



2023 Perceptions & Insights Study

Global trends in public and patient attitudes about, and experience with, clinical research.

GENERAL PERCEPTIONS

Introduction

In general, clinical research perceptions remain steady, with much of the population still perceiving clinical research as safe. While awareness of clinical research generally stayed the same in comparison to 2021 results, most people still do not discuss clinical research with their doctors.

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. The findings can help inform the development of targeted outreach and educational strategies.

Like findings in 2021, **over half** indicate **seeing or hearing about a clinical research study** during the past six months.

There is still a gap between where people would prefer to learn about clinical research and actual sources, with **most still preferring to learn about a clinical research study through their doctor.**

Factors that can **build trust** in pharmaceutical companies or organizations that run clinical studies include **transparency** and **the use of patient engagement practices.**

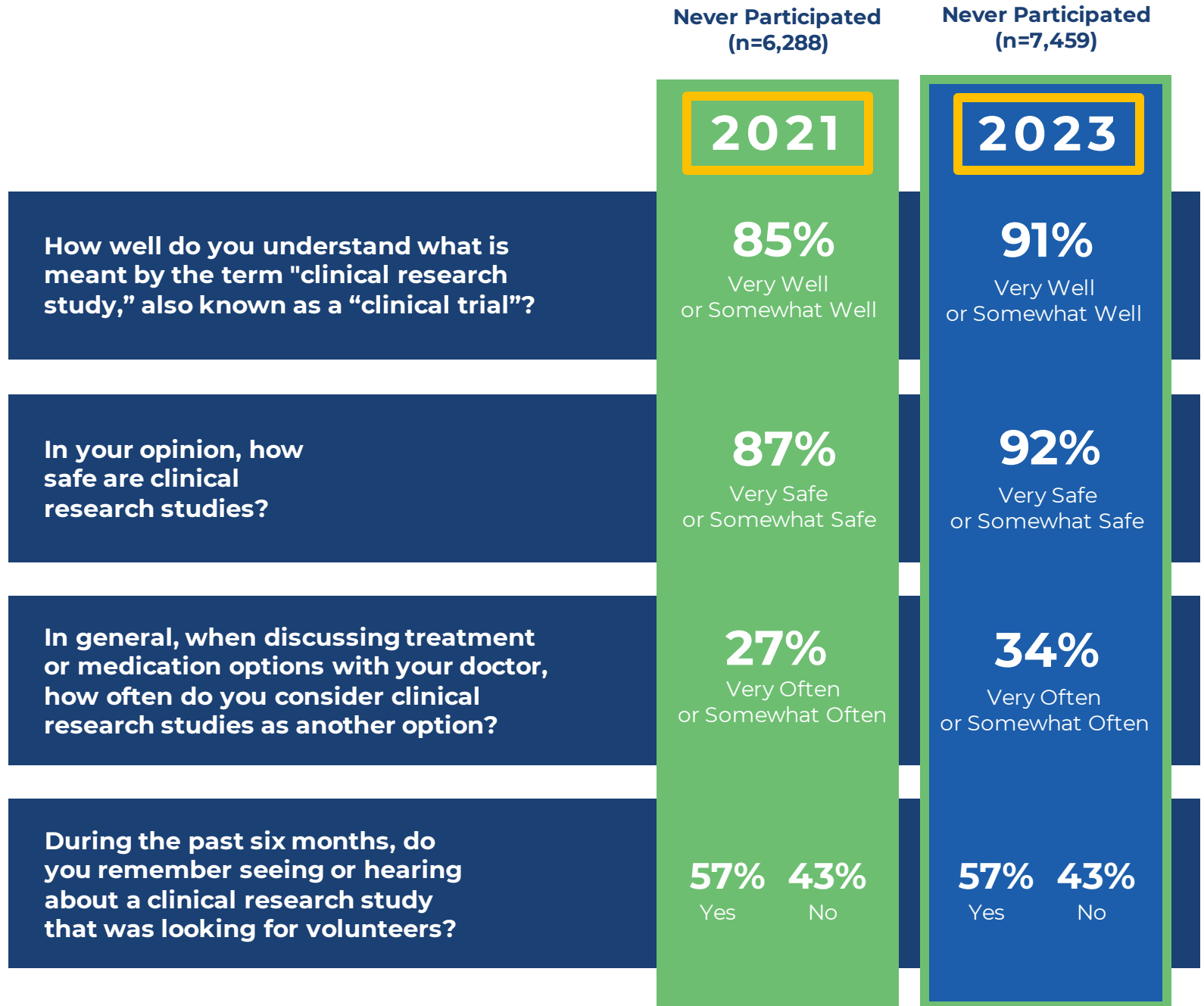
Black and Hispanic patient communities perceive the employment of **diverse staff** and the enrollment of **diverse study participants** in clinical studies as **particularly important.**



Key Comparisons Over the Years

General Perceptions, Awareness, and Understanding

Self-reported general understanding of clinical research and safety perception measures remain steady. However, the prevalence of clinical research discussions with healthcare providers remains low. In 2021, over half of those surveyed indicated seeing or hearing about a clinical research study during the past six months.



Notable Subgroup Differences

General Perceptions, Awareness, and Understanding



Black (52%) respondents were more likely to report **understanding clinical research 'Very Well'** compared to those identifying as **White (42%)** and **Asian (30%)**.



North American respondents were more likely to report **understanding clinical research 'Very Well'** compared to other regions.

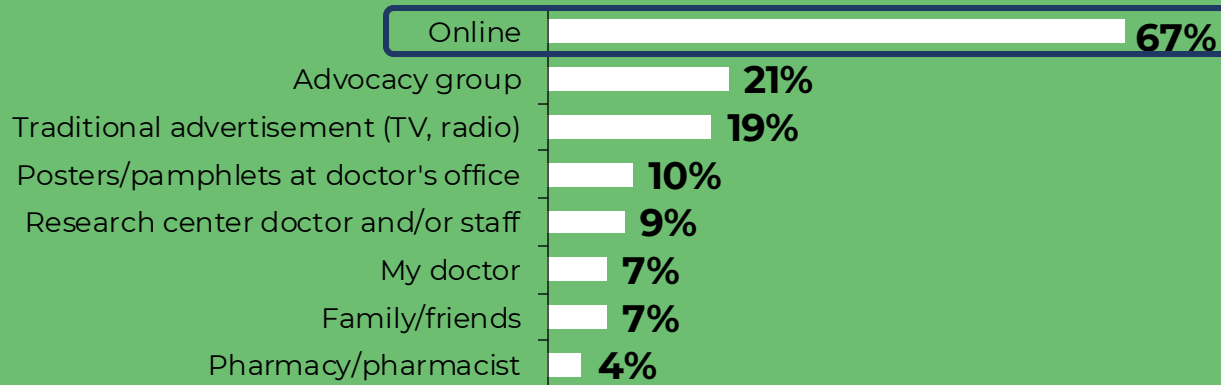


More **Black (56%)** and **White (52%) respondents** remember seeing **clinical research studies looking for volunteers** compared to other races. **Hispanics (42%)** were **less likely to remember** compared to **non-Hispanics (54%)**.

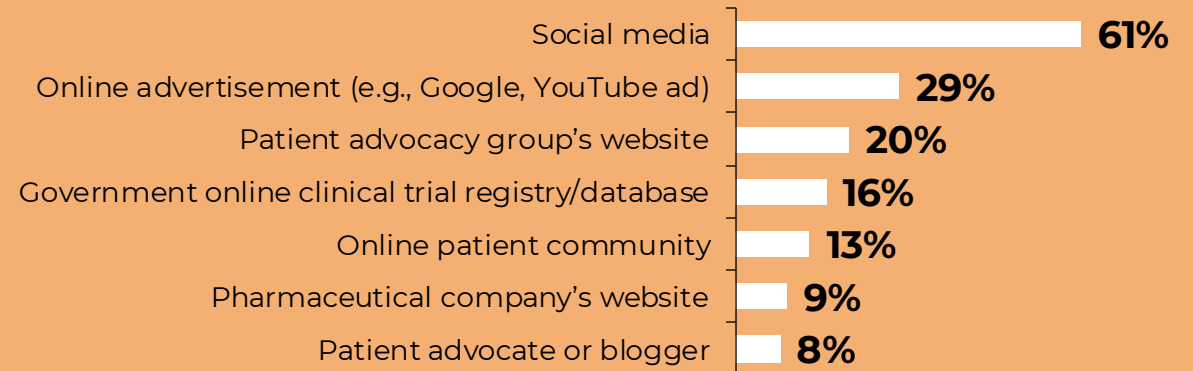
Clinical Research Awareness: Current Sources

Among those hearing about a clinical research study in the past six months, most indicate learning about the study online. Social media is the leading online resource, followed by online advertisements and patient advocacy group websites.

Where did you see or hear about a clinical research study?



Where online did you see or hear about a clinical research study?



Sample Size = 3,810; Base: Those that never participated and heard of a clinical research study in the past six months

Sample Size = 2,538; Base: Those that never participated and heard of a clinical research study online



North American respondents were more likely to **hear through a patient advocacy group** compared to other regions.



Hispanic respondents were more likely to hear through **their doctor (11%), family and friends (12%), and pharmacist (7%),** compared to **non-Hispanic respondents.**

Black, Asian, and younger respondents, were more likely to **learn about a study online** through a **patient advocate or blogger.**



Female (23%) respondents were more likely to report **hearing through advocacy groups,** compared to **male respondents (15%).**

Clinical Research Benefits and Risks Perceptions

The top mentions for perceived benefits and risks associated with clinical research participation remain consistent when compared to prior studies.

Which of the following do you consider to be the greatest benefits of participating in a clinical research study?
(Top 3 mentioned)



55%

May help advance science and the treatment of my disease/condition



53%

May help save or improve the lives of other patients with my disease/condition



39%

May help improve my disease/condition

Which of the following do you consider to be the greatest risks of participating in a clinical research study?
(Top 3 mentioned)



81%

Possibility of side effects



63%

Possible risks to my overall health



45%

Possibility of receiving a placebo (i.e., inactive substance/sugar pill)

Sample Size = 12,017; Base: All respondents



Older respondents were more likely to mention **altruistic benefits** compared to younger respondents.

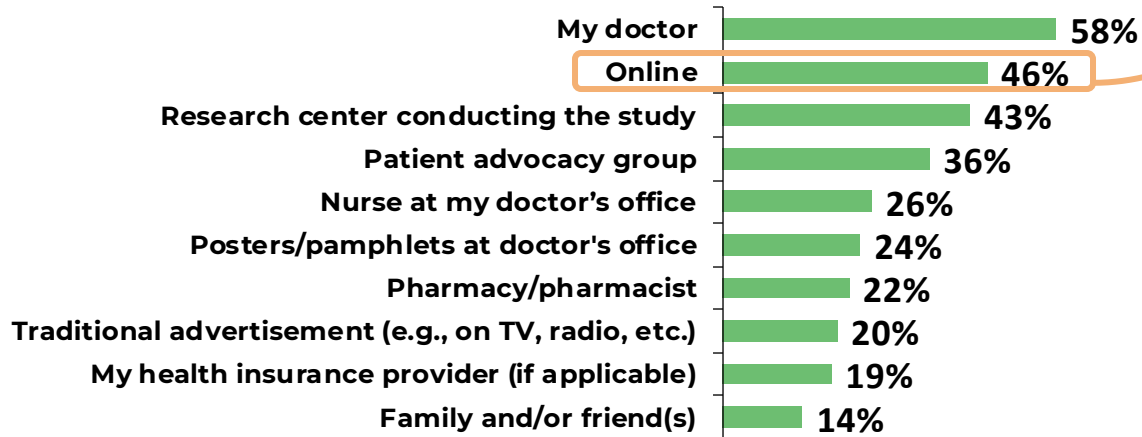


North American and European respondents were more likely to mention the **possibility of side effects** compared to other regions.

Clinical Research Awareness Preferences

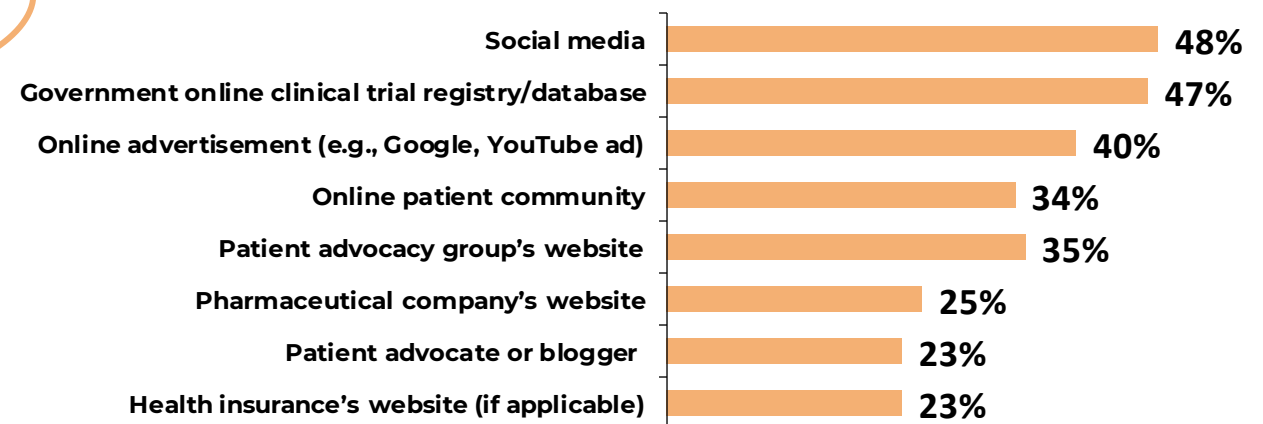
There is still a gap between where people would prefer to learn about clinical research and actual sources. As in years past, most would prefer to learn about a clinical research study through their doctor. For those who prefer online resources, social media and clinical trial registries are the top online choices.

In general, how would you prefer to learn about a clinical research study?



Sample Size = 7,459
Base: Those that never participated

Where online would you most prefer to learn about a clinical research study?



Sample Size = 3,435
Base: Those that never participated and would prefer to learn of a clinical research study online



Younger respondents were more likely to prefer hearing from an **advocacy group**, through **posters/pamphlets in doctor's office**, and **family/friends** compared to older respondents.



Black respondents were more likely to prefer **hearing about a study online (55%)** compared to White respondents (46%).



Hispanic respondents were more likely to prefer **hearing about a study online through a pharmaceutical company's website (33%)** or **health insurance website (30%)** compared to non-Hispanic respondents (24% vs. 22%, respectively).



Black respondents were more likely to prefer **hearing about a study online through a patient advocate or blogger (33%)** compared to White respondents (22%).

Increasing Trust in Pharmaceutical Companies

Transparency and the incorporation of patient engagement practices can help build trust in pharmaceutical companies.



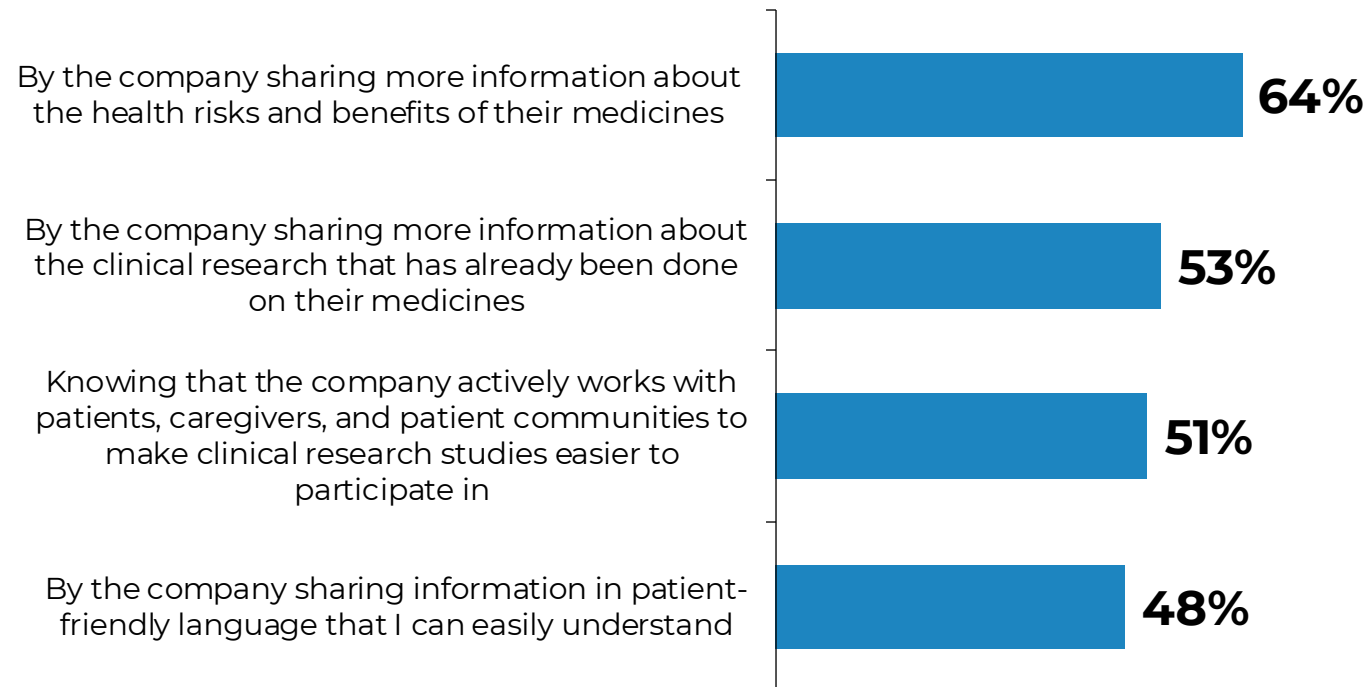
Black respondents' trust in pharmaceutical companies was more likely to be increased by knowing that the company **employed staff that was diverse (32%)** and that the company **included a diverse set of participants** in their clinical studies **(52%)**.

Hispanic respondents' trust in pharmaceutical companies was more likely to be increased by knowing that the company **employed staff that was diverse (22%)**.



North American and European respondents' trust was more likely to be increased by knowing the company **actively works with patients and caregivers** compared to other regions.

What, if anything, might increase your trust in pharmaceutical companies that are conducting clinical research studies?



Sample Size = 12,017 | Base: All respondents

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 June 2023, 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; investigative sites; and patients. The survey instrument was reviewed by an ethical review committee. CISCRP collaborated with Clariness, James Lind Care, Benchmark Research, and Rare Patient Voice to reach and engage respondents.

12,017

Survey Respondents

Respondent characteristics are as follows:

Gender	61% Female 37% Male 2% All other genders
Region	47% North America 2% South America 46% Europe 4% Asia-Pacific 1% Africa
Age	19% 18–34 years old 18% 35–44 years old 18% 45–54 years old 21% 55–64 years old 24% 65 or older
Race (top mentions)	81% White 6% Black or African American 6% Asian
Ethnicity	85% Non-Hispanic 15% Hispanic
Incidence of participation in a clinical trial	62% have never participated 38% 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.



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
- Educational Brochures
- Review Panels



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



Helpful facts and information about clinical research

- Content Licensing
- Patient Diversity Campaign
- Website Content Development



Thank You

CISCRP thanks the following organizations for their support of the 2023 P&I Study:

abbvie

AMGEN

AstraZeneca

Benchmark
Research
Raising the standard.™

Biogen

CLARINNESS

Daiichi-Sankyo

EMD
SERONO

greenphire®

janssen

PHARMACEUTICAL COMPANIES
OF Johnson & Johnson

JLC JAMES LIND
CARE.

Lilly

MERCK

Otsuka

RARE
PATIENT
Voice^{uc}
Also Non-Rare!

sanofi

Connect With Us

ciscrp.org | info@ciscrp.org | (617) 725 2750