

Partnering with Patients, Families, and Other Stakeholders in Healthcare Systems Research: Examples and Lessons Learned from Six PCORI-Funded Studies

Session Facilitator

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Panel Members

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Thematic Area Innovative Methods of Community Engagement

Abstract

Engagement of patients, families, and other stakeholders in healthcare research can help bridge the gap between academia and the healthcare world. Engaging all stakeholders in research helps to ensure that study questions are relevant to patients, families, clinicians, and the healthcare system. It allows for the design of stakeholder-centered interventions that can be implemented and sustained. Patients and other stakeholders have traditionally been involved in research as study subjects with their perspectives elicited via focus group, interviews, and surveys. Recent studies have begun to involve patients and stakeholders in advisory and partnership roles, building in structures and processes for ongoing engagement throughout the research from the development of study questions to dissemination of study findings. Systematic reviews of engagement of patients and stakeholders in research have demonstrated that it is feasible, have informed the research questions and protocols, and have occasionally helped secure financial resources. However, it is still unclear what engagement methods are most effective and concerns have been reported about tokenistic engagement and logistical challenges.

In this learning lab, we bring together project leads, patients, and stakeholder partners from six PCORI funded studies that are devoting particular attention to patient and stakeholder engagement in their research. Using a panel format, the panelists will respond to key questions that will 1) inform the session participants about the engagement structure, process, and impact in the six studies; and, 2) help them advocate for and achieve successful engagement in their own work. Questions to

panelists will include how they identified and recruited patient and stakeholder partners; got them to 'buy into' the process and understand their roles in the research; facilitated discussions about the research; ensured that various groups are represented and various voices are heard; evaluated the engagement process, and sustained it. Workshop participants will hear examples of how engagement was achieved at the various stages of the research from agreeing on the research questions/ study focus, co-development of interventions, conducting the research, to interpretation and dissemination of research findings. Panelists will explore how engagement impacted their studies, the challenges met, and how they addressed those. Session participants will receive written materials describing the various studies and their engagement approaches, along with references/resources for engaging patients and stakeholders in research. The panel facilitators will take questions from the audience during the session and ensure ample time for panelists to respond to those questions.

Learning Objectives

By the end of this session, participants will be able to:

- 1) Describe multiple approaches for engaging patients, families, and other stakeholders in research, and cite examples of engagement structures and processes within select PCORI-funded research studies
- 2) Discuss the value that engagement adds to the research, and how it can impact the various research stages – including determining research questions, co-development of interventions, conduct of the research, and interpretation and dissemination of research findings.
- 3) List challenges encountered by research leaders in establishing and sustaining engagement activities and how those were addressed.

Session Description

In this session we will bring together a panel of researchers, patients, and stakeholders from six projects who will respond to facilitator and audience questions about engagement in research. At start of the session, participants will be provided with a handout that includes a one page summary of each project to inform the session participants' about the individual projects, and facilitate their efforts to ask questions to the panelists. The one page summaries will include study goals, design, interventions, and description of how patients, families, and stakeholders were engaged within the project.

The session will follow a question/answer open dialogue format with no didactic PowerPoint presentations. The facilitator will start by asking select pre-determined questions to ensure that the session objectives will be met. The facilitator will address these questions to specific members of the panel based on their innovative work in that area. The panelists will then respond to questions from the audience.

Schedule

- 1) Introductions (10 mins) - Each panel member will provide only their name/ institution/project name
- 2) Facilitator asks pre-determined set of questions (50 mins) - Each question will be

asked to select panel members (questions will be pre-assigned to the various projects based on the areas that the project leads pre-determine that they have done the most innovative work in). Other project leads may comment based on the discussion.

- 3) Questions from the audience (30 mins) - The session is designed to 'protect' this time for audience to ask their questions to the panelists. In the event that the audience did not have enough questions to fill in the full 30 minutes, the facilitator will use a backup set of questions after all questions from the audience have been addressed.

Sample Questions

- How did you elicit patient, family, and stakeholder input in your study? How did you partner at the various stages of the research?
- What engagement structures did you create? How were study partners identified and recruited? What were the costs involved?
- How did you ensure representation from various groups? Whose voice was missing? How did you address this?
- How did you evaluate engagement in your study? How did you sustain it? How did it impact your research?
- What challenges did you have, and how did you overcome those?
- What approaches have you found helpful to organize and focus your engagement efforts?

Additional 'back up questions' would pertain to IRB issues, human subjects versus partners, traditional versus innovative methods for eliciting perspectives, etc.