

PCORI in Practice Webinar Series

Patient and Stakeholder Engagement in Research: Strategies for Initiating Research Partnerships

July 19, 2017

Featured Projects and Panelists

<u>Comparative Effectiveness of Surveillance Imaging Modalities in Breast Cancer Survivors (SIMBA Study)</u>	<u>Comparing Outcomes of Drugs and Appendectomy (CODA Study)</u>
Karen Wernli, PhD, MS (PI) Associate Investigator Kaiser Permanente Washington Health Research Institute	Giana H. Davidson, MD, MPH (Co-investigator) Assistant Professor, Division of General Surgery University of Washington Seattle
Dianne Johnson, Patient Partner	Nathan Shapiro, MD, MPH (emergency medicine), Clinician 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
1. Did you use an engagement rubric when working with your partners? If so, which aspect of the engagement rubric did you find most helpful?	Karen: The engagement rubric was not out when I first began my project, but this might be a good resource for patient engagement. There are several other resources now available. http://www.inspireresearch.org/
2. When do you start clinician engagement before writing a grant proposal?	Karen: I had several clinical colleagues already involved in my research collaboration to understand both perspectives and direction for the research goals. I had additional clinical colleagues that I engaged in the 6-8 weeks before grant submission. I believe that you can write a PCORI grant with clinical goals as long as you recognize that outcomes for patients. Patient reported outcomes are not themselves the only thing relevant to patients. Patients are also interested in clinical goals. Giana: We started routinely meeting with clinical partners in Washington State approximately 9 months prior to submitting the PCORI proposal to ensure we had a strong network of hospitals and engaged clinicians to carry out this work. We expanded this group overtime as we brought on additional partner hospitals.

<p>3. Do the speakers have any advice regarding how to work together on a program of research rather than a specific project in case an individual project isn't funded right away?</p>	<p>Karen: I don't have specific advice on this, but I think this is also a fine approach. I think research questions broadly in breast cancer, in my case, can be of further interest to patient partners. I think you can build discussion regarding certain issues and allow the relationship to grow organically. I think patients in particular enjoy social interaction through in person discussions, food, and discussion.</p>
<p>4. Does anyone have any insights into how these strategies may look different when engaging with youth as research partners? Or would researchers expect to use a similar approach? Any resources to share in this area?</p>	<p>Karen: I have recently taken to twitter to engage adolescent and young adult cancer patients. I have not specifically identified patient partners this way, but I think you need to think creatively in this partnerships. I was speaking with another group hoping to engage adolescents, and suggested that you try to understand their currency. For example, many youth are required by their high school to volunteer a certain number of hours during their four years. If you are able to offer volunteer credit for HS, this might be one way to engage youth. I have also seen projects that recruit youth and parent dyads for engagement. I would suggest to recruit youth separate from their parents to encourage discussion. I think it is important for everyone to hear all perspectives, and kids will not speak up differently from their parents in those settings.</p>
<p>5. How does the appendicitis study differ from a classic NIH-funded RCT?</p>	<p>Giana: PCORI promotes and requires stakeholder engagement prior to funding. This is the first trial we know of that uses patient reported outcomes as a primary analytic outcome for appendicitis. This is a pragmatic trial that encourages heterogeneity and PCORI also has a commitment to public release of data for transparency.</p>
