



14 Ways to Empower Patients as Partners in Clinical Trials

1. Establish Patient Advisory Boards:



Establishing Patient Advisory Boards or Councils can involve patients in designing, implementing, and monitoring trials. These boards can provide direct feedback from a patient's perspective.

2. Co-Design Clinical Trials:



Patients can be involved from the outset in designing trials, from selecting outcomes that matter most to them, to deciding on the best methods of data collection.

3. Establish a Clear Informed Consent Process:



Ensure that informed consent documents are clear, transparent, and patient-friendly. Patients should fully understand the potential risks and benefits of participating.

4. Increase Patient Education:



Offering seminars, workshops, or educational materials helps patients understand the clinical trial process, its importance, and their rights as participants.

5. Offer Accessible Feedback Mechanisms



Regularly collecting feedback from patients during and after trials, and using this feedback to make improvements.

6. Keep Transparent Communication



Keeping lines of communication open, honest, and two-way. This might include regularly updating patients on trial progress or any changes to the trial.

7. Offer Flexible Visit Schedules:



Adapting trial protocols to fit patients' personal schedules or needs, thus reducing the burden of participation.

8. Utilize Technology



Using patient-friendly technology to monitor health metrics, report side effects, and provide reminders can make the trial process more engaging and less burdensome.

9. Prioritize Representation



Ensuring diverse patient representation in trial planning can help to ensure the trial is inclusive and takes into account a broad spectrum of patient experiences and needs.

10. Share Decision Making



Engaging patients in decisions about their care, from choosing which treatments to trial to deciding on stopping criteria.

11. Respect and Empathize



Treating patients with utmost respect, recognizing the sacrifices they're making, and empathizing with their experiences. Creating a culture of appreciation can help patients feel valued and understood.

12. Return Results



Sharing the results of the trial with participants, whether they are positive, negative, or inconclusive, is a way of acknowledging their contribution and emphasizing their partnership role.

13. Offer Community Engagement



Hosting community engagement events where patients and researchers can interact, exchange ideas, and co-learn.

14. Collaborate on Publications



Co-authoring publications with patient partners to ensure that the patient perspective is represented in the wider dissemination of trial findings.