



Costs of Clinical Trial Participation

2025 Survey Results

The Mural Health Patient Kindness Group



About Mural Health

Mural Health creates solutions that make it easier for patients and caregivers to participate in clinical trials. Specifically, **our participant management platform, Mural Link, is designed to meet the needs of modern-day participants.**

We lead with empathy and advocate for the support, both financially and emotionally, that patients and caregivers need during a clinical trial. We've led initiatives such as the **Harley Jacobsen Clinical Trial Participant Income Exemption Act**, to remove income tax for financial support provided to patients and caregivers participating in a clinical trial. In addition, our **Portrait Project** highlights the authentic stories of the individuals at the heart of trials. Serving participants is at the core of everything we do.



Taken from The Portrait Project by Mural Health.
Maureen Jacobsen, wife, mother, and caregiver.
Lost her husband Harley, a clinical trial participant, to ALS.

About the Mural Health Patient Kindness Group

The Patient Kindness Group was formed in early 2024, to deepen our understanding of the participant experience in clinical trials, show patients sincere compassion and kindness, and advocate for their needs. Alongside this work, the Patient Kindness Group offers high touch, dedicated support to patients in trials using Mural Health's platform. This high touch service includes a dedicated point of contact for each patient who is familiar with the patient's needs (and where applicable, the needs of their caregiver or family), and helps address any logistical issue they are facing. This personalized service allows participants and caregivers to focus on what matters the most: the patient's health and trial participation. The work of the Patient Kindness Group exemplifies Mural Health's mission to make trial participation easier.

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Message from Patient Kindness

Thank you to all patients and caregivers who took the time to complete our survey. We know your time and experience is invaluable. We appreciate you.

Nora DeSimone,
Director of Patient Kindness at Mural Health



Why did we conduct the survey?

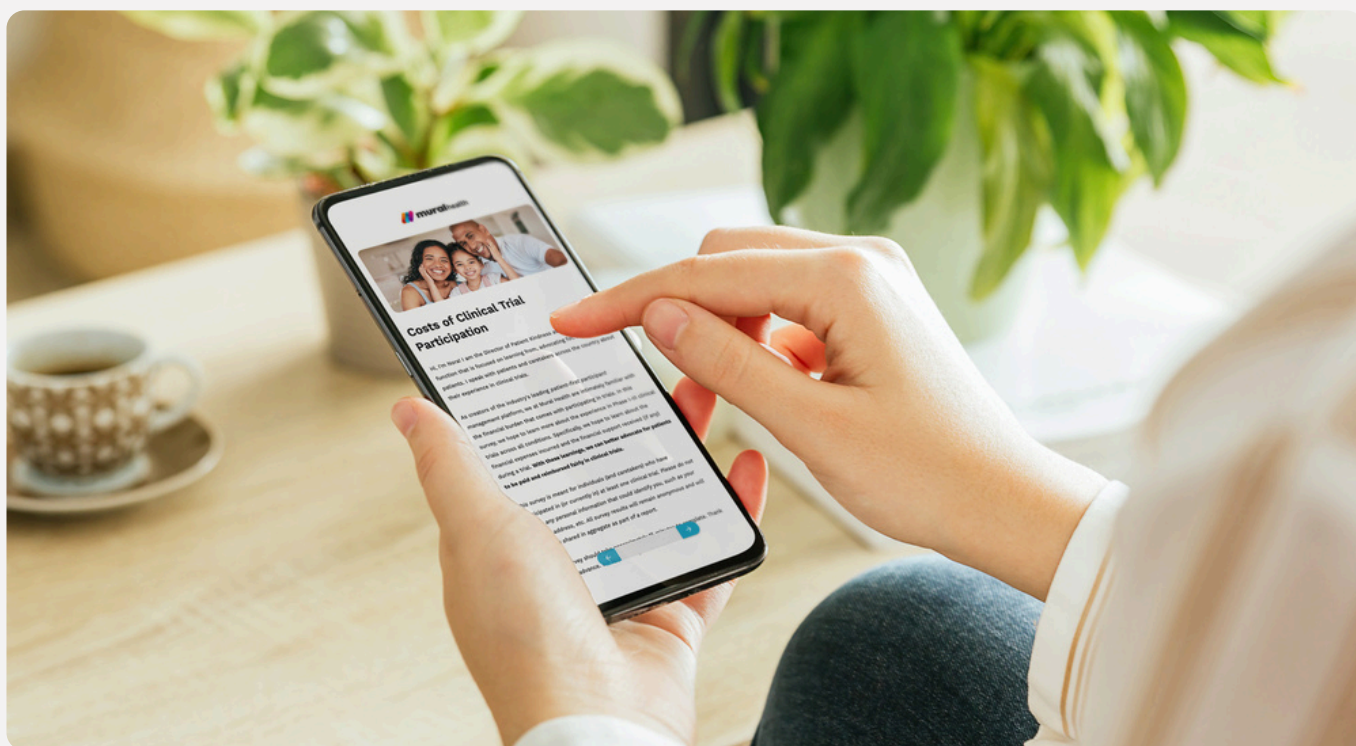
Through our work, we've seen the financial burden that participants incur when being a part of a clinical trial. We've heard firsthand about the financial hardships the families undergo and the impact it has on their life and those around them.

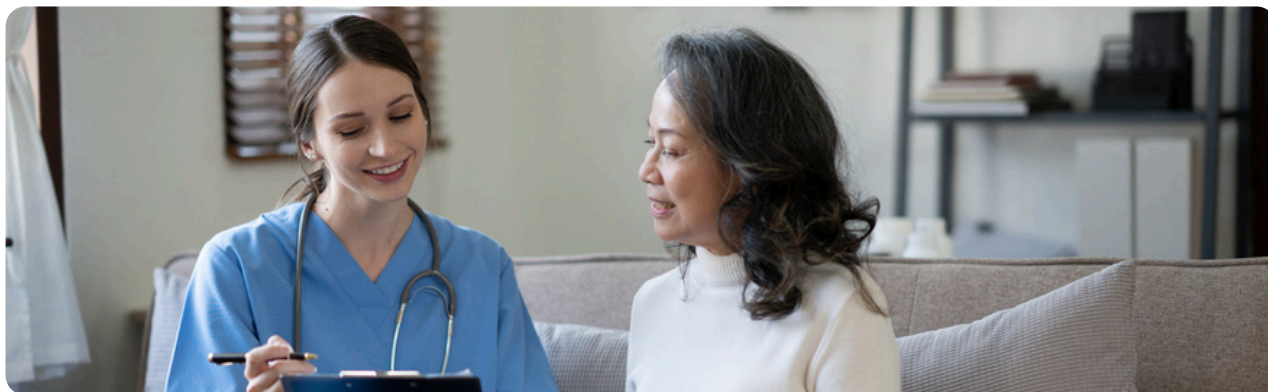
At Mural Health, we strived to uncover the true demands of clinical trials by directly surveying patients and caregivers and assuring they have a voice in the trial experience.

Survey overview

Mural Health conducted a survey with over **100+ US clinical trial participants and caregivers** about their trial experience, with an intended focus on the expenses they incur. The survey was shared via various methods including foundations, patient organizations, LinkedIn groups, social media platforms, customers, Mural Health's social media following, patient referrals, and word of mouth.

The survey incorporated different questioning methods to gather comprehensive insights. Respondents provided information including demographics, medical diagnosis, clinical trial participation details, trial-related expenses, and financial support. Additionally the survey aimed to identify key challenges faced throughout the trial process.





Respondent Profile

While respondents were from diverse populations, the data points below summarize the general profile of respondents.



Demographic

- 71% of participants identified as female.
- 5% of participants covered in the survey were under 18, 16% were 18-34, 62% were 35-64, and 16% of participants were over 65.
- 85% of participants identified as White, 6% as Black or African American, 4% as Hispanic, and the remainder were Native American or preferred not to say.



Financial

- Nearly half of respondents (46%) had a household income of \$100,000 or less, and over a third (33%) relied on government assistance or welfare, indicating a mix of middle-income and financially vulnerable individuals.



Therapeutic

- Participants and caregivers that contributed to the survey participated in trials that covered over 17 therapeutic areas (with Oncology being the most common at 36%) and more than 50 diseases.



Trial

- Most trials (52%) were conducted fully on-site and a majority (48%) were sponsored by pharmaceutical or biotech companies.

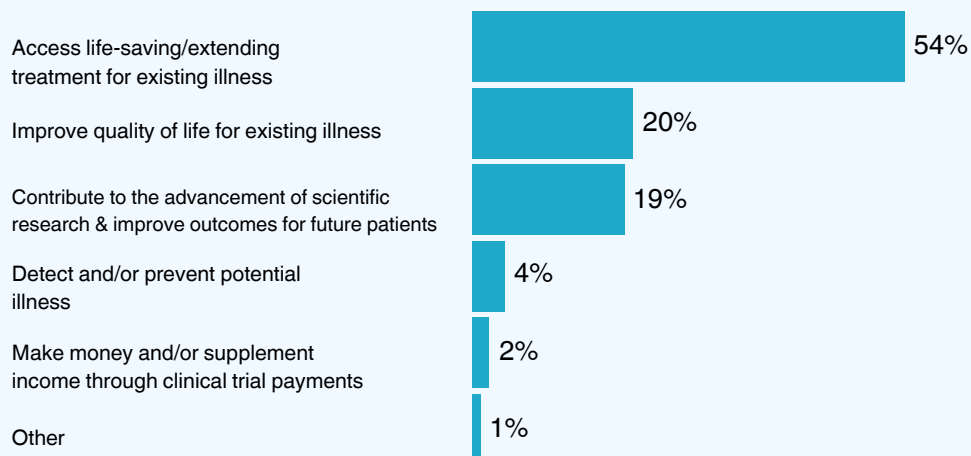
5 Key Survey Insights

Key Insight #1

People participate in clinical trials to save their life

There is a common misconception that patients participate in trials with ulterior motives such as financial benefit or solely to get early access to treatments. The data we collected dispels that myth; with the vast majority of participants (74%) enrolling to save their life or improve their quality of life, whereas only 2% of participants doing so to supplement their income.

Why Did You Participate in this Trial?



“

“This was my only option. It was take this trial or die, risks or not this was my option and only option.”

“

“The trial saved my life but it has financially devastated me.”



Taken from The Portrait Project by Mural Health.

Marcelo Ortigao, father and caregiver, scientist, professor, and advocate. Lost his daughter Juliana, who participated in a clinical trial, to DIPG.

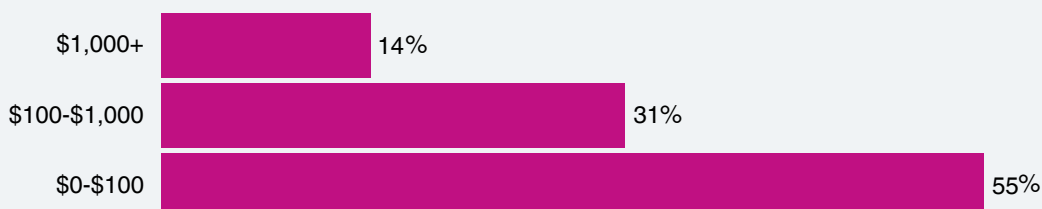
Key Insight #2

Participating in clinical trials creates financial challenges for patients and their families

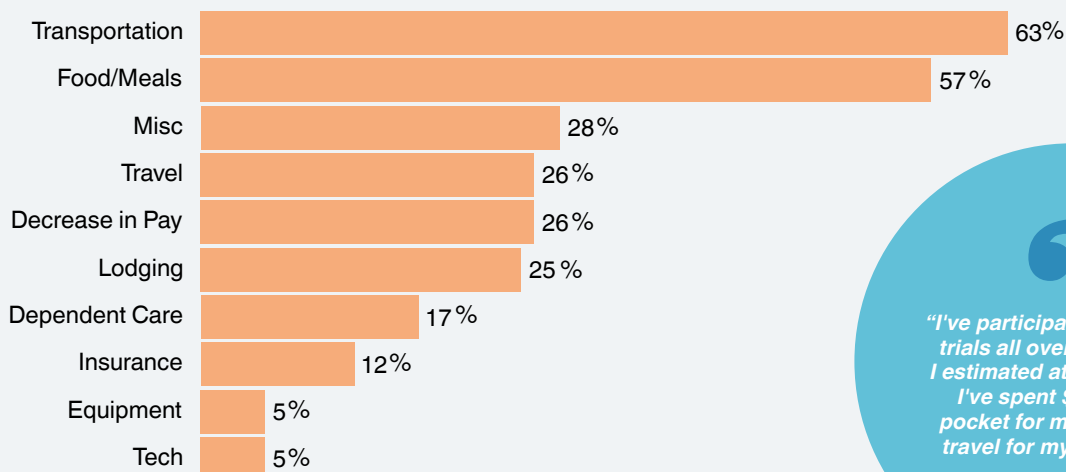
Patients are spending a significant amount of money to participate in a clinical trial. When reviewing the average out of pocket costs per trial visit, it is important to keep in mind that trials often have many visits. Trials that use the Mural Link platform have an average of 20 visits to the trial site, with some trials having upwards of 50 visits or more.

These costs add up quickly and significantly over the duration of the trial. Looking at this data, an average participant spending \$500 per visit could be required to spend ~\$10,000 out of pocket to participate if they aren't reimbursed, with some participants paying north of ~\$25,000.

Average Out of Pocket Cost Per Visit



Types of Incurred Out of Pocket Expenses



“
“I’ve participated in 4 clinical trials all over the country. I estimated at one point that I’ve spent \$35k+ out of pocket for myself alone to travel for my treatments.”
”

Key Insight #3

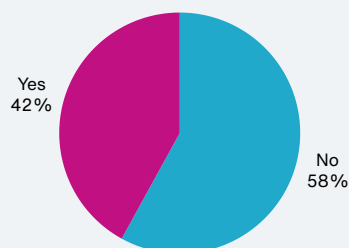
Providing reimbursements can improve trial retention

Our findings indicate that while most trials (58%) didn't provide reimbursements for expenses incurred, of the trials that did provide reimbursements, the majority (60%) of participants indicated that financial support was essential in order for them to stay in the trial.

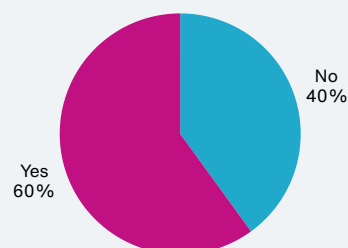
Reimbursing participants is not only a fair practice that improves the overall patient experience, but it also plays a crucial role in supporting enrollment and retention.

*We asked participants who received reimbursements in their trial if that impacted their ability to participate. Over half of respondents stated that without receiving reimbursements their trial participation would have been impacted (bottom chart).

Reimbursements in Trials



Did Reimbursements Impact Your Ability to Stay in the Trial?*



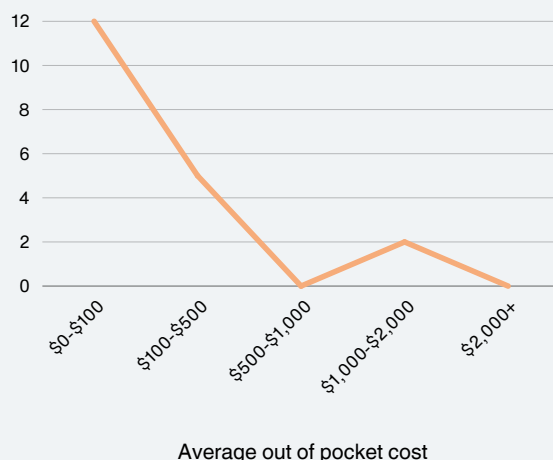
Key Insight #4

Lower-income households struggle to participate due to financial barriers

Not surprisingly, lower-income households are less likely to participate in trials with higher out-of-pocket costs. The data reveals a significant decline in the participation of people from lower-income households as trial costs increase, demonstrating that expenses prohibit these patients from staying in trials due to the financial burden to them and their families.

*Trial distribution in respondents with an average household income of \$50,000 and lower.

Participation in Lower-Income Households by Out of Pocket Cost*



Key Insight #5

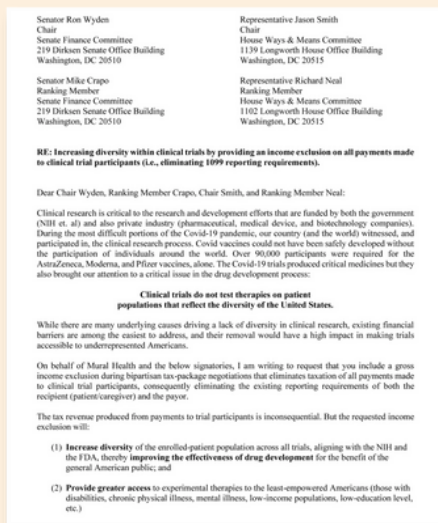
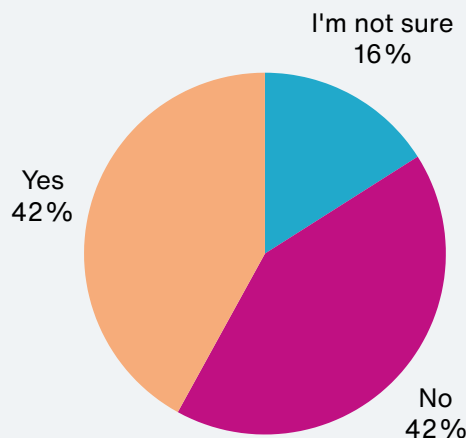
Incorrectly labeling payments as stipends further hurts low-income patients

A significant challenge in clinical trials is the taxation of financial support to participants, when payments are classified as stipends vs. reimbursements. This further exacerbates financial barriers to participation. **Disappointingly, despite the significant out of pocket expenses described above, over one-third of respondents who received stipends reported being taxed on the stipends they received.** Furthermore, 16% of stipend receivers were unaware of whether they were taxed or not.

By not excluding clinical trial payments from tax reporting requirements, current U.S. tax regulations inadvertently discourage participation, effectively preventing more than 100 million Americans— ~27% of the U.S. population—from enrolling in clinical trials. Many of these individuals come from communities that are already severely underrepresented in clinical research, further deepening disparities in medical advancements.

Image (on right) taken from the Harley Jacobsen Clinical Trial Participant Income Exemption Act that aims to address this issue. Learn more about the Act at <https://diversity.muralhealth.com/>.

Were You Taxed on Your Stipends?





Our Key Takeaways

Patients and families deserve a seamless and cost neutral experience

When we began creating this report, we set out to provide a recommendation for each key insight. However, we soon realized that the survey data and recommendations centered around a common theme: making the trial process as seamless and cost-neutral as possible for patients and their caregivers.

Clinical trials are often a vital option for patients and a necessary component of the drug development process. Ensuring that participation is accessible to all requires addressing the significant physical, emotional, and financial challenges patients face. Equitable reimbursements for essential costs such as travel, lodging, and meals can alleviate financial strain, while trial designs that accommodate low-income participants improve accessibility. Additionally, eliminating taxes on stipends ensures financial support remains a true benefit. By prioritizing the patient voice and the patient needs, clinical trials can be more inclusive, equitable, and ultimately more effective in advancing medical research and improving health outcomes.

What can you do today?

- **Engage patients during protocol design** to better align the specific needs of those that will be participating and **gather patient feedback throughout the trial process.**
- **Expand outreach and education efforts** to raise awareness about clinical trials in underrepresented and underserved communities.
- **Establish fair reimbursement policies** to ensure timely and comprehensive expenses coverage, that addresses both the obvious and less frequently considered costs.
- **Attempt to cover larger expenses upfront**—such as travel and lodging—to minimize out-of-pocket costs for participants, especially when traveling with families.
- **Support favorable tax legislation** that reduces the financial burden on trial participants, such as the Harley Jacobsen Clinical Trial Participant Income Exemption Act.



Final Thoughts

Mural Health has uncovered valuable insights from this survey through real patient experiences. However, more work remains. In conducting surveys like this in the future, we hope to have a better range of respondent demographic representation.

This survey represents only a small portion of all patients who deserve to be heard. Patients need a voice in trial design, with their real-world costs and burdens carefully considered. By prioritizing patient input and health equity, we can build a clinical trial ecosystem that is truly accessible, ethical, and patient-centered, while improving medical research and the future lives to come.



If you have any questions or want to discuss our findings in further detail, please contact **Nora DeSimone**, the Director of Patient Kindness at Mural Health.

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