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.
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

<table>
<thead>
<tr>
<th>Question</th>
<th>2019</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well do you understand what is meant by the term “clinical research study”, also known as a “clinical trial”?</td>
<td>Very Well: 40%</td>
<td>31%</td>
</tr>
<tr>
<td></td>
<td>Somewhat Well: 50%</td>
<td>54%</td>
</tr>
<tr>
<td>In your opinion, how safe are clinical research studies?</td>
<td>Very Safe: 20%</td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>Somewhat Safe: 69%</td>
<td>69%</td>
</tr>
<tr>
<td>How important do you feel it is for your doctor to be aware of clinical research studies being conducted in your community?</td>
<td>Very Important: 65%</td>
<td>59%</td>
</tr>
<tr>
<td></td>
<td>Somewhat Important: 29%</td>
<td>33%</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>Very often: 8%</td>
<td>7%</td>
</tr>
<tr>
<td></td>
<td>Somewhat Often: 22%</td>
<td>20%</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>Yes: 50%</td>
<td>57%</td>
</tr>
<tr>
<td></td>
<td>No: 50%</td>
<td>43%</td>
</tr>
</tbody>
</table>

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.

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%).
IMPACT OF THE PANDEMIC

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

- 41% B (A) Clinical Trial Participant
- 37%
- 22% (A) Never Participated

- 33% It has greatly increased my awareness of clinical research
- 40% A It has somewhat increased my awareness of clinical research
- 28% A It has not changed my awareness of clinical research 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%)
- Felt uncomfortable going to doctor’s appointments/getting medical care (36)
How important do you think clinical research studies are to the discovery and development of new medicines?

<table>
<thead>
<tr>
<th>Year</th>
<th>Very Important</th>
<th>Somewhat Important</th>
<th>Not very Important</th>
<th>Not at all important</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015</td>
<td>81%</td>
<td>18%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>2017</td>
<td>85%</td>
<td>14%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>2019</td>
<td>79%</td>
<td>19%</td>
<td>2%</td>
<td></td>
</tr>
<tr>
<td>2021</td>
<td>76%</td>
<td></td>
<td></td>
<td>21%</td>
</tr>
</tbody>
</table>

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.
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.

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

<table>
<thead>
<tr>
<th>Organization</th>
<th>Not at all</th>
<th>Not too much</th>
<th>Some</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pharmaceutical (drug) companies that develop medicines and pay for clinical research studies</td>
<td>6%</td>
<td>19%</td>
<td>53%</td>
<td>22%</td>
</tr>
<tr>
<td>Research centers that conduct clinical research studies</td>
<td>3%</td>
<td>12%</td>
<td>47%</td>
<td>38%</td>
</tr>
<tr>
<td>Government research organizations that design and pay for clinical research studies</td>
<td>3%</td>
<td>13%</td>
<td>45%</td>
<td>39%</td>
</tr>
<tr>
<td>Government regulatory agencies that oversee the safety of clinical research studies</td>
<td>4%</td>
<td>14%</td>
<td>45%</td>
<td>37%</td>
</tr>
</tbody>
</table>

Sample Size = 11,793; Base: All respondents

- 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%).

- 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%).

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

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

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, CiSCRPs conducted an online international survey. The survey instrument was based in part on questions posed in past surveys. CiSCRPs 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. CiSCRPs collaborated with Clarness, 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:

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>51% Female</td>
</tr>
<tr>
<td>Region</td>
<td>69% North America</td>
</tr>
<tr>
<td>Age</td>
<td>31% 18 - 34 years old</td>
</tr>
<tr>
<td>Race</td>
<td>74% White</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>72% Non-Hispanic</td>
</tr>
<tr>
<td>Incidence of participation in a clinical trial</td>
<td>53% 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
• Health Communication Projects
• Review Panels

INTERNATIONAL EDUCATION & AWARENESS

Helpful facts and information about clinical research
• Content Licensing
• Media Awareness Campaigns: USA Today, Patient Diversity
• Website Content Development
• New Brochure Development