Survey Says:

Global Patient Perceptions & Engagement Preferences in Clinical Research

The State of the Industry

Every two years, the Center for Information and Study on Clinical Research Participation (CISCRP) releases a global survey with the primary goal of uncovering the thoughts and perceptions of clinical trial participants and the general public as it relates to clinical research. By providing a comprehensive view of the global patient voice, this survey helps us better understand patients' needs and concerns and develop more effective strategies for engaging with them.

Over 12,000 people from around the world participated in this past year's survey. The number of European respondents for the Perceptions and Insights study was higher than ever before, thanks to the efforts of James Lind Care, a European patient enrolment company that focuses on clinical trials and has patient communities in eight countries across Europe.

In combination with Greenphire's 2023 summer survey and the more balanced representation between North America and Europe this year, we have gained a better understanding of the reasons why people enroll in clinical trials and what factors contribute to their dropout, particularly in North America and Europe. At Greenphire, this data is crucial in helping us comprehend patient preferences, reduce their burden, and chart a course for future product innovation.

2023 CISCRP Perceptions & Insights Study

- Location: 47% North America; 2% South America; 46% Europe; 4% Asia-pacific; 1% Africa
- Clinical Trial Participation: 62% have never participated; 38% have participated
- Eduction: 19% some/completed high school; 62% some/completed college, 18% some/completed post-graduate

North America vs. Europe: Recognizing Geographical, Cultural, and Socioeconomic Differences

There are notable differences in survey culture between North America and Europe. European participants tend to select the more "moderate" options in the answer choices compared to their North American counterparts. Additionally, there are differences in response rates between the two regions. Some of these differences can be attributed to the regulatory environment, healthcare systems, and population density.

Thanks to organizations like James Lind Care and EUPATI, there has been a growing awareness of the benefits of participating in clinical trials across the European continent. Efforts have been made to inform patients about the opportunities available, resulting in increased education and awareness among patients about the advantages of participating in a trial.

As clinical trials become more complex, we are seeing an increasing need globally for support systems that can assist patients in comprehending and managing the burdens associated with trial participation. This year's survey results have confirmed that certain crucial factors impact the long-term retention of clinical study participants. These include access to local study clinics or travel support, compensation, and regular communication. This paper will discuss these three factors often seen as pain points for many clinical trial participants and explore potential solutions to overcome them.

Top factors that impact long-term retention:

- Access to local clinics/travel support
- Compensation
- Consistent communication

Overcoming the Travel Hurdles of Clinical Trial Participation

56%

of respondents indicated that having to travel to the study clinic was the biggest factor that disrupted their participation in the clinical research study.

In Greenphire's Market Trends survey, both sponsors and CROs expressed that participant travel is the top area in which they would like to invest in terms of improving the patient experience. Further supporting this point, in CISCRP's 2023 survey, logistical factors still pose the greatest challenge for clinical trial participants. When asked about what factors disrupted their participation in a clinical research study, 56% of participants reported that having to travel to the study clinic was the biggest issue. Other top disruptors included overall time commitment and missing work, all of which can greatly disrupt daily routines. These obstacles are particularly challenging for individuals living in rural areas without easy access to public transportation, those who can't afford to take extended time off work, and individuals who are responsible for caring for their own families. Finding ways to ease these burdens and meet patient-specific needs could help eliminate these barriers, allowing more people to participate in and complete clinical trials.

Over the past few years, there has been a noticeable increase in hybrid trials and the use of remote monitoring tools. This shift has been partially due to the COVID-19 pandemic and has helped ease some of the logistical challenges involved. When asked about their willingness to participate in a hybrid or remote model clinical study, 43% of respondents said they would be 'very willing.' More sponsors are designing studies with this in mind to reduce the burden on study participants, especially as it relates to travel. However, some participants may feel that having the clinical trial visit take place in their homes is an invasion of their privacy. They may also have concerns about facilities, data privacy, and quality of care. As such, introducing flexibility into trial designs to meet unique participant needs is crucial.

Key Clinical Trial Decision Factors:

- Location of study center
- Length of participation
- Number and duration of study visits
- Medical procedures required
- Flexible visit scheduling
- Remote visits

The Hidden Pain of Clinical Trials:
The Financial Impact on Participants

Sadly, many people who qualify for clinical trials choose not to participate due to financial considerations. It was found that 56% of people who have never taken part in a clinical trial said that knowing what potential costs and reimbursements will be is very important before deciding to participate. Some patients are unaware that participating in a clinical trial could require them to pay out-of-pocket expenses, leading to dropouts due to affordability issues. About 60% of clinical trial participants expect reimbursement for all out-of-pocket expenses and believe they are not responsible for covering costs. As a result, they may be surprised to find out that this is not always the case when they join a study. Reimbursing any out-of-pocket expenses is among the top five factors that encourage patients to stay enrolled in clinical research until the end of a study.

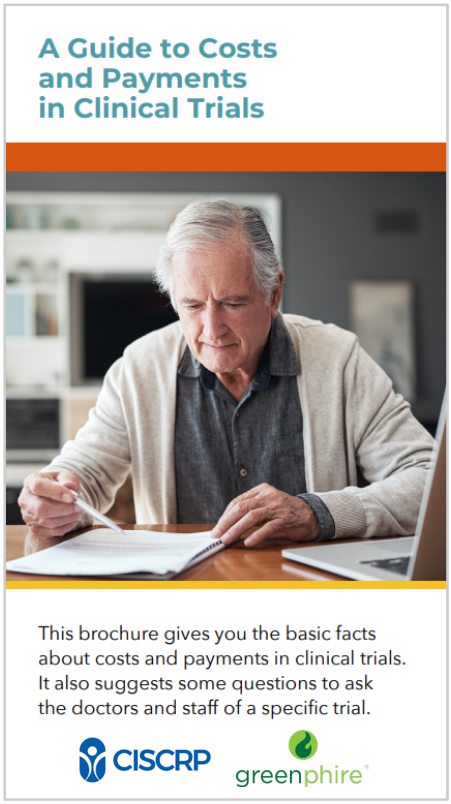
It's clear that financial concerns and the ability to be reimbursed remain an important aspect in improving participant engagement and retention. To address this challenge, providing immediate assistance and global financial reimbursement through preferred methods, such as digital, direct deposit/bank transfer, or reloadable cards can be a solution. By improving access and reducing financial hurdles, we can improve recruitment and retention in clinical trials, which can lead to more timely and cost effective studies while driving better results.

60%

of clinical trial participants expect to be reimbursed for all out-of-pocket expenses and believe they are not responsible for covering costs.

Top Financial Disruptors:

1. Missing work or not getting paid
2. Not receiving compensation for their time
3. Not being reimbursed for their expenses



Download this patient Guide to Clinical Trial Costs and Payments in Clinical Trials, or order copies for your inventory.

Breaking the Silence: How Lack of Communication Can Affect Clinical Trial Participation

65%

of clinical trial participants found smartphone apps very useful for study communication.

The survey confirmed that participants have stopped participating in a clinical trial due to "poor communication with the study center." Consistent and clear communication is crucial for participants to understand study details, especially as clinical trials can be daunting and unfamiliar for many people. Providing participants with study visit protocols, updates, reimbursement methods, rideshare services, and proactive notifications will help them feel valued and less overwhelmed.

The survey revealed that reminders and mobile applications are beneficial to participants. In today's world, most people are accustomed to having everything at their fingertips through their cell phones. In fact, 65% of survey participants found smartphone apps very useful for study communication, and 59% said they would feel comfortable downloading an app for a clinical research study on their phone. It is worth noting that 85% of the respondents are willing to participate in hybrid model clinical trials. This is important because some form of digital technology will be required for communication. Therefore, providing an app or portal where participants can access all the study details can be extremely beneficial. Providing participants with proactive notifications regarding study visits, as well as reimbursement and logistical services, can help them feel valued and less overwhelmed.

47% said being provided with supporting information on the clinical research study was 'very important' to their participation.

48% said they would have more trust in the clinical trial if they shared information in patient-friendly language that can be easily understood.

65% said text messaging was 'very helpful' throughout the clinical trial.

Conclusion

The CISCRP Perceptions and Insights Study remains the most authoritative resource to understand why people enroll in clinical trials as well as the factors that cause them to drop out or refrain from participating at all. We know that participants are still willing to participate in research, not just for themselves but for their community as well, but the challenges that they face are not going away. In fact, they are only increasing as trials become more complex. With the inclusion of decentralized trial elements, participants have to bear more of the responsibilities and requirements in their homes. This makes it even more crucial to consider these factors when designing trials and focus on ensuring that any added burdens are minimized.

To make participation more accessible, we must recognize the hurdles participants face and meet their needs. By providing financial and logistical support as well as clear and constant communication, we can continue to build trust and remove barriers.

As an industry, we need to continue to listen to patients and understand their pain points and preferences. Only by incorporating the patient voice into our trial designs and innovative solutions can we work towards a truly participant centric clinical trial landscape where we mitigate their burdens and drive overall trial success and better health outcomes.

Take the Next Step

Modern medicine is innovating at a speed unlike any other time in history, inspiring hope for cures and treatments for patients and families across the globe. However, today's clinical trials are more complex and cumbersome than ever before.

By connecting the dots of disparate manual processes through financial technology, it is possible to speed clinical research and deliver an optimal patient experience throughout the study.

Contact us today to understand new and emerging trends in clinical trial financial and logistical operations so you can build an effective business case for future strategic initiatives.

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