# 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) surveys global clinical trial participants as well as the public to gauge their thoughts on and preferences for participating in clinical research. In 2021, nearly 12,000 individuals took part in the survey, with 47% indicating they've previously been enrolled in research studies. Greenphire is one of the sponsors of this biennial global CISCRP study.

This research, coupled with Greenphire's own market research studies conducted among sponsors and contract research organizations in 2022, has been summarized in this paper to describe patient and public perceptions, and how the industry is evolving to deliver an improved clinical trial participant experience.

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# The Patient and Public View of Clinical Trials

For those of us working in the clinical trial industry, we know just how critical research is to improve the future of human health. But is that feeling shared by the public at large? According to the 2021 CISCRP study, the answer is a resounding "yes."

In the study, 97% of survey respondents believe that clinical research studies are important to the discovery and development of new medicines. Notably, respondents from Europe are significantly more likely to report that clinical studies are "very important" compared to other regions.

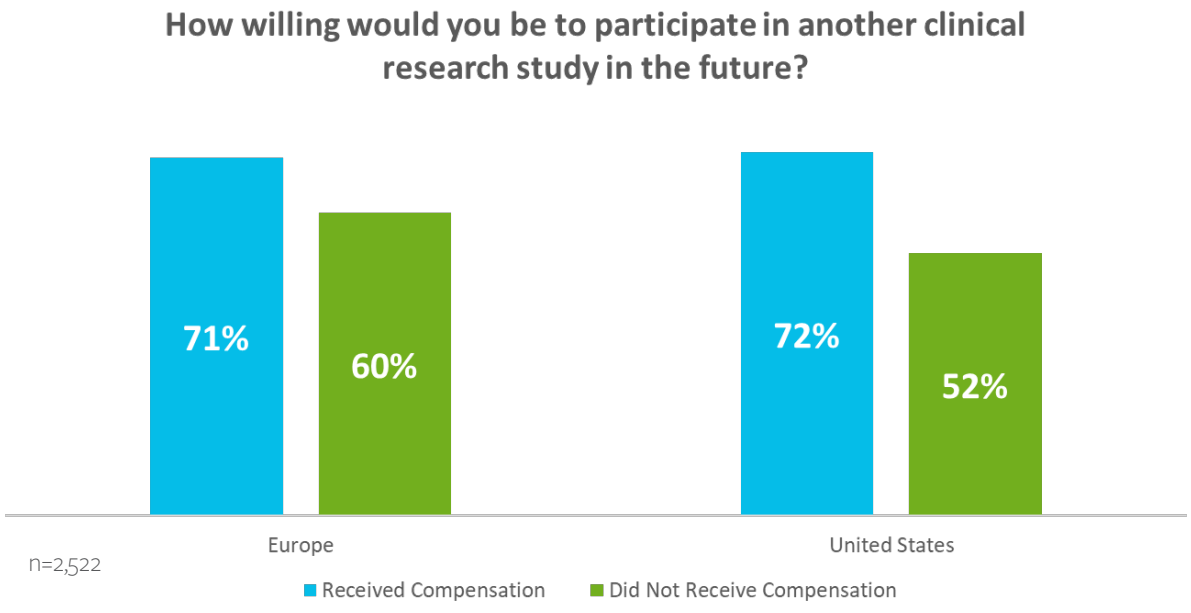
Altruism is one of the driving forces for participation, with the greatest benefits for taking part being cited as "helping to advance science and the treatment of my disease/condition" and "helping to save or improve the lives of other patients with my disease/condition."

Another critical factor is representation; 97% of respondents felt that it was important for clinical research studies to include a diverse group of study participants who will ultimately reflect the therapy being tested. The majority additionally indicated that knowing the study staff was representative of diverse communities was also very important.

When looking into the experiences of those who have participated in research in the past, some interesting observations surface.

Among prior study participants, just 11% reported that participating in a research study did not meet expectations (4% indicated their experience "didn't meet their expectations", and 7% indicated their experience "fell well short of their expectations.")

Additionally, the majority are "very willing" to participate in another clinical research study in the future, particularly among those who received compensation for their participation.



# Clinical Trial Participation:
## Decision Factors & Engagement Preferences

**68%**

of clinical trial participants reported at least some disruption to daily routines due to required travel or time commitments for their participation.

According to a 2022 survey conducted by Greenphire among sponsors and CROs, the number one challenge in the study startup process is enrollment planning or determining whether the right mix of patients exists. If identifying potential populations is such a pain point, then it's equally important to understand what the key decision factors are for attracting individuals to participate in studies.

In the CISCRP study, individuals who had never participated in research studies were asked what information would be most important for them to know when deciding to join. Not surprisingly, "potential risks and benefits" and the "purpose of the clinical research study" were the top decision criteria cited. The following were also frequently mentioned as "very important":

- Potential costs and reimbursements
- Length of participation in the clinical research study
- Physical location of the research study center

These elements all point to the burdens – of time, cost and effort placed on participants; and these were perceived as universally important among survey respondents across the globe.

Furthermore, the CISCRP study revealed that 68% of clinical trial participants reported at least some disruption to daily routines – with reasons for the disruption often pointing to logistical aspects such as traveling to the clinic or the time commitment required.

**Top Responses: What made your participation in the clinical research study disruptive?**

- Having to travel to the study clinic
- Too much time required
- Having to complete study requirements at home

# Quantifying the Burden of Clinical Trial Travel

Physically getting to clinical trial visits weighs heavily on study participants. Regardless of the type of trial, transportation to and from the clinic is an endeavor which can cause emotional strain and financial expense.

According to the CISCRP study, 60% of trial participants had to travel more than 30 minutes one way to get to the study clinic. When contrasting the CISCRP survey data from 2019 to 2021, clinical trial travel has become more burdensome, not less, by a whopping 15% (29% in 2019 to 44% in 2021). It's not surprising that one of the top reasons for study drop out was the location of the study center.

Additionally, Greenphire separately analyzed its global clinical trial participant payment data and discovered that on average, clinical trial participants in 2022 are travelling 67 miles one way. For those participating in rare disease studies, the distance more than doubles – rising to 135 miles on average. This is drastically higher than previously cited industry data which estimated that the average distance travelled by patients was 25.8 miles.

Despite this upward trend in travel burden, the majority of clinical trial patients remain willing to participate.

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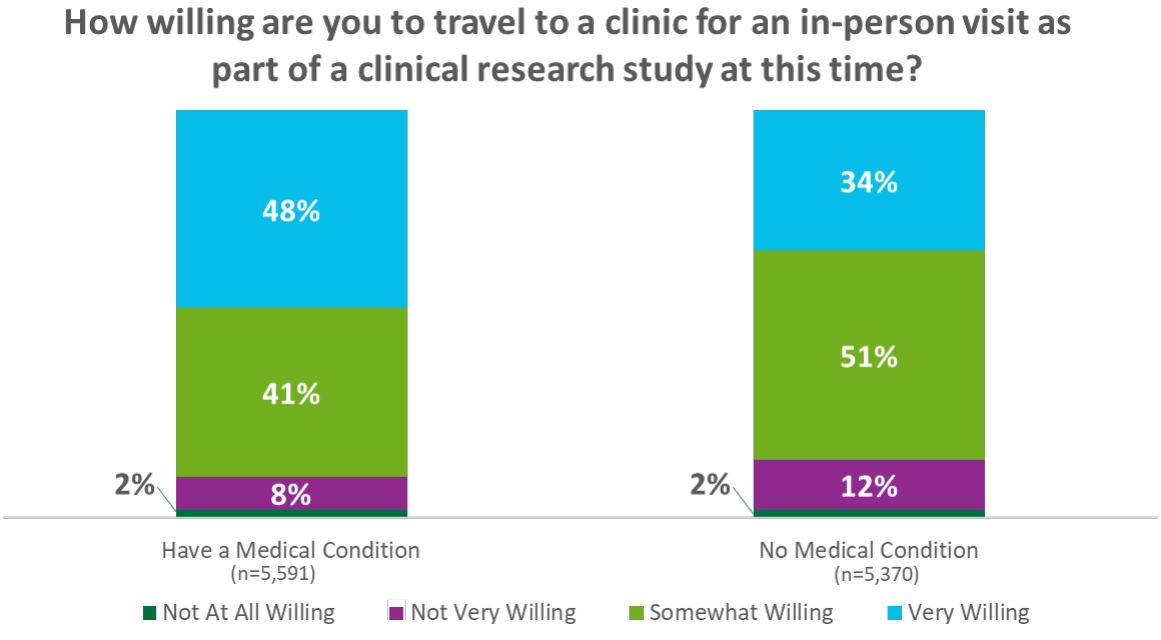


# Patients Weigh In

Individuals from the 2021 CISCRP study offered several suggestions for how to make participation less disruptive:

- Virtual study visits
- Not having to travel as far to get to my study visits
- Having a study nurse or doctor come to my home for some of my study visits
- Receiving a pre-paid debit card for study-related expenses
- Having help/assistance to and from the study

Today's clinical trial participants want more flexibility for how to participate. If the study requires them to physically come into the clinic (even part of the time) logistical and financial assistance can help remove the burden of this intense trial requirement. This investment in the patient experience can pay dividends to study success, as sponsors who elect to cover travel costs often realize higher retention rates for their studies.

# Time:
## The Most Precious Resource of Clinical Trial Participants

While clinical trial travel has been cited as a top disruptor of trial participation, so is the time spent for study activities – both in and out of the clinic.

According to the CISCRP study, 35% of trial participants reported that "too much time was required." Additionally, the length of study visits was cited as "somewhat" to "very burdensome," with the proportions indicating this burden increasing from 21% in 2019 to 40% in 2021.

An increasing number of study sponsors and research sites are offering reimbursement for both indirect and direct expenses. In the CISCRP study, 57% of participants enrolled in a traditional, in-person research study or a hybrid research study reported that they received financial compensation for their time. On the other hand, only 36% of those participating in a remote/virtual clinical research study indicated receiving compensation.

How can we honor the investment of time made by clinical trial participants?

## Patients Weigh In

Here are some of the solutions offered by participants for how to better keep them engaged and enrolled in studies:

- Having study visits with flexible times
- Offering the option to have study visits at home (i.e., remote study visits) rather than travelling to a study clinic
- Receiving small amounts of compensation (money) after every study visit
- Having my study visits not last longer than one hour

# Friend or Foe?
## Remote Patient Engagement

While many are citing the rise of decentralized and hybrid trials as the answer to removing clinical trial patient burden, there is a downside.

In essence, at-home activity places increased convenience, but also increased responsibility on the trial participant to remember to conduct and execute on study requirements that historically have taken place at the clinic.

The CISCRP study captured this nuance, notably when participants were prompted on what made their participation in the clinical research study disruptive - 31% reported that "having to complete study requirements at home (such as completing questionnaires)" as a reason.

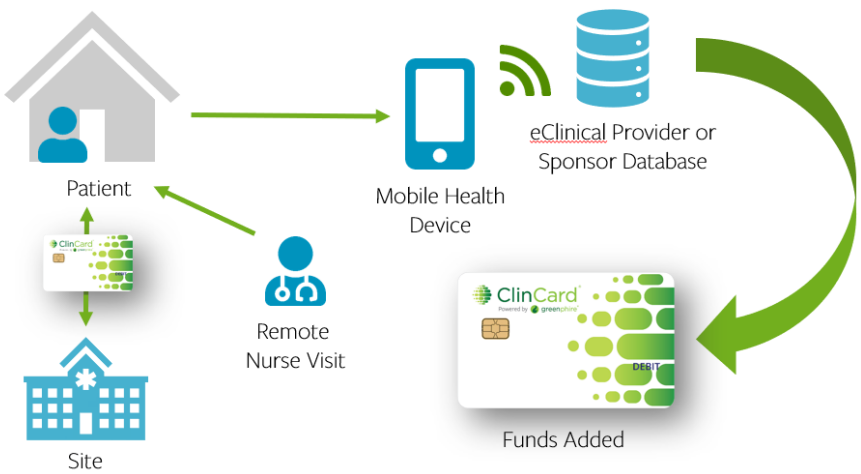
As confirmed by the CISCRP study, home-based study visits do have appeal, with 81% of respondents citing a preference for a hybrid model. As such, there is an appetite for flexibility as it relates to the execution of study activity but perhaps the methodologies used to conduct such remote activity today are not as convenient as they could be. It is up to industry to continue to innovate the patient experience to make it as accessible and seamless as possible.

## Data-Triggered Micropayments

For patients who are completing clinical trial diaries, arctivities and virtual visits at home, Greenphire can process an automatic payment upon activity completion. This simple integration is proven to keep patients engaged and enrolled with no additional effort required by research site staff.

## Hybrid Trial Patient Engagement Journey

- Standard use case: Integrate ClinCard with the trial experience (card issuance & payments)
- Add hybrid options into the traditional experience (remote nurse visit, home devices, telemedicine, wearables etc.)
- Drive compliance via ePRO/eCOA Integration, and automatic funding



# Conclusion:
## Driving Towards a Better Clinical Trial Experience

Participants are spending a significant amount of time, effort and money when enrolled in a clinical research study. From longer and more demanding visits to greater distances travelled, the level of burden experienced is only increasing. Despite this, participants are seeing the importance of clinical trials and willing to partake in studies.

Participants do, however, want to be recognized and appreciated for their contribution – most notably in the form of reimbursement for expenses incurred or compensation for time and effort expended but also a desire for increased flexibility and convenience.

As we see options offered such as where trial visits and activities are conducted, technology and standards need to evolve to fit this expanding model; and not simply to enable these activities but to do so in a way that seamlessly integrates into the participant's life.

Like any other industry, clinical research will need to continue to innovate and stay ahead of the challenges. In order to do this, we as sponsors, CROs, sites and solution providers must continue to listen to participants and keep their needs front and center as we pave the way towards a better clinical trial experience.

**95%**

**of sponsors and CROs agree that providing tech solutions for patient engagement in cinical trials can positively impact recruitment and retention.**

*Greenphire Summer 2022 Market Trends Survey*

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