

Empowering Patients through Clinical Trial Design

We asked 67 community members how their perception of a clinical trial might change if they were invited to contribute to its design.

KEY FINDINGS

22%

Increased Willingness to Participate

Patients express a greater willingness to participate in trials they've helped shape, highlighting the value of personal engagement.

I would likely be a more willing participant.

It would make me think they cared more about the end user.

I will feel it is more patient-centered and oriented; will make more patients sign-up for clinical trials (the current rate is dismal)

Would hope it would be planned around the needs of the patient and family above all.

27%

Patient-Centered Design

A focus on patient-centered design is crucial, with many advocating for trials that prioritize patient needs and experiences.

13%

Interest in Outcome / Personal Investment

Engaging patients in design sparks increased interest in trial outcomes and a sense of personal investment



12%

Need for Inclusivity and Understanding

Calls for more inclusive criteria and clear communication highlight the need for understanding and accessibility in trial design.

18%

Enhanced Trust and Hope

Patient input increases trust in the trial process and fosters hope for meaningful outcomes.

It would increase my hope that the trial can help more patients live longer.

It would heighten trust in the outcome, and the process would feel more relevant to my situation.

I would perceive trials that 'benefited' from my input in a more positive way, perhaps erroneously so.

Not sure. The issue is that companies tend to do 'beta' testing based on the data that they need to capture.

7%

Skepticism and Uncertainty

A minority express skepticism or uncertainty about the impact of their input, underscoring the importance of transparent communication.

ACTIONABLE STEPS



Structured Feedback Mechanism



Enhance Design Accessibility



Build Trust Through Transparency



Expand Criteria for Participation

CONCLUSION

Incorporating patient input not only fosters a more engaged and hopeful participant community but also drives forward the design of clinical trials that are truly patient-centered. This collaboration promises to advance clinical research in a way that respects and incorporates the valuable insights of those it aims to benefit.



Smart Patients