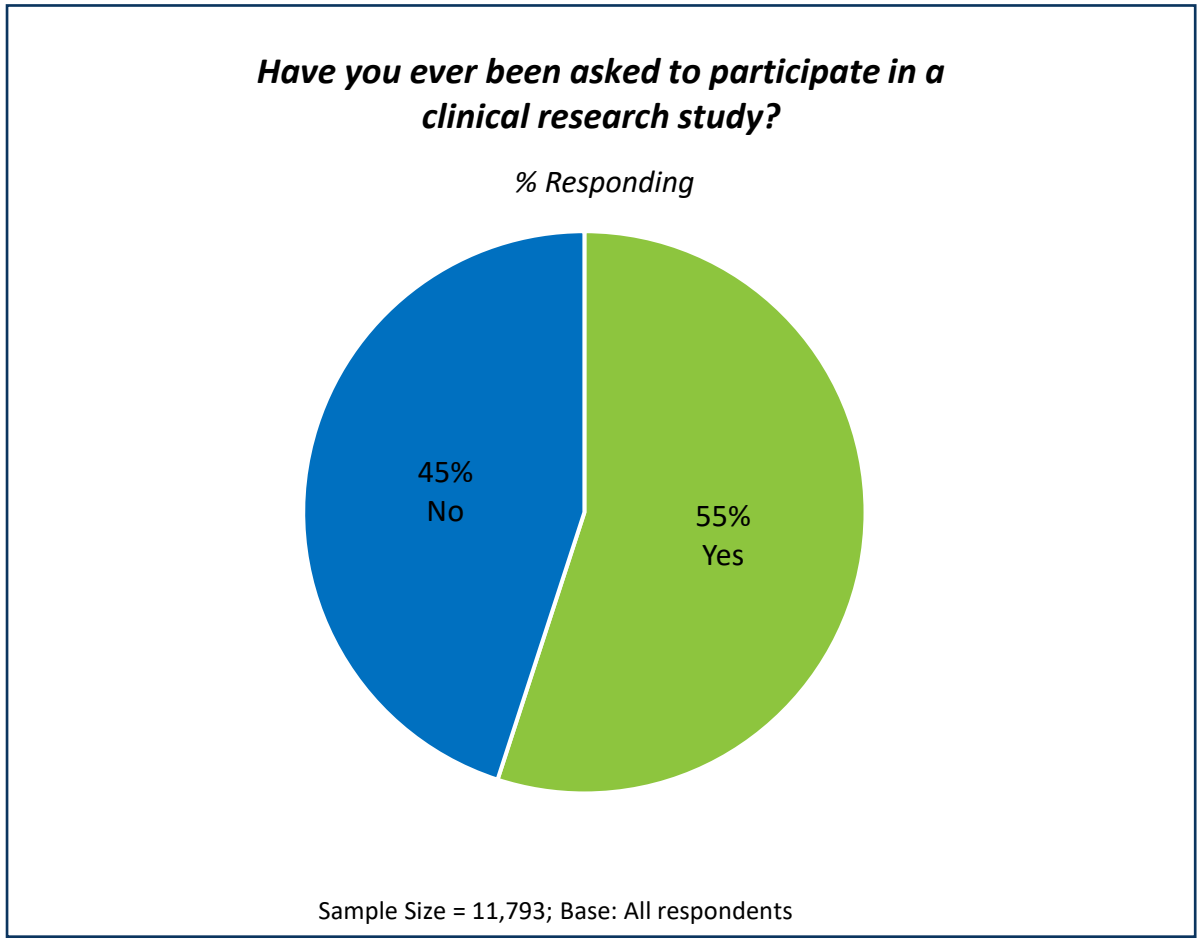
Letters indicate statistical significance at 95%

Sample Size = 11,793; Base: All respondents

Non-Hispanic respondents were more likely to be 'Very Willing' to participate in a clinical research study (44%) than Hispanic respondents (35%).

Those from South America were more likely to report that the pandemic 'Greatly Increased' their willingness to participate than any other region, with respondents from Africa and Asia-Pacific more likely to report the pandemic decreasing their willingness to participate than other regions.

BECOMING AWARE OF RESEARCH OPPORTUNITIES



Those from North and South America were less likely to report being asked to participate in a clinical research study (52% and 41%) than those from Europe (62%), Asia-Pacific (62%), and Africa (63%).

Over half of respondents reported that they had been asked to participate in a clinical research study in 2021 (55%), an increase from 2019 when less than half (45%) of respondents had been asked to participate.

- In 2021, Hispanic respondents were more likely to have been asked to participate in a clinical research study (65%) than non-Hispanic respondents (52%), and Black respondents were more likely to be asked to participate (65%) than White respondents (52%).

The most common ways study volunteers were asked to participate were through direct contact or targeted social media, with social media rising as a leading method compared to 2019.

Top Mentions:

Through an email I received from a research study center or patient recruitment company (30%)

Through a telephone call from a research study center or patient recruitment company (17%)

Through social media (e.g., Facebook, Twitter, Instagram) (16%)

Through my doctor (14%)

INFORMATION NEEDED

Prior to deciding to participate in a clinical research study, the majority of respondents indicated it was most important to know about the potential risks and benefits of the study, the purpose, and information about the study drug.

- For "high importance" information, non-Hispanic subgroups were more likely to select 'Very Important' than Hispanic subgroups.

HIGH IMPORTANCE

Before making a decision to participate in a clinical research study, how important is it to you to know each of the following types of information? % indicating 'Very Important'	Never Participated (n=6,288)
Potential risks and benefits	77%
Purpose of the clinical research study	71%
Information about the study drug being researched	68%
Types of medical procedures required	67%
How my confidentiality would be protected	62%
Results and information from earlier phase studies on the study drug	56%
If I would receive a summary of the study results after my participation ended	55%
Potential costs and reimbursements	54%
Length of participation in the clinical research study	51%
Physical location of the research study center	50%

n= 11,793; Base: All respondents

White respondents were more likely to report that it was 'Very Important' to know each of the top four types of "high importance" information than any other racial group.

As a general trend, older respondents were more likely to report that knowing the purpose of the study was 'Very Important' (45-54 76%; 55-64, 82%; 65+, 83%) compared to younger respondents (18-34, 51%; 35-44, 65%).

Black (66%) and White (62%) respondents were more likely to report that knowing their confidentiality would be protected was 'Very Important', compared to Asian respondents (55%).

Respondents without clinical research experience from Europe, Asia-Pacific, and Africa were less likely to think knowing results and information from earlier phase studies on the study drug was 'Very Important' (48%, 44%, 46%) than those from North (59%) and South America (62%).

INFORMATION NEEDED (continued)

LOWER IMPORTANCE

Before making a decision to participate in a clinical research study, how important is it to you to know each of the following types of information? % indicating 'Very important'	Never Participated (n=6,288)
Information about the company sponsoring the study	48%
If I would have access to the study drug after my participation ended	46%
Hearing about the experiences of previous research participants	45%
Duration of each study visit	44%
Number of study visits	43%
Flexible visit scheduling	42%
Knowing a group of patients and caregivers with your condition had provided feedback on the study design before beginning to enroll study volunteers	41%
If time off from work is compensated	40%
Knowing that other clinical trial participants are representative of diverse communities	35%
Knowing that the staff conducting the study are representative of diverse communities	28%

n= 11,793; Base: All respondents

Having information about the company sponsoring the study drug, having access to the study drug after participation, and hearing the experiences of previous research participants are viewed as 'Very Important' to know prior to joining a study.

- However, Black respondents were more likely to cite knowing participants and staff represent diverse communities, knowing feedback has been provided on the trial from patients, and hearing previous participants' experiences as 'Very important'.

Middle-aged respondents (45-64) were more likely to think that flexible visit scheduling and number of study visits were 'Very Important' than any other age subgroup.

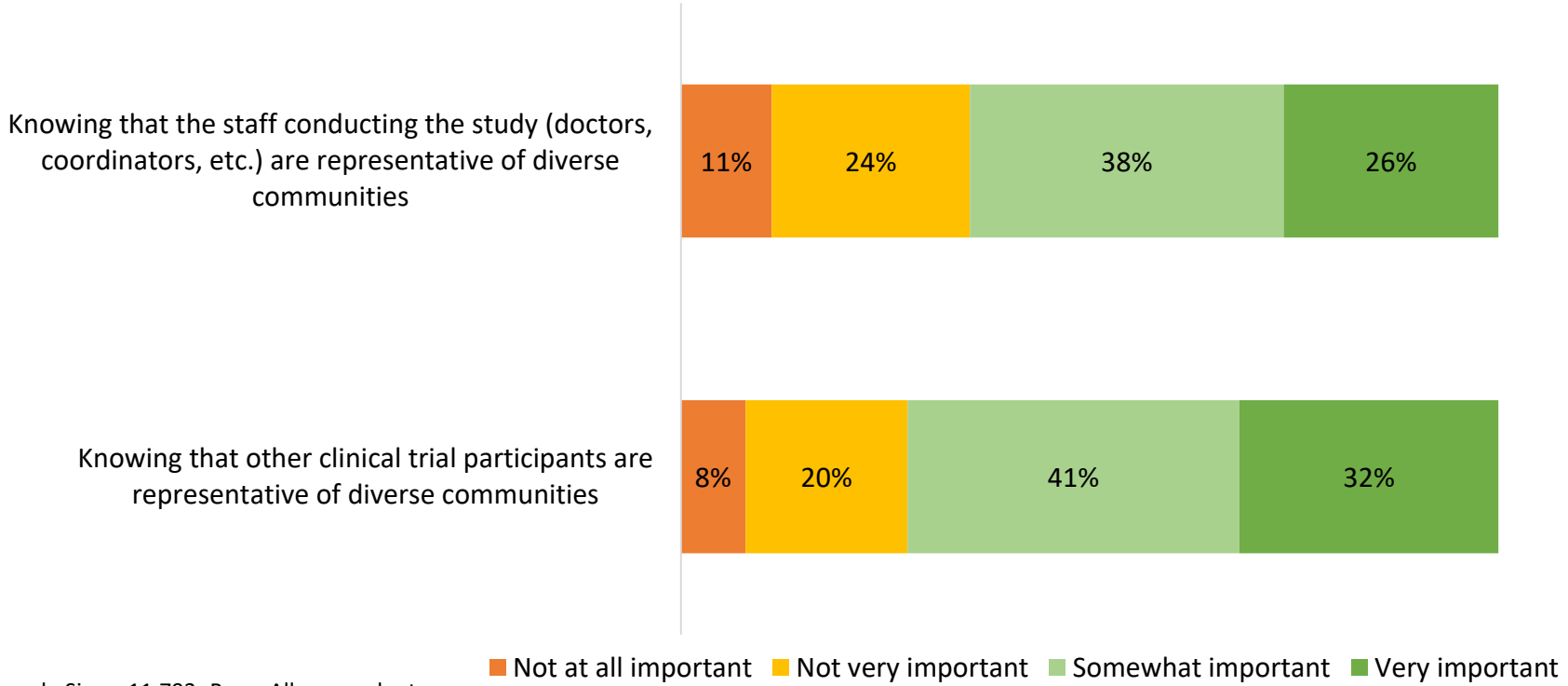
Those from North and South America without clinical research experience were more likely to think that knowing information about the company sponsoring the study was 'Very Important' (52% and 57%) than those from Europe (37%), Asia-Pacific (36%), and Africa (39%).

IMPORTANCE OF DIVERSITY

Overall, most respondents indicated that knowing the study staff and study participants are representative of diverse communities was important, highlighting the importance of diversity and inclusion within clinical research.

- Black respondents were more likely to report that having both diverse staff and diverse participants was 'Very Important' (39%, 44%) than White (25%, 31%) and Asian respondents (27%, 31%).
- Hispanic subgroups were more likely to report that having diverse staff and participants was 'Very Important' (29%) than non-Hispanic subgroups (25%).

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



Sample Size = 11,793; Base: All respondents

Female respondents were more likely to report that having study staff (28%) and participants (36%) representative of diverse communities was 'Very Important', compared to male respondents (25%, 29%).

Older respondents (45 and older) were more likely to report that knowing study staff (14-17%) and participants (8-10%) represented diverse communities was 'Not At All Important' than younger respondents (18-44) (5-7%, 5-6%).

Those from North America were more likely to think that knowing participants are representative of diverse communities was 'Very Important' (35%) than those from Europe (23%), Asia-Pacific (26%), and Africa (27%).

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 July 2021, 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, and from investigative sites. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, AES, CureClick, Benchmark Research, and IQVIA to reach and engage respondents.

A total of 11,793 respondents completed the survey. Respondent characteristics are as follows:

Gender	51% Female | 45% Male | 4% All other genders
Region	69% North America | 3% South America | 19% Europe | 6% Asia-Pacific | 3% Africa
Age	31% 18 - 34 years old | 16% 35 - 44 years old | 14% 45 - 54 years old | 18% 55 - 64 years old | 21% 65 or older
Race	74% White | 7% Black or African American | 5% Asian
Ethnicity	72% Non-Hispanic | 28% Hispanic
Incidence of participation in a clinical trial	53% have never participated | 47% 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

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

HEALTH COMMUNICATION SERVICES

Information in plain and easy-to-read language

- Trial Results Summaries
- Educational Brochures
- Health Communication Projects
- Review Panels

INTERNATIONAL EDUCATION & AWARENESS

Helpful facts and information about clinical research

- Content Licensing
- Media Awareness Campaigns: USA Today, Patient Diversity
- Website Content Development
- New Brochure Development

CISCRP

Engage

Educate

Inform