



# PERCEPTIONS AND INSIGHTS STUDY 2021


*ENGAGEMENT PREFERENCES*


# INTRODUCTION


Supportive services and flexible study visit options continue to play a critical role in improving access to clinical research studies particularly among underrepresented communities.

In this report, CISCRP highlights engagement preferences for participation in clinical research studies. These findings identify important elements of participation, as well as provide a comprehensive view of receptivity to various decentralized clinical research models. The findings can help inform the design and optimize the implementation of these clinical research studies.

## HIGHLIGHTS

 Options continue to be key as engagement preferences vary widely - no single clinical research model more appealing than another among respondents.

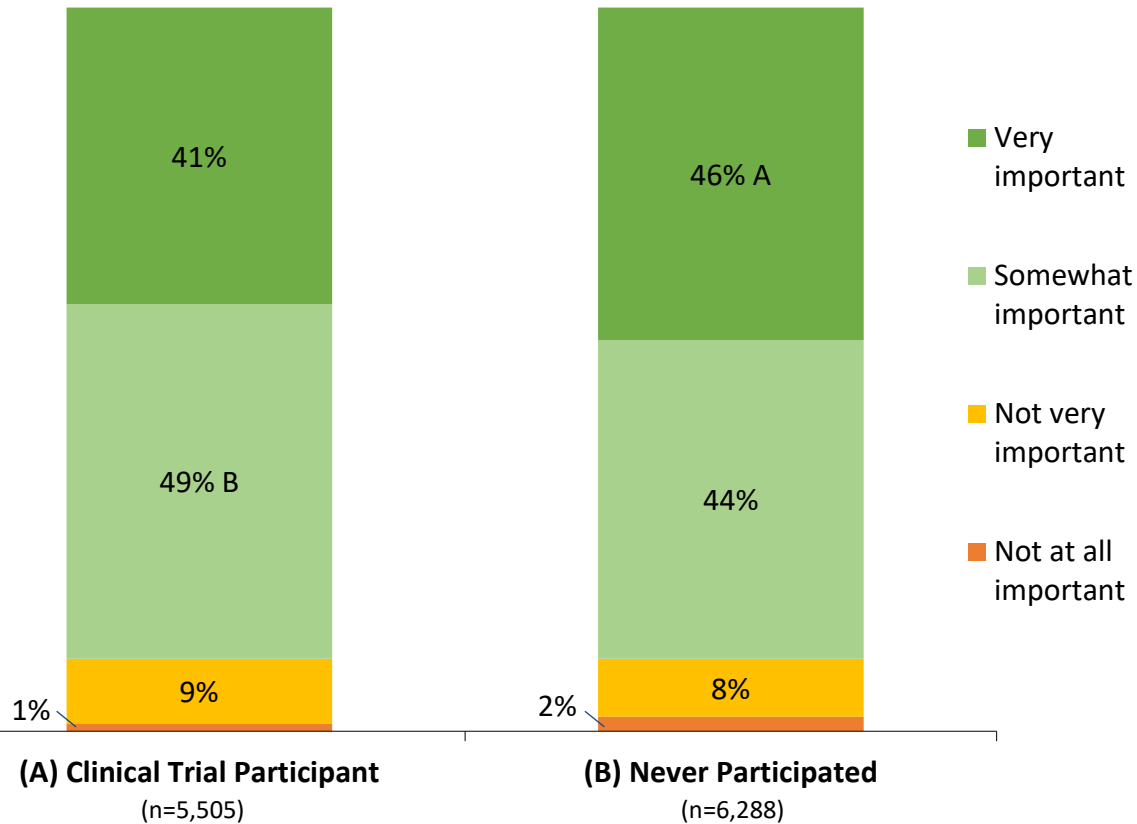
 As seen in 2019 findings, access to educational information about condition and study is most important.

 Consistent with previous findings, there is continued high interest in receiving a summary of study results, as well as individual results - with e-mail and regular mail as the most preferred methods of delivery.



# PROVIDING OPTIONS FOR STUDY VISITS

*When thinking about the different ways you could participate in a clinical research study (i.e., study visits at the clinic, virtual visits from home, etc.), how important is it to you to be presented with options for where to have your study visits?*



Letters indicate statistical significance at 95%

Sample Size = 11,793; Base: All respondents

The majority of respondents stress the importance of being provided options for completing study visits, such as virtual and home visits.

- Hispanic respondents (41%) were less likely to report being presented options as 'Very Important' compared to non-Hispanic respondents (45%).
- No significant differences were found among White (45%), Black (46%), or Asian (42%) respondents when indicating 'Very Important'.

Female respondents were more likely to cite being provided options as 'Very Important' (48%) compared to male respondents (42%).

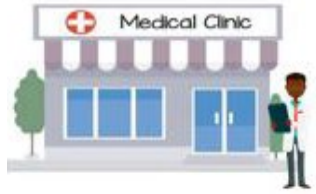
As a general trend, younger respondents were less likely to report that being provided options was 'Very Important' (18-34, 37%), compared to older respondents (55-64, 51%; 65+, 47%).



North (45%) and South (59%) American respondents were more likely to report 'Very Important' than all other regions.

# CLINICAL RESEARCH STUDY MODELS

How willing would you be to participate in each of the following types of clinical research studies?



Having **all** study visits at the study clinic and seeing the study doctor and staff in-person at the clinic **only**



Having **some** study visits at home and **some** visits at the study clinic, and seeing the study doctor sometimes via video conference from home or in-person at the clinic



Having a nurse come to your home for **all** of your study visits and speaking to the study doctors via video conference from home



Collecting **all** of your health data on your own at home using technology and only talking to the study team via video conference from home



Sample Size = 11,793; Base: All respondents

Consistent with findings from 2019, individual preferences for engaging in clinical research vary. Importantly, there is a general strong willingness to participate in a range of models.

- Non-Hispanic respondents were significantly more likely to report 'Very Willing' for all types of clinical research study models compared to Hispanic respondents.

As a general trend, those with higher self-reported levels of education were more likely to cite 'Very Willing' for having some study visits at home and some at the study clinic.

Black respondents were more likely to report 'Very Willing' to collect all data at home (38%) compared to Asian respondents (30%), and All Other Races (29%).

2019

- ✓ A slight increase was displayed in those 'Very Willing' to have a nurse come to the home for all visits (36%) compared to 2019 (30%).

# RESEARCH STUDY FEATURES

**When deciding to participate, those who have never participated in a clinical research study value being provided information on both their general health and the clinical research study, as well as the opportunity to complete a satisfaction survey.**

- Hispanic and Black subgroups were more likely to cite the following as 'Very Important' compared to non-Hispanic and White subgroups: mobile app availability, information specific to caregivers, having documents in electronic format, and some or all study visits conducted at home/office.

If you were to participate in a clinical research study, how important are the following to your participation? % indicating 'Very Important'	Never Participated (n=6,288)
Being provided with supporting information on managing my health condition in general	52%
Being provided with supporting information on the clinical research study	50%
Being provided the opportunity to complete a satisfaction survey on your clinical research study experience to provide feedback	44%
Supportive services	41%
Availability of mobile applications	33%
Availability of clinical research study information designed specifically for caregivers	36%
Being able to review and sign study documents in an electronic format	31%
Clinical study medicine delivered to my home	33%
Some or all study visits conducted at my home or my office	23%

Females were more likely to report 'Very Important' for being provided supporting information on managing the health condition (57%) and on the clinical research study (57%), compared to males (47%, 42%).

Those with a household income of less than \$25,000 were more likely to rank supportive services as 'Very Important' (58%) than any other income group.

**2019**

✓ Information on managing the health condition, supporting information on the study, and the opportunity to complete a satisfaction survey were consistent from 2019 top mentions.

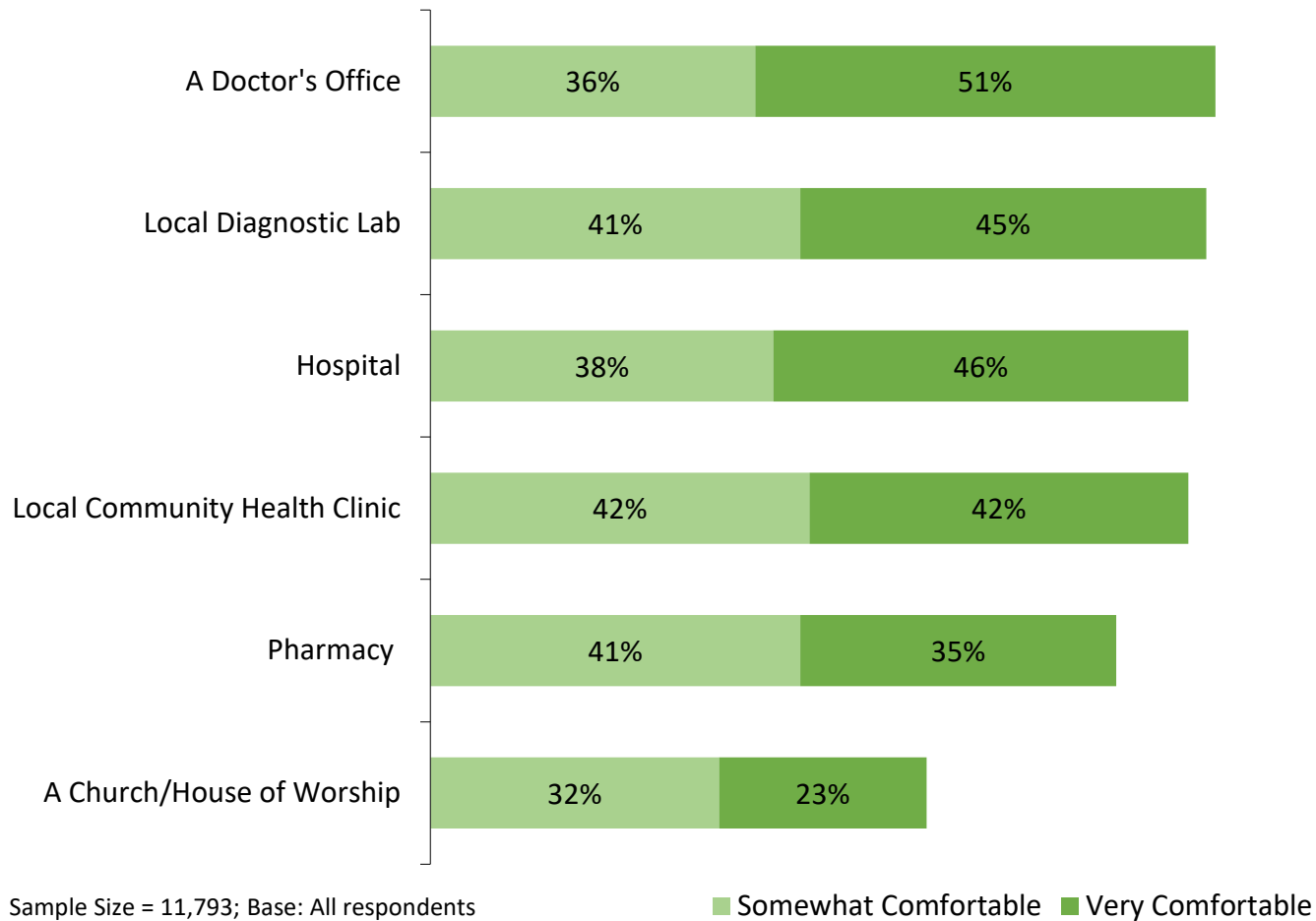
n= 11,793; Base: All respondents



As a general trend, those from South America were significantly more likely to report 'Very Important' for all features compared to all other regions.

# WILLINGNESS TO TRAVEL FOR IN-PERSON VISITS

*If you were to participate in a clinical research study, how comfortable (if at all) would you feel going to each of these locations for your study visits?*



The majority of respondents are generally comfortable traveling at this time for in-person visits, with preference for doctor's offices and local diagnostic labs. Notably, individuals from diverse communities are less willing to attend in-person clinic visits regardless of location type.

- Hispanic respondents were significantly less likely to cite 'Very Comfortable' for all study visit locations compared to non-Hispanic respondents.
- Comparatively, White respondents were significantly more likely to report 'Very Comfortable' for all locations.

Black respondents were more likely to report 'Very Comfortable' at a doctor's office and hospital (41%, 42%) compared to Asian respondents (34%, 34%) and those indicating All Other Races (32%, 32%).

Respondents with a self-reported medical condition were significantly more likely to report being 'Very Willing' to travel for in-person visits (48%), compared to those without a self-reported medical condition (34%).



Europeans were more likely to cite 'Very Comfortable' at local community health clinics (57%) and a doctor's office (57%) compared to all other regions.

# RETENTION FACTORS

Please rank the following starting with the items that would be most likely to keep you enrolled in a clinical research study until the end (i.e., not drop out) and ending with the item that would be least likely to keep you enrolled.	Overall Rank	Total Score*
Feeling/seeing benefit from the study drug	1	79,516
Being informed of the clinical research progress on a regular basis	2	75,617
Having study visits with flexible times	3	73,924
Reimbursing any out-of-pocket expenses	4	69,077
The ability to have my study visits at home (i.e., remote study visits) rather than traveling to a study clinic	5	68,782
Knowing I would receive a larger amount of compensation (money) at the end of the study	6	64,221
Receiving small amounts of compensation (money) after every study visit	7	62,449
Having my study visits not last longer than one hour	8	62,229
Having transportation provided to me to/from the study clinic	9	60,271
Having childcare available	10	32,652

**Top retention drivers include feeling/seeing benefit from the study drug, being informed of study progress, and having flexible visit times.**

- No statistical differences were found by age, gender, race, or ethnicity for the top four retention factors.

Hispanic respondents were significantly more likely to rank having study visits at home higher (4.93) than non-Hispanic respondents (5.26).

Compared to males, female respondents were slightly more likely to rank receiving a larger amount of compensation at the end of the study lower (5.63 for females and 5.49 for males).

On average, Black (5.57) and Asian (5.48) respondents ranked transportation to the clinic higher than White respondents (6.03).



Individuals from South America ranked receiving compensation at the end of the study (6.29) significantly lower than all other regions.

\*Total score calculated through assigning a weighted value to each rank. Total score is sum of weighted values across all respondents.

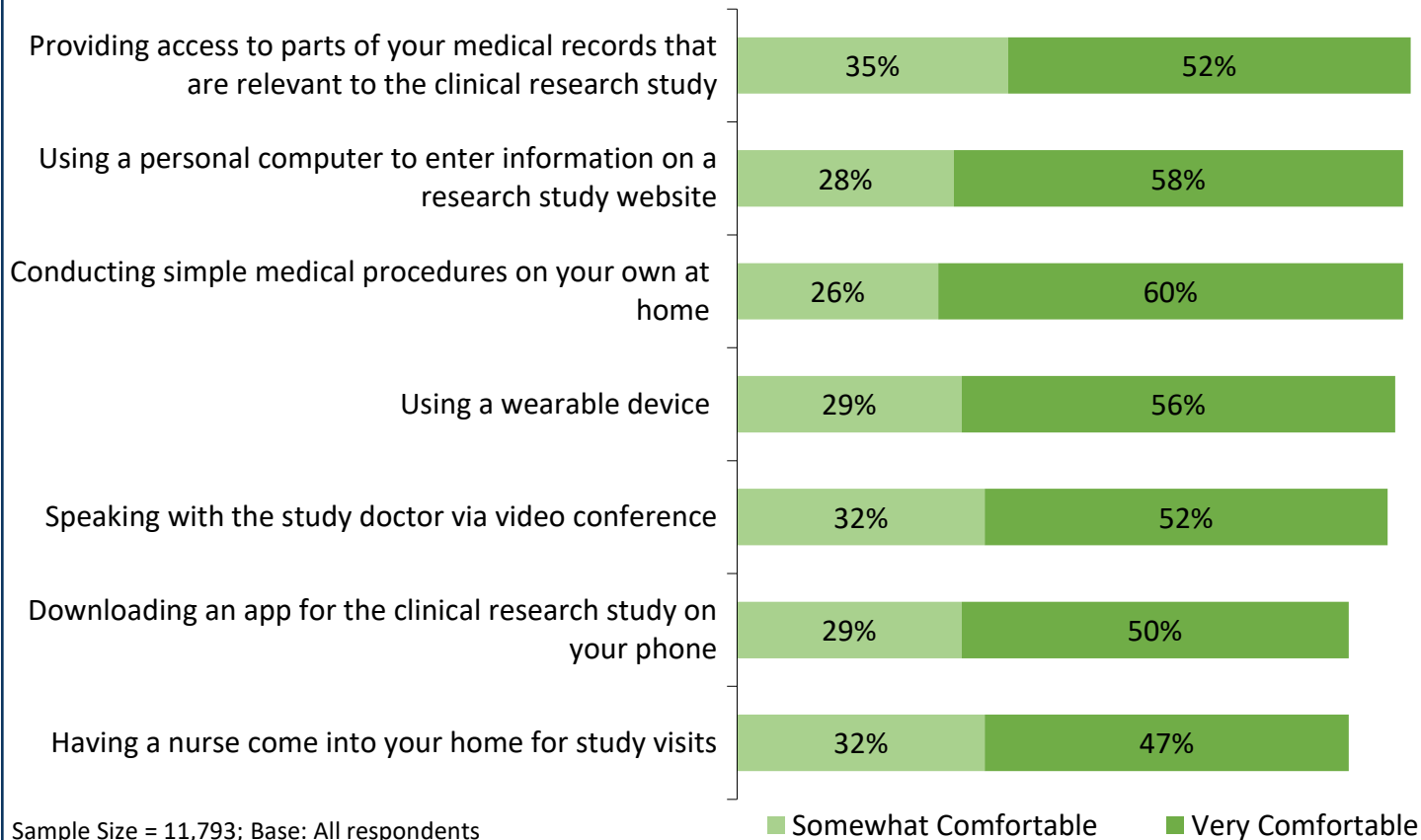
Sample Size = 11,793; Base: All respondents

# AT-HOME AND TECHNOLOGY PREFERENCES

The majority of respondents report being comfortable providing access to their medical records and completing elements of the clinical research study at home, such as using a personal computer to enter information and conducting simple medical procedures.

- Notably, results showed that White and non-Hispanic respondents were more comfortable providing access to parts of their medical records (55%, 55%) than Black (46%) and Asian respondents (39%), as well as Hispanic respondents (44%).

*If you were to participate in a clinical research study, how comfortable would you be with each of the following:*



**For those not comfortable with using technology, privacy concerns are raised, highlighting the need for additional safety reassurances.**

- Black respondents were more likely to be concerned about their privacy and confidentiality (64%) than White (53%) and Asian (49%) respondents.



**Reasons not comfortable:**  
(top mentions)

- ✓ I am concerned my privacy/confidentiality would not be protected (53%)
- ✓ I do not feel comfortable using this/these type(s) of technology (43%)
- ✓ I am concerned the use of technology may cost me money (e.g., data/internet usage) (32%)

Sample Size = 3,256

Base: Those indicating 'Not very' or 'Not at all' comfortable with video conference, app, or wearable device

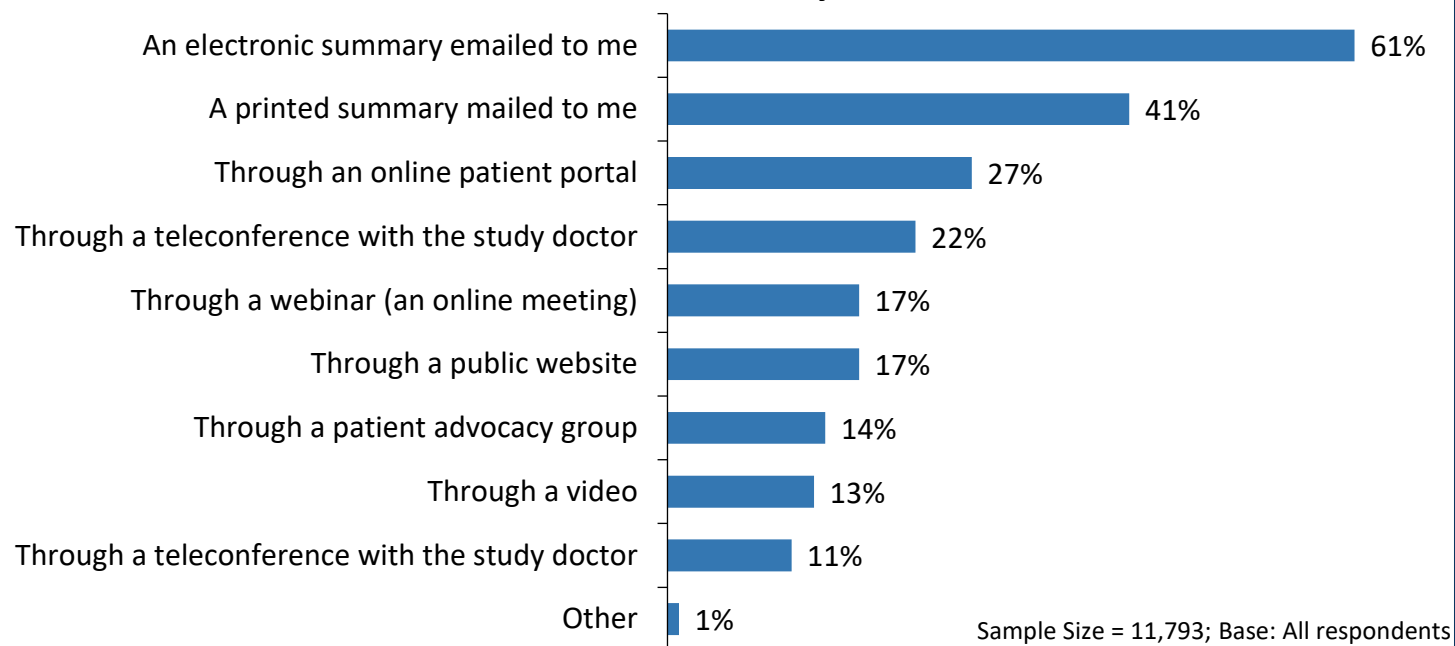


# STUDY RESULTS PREFERENCES

**Overall preference is to receive a summary of the results via email followed by regular mail. Individuals are most interested in receiving their individual study results and overall study results after completing their participation in a clinical research study.**






- As a general trend, older and middle-aged populations preferred printed and electronic summaries, whereas younger populations preferred a webinar, video, teleconference, or public website to share summary results.

## How would you prefer to receive the summary on the results of the clinical research study?



## What information would you be most interested in receiving after completing your participation in a clinical research study?

### Top Mentions:

-  My individual study results (i.e., procedures and test results) (67%)
-  A summary of the study results (65%)
-  Whether I received the study drug or placebo (sugar pill/inactive substance) (58%)
-  Drug approval status by the regulatory agency in your country (45%)
-  The brand name for the study drug (43%)

2019

- ✓ 91% report it was 'Somewhat/Very Important' to receive a summary on the results in 2021, compared to 85% in 2019.



Respondents from Europe showed greater preference for an electronic summary (67%) than those from North America (60%), Asia-Pacific (55%), or Africa (46%).

2019

- ✓ Consistent with 2019 findings, top mentions were: a summary (68%), individual results (64%), and study drug vs. placebo (52%).

# TRANSPARENCY AND PLAIN LANGUAGE

**Overall, there is a strong desire for transparency and the use of plain language when sharing the results of the clinical research study with study participants.**

- As a general trend, non-Hispanic respondents were more likely to report 'Strongly Agree' compared to Hispanic respondents for all indicators.
- White respondents were also more likely to report 'Strongly Agree' compared to Black and Asian respondents for all indicators.

**Please indicate your level of agreement with each of the following statements.**



Male respondents were less likely to 'Strongly Agree' (52%) that it is important to receive overall results in plain, easy-to-understand language compared to females (65%).

Respondents with a self-reported medical condition were more likely to 'Strongly Agree' that it is important to share medical data with their health care providers (71%) than those without a self-reported medical condition (40%).

As a general trend, older respondents were more likely to cite 'Strongly Agree' for returning results in easy-to-understand language: 18-34 years (33%), 35-44 years (46%), 45-54 years (61%), 55-64 years (69%), 65+ years (72%).



Respondents from South America (67%) were more likely to report they 'Strongly Agree' with research sponsors returning results in easy-to-understand language compared to those from North America (55%), Europe (55%), Asia-Pacific (35%), and Africa (35%).

# 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:**

<b>Gender</b>	51% Female   45% Male   4% All other genders
<b>Region</b>	69% North America   3% South America   19% Europe   6% Asia-Pacific   3% Africa
<b>Age</b>	31% 18 - 34 years old   16% 35 - 44 years old   14% 45 - 54 years old   18% 55 - 64 years old   21% 65 or older
<b>Race</b>	74% White   7% Black or African American   5% Asian
<b>Ethnicity</b>	72% Non-Hispanic   28% Hispanic
<b>Incidence of participation in a clinical trial</b>	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.



Engage



**Insights guiding public and patient engagement in clinical research**

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



**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



**Information in plain and easy-to-read language**

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



**Helpful facts and information about clinical research**

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



Educate



Inform

