

PCORI in Practice Webinar Series

Patient and Stakeholder Engagement in Research: Making a Difference in PCORI Projects

September 19, 2017

Featured Projects and Panelists

<u>Improving Asthma Outcomes through Stress Management</u>	<u>Patient-Centered Trauma Treatment for PTSD and Substance Abuse: Is It an Effective Treatment Option?</u>
Deborah Quint Shelef, MPH, CCRP, AE-C (Research Team)	Annette Crisanti, PhD (Principal Investigator)
Tiara Cuthbertson (Parent Partner)	Gina James, CPSW (Patient Partner)

Webinar Q&A

After the webinar, panelists responded to questions that were not answered during the webinar's Q&A session.

Audience Questions	Panelist Answers
<p>1. In Phase 1 of the study, you partner with stakeholders--and that drives what you will actually do in Phase 2 of the study (question, measures, intervention etc). So how do you write the grant? What do you say you'll do in Phase 2 since it is largely determined by Phase 1?</p>	Answered by panelists during webinar (webinar recording available here)
<p>2. To secure effective texting, did you provide phones or phone service for participants? And did you use an automated text delivery system?</p>	Debbie: We did not provide phones or phone service for participants. At enrollment, all participants were informed that charges may apply for calls and/or text messages, and this was included in the consent. In the rare case when a participant did not have a cell phone, reminders were provided by phone call. We used an automated text service that let us pre-program messages and also tailor them as needed.
<p>3. University of New Mexico has been a leader in Tele-Health activities. I am curious whether the speakers from UNM are considering ways to work with a Telehealth model. More generally, I am curious whether the PCORI portfolio currently has Telehealth projects.</p>	Annette: The primary data collection agency (Inside Out) is using telehealth. We are considering ways to work with the ECHO model. Dr. Crisanti is currently the PI for a 3-year grant awarded by the U.S. Department of Justice to implement the CIT ECHO. The CIT ECHO is a partnership between the Albuquerque Police Department, the Department of Psychiatry and Behavioral Sciences, and CIT Inc., which aims to improve law enforcement interactions with people living with mental illness with a goal of

creating safer interactions and fostering connections with the mental health system.

PCORI staff: [See this handout for information about PCORI research studies related to telehealth](#)

4. What helped the most in teaching all levels of stakeholders (non-researchers) what was needed to be involved in a research project?	Answered by panelists during webinar (webinar recording available here)
5. Within academia, how did either study personnel deal with defending the qualitative part of the design and outcomes? /for example, changing outcomes and even questions as the project develops?	Answered by panelists during webinar (webinar recording available here)