

04

UNLEASH FEEDBACK

The clinical trials system needs platforms and communities where participants can freely share their experiences without compromising trial integrity.



MIT COLLABORATIVE INITIATIVES

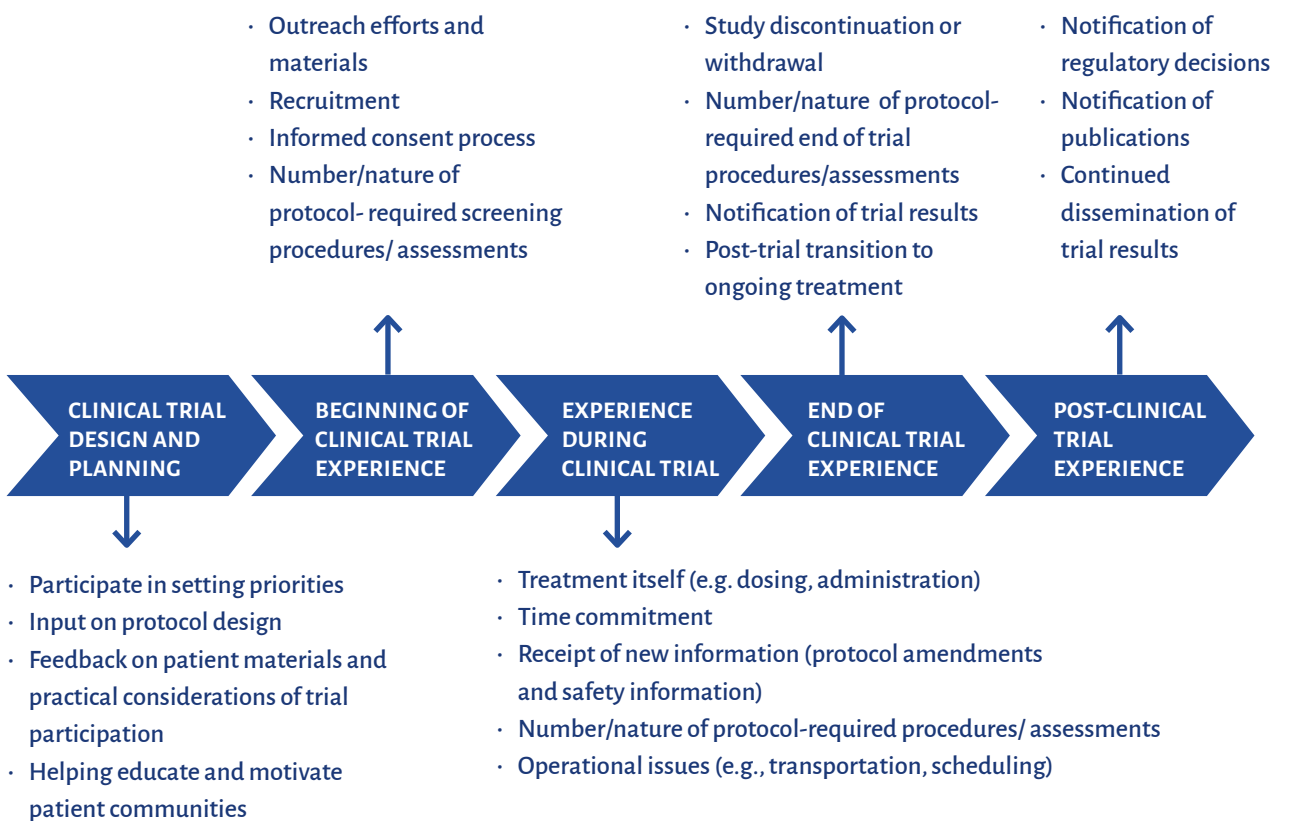


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THE PROBLEM

Existing efforts to improve clinical trial participant experience and satisfaction do not take advantage of the ways in which patient feedback can improve the overall transparency, interactiveness, and inclusivity of the treatment development system.

There is a significant movement afoot to systematically involve people, including patients (persons with personal experience of living with a condition or illness), caregivers, and patient advocates among others, throughout the treatment development process. Importantly, many stakeholders are working on creating feedback mechanisms for patients who become clinical trial participants so that feedback might be used to better integrate patient needs, perspectives, and priorities into all aspects of clinical trial functioning, from beginning to end (see below).



Feedback mechanisms can improve clinical trials and participants' sense of inclusion and ownership of the research process, but they don't give participants a public voice. Sponsors and trialists have long feared that public expression of clinical trial experiences would put trial integrity at risk. While this concern is understandable, it's both belated and shortsighted. Belated, because in the absence of dedicated, public fora for

expression, participants who are accustomed to crowd-sourced user reviews like Yelp and Healthgrades are using social media and other outlets to discuss trial experiences; and companies are mining those expressions through social listening. Shortsighted, because public fora for trial participant feedback is a vital missed opportunity for the sustainability of the treatment development system.

VISION

A 21st century treatment development system must be transparent, interactive, and inclusive.

SOLUTION

Participants could share feedback throughout their trial experience which would then be released incrementally on specially designed public fora in order to maintain trial integrity.

For some treatments this could mean posting feedback once a trial's findings have been publicly released or once a drug has received regulatory approval; for other lower risk trials, feedback might be shared in real time.

Sponsors and trialists should conceive flexible trial designs that encourage feedback and do not compromise trial integrity.

UNLEASHING PATIENT FEEDBACK WITHIN THE TREATMENT DEVELOPMENT SYSTEM SERVES THREE IMPORTANT GOALS:



First, like peer reviews posted on Uber, Amazon and TripAdvisor, participant feedback about clinical trial experiences can help mitigate the current information asymmetry about clinical trials, and allow patients to make more informed decisions when considering participating in a trial. Providing people more understanding of the trial experience can give them more confidence to consider trial participation when/if a clinician presents one as a treatment option.

improve through iteration based upon their feedback (e.g., every new version of the iPhone); so, they are beginning to expect the same from all aspects of healthcare.



Second, eliciting participant feedback in all of its forms demonstrates a willingness to participate in the culture of continuous learning which is rapidly becoming expected in all aspects of product development, including healthcare. Americans have become accustomed to seeing products change and



Third, sponsors and trialists who voluntarily share participant feedback will create a culture of transparency and trust, a particularly critical issue when considering misconceptions about research which act as significant barriers to participation. The legacy of research such as the Tuskegee Studies continues to create mistrust of all forms of research, particularly among minority and underserved populations; sponsors and trialists have begun to counter those fears and stereotypes through education campaigns, but transparency about the actual experience itself could serve to wipe away the last vestiges of these destructive misconceptions.

CONCLUSION

Participants are the most important stakeholder in the treatment development system; without them the entire research enterprise crumbles. The vast majority are accustomed to sharing their lives on multiple platforms, expressing opinions about products and services, and providing feedback about tech bugs and problems; so, it's only natural that they should look for a similar opportunity when they participate in clinical trials.

Unleashing participant feedback has the potential to improve the participant trial experience, thereby reducing participant attrition and attracting more participants. Importantly, it can also bring much-needed transparency and responsiveness to a system that is currently an unknown to so many Americans.

CITATIONS

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KNOW MORE:

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