



2019  
Perceptions  
and Insights  
Study



# *Deciding to Participate*

## **Introduction:**

The decision to participate in a clinical trial is highly personal and each pathway to that decision is different. Patients and their loved ones often turn to their personal doctors for advice, therefore gaining a better understanding of the role healthcare providers play in the decision-making process is critical. Most additionally consult the wealth of information that is available in the public domain, however content can often be unreliable and overwhelming. Consequently, arming prospective study volunteers and their loved ones with the right information from a trusted source has become increasingly important in helping them navigate their decision-making process.

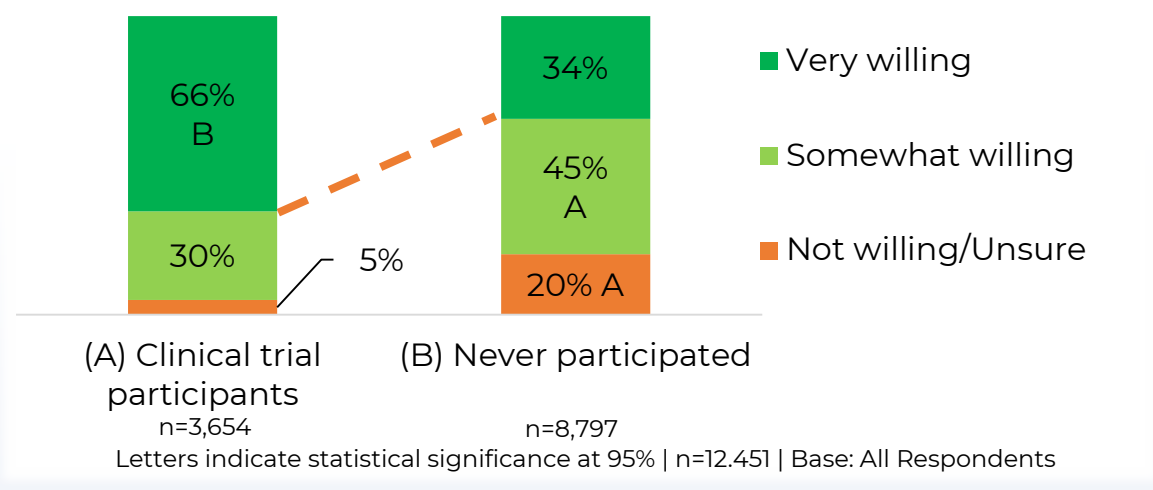
In this report, CISCRP provides a summary of the results of the latest global survey of the general public and patient perceptions about clinical research – including valuable insights on the decision-making process. The findings illustrate what matters most to patients and offers ways to best support and inform prospective volunteers during this process.



The Center for Information and Study on Clinical Research Participation (CISCRP), founded in 2003, is a non-profit organization dedicated to educating the public and patients about the important role that clinical research plays in advancing public health. As part of its mission, CISCRP provides a variety of services designed to assist clinical research stakeholders in (1) understanding public and patient attitudes and experiences and (2) improving volunteer participation experiences and satisfaction. Please consider making a charitable donation to support our mission.



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



**Overall, the majority (85%) of participants continue to be willing to participate in a clinical research study, as seen in studies from previous years.**

- Past clinical trial participants are much more willing to participate compared to those who have never participated.
- Older age groups tend to show more willingness to participate compared to younger age groups.
- Though most of the general public are willing to participate, only 38% were ever asked to participate in a study. Of those who were ever asked to participate, most (62%) have been asked by a study center or patient recruitment company. This number was lower in 2017, with 49% saying that they were contacted by a study center or patient recruitment company.

# Why would or wouldn't you consider participating in a clinical research study?

| Motivations<br>Top 5 Mentions  | Barriers<br>Top 5 Mentions   |
|--|--|
| <ul style="list-style-type: none"> <li>• To help advance science and treatments (62%)</li> <li>• To help others who may suffer from my disease (57%)</li> <li>• To obtain better treatment (51%)</li> <li>• To obtain education about treatment (47%)</li> <li>• To receive money (42%)</li> </ul> | <ul style="list-style-type: none"> <li>• I do not want to take a chance with my health (49%)</li> <li>• Risks of clinical studies (46%)</li> <li>• Don't know enough about clinical research (25%)</li> <li>• Don't want to be treated as a test subject (22%)</li> <li>• Risk of placebo (16%)</li> </ul> |

n=10,479 | Base: Those who said they would be 'Very' or 'Somewhat willing' to participate | n=1,974 | Base: Those who said they would be 'Not at all' or 'Not very willing' or were 'Unsure'

**As seen in previous years, altruistic motivations remain some of the top reasons for participation. Concerns about possible risks remain among the top barriers to participation.**

- Older age groups, especially those over 65, are more likely to be motivated by the advancement of science (68%) and helping others with the same condition (61%) compared to all other age groups.
- 63% of those with 'Very Severe' medical conditions are motivated by the possibility of obtaining better treatment for their disease/condition. This is significantly higher than the 40% of those with 'Very mild' conditions who are motivated by obtaining better treatments.
- One in four of those who are not willing to participate reported that they feel unwilling because they do not know enough about clinical research.

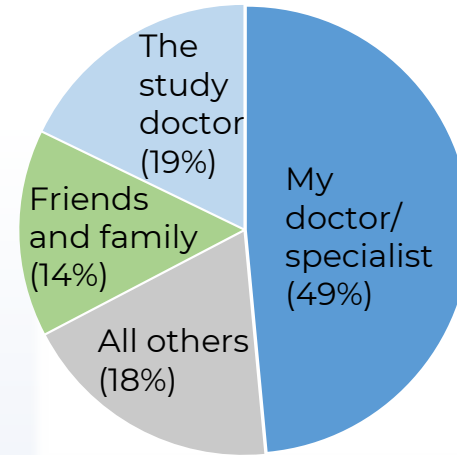
# Before making a decision to participate in a clinical research study, how important is it to you to know each of the following types of information?

| Values indicate % responding 'Very important'          | Never Participated (n=8,797) |
|--|------------------------------|
| Potential risks and benefits                           | 83%                          |
| Purpose of the clinical research study                 | 74%                          |
| Types of medical procedures required                   | 72%                          |
| If my confidentiality would be protected               | 65%                          |
| Physical location of the research study center         | 58%                          |
| Potential costs and reimbursements                     | 60%                          |
| Length of participation in the clinical research study | 56%                          |
| If I would receive the study results afterward         | 57%                          |
| Information from earlier phase studies                 | 55%                          |
| Number of study visits                                 | 48%                          |

**Several different types of information are 'very important' to the participation decision. Overall, risks and benefits, purpose of the study, and types of procedures are the most important information for participants.**

- Priorities remain the same between past participants and those who have never participated, with both groups indicating that risks and benefits are the type of information they want most.
- Women are significantly more likely than men to select 'Very important' for every available option, indicating that a wide array of information is high priority for this group's participation decision. Similarly, those who identify as Black are more likely to select 'Very important' for most options compared to other race subgroups.
- Those living in South America are more likely than all other regions to prioritize previous study results and previous participant experiences as 'Very important.'

# If you were making a decision about whether to participate in a clinical trial, whose advice would you trust the most?



**If you knew your primary care physician or specialist was conducting the clinical research study, how much of an impact, if any, would this have on your willingness to participate?**

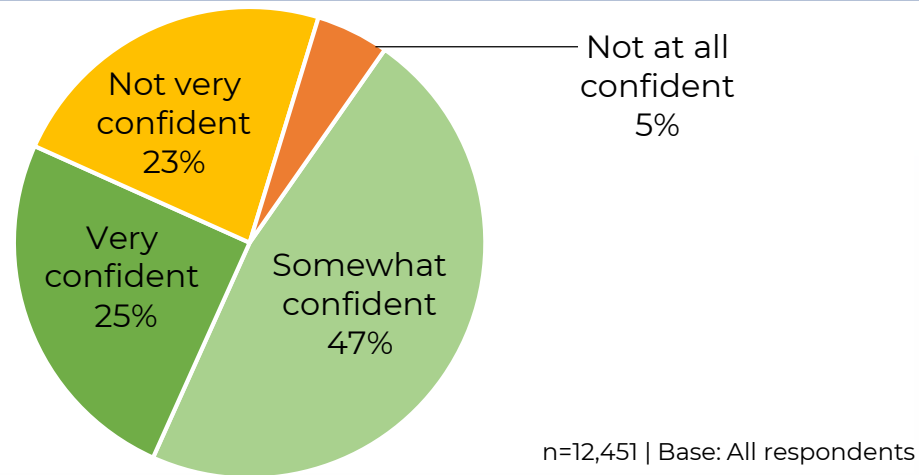


n=12,451 | Base: All respondents

**Healthcare professionals are very influential during the decision-making process. 49% of participants trust the advice of their general practitioner/specialist the most, showing the value of existing patient-provider relationships.**

- Past participants are more likely to trust the study doctor the most (26%) compared to those who have never participated (16%).
- More than half (54%) indicate that they are more willing to participate if they know that their primary care physician or specialist would be conducting the clinical research study.
- Those residing in North America are more likely to trust their own doctor the most compared to all other regions. This population also reports being more willing to participate if their doctor would be involved in the study.

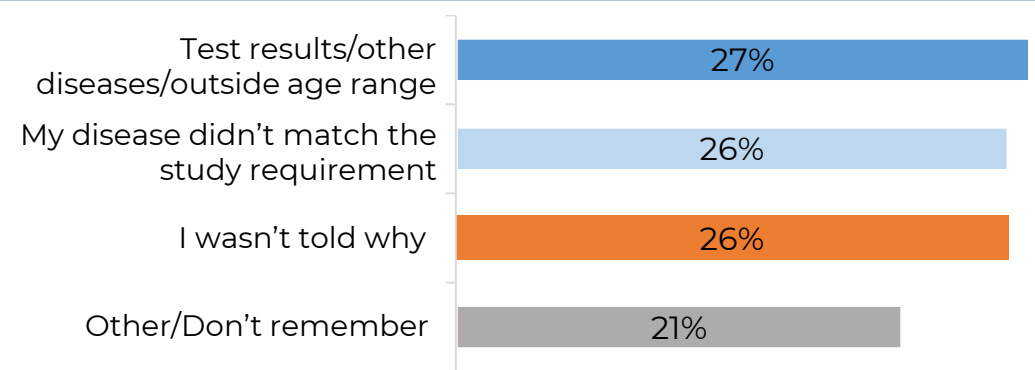
# How confident are you that you could find a clinical research study that is right for you?



**The majority are confident that they could find an appropriate clinical research study. However, 28% report that they are ‘Not very confident’ or ‘Not at all confident,’ showing a need for improvement.**

- When thinking about beginning to conduct their search for a potential study, 50% of participants report that they would ask their primary care physician. Other top mentions include government-maintained databases (42%) and internet search engines (35%).
- Those over 65 are more likely to start their search with their primary care provider, and less likely to start their search using online social platforms, friends/family, and patient communities, compared to all younger age groups.
- After learning of a clinical trial, 67% of individuals reported that they contacted the study center for more information themselves, while 15% report that someone else contacted the study center on their behalf.

# Which of the following reasons best describes why you did not qualify for the clinical research study?



n=1,823 | Base: Those who have never participated, but have tried to participate, and did not qualify for a clinical study

**Of those individuals who tried to participate in a study in the past but were told that they were not eligible for participation, 26% were not told why they did not qualify. This percentage (26%) has not changed since 2017.**

- The majority (69%) of those who were told they were ineligible for participation say that they are still searching for a clinical study at the time of the survey.
- One in five of those who were deemed ineligible say that they will not continue their search for a study, and only 2% report that they have found and enrolled in another study.
- Despite these barriers, 97% of those who were deemed ineligible for a study indicate that they are willing to try to participate in another study in the future, with 66% reporting that they are ‘Very willing.’

# 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 participation 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 June and July 2019, 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 Acurian, Clariness, Continuum Clinical, CureClick, and IQVIA to reach and engage respondents.

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## **A total of 12,451 respondents completed the survey. Respondent characteristics are as follows:**

|   |   |
|---|---|
| <b>Gender</b>   | 55% Female   44% Male   1% All other genders  |
| <b>Region</b>   | 55% North America   6% South America   27% Europe   11% Asia-Pacific   1% Africa                                |
| <b>Age</b>  | 13% 18 - 34 years old   14% 35 - 44 years old   20% 45 - 54 years old   26% 55 - 64 years old   26% 65 or older |
| <b>Race</b>   | 80% White   6% Black or African American   10% Asian  |
| <b>Ethnicity</b>                                      | 85% Non-Hispanic   13% Hispanic   |
| <b>Incidence of participation in a clinical trial</b> | 71% have never participated   29% have participated   |



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.



## Insights guiding public and patient engagement in clinical research

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



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

- Trial Results Summaries
- Health Communication Projects
- Editorial Panels



## Helpful facts and information about clinical research

- Content Licensing
- Media Awareness Campaign: USA Today; Patient Diversity
- Website Content Development; New Brochure Development
- Volunteer Community: Medical Hero's Alumni; Ambassador Network



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

- AWARE-for-All
- Medical Hero's Appreciation 5K
- Journey to Better Health Traveling Exhibit

## Additional Resources

Designed to help professionals best engage patients as partners in the clinical research process. [www.ciscrp.org](http://www.ciscrp.org) Education Center, Quarterly eNewsletter, Search Clinical Trials, Sponsorship Opportunities, Webinars, Online Store