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.

<table>
<thead>
<tr>
<th>Question</th>
<th>2021</th>
<th>2023</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well do you understand what is meant by the term &quot;clinical research study,&quot; also known as a “clinical trial&quot;?</td>
<td>85% Very Well or Somewhat Well</td>
<td>91% Very Well or Somewhat Well</td>
</tr>
<tr>
<td>In your opinion, how safe are clinical research studies?</td>
<td>87% Very Safe or Somewhat Safe</td>
<td>92% Very Safe or Somewhat Safe</td>
</tr>
<tr>
<td>In general, when discussing treatment or medication options with your doctor, how often do you consider clinical research studies as another option?</td>
<td>27% Very Often or Somewhat Often</td>
<td>34% Very Often or Somewhat Often</td>
</tr>
<tr>
<td>During the past six months, do you remember seeing or hearing about a clinical research study that was looking for volunteers?</td>
<td>57% Yes 43% No</td>
<td>57% Yes 43% No</td>
</tr>
</tbody>
</table>
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?**

- Online: 67%
  - Advocacy group: 21%
  - Traditional advertisement (TV, radio): 19%
  - Posters/pamphlets at doctor's office: 10%
  - Research center doctor and/or staff: 9%
  - My doctor: 7%
  - Family/friends: 7%
  - Pharmacy/pharmacist: 4%

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

- Social media: 61%
  - Online advertisement (e.g., Google, YouTube ad): 29%
  - Patient advocacy group's website: 20%
  - Government online clinical trial registry/database: 16%
  - Online patient community: 13%
  - Pharmaceutical company's website: 9%
  - Patient advocate or blogger: 8%

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.

<table>
<thead>
<tr>
<th>Benefits</th>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>May help advance science and the treatment of my disease/condition</td>
<td>55%</td>
<td></td>
</tr>
<tr>
<td>May help save or improve the lives of other patients with my disease/condition</td>
<td>53%</td>
<td></td>
</tr>
<tr>
<td>May help improve my disease/condition</td>
<td>39%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Risks</th>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Possibility of side effects</td>
<td>81%</td>
<td></td>
</tr>
<tr>
<td>Possible risks to my overall health</td>
<td>63%</td>
<td></td>
</tr>
<tr>
<td>Possibility of receiving a placebo (i.e., inactive substance/sugar pill)</td>
<td>45%</td>
<td></td>
</tr>
</tbody>
</table>

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?**

- My doctor: 58%
- Patient advocacy group: 43%
- Online advertisement (e.g., Google, YouTube ad): 36%
- Research center conducting the study: 26%
- Posters/pamphlets at doctor's office: 24%
- Nurse at my doctor's office: 22%
- Pharmacy/pharmacist: 20%
- Traditional advertisement (e.g., on TV, radio, etc.): 19%
- Family and/or friend(s): 14%
- Online: 46%

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

- Social media: 48%
- Government online clinical trial registry/database: 47%
- Online advertisement (e.g., Google, YouTube ad): 40%
- Online patient community: 34%
- Pharmaceutical company's website: 35%
- Patient advocate or blogger: 25%
- Pharmaceutical company's website: 23%
- Health insurance's website (if applicable): 23%

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

**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%).

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

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

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

- By the company sharing more information about the health risks and benefits of their medicines: 64%
- By the company sharing more information about the clinical research that has already been done on their medicines: 53%
- Knowing that the company actively works with patients, caregivers, and patient communities to make clinical research studies easier to participate in: 51%
- By the company sharing information in patient-friendly language that I can easily understand: 48%

Sample Size = 12,017 | Base: All respondents

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 that the company **actively works with patients and caregivers** compared to other regions.
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.

### Respondent characteristics are as follows:

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>61% Female</td>
</tr>
<tr>
<td>Region</td>
<td>47% North America</td>
</tr>
<tr>
<td>Age</td>
<td>19% 18–34 years old</td>
</tr>
<tr>
<td>Race (top mentions)</td>
<td>81% White</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>85% Non-Hispanic</td>
</tr>
<tr>
<td>Incidence of participation in a clinical trial</td>
<td>62% have never participated</td>
</tr>
</tbody>
</table>

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.

**Research Services**

Insights guiding public and patient engagement in clinical research
- Perceptions & Insights Study
- Patient Advisory Boards
- Patient Clinical Trial Journey Workshops
- Custom Research Projects

**Community Engagement**

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

**Health Communication Services**

Information in plain and easy-to-read language
- Trial Results Summaries
- Educational Brochures
- Review Panels

**International Education & Awareness**

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
- Biogen
- CLARINESS
- Daiichi-Sankyo
- EMD Serono
- greenphire
- Janssen
- JLC James Lind Care
- Lilly
- MERCK
- Otsuka
- RARE Patient Voice
- sanofi