Lessons Learned about Pragmatic Patient-Centered Research from the ADAPTABLE Research Community

ADAPTABLE (Aspirin Dosing: A Patient-centric Trial Assessing Benefits and Long-Term Effectiveness) is a pragmatic patient-centered study comparing the effectiveness of two different daily doses of aspirin widely used to prevent heart attacks and strokes in individuals living with heart disease. Embedded in the healthcare system, ADAPTABLE leverages electronic health records to screen and identify potential study participants, and claims data to capture primary endpoints.

In ADAPTABLE, patients are more than study participants, they are integral members of the study team who collaborate with researchers and clinicians to improve cardiovascular health for all patients. These patient partners called the Adaptors draw on their personal work and life experiences to improve the study participant experience for current and future research participants.

We asked the Adaptors to share lessons learned and insights from their experiences in the ADAPTABLE Study. On the flip side, researchers and clinicians share their learned experiences and insights.

Insights from Patient Partners

- Mutual respect between patient leaders and researchers has helped build an engaged & caring community that improves the research experience for all involved.
- Our involvement as patient advisors in research is important because it can help our friends and family in the future.
- It is harder than we realized to recruit patients for studies like ADAPTABLE. That is why personal involvement from study participants is so important.
- We are encouraged by the participants who share their personal reasons for enrolling in ADAPTABLE and enjoy reading their stories.
- Patients have valuable insights about study procedures and how to address challenges. ADAPTABLE is truly an authentic patient-centered study!
- We learned researchers can be fun and are real people.
- Patient involvement from the beginning of a study can make a friendlier and better study.
- Patients shaping study communications has helped to engage our study community.
- Being involved in ADAPTABLE has made us feel more empowered and proactive with our own healthcare. We hope this is also true for study participants.
- Patients and researchers need to be connected. Patient advisors can help researchers keep patients at the center of research by refining the research questions. The answers to these questions may help improve your quality of life.
- A good facilitator or liaison is crucial in helping guide and direct communications between the patient advisors and researchers. Study research budgets should account for the role of a facilitator.

“As an African American female, I recognize the importance of researchers including a wider and more diverse population to ascertain better and more effective medical practices. Traditionally, most studies have captured data from white males and over time we are slowly learning that medicine affects people differently. This was the first time I’ve ever been asked to participate in a study thus given the chance, I had to agree!”

Patricia—North Carolina

Want to read more reasons why people enroll in ADAPTABLE? Visit theaspirinstudy.org/participantvoice
Insights from Study Researchers and Clinicians

- It takes a village (and a lot of collaboration between very diverse organizations) to enroll 15,000 patients!
- It is critical to have processes in place for maintaining and protecting patient privacy, informing the care team of patient participation in the study, and extracting electronic health data.
- The ADAPTABLE study has encouraged increased collaboration and inspired us to work together to solve new, interesting research challenges with a pragmatic approach.
- Do not assume one model of recruitment will operate throughout the trial. Contacting patients via a variety of methods is important: snail mail, email, MyChart, phone, and in person.
- Celebrate successes or landmarks, such as enrolling 100 or 500 patients with a small party, free breakfast, happy hour, or snacks in the clinic to say, “thank you!”
- Patient engagement and feedback is essential at all stages of pragmatic clinical trials.
- Collaborating with patient partners has shaped our approach to recruiting. After hearing patients’ lived experiences with doctors and with research, our staff has a better appreciation of why patient-centered research is so important.
- We have learned that it is important to ask about a patient independent from the study. We also learned that being vulnerable ourselves could allow us to better connect with patients.
- Presenting ADAPTABLE as one of the first patient-centered pragmatic trials at local and national meetings along with patient partners provides a unique experience to educate others on the value collaborating with patients brings to clinical research.
- Physician champions are key to educating and engaging providers about the importance of the study.

“By far my favorite part of ADAPTABLE is the genuine spirit of collaboration across 40 sites around the country. Everyone wins when we share ideas and share important wins/losses.”

Daniel Muñoz, MD, MPA, ADAPTABLE Study Investigator

ADAPTABLE is funded by a PCORI (Patient Centered Outcomes Research Institute) grant and is the first pragmatic clinical trial conducted by PCORnet, the National Patient-Centered Clinical Research Network. PCORnet is a PCORI-funded innovative initiative to harness the power of data and make clinical research more patient-centered, faster, easier, and less costly.