



PERCEPTIONS AND INSIGHTS STUDY 2021


GENERAL PERCEPTIONS


INTRODUCTION

Consistent with prior years, clinical research continues to be viewed as important and generally safe by most. However, perceptions of research have changed over the last two years, in part due to the COVID-19 pandemic.


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.

HIGHLIGHTS

 While overall awareness has increased, self-reported understanding of clinical research has decreased compared to 2019 – particularly among diverse communities and those who have never participated in clinical research.

 A substantial proportion distrust pharmaceutical companies when compared to trust in other organizations – similar to 2019 findings.

 Nearly all respondents recognize the importance of including diverse participants in clinical research studies.

 Technology and other convenience-enhancing initiatives continue to positively impact overall experiences – smart phone apps, text messaging, and video conferencing are viewed as most helpful.



KEY COMPARISONS (2019 V. 2021)

While perceptions of safety and the importance of clinical research remain generally stable from 2019 to 2021, self-reported understanding has decreased somewhat.

- Despite higher levels of awareness, a quarter of respondents are not confident in their ability to find a clinical research study that is right for them. This is consistent with responses in past years.

GENERAL PERCEPTIONS, AWARENESS, AND UNDERSTANDING		2019		2021	
		Never Participated (n=8,797)		Never Participated (n=6,288)	
How well do you understand what is meant by the term "clinical research study", also known as a "clinical trial"?	Very Well	40%		31%	
	Somewhat Well	50%		54%	
In your opinion, how safe are clinical research studies?	Very Safe	20%		18%	
	Somewhat Safe	69%		69%	
How important do you feel it is for your doctor to be aware of clinical research studies being conducted in your community?	Very Important	65%		59%	
	Somewhat Important	29%		33%	
	Important				
In general, when discussing treatment or medication options with your doctor, how often do you consider clinical research studies as another option?	Very often	8%		7%	
	Somewhat Often	22%		20%	
During the past six months, do you remember seeing or hearing about a clinical research study that was looking for volunteers?	Yes	50%		57%	
	No	50%		43%	

Black (35%) and White (31%) respondents were more likely to report they understand clinical research 'Very Well' compared to those identifying as Asian respondents (23%).

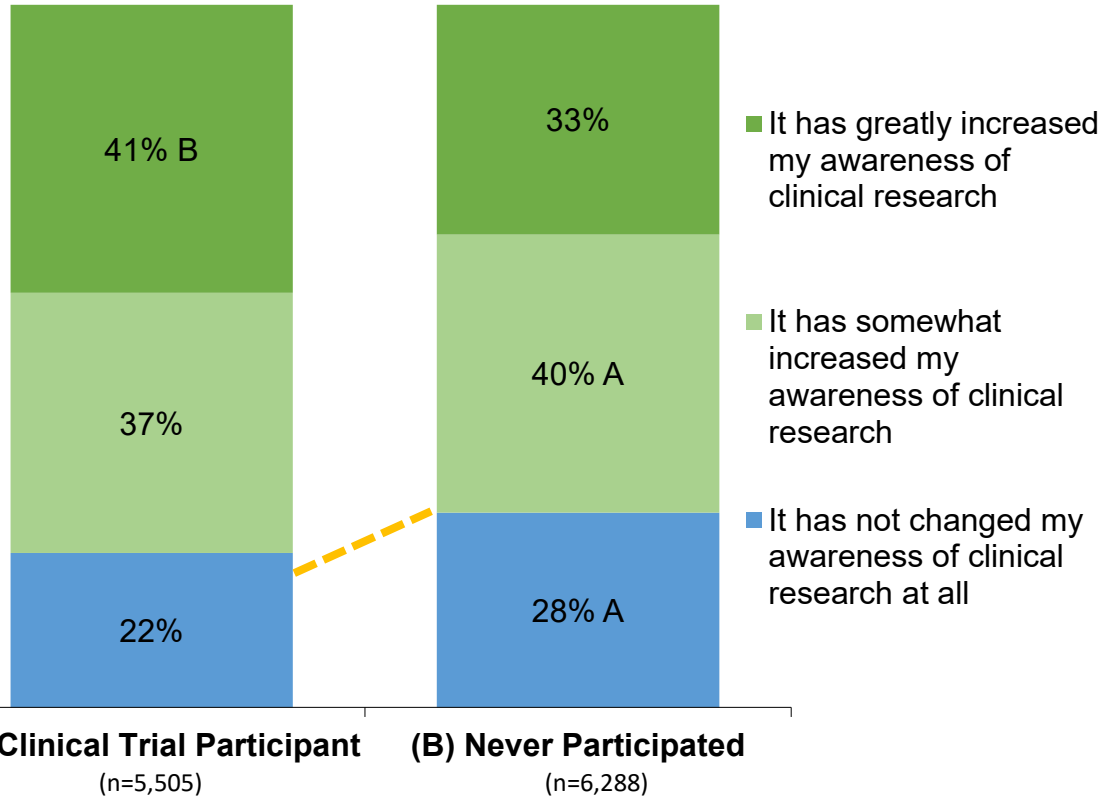
Top mentions for why clinical research studies are unsafe:
There may be side effects (72%); I saw or heard negative news (41%); I don't trust pharmaceutical companies (39%); The safety and quality are not monitored closely enough (37%).

Hispanic subgroups remember seeing more clinical research studies looking for volunteers (80%) compared to Non-Hispanic subgroups (69%).



South American respondents were more likely to report that they understand clinical research 'Very Well', compared to other regions. Additionally, South American and European respondents viewed clinical research studies as the safest.

How has the COVID-19 pandemic changed your awareness of clinical research studies, if at all?



Sample Size = 11,793; Base: All respondents
Letters indicate statistical significance at 95%

Most respondents feel the pandemic has made them more aware of clinical research studies – this increased awareness is even greater among communities historically underrepresented in research.

- Hispanic respondents (46%) were more likely to report ‘Greatly Increased Awareness’ compared to non-Hispanic respondents (33%). Black respondents (43%) were also more likely to report ‘Greatly Increased Awareness’ compared to White (35%) and Asian (35%) respondents.



South American respondents were most likely to report ‘Greatly Increased Awareness’ (55%) compared to all other regions.



HEALTHCARE EXPERIENCES

In addition to increasing awareness of clinical research, the pandemic impacted healthcare experiences. More than half of respondents (56%) shared their healthcare had been impacted ‘Somewhat’ or ‘A Lot’ by COVID-19.

- Hispanic subgroups were more likely to indicate ‘A Lot’ (29%) and ‘Somewhat’ (51%) than non-Hispanic subgroups (15%, 31%).

In what ways has your healthcare been impacted because of the COVID-19 pandemic? (top 3 mentions)



How I prepare for and attend my doctor’s appointments has changed (44%)



My doctor has switched to virtual visits (32%)

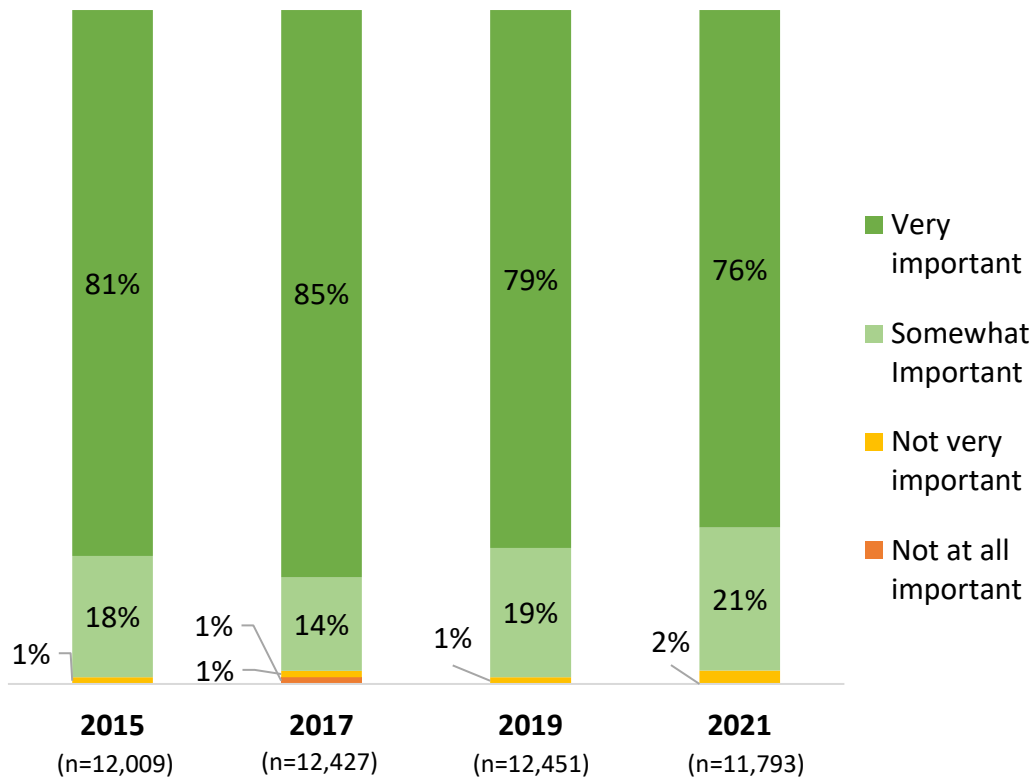
White respondents more likely to report that their doctor has switched to virtual visits (35%) than Black, Asian, and other race subgroups (27%, 26%, and 28%, respectively).



Felt uncomfortable going to doctor’s appointments/getting medical care (36%)

IMPORTANCE AND SAFETY

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



Base: All respondents

Since 2015, public opinion has stayed relatively consistent with most believing that clinical research is ‘Very Important’ to the discovery and development of new medicines.

- White and non-Hispanic respondents were more likely to perceive clinical research as ‘Very Important’ (81% and 84%, respectively) as compared to other racial and ethnic subgroups.
- Older respondents were more likely to perceive clinical research as ‘Very Important’ (91% among those 55 to 64 years of age and 93% among those 65 and older) compared to just 57% among 18- to 34-year-old respondents.

Most respondents feel clinical research studies are relatively safe but concerns around potential side effects, health risks, and stopping beneficial treatments are the greatest perceived risks.



Greatest Benefits (Top 3 Mentioned)

- ✓ May help advance science and treatment of my disease/condition (50%)
- ✓ May help save or improve the lives of other patients with my disease/condition (50%)
- ✓ May help improve my disease/condition (35%)



Greatest Risks (Top 3 Mentioned)

- ✓ Possibility of side effects (67%)
- ✓ Possible risk to my overall health (59%)
- ✓ Possibility of stopping treatments that may be providing some benefit to me already (30%)



Notably, European respondents (85%) were significantly more likely to report clinical studies are ‘Very Important’ compared to all other regions.

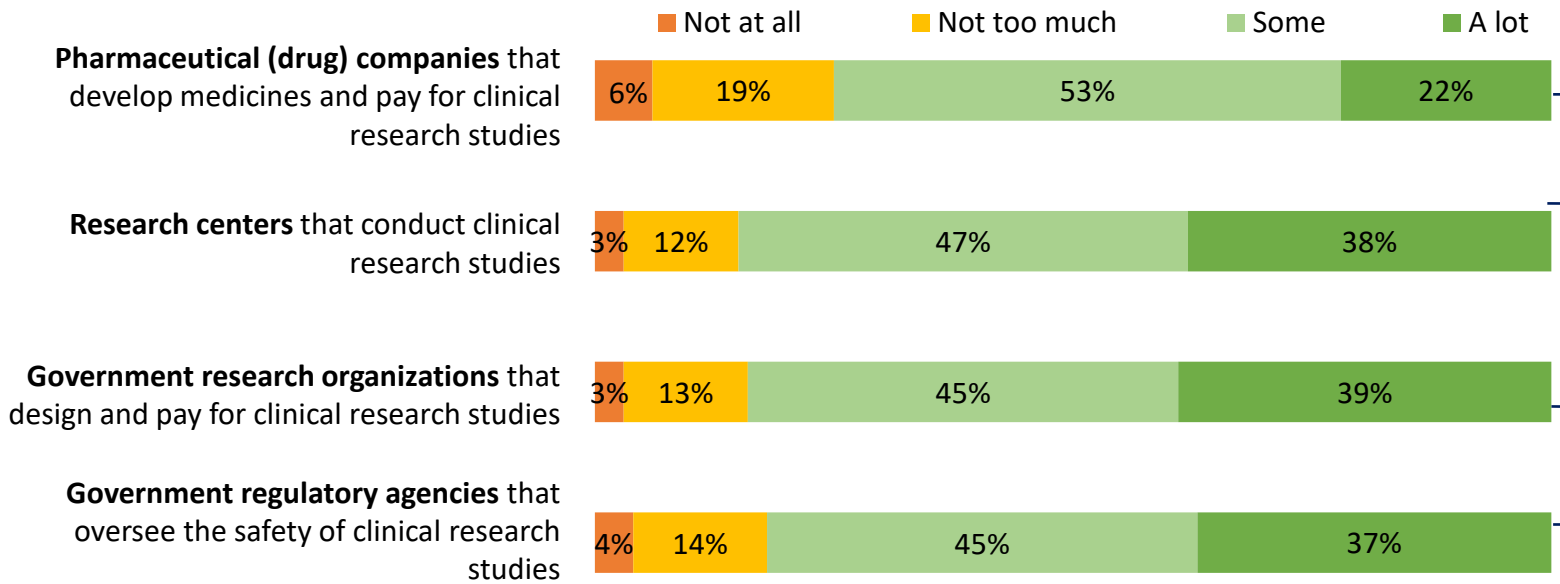
PUBLIC TRUST

While the public's trust in research centers/clinics, government research organizations, and regulatory agencies increased since 2019, trust in pharmaceutical companies remains low.

- Results show that White respondents placed greater trust in government research organizations and research centers than any other race subgroup did.

2019

How much do you trust each of the following organizations, if at all?



Sample Size = 11,793; Base: All respondents

✓ General trustworthiness increased for those reporting 'A Lot' from 2019 for research centers/clinics (31%), government research organizations (29%), and regulatory agencies (27%).

Male respondents were more likely to trust pharma 'A Lot' (23%) compared to females (21%).

White respondents were also more likely to trust research centers 'A Lot' (41%) compared to other races.

Respondents with higher levels of education were generally more trusting of government organizations and authorities.

Older respondents (55 or older) were more likely to trust government regulatory agencies 'A Lot' (39-44%) than younger subgroups (18-54) (33-37%).



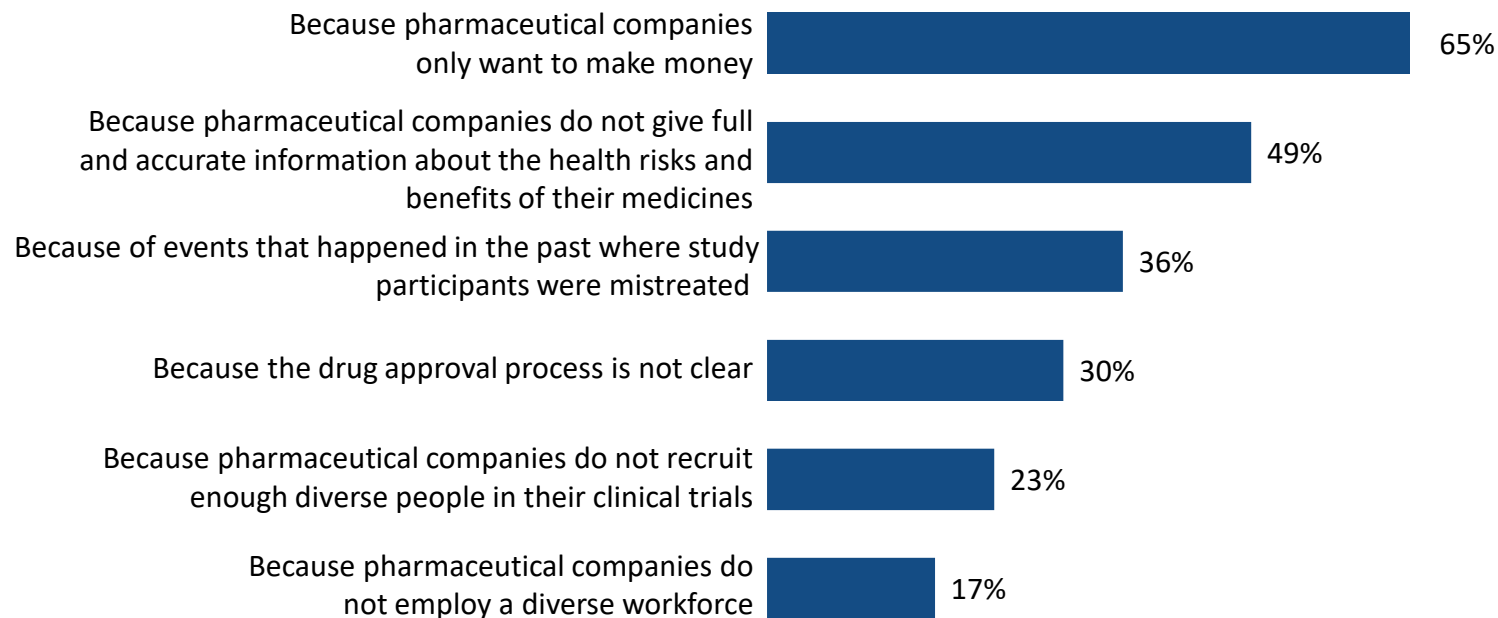
South American respondents (32%) were significantly more likely to cite trusting pharmaceutical companies 'A Lot' compared to all other regions (19-22%). African respondents (25%) were less likely to report trusting government research organizations than those in any other region (34-42%).

INCREASING TRUST IN PHARMACEUTICAL COMPANIES

Financial motivations, withholding information about health risks, and past mistreatment of clinical research participants are cited as the top reasons respondents do not trust pharmaceutical companies.

- Black respondents were more concerned than any other race about past events where participants were mistreated (47%).
- White respondents were distrustful due to pharma's focus on money (72%) more than other racial groups (47-51%). Female respondents were also more concerned (71%) than males (63%) about this focus on money.

Why do you not trust pharmaceutical companies?



Sample Size = 2,946

Base: Those that indicated 'not at all' or 'not much' trust in pharmaceutical companies

Trust in pharmaceutical companies can be improved by sharing information, increasing education, and having inclusive practices.



What, if anything, might increase your trust in pharmaceutical companies? (top mentions)

- ✓ By the company sharing more information about health risks/benefits of their medicines (63%)
- ✓ By the company sharing more information about the clinical research that has been done on their medicines (60%)
- ✓ By the company sharing more information about the drug approval process for their medicines (54%)
- ✓ By knowing that the company included a diverse set of participants in their clinical trials (49%)



North American and European respondents were more distrustful due to pharma's focus on money compared to respondents from Asia-Pacific and Africa. Trust among European respondents would be increased more than most other regions by sharing more information about past clinical research (62%) and drug approval processes (57%).

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.



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

