

Greater Plains Collaborative Learning and Engagement Conference

Types and Needs of Investigators Doing Trials and Observational Studies PCORnet

Focus on Investigators Engaging Patient Partners

August 26, 2024

Context: Researcher Preparation to Engage with Patients

PCORI just released updated guidance for engagement in research

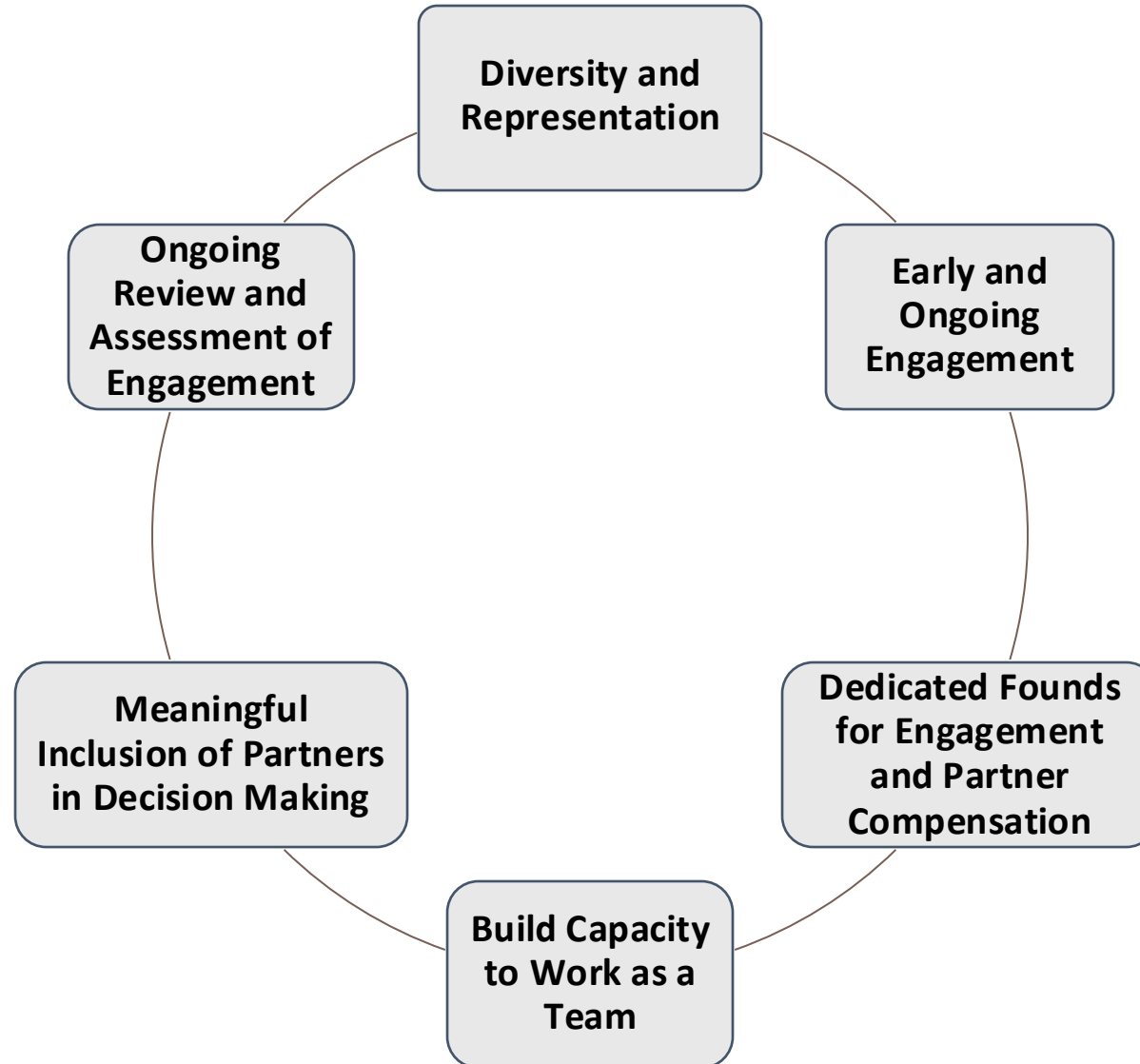
- Project teams now expected to address the *Foundational Expectations for Partnerships in Research* from application through award, development and implementation
- Must demonstrate meaningful patient and stakeholder engagement
- PLACER feasibility phase can further develop engagement plans and activities

PCORI's Engagement Tool and Resource Repository has 375 tools for researchers (!) (Fortunately for GPC, Jeff Ordway helped develop the repository and is primed to assist investigators to use it during Phase 4)

- Educational Materials (194)
- Engagement Approaches (157)
- Evaluation Tools (36)
- Event Materials (30)
- Study Findings on Engagement Capacity Building (73)
- Study Outreach (53)
- Team Management (115)

Are researchers ready for this?
What help do they need?

The New Foundational Expectations



Some Types and Needs of PCORI/PCORnet Investigators

Observations from my experience working with a few patient or community advisory committees, thinking forward to the Phase 4 “Investigator Incubator”

Some Types and Needs of Investigators

"I need a letter of support from patient partners for my grant proposal"

"I want to work with patient partners on study design, designing forms, and interpreting results"

"I only need to use data from medical records, no patient-reported data"


"I want to collect data from patients through a survey"

"I want to do a clinical trial"

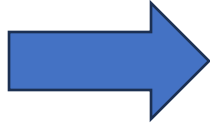
I have experience working with patient partners

I don't have experience working with patient partners

Types and Needs of PCORI Investigators



"I need a letter of support from patient partners for my grant proposal"



May have little experience working with patient partners. May need coaching in how to present to a patient advisory committee

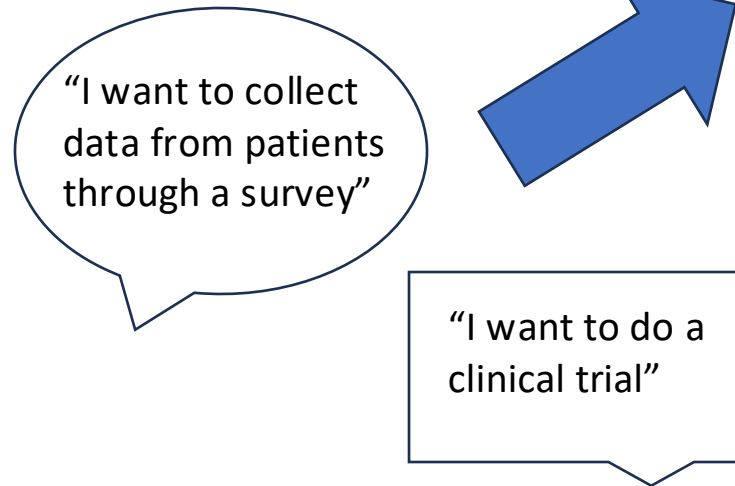
Types and Needs of PCORI Investigators

“I want to work with patient partners on study design, designing forms, and interpreting results”



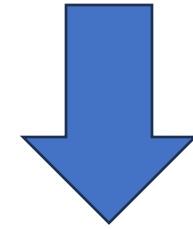
- May need advice during proposal stage.
- May or may not have experience working with patient partners.
- May want to include a patient co-investigator and advice on how to set up a patient advisory committee for their study.
- Often working with patients who have a specific condition and may already have formed relationships with condition-oriented advocacy organizations.

Types and Needs of PCORI Investigators



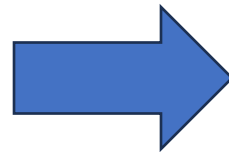
Types and Needs of PCORI Investigators

“I only need to use data from medical records, no patient-reported data”



May need help identifying a role for patient partners

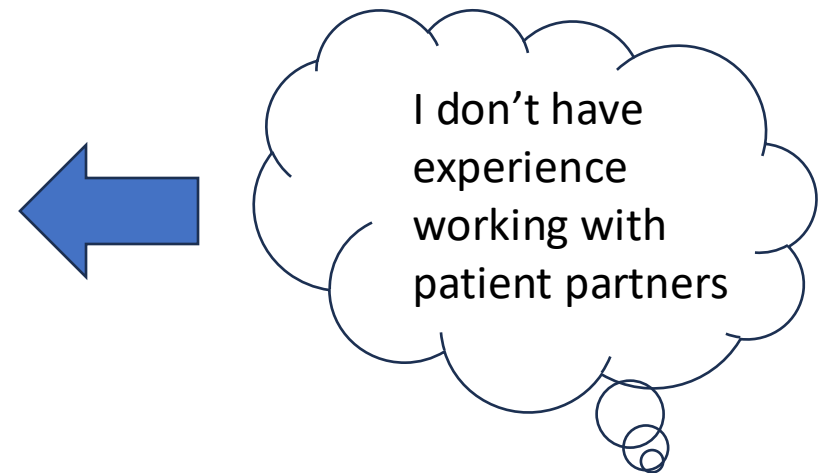
Types and Needs of PCORI Investigators



May be highly evolved and feel the more patient input the better, will come better prepared and better able to communicate their work and needs

Types and Needs of PCORI Investigators

Without guidance, will often miss the mark when presenting to patient groups, use technical and detailed language, fail to provide the types of information that would make it easy for patient partners to help



Preliminary thoughts on some resources that might be helpful for GPC

- **Coaching investigators before meeting**

- ✓ Slide review

- Checklist of considerations in preparing to meet with PAC

- **Guidelines for PAC members:**

- how to evaluate the request and assist investigators

- **Follow-up**

- Summary of meeting
 - Letter of support
 - Etc

Investigators: Considerations before approaching the PAC:

Do you understand how the research relates to patient needs?

- Does the research topic or question reflect a major need or concern expressed by the patient community?

Have you considered or articulated how you want to engage with patients/the community?

- What are your goals for having patient/community partners involved?
- What are you asking the patient community to do?
- What is the purpose of the research and what type of follow-up will occur?
- What will be offered in return for participation in research?
- How will you return results?

How will you assist PAC members to understand the specific research?

- Are materials in plain language? Do you need to translate any materials into another language?
- How will you assist the CAB to evaluate what the research means to the community?
- Have you prepared a one-page fact sheet to share?

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Patient Advisors: Guidelines for engaging researchers

Evaluate –

- Whether the research reflects a major concern of the community
- Whether the research involves knowledge from the affected community, to develop bi-directional relationship with researchers
- How research might affect you and your community

Learn –

- Work with researchers to understand the basic science and research methods that will occur
- Work with researchers to help communicate the research in words the community can understand

Assist –

- Identify local organizations/networks/patient communities
- Explain how to engage with awareness of cultural differences and community diversity
- Articulate barriers that might be present

Discussion

- What else?
- What other scenarios come to mind?
- What has worked?
- What other resources would help?