PROJECT INFORMATION

November 2019

Developing a Guide on How to Involve Patients in Research Studies

Principal investigator

C. Daniel Mullins, PhD

Organization

University of Maryland, Baltimore

What was the project about?

To make research findings more useful to patients, researchers can involve, or engage, patients in research studies. For example, patients can help plan what the study will be about. Researchers can use different methods to engage patients. Some methods may be most helpful at certain steps in a research study.

In this study, the research team developed a guide on how to engage patients in the different steps of research.

What did the research team do?

In part 1, the research team reviewed 200 research articles and other reports. The goal of this review was to find methods researchers use for engaging patients. The team found nine methods: community partnerships, focus groups, interviews, meetings, sharing print materials, connecting through social media, storytelling, surveys, and including patients as research team members. The team created a draft guide in which they paired these methods with each research step.

In part 2, the research team interviewed and had group discussions with people who represented three different viewpoints: patients, researchers, and other research partners. Before the interviews, each person matched methods from part 1 with research steps, based on what they thought would work best together. Afterwards, the groups discussed the reasons for their choices. The team then created three more draft guides, one for each of the three viewpoints.

The interviews and group discussions included 160 patients, caregivers, patient advocates, healthcare providers, researchers, and policy makers from Baltimore, Maryland. Of these, 59 percent were African American, 43 percent were white, and 8 percent were Latino or Hispanic. The average age was 53.

In part 3, the research team worked with an advisory board to create the final guide. The board included patients, researchers, and healthcare professionals. First, the team combined the four draft guides from the first two parts of the study. Next, after receiving three rounds of feedback from the board, the team created the final guide. The final guide rated how suitable each method of engaging patients was for each research step.

The advisory board also helped plan and conduct the study.

What were the results?

Two methods—community partnerships and including patients as research team members—were highly rated methods for each step. For specific research steps, the following methods received high ratings:

- **Planning research:** focus groups, interviews, meetings, and surveys
- **Conducting research:** meetings
- **Sharing results:** focus groups, meetings, and storytelling

- **Evaluating patient engagement:** focus groups, interviews, and surveys

Sharing print materials and connecting on social media were the lowest rated methods.

What were the limits of the project?

The research team didn't find much information on which methods don't work. As a result, the guide didn't include suggestions for which methods not to use during each step.

Future research could update the guide with new information on the best methods to use for each research step.

How can people use the results?

Researchers could use the guide to help choose which engagement methods to use in their studies.

To learn more about this project, visit www.pcori.org/Mullins288.