



2019
Perceptions
and Insights
Study



General Perceptions Report

Introduction:

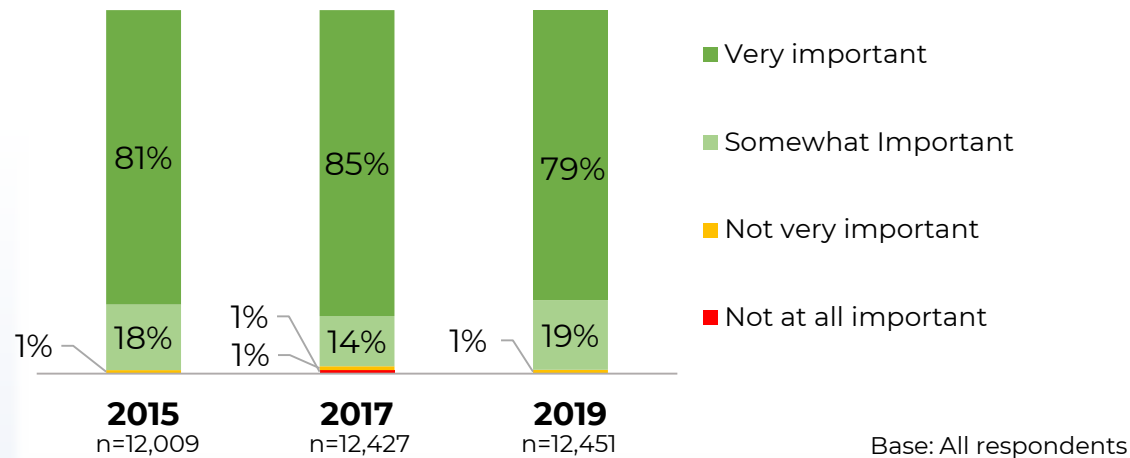
While the public continues to acknowledge the importance of clinical research in identifying new medicines, general awareness of and participation in clinical research studies remain low for a variety of reasons. However, many initiatives are underway to help change this paradigm. In recent years, patients and their loved ones have played a more active role in helping to identify the outcomes most relevant to them and by suggesting ways to minimize the burden of clinical trial participation for study volunteers. Patient advocacy groups and local communities, in partnership with other industry stakeholders, are also developing innovative campaigns and programs to raise awareness. Together, the hope is that these initiatives can help accelerate the pace at which new treatments are developed and become available to patients.

In this report, CISCRP provides a summary of the results of the latest global survey of general public and patient perceptions about clinical research. The findings can help inform the development of targeted outreach and educational strategies.



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.

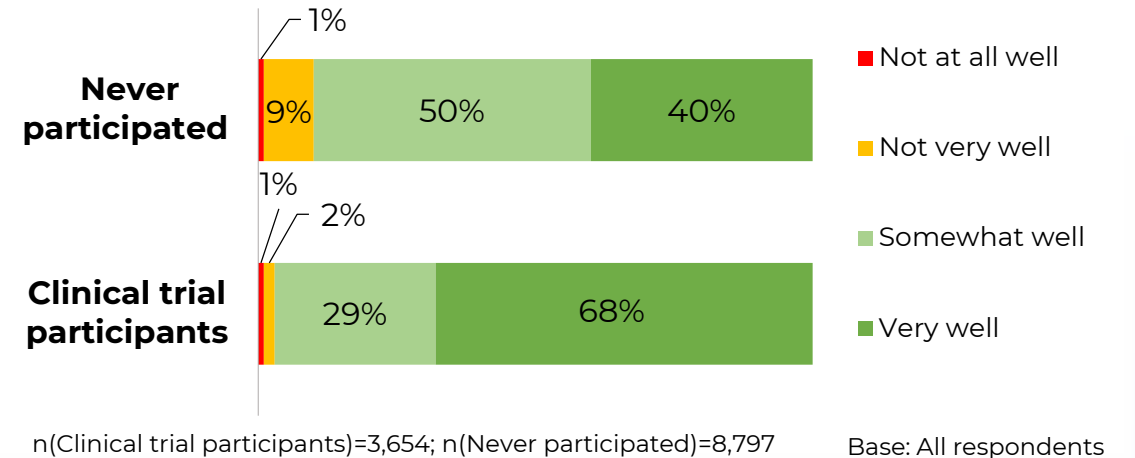
How important do you think clinical research studies are to the discovery and development of new medicines?



Since 2015, public opinion has not changed as most people continue to consider clinical research to be important to the discovery and development of new medicines.

- Those who identify as Black and those who identify as White are more likely to feel that clinical research is 'very important' as compared to other subgroups.
- Past study participants are significantly more likely to find research to be 'very important' (86%) compared to those without previous clinical trial experience (with 76% indicating studies as 'very important').
- Additionally, those who have previously participated place significantly higher value on study participation in general compared to other ways of contributing to human health. 60% of past participants indicate that clinical trial participants make the greatest contribution to human health, a significantly higher proportion than the 52% among those with no previous participation experience.

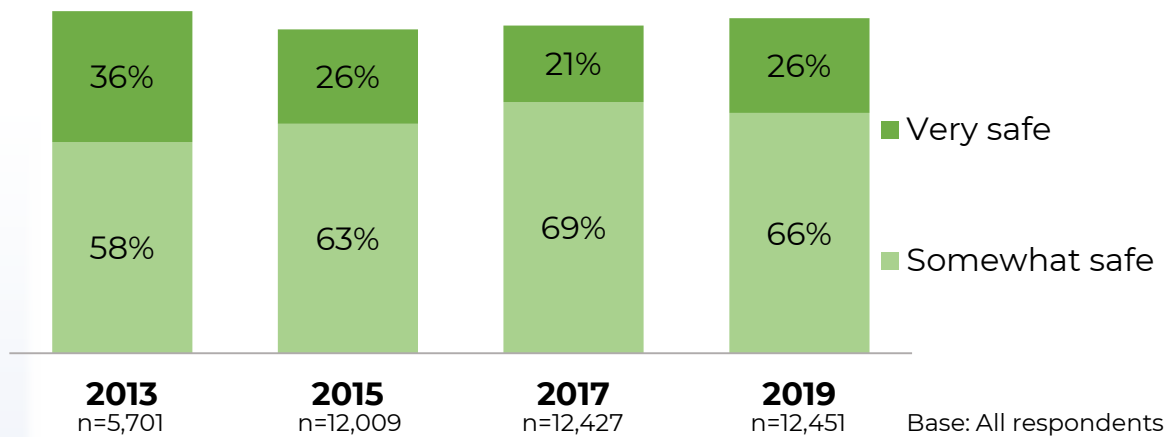
How well do you understand what is meant by the term "clinical research study"?



As in prior years, most continue to say they are informed about clinical research. In 2019, 92% of all those surveyed state that they understand the term clinical research well.

- Past participants are much more likely to indicate that they understand the term clinical research compared to those who have never participated.
- Those who identify as Black as well as older adults are also more likely to report a better understanding of the term as opposed to other subgroups. Those in the Asia Pacific region are the least likely of all regions to report understanding clinical research "very well."
- While the majority of the public may self-report an understanding of the term 'clinical research,' about a quarter of all who responded are not confident in their ability to find a clinical research study that is right for them.

In your opinion, how safe are clinical research studies?



The public continues to consider clinical research studies to be relatively safe. However, the risk of side effects and a lack of trust in pharmaceutical companies are still ranked high among those who express concerns around safety.

- In general, those who report a poor understanding of clinical research also perceive it to be less safe. Younger people, those who have never participated, and those who reside in the Asia/Pacific region are more apt to have concerns about safety compared to other subgroups.
- Those who do not believe clinical trials are safe cite the risk of side effects (67%), lack of trust in pharmaceutical companies (35%), and concerns about placebo (29%).
- Younger people report hearing more negative news stories about clinical research safety, while older people tend to be more wary of pharmaceutical companies and clinical trial safety/quality monitoring standards.

How much do you trust each of the following organizations?

Organization Type	% Trust "a lot"
Research centers/clinics conducting studies	31%
Government research organizations	29%
Regulatory agencies that oversee safety	27%
Pharmaceutical companies	18%

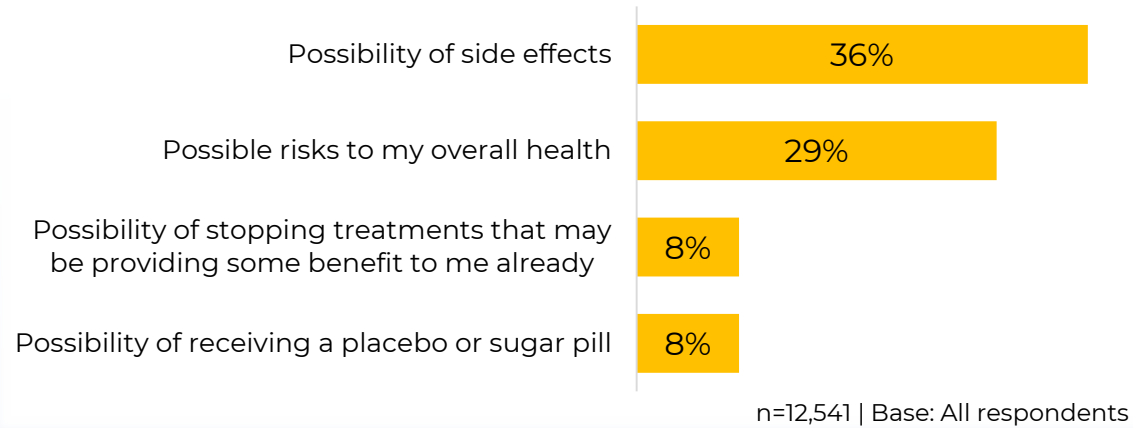
n= 12,451 | Base: All respondents

While all listed institutions are trusted 'Some' or 'A lot' by the majority of people, pharmaceutical companies are the least trusted of these institutions.

- The level of trust in pharmaceutical companies has largely remained the same since 2017, when 16% said they trusted pharmaceutical companies 'a lot,' compared to 18% in 2019.
- Those in North America are significantly less likely to trust pharmaceutical companies compared to those residing in other regions.
- Those living in the Asia/Pacific region are the least likely to trust research centers, which may be a reflection of the overall decrease in safety perceptions expressed by those in this region.
- Notably, while people of Asian descent are significantly less likely to believe clinical research to be safe, they are also significantly more likely to trust pharmaceutical companies compared to other subgroups.

Which one of the following do you consider to be the greatest risk of participating in a clinical research study?

Top Mentions

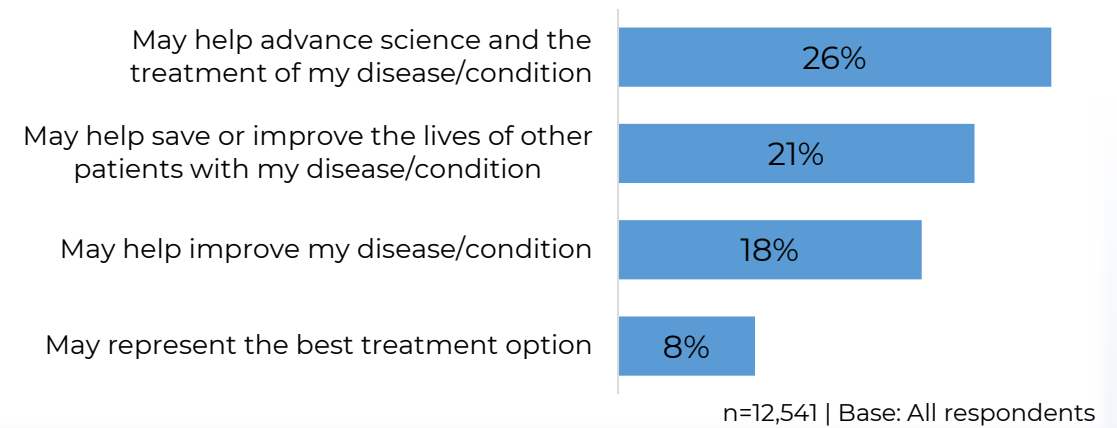


Top perceived risks include the possibility of side effects and possible risks to overall health, consistent with findings in prior years. Some are also concerned about stopping current treatments or receiving placebo.

- Those who have not previously participated are more concerned about the risks to their overall health compared to past clinical trial participants.
- Those who reside in the Asia/Pacific region are most likely to select “possibility of side effects” as their top perceived risk. This trend was also observed in 2017.
- Similar to findings in 2017, older people are more concerned about placebo and the possibility of stopping a treatment that works for them compared to younger people.

Which one of the following do you consider to be the greatest benefit of participating in a clinical research study?

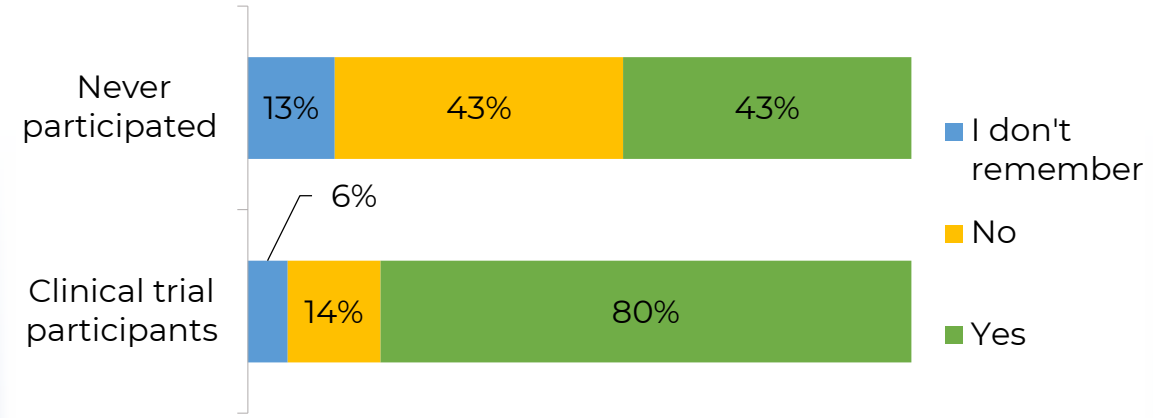
Top Mentions



As seen in prior studies, altruistic reasons continue to top the list of perceived benefits of participating in clinical research.

- Older people are more likely to value scientific advancements as well as the possibility of improving their own condition compared to younger people.
- Monetary compensation is more likely to be mentioned by healthy volunteers as a top benefit of participation (15%). However, advancing science (27%) and improving the lives of other patients (22%) remain the top two items among these healthy volunteers.
- Those living in North America are the most likely to indicate that the chance to improve their disease/condition was the greatest benefit of participation compared to other regions.

Over the past six months, do you remember seeing or hearing about a clinical research study that was looking for volunteers?

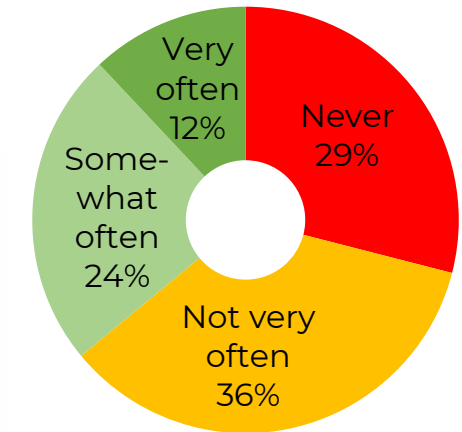


n(Clinical trial participants)=3,654; n(Never participated)=8,797 | Base: All respondents

Though the majority (54%) of all surveyed report recently hearing about a recruiting study, this proportion falls to less than half (43%) among those who have not previously participated in a clinical trial.

- Online advertisements (41%), traditional print advertising (30%), online patient communities (22%), and government databases (17%) are the top places people report seeing or hearing of these opportunities.
- Those living in North America are the most likely to hear about clinical studies and often learn about these studies via online advertisement (43%), traditional print advertising (32%) and online patient communities (23%).
- In general, older individuals are more likely to report hearing about recruiting studies. For example, 64% of those over 65 hear about such studies, while the same is true for only 42% of those under 35.

When discussing treatment options with your doctor, how often do you consider clinical research studies?



n=12,541 | Base: All respondents

If your primary care physician (general practitioner) or specialist was not interested in recommending a clinical research study to you as an option, how confident do you feel that you could convince him/her otherwise?

Very/Somewhat	Not very/Not at all
65%	34%

Despite valuing the importance of clinical research, most do not report regularly discussing clinical trials with their healthcare providers.

- While most do not have conversations with their doctor about clinical research, more than half (65%) believe that they could convince their doctor they should participate in a trial if they identified one that was appropriate for them.
- Although more likely to hear about clinical research studies looking for volunteers, older people report discussing clinical trials with their doctor less often than younger people.
- Younger people are not only more likely to discuss clinical research with their doctors but are also more confident that they could convince their doctors of a clinical research opportunity.

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.

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

Gender	55% Female 44% Male 1% All other genders
Region	55% North America 6% South America 27% Europe 11% Asia-Pacific 1% Africa
Age	13% 18 - 34 years old 14% 35 - 44 years old 20% 45 - 54 years old 26% 55 - 64 years old 26% 65 or older
Race	80% White 6% Black or African American 10% Asian
Ethnicity	85% Non-Hispanic 13% Hispanic
Incidence of participation in a clinical trial	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 Education Center, Quarterly eNewsletter, Search Clinical Trials, Sponsorship Opportunities, Webinars, Online Store