



#PCORI2016

Patient and Stakeholder Engagement in Research: Identifying Challenges and Developing Solutions

CHANGING THE CONVERSATION ABOUT HEALTH RESEARCH

Disclosures

The faculty/presenters in this session have reported no interest or other relationship(s) with commercial interests (drug/device companies) that may relate to the educational content of this activity.

Today's Agenda

- Learnings on engagement from PCORI awardees and partners
- Panel discussion with awardees and partners
- Small group discussions
- Report back and wrap-up



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Learnings on engagement from PCORI awardees and partners

Laura Forsythe, PhD, MPH

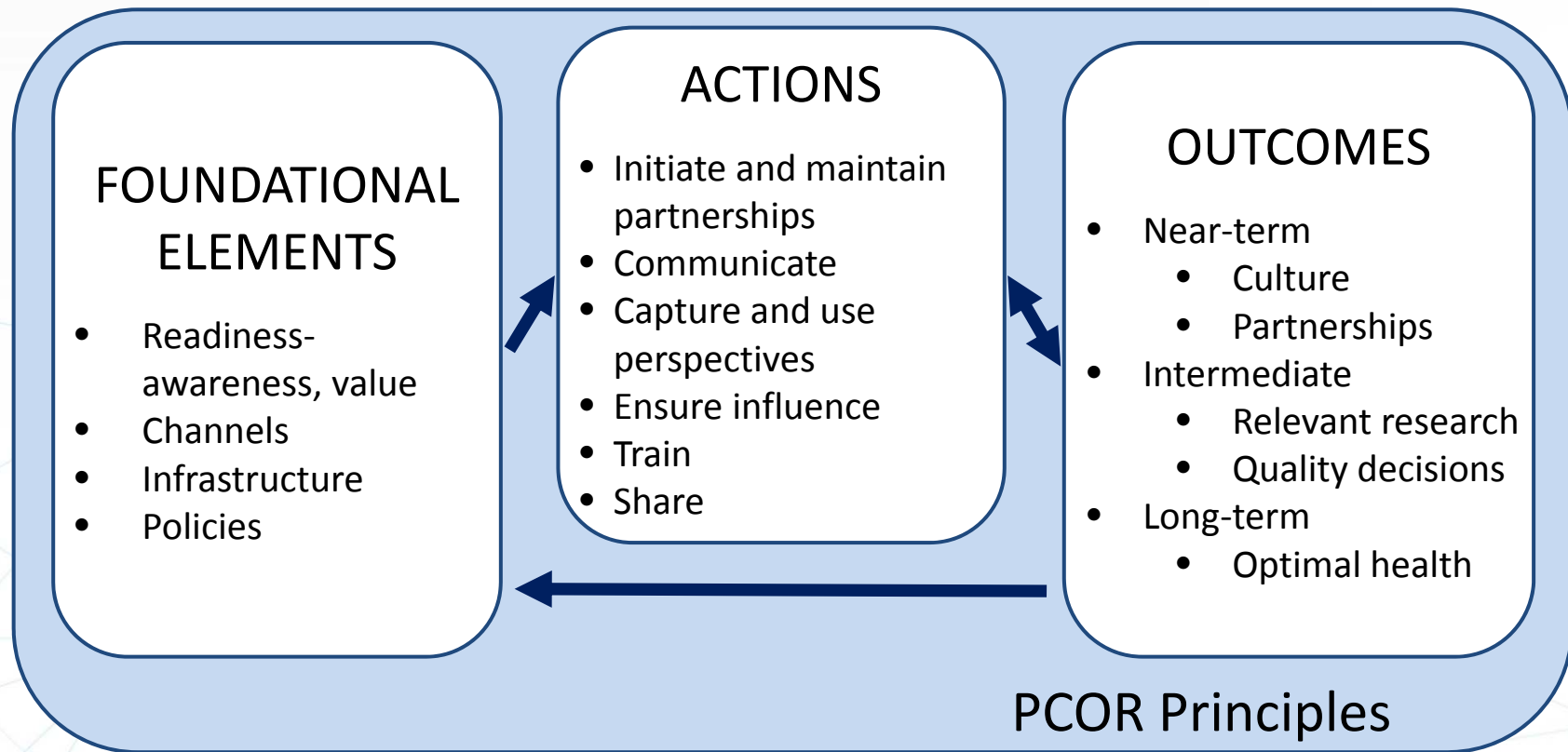
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CHANGING THE CONVERSATION ABOUT HEALTH RESEARCH

Today's Agenda

- Learnings on engagement from PCORI awardees and partners
 - Background & Methods
 - Findings to Share:
 1. What does engagement look like in PCORI projects?
 2. How does engagement in research affect study questions, design, processes, or outcomes?
 3. What are common challenges for engagement in research?
 4. What solutions do awardees and partners recommend?

Background: Conceptual Model of PCOR #PCORI2016



Frank L, Forsythe L, Ellis L, Schrandt S, Sheridan S, Gerson J, Konopka K, Daugherty S. Conceptual and Practical Foundations of Patient Engagement in Research at the Patient-Centered Outcomes Research Institute Plans. *Quality of Life Research* 2015. 24(5):1033-1041 DOI 10.1007/s11136-014-0893-3

Methods

- Data collected from awardees via [interim progress reports](#)
- Awardees nominate partners to receive invitation to complete the [Ways of Engagement- Engagement Activity Tool](#) (WE-ENACT)
- Open and closed ended items
- Qualitative analysis
 - Hierarchical codebook developed & applied
 - Thematic analysis
 - Documentation of code frequency
 - Compare responses from awardees and partners

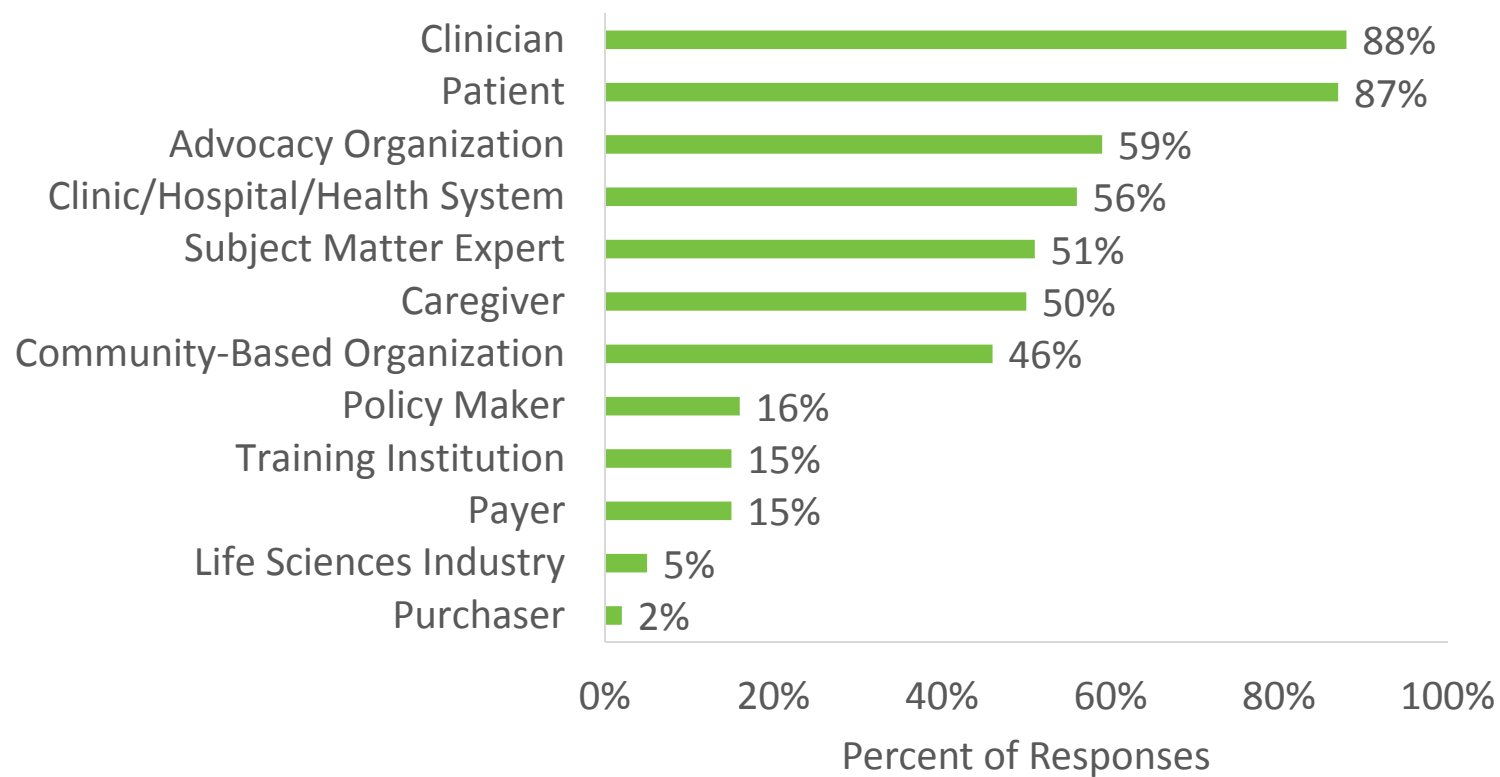
Findings

1. What does engagement look like in PCORI projects?

2. How does engagement in research affect study questions, design, processes, or outcomes?
3. What are common challenges for engagement in research?
4. What solutions do awardees and partners recommend?

Who is engaged?

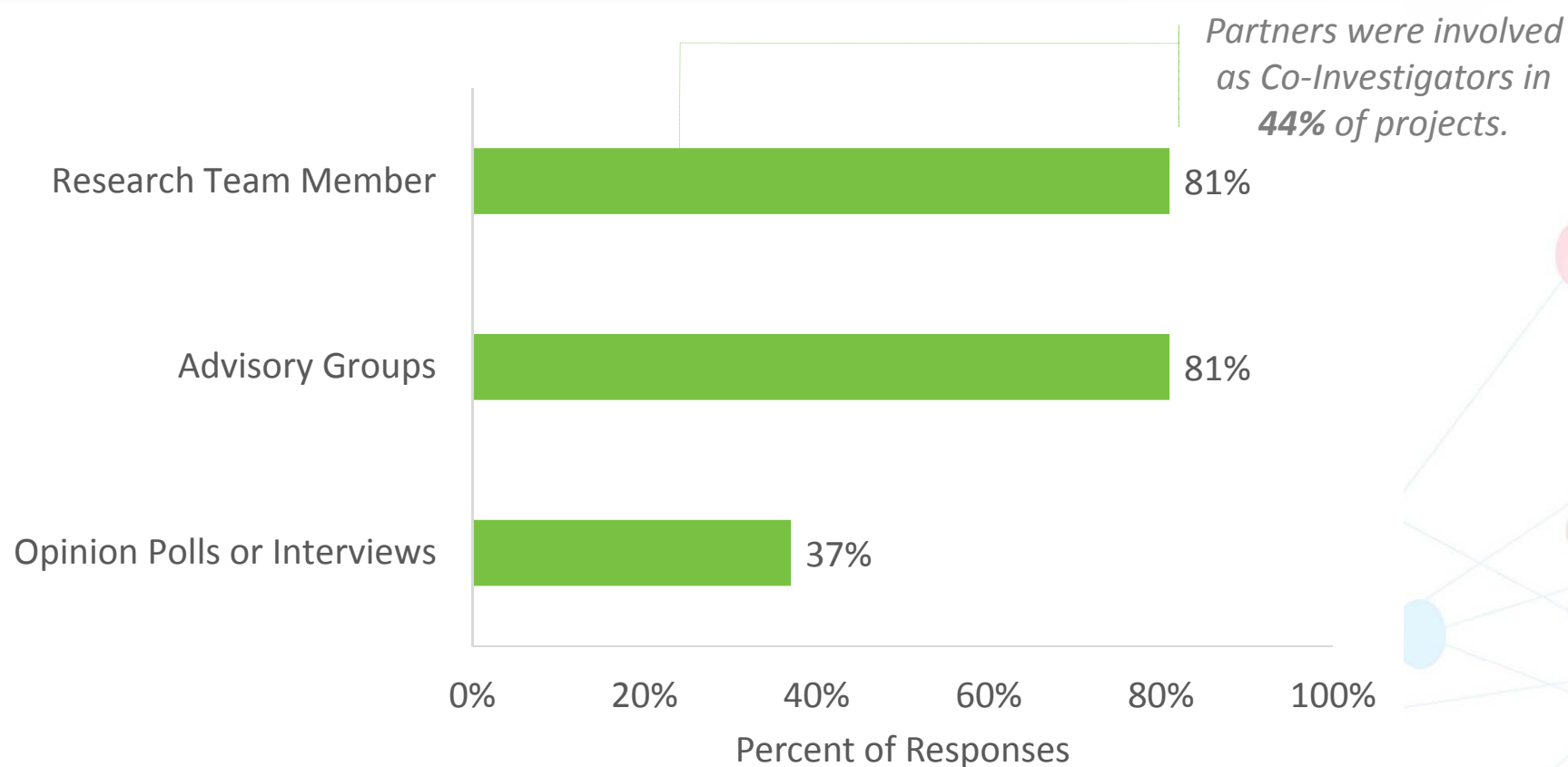
Awardee report of partner types engaged in the prior year (N = 240)



Note: Data from annual awardee report;
94 responses about project year 1, 146 responses about project year 2

How are they engaged?

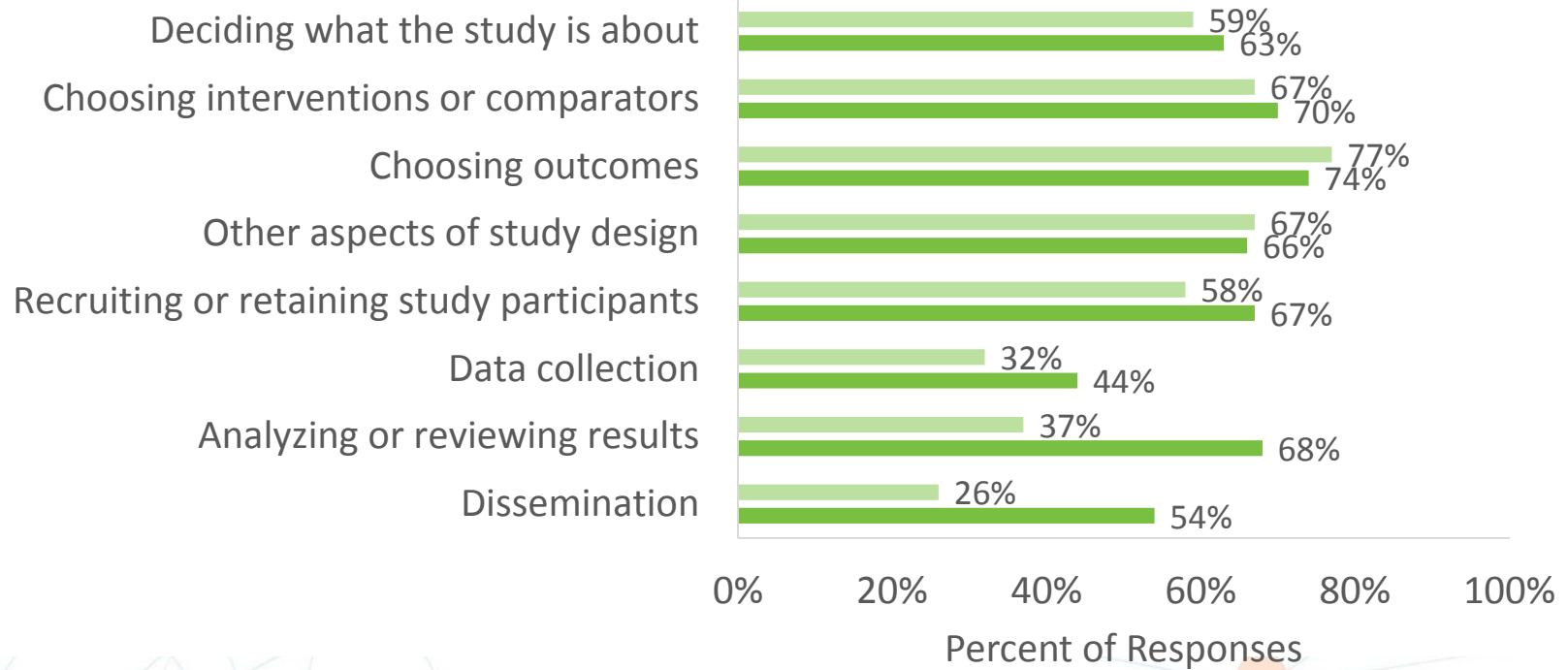
Awardee report approaches to engagement in prior year (N = 240)



Note: Data from annual awardee report;
94 responses about project year 1, 146 responses about project year 2.

In what phases of PCORI projects are partners engaged?

Awardee report, prior year (N = 238)



■ Year 1 (N=93) ■ Year 2 (N=145)

Note: Data from annual awardee report.

What are common engagement activities?

Researchers & Partners reported partner activities in the last year
(*N* = 258 awardees, 254 partners)

Partners

Awardees

- **Shared personal perspective** (*e.g., priorities, experiences*)
- **Guidance and feedback about research project processes and materials**
- **Decision-making role about research project processes and materials**
- **Direct participation in conduct and dissemination** (*e.g., recruiting participants, collecting data, presenting*)

Findings: Summary #1

1. What does engagement look like in PCORI projects?

- PCORI projects display substantial engagement with multiple partner types engaged via multiple approaches across multiple phases.

Findings

1. What does engagement look like in PCORI projects?
- 2. How does engagement in research affect study questions, design, processes, or outcomes?**
3. What are common challenges for engagement in research?
4. What solutions do awardees and partners recommend?

In what ways is engagement making a difference? #PCORI2016

Key themes from project years 1 and 2 (*N* = 258 awardees, 254 partners)

Partners

Better understanding of partner perspective (e.g., priorities, experiences)

Awardees

Refined the study & make more patient-centered

- Research questions
- Interventions and/or comparators
- Outcomes and measures
- Data collection
- Recruitment/retention strategies

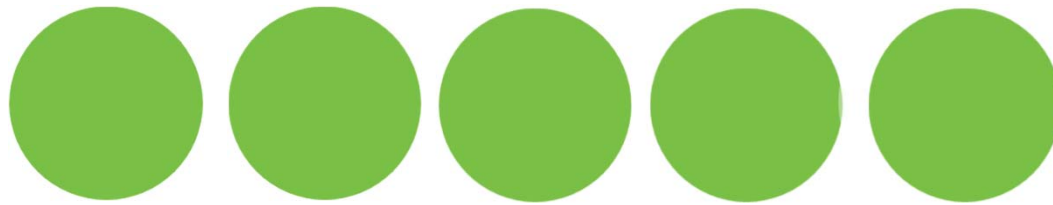
Enhanced enrollment rates

pcori
Themes mentioned in $\geq 10\%$ of responses.

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Case Example: Effects of Engagement

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Phases of Research Project

Research Topics & Research Questions

Interventions & Comparators

Outcomes & Measurement

Other Aspects of Study Design

Study Participant Recruitment & Retention

Data Collection

Data Analysis & Results Review

Dissemination



Interventions & Comparators



We gave our opinion on **what information families would like** to have available to them...what order the information should be presented, ...**The team was able to tweak the presentation to make it more user friendly.** – *Caregiver/Family Member*



Phases of Research Project

Research Topics & Research Questions

Interventions & Comparators

Outcomes & Measurement

Other Aspects of Study Design

Study Participant Recruitment & Retention

Data Collection

Data Analysis & Results Review

Dissemination



Outcomes & Measurements

“ [I] discussed my priorities with researchers. They described how they would measure those issues.
– Payer (public or private insurance)

“ All stakeholders assisted us in deciding on important outcomes to measure... **This input resulted in our primary medical outcome being disability days at one year after treatment.** – Awardee



Phases of Research Project

Research Topics & Research Questions

Interventions & Comparators

Outcomes & Measurement

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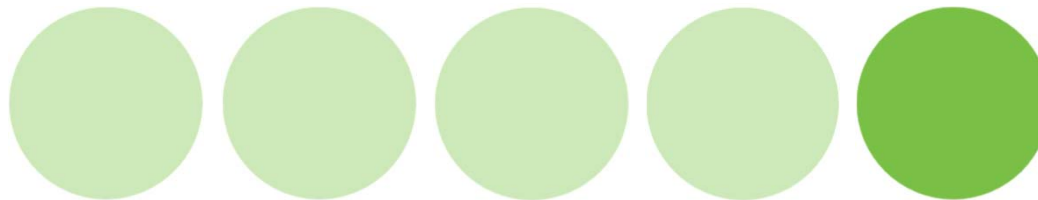


Study Participant Recruitment & Retention #PCORI2016



We brainstormed ways to **change their approach** so that families are more at ease...they changed how they reach out to patients based on feedback.

We discussed why families might choose to withdraw from the study and ... about better ways to communicate with families that are involved in the study. [As a result], **more families stayed in the study.** – Caregiver/Family Member



These changes **increased enrollment in the trial from 65% to 95%** and **increased retention from 58% to 85%.** – Awardee

Phases of Research Project

Research Topics & Research Questions

Interventions & Comparators

Outcomes & Measurement

Other Aspects of Study Design

Study Participant Recruitment & Retention

Data Collection

Data Analysis & Results Review

Dissemination



Findings: Summary #2

2. How does engagement in research affect study questions, design, processes, or outcomes?

- PCORI awardees and partners report changes to study interventions or comparators, recruitment strategies, and outcomes and measurement.

Findings

1. What does engagement look like in PCORI projects?
2. How does engagement in research affect study questions, design, processes, or outcomes?
- 3. What are common challenges for engagement in research?**
- 4. What solutions to awardees and partners recommend?**

What are common challenges for engagement in research?

(N = 50 awardees, 254 partners)

Partners

Awardees

- Scheduling logistics

Scheduling Challenges

“ Most of the meetings were held early in the afternoon which made it difficult to attend.
– *Patient/Consumer*

“ Because I am the primary caregiver of my son, being able to schedule time to meet has been my greatest challenge.
– *Caregiver/Family Member*

“ Another challenge with patient/stakeholder engagement is finding a common meeting time for Community Stakeholders since these are busy individuals with varying priorities. – *Awardee*

Scheduling Challenges: Solutions

- Flexibility
- Using patient/stakeholder input to schedule activities
- Additional staff time

“ No one time worked, so we scheduled the meeting at two different set times, alternating between those two times every other month... **Every study team member is able to attend the calls bimonthly.** – Awardee

“ We solved the problem by **setting a scheduled date for the monthly meetings...** [which] now works for all team members. Also, the site rotation with telephone attendance as needed has worked very well. – Awardee

“ We hold the **phone calls in the evening** to allow greater participation. – Awardee

“ I often **take additional time to complete follow-up calls** for individuals who could not make the meetings. – Awardee

What are common challenges for engagement in research?

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(N = 50 awardees, 254 partners)

Partners

Awardees

- Scheduling logistics
- Inconsistent partner participation/limits due to health

- Difficulty identifying & inviting partners
- Difficulty identifying & fully including diverse partners
- Additional time & effort

Solutions Recommended by Awardees

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- Flexibility
 - In project timelines
 - In strategies for finding partners

“ We overcame these challenges by improving the language of the flyer to make eligibility criteria clearer. – *Awardee* ”

“ We also may conduct some individual interviews via Skype so that we can include [partner organization] recruits outside the [area]. – *Awardee* ”

“ Originally did not have any male applicants respond to our recruitment efforts, despite reaching out to a wide array of community agencies and schools. However, we overcame this challenge by engaging in personal outreach, and now have 3 male members of the board. – *Awardee* ”

Solutions Recommended by Awardees

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- Flexibility
 - In project timelines
 - In strategies for finding partners
 - In how meetings are set up

“ We will continue to try different formats and techniques for these meetings and possibly move to holding simultaneous, but separate meetings for members who prefer Spanish and those who prefer English. – *Awardee* ”

“ We agreed to meet with patients individually or in small groups. – *Awardee* ”

“ The structure of the meeting was changed so that youth were given an opportunity to speak before adults could. – *Awardee* ”

Solutions Recommended by Awardees

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- Flexibility
- Consistent involvement of partners
- Diversity of partners
- Dedicated staff time for engagement
- Establishing community rapport
- Using everyone's contacts to identify partners
- Sensitivity to partner needs

What are common challenges for engagement in research?

(N = 50 awardees, 254 partners)

Partners

- Project delays
- Managing different perspectives
- Difficulty understanding research jargon
- Perceived lack of contribution
- Limited connection to others

Awardees

- Difficulty identifying & inviting partners
 - Difficulty identifying & fully including diverse partners
 - Additional time & effort
- Scheduling logistics
 - Inconsistent partner participation/limits due to health

Solutions Recommended by Partners

- Valuing partner contributions

“

Having the round table discussions where every persons ideas were valued equally was really important. It made it so that everyone was more willing to share honestly because they weren't intimidated or made to feel that the doctors/researchers knew better than we as parents/caregivers did. – *Caregiver/Family Member*

“

Providing detailed responses to feedback so that we know our work is valued is the most important part.
– *Patient/Consumer*

“

A quarterly update is sent to stakeholders regarding the progress of the study and how their suggestions have impacted the study. – *Awardee*

Solutions Recommended by Partners

- Valuing partner contributions
- Creating a supportive, respectful atmosphere

“ They were open to our input and did a VERY good job of making everyone feel comfortable. There was no coddling, but they talked to us like adults—like they would talk to anyone without mental illness. We felt like our opinions mattered ... They made everyone feel like we were on an even plane. – *Patient/Consumer*

“ We got together quarterly as a team, we shared a meal together and sat at a big round table where we were asked and given the opportunity to express our thoughts, ideas and opinions. Everyone was given the chance to share and respond. – *Caregiver/Family Member*

Solutions Recommended by Partners

- Valuing partner contributions
- Creating a supportive, respectful atmosphere
- Frequent meetings and/or communication
- Training to increase partner knowledge

“

Not having a medical background, I grabbed any newspaper or magazine article or anywhere else on health issues (BP, walking, exercise) that I could get my hands on. – *Patient/Consumer*

“

Many patients and caregivers could be helped to move beyond their personal experiences to look at the broader issues. Perhaps some orientation could give the background of the reason for the project, what activities will be included, and the population to be studied. – *Caregiver/Family Member*

Solutions Recommended by Partners

- Valuing partner contributions
- Creating a supportive, respectful atmosphere
- Frequent meetings and/or communication
- Training to increase partner knowledge
- Engagement from the beginning
- Clear expectations
- Connecting partners to the research team
- Improving identification of partners
- Using plain language

Findings: Summary #3 and #4

3. What are common challenges for engagement in research?

- Scheduling is the most common challenge. Other challenges relate to how to find and effectively include partners.

4. What solutions do awardees and partners recommend?

- Awardees and partners recommend flexibility and attention to both researcher and partner needs to achieve project goals together.

Questions?





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Thank You!

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November 17-19, 2016

Panel Discussion

- Moderator:
 - Chinenye Anyanwu, PharmD, MPH, Engagement Officer, PCORI
- Panelists:
 - Francine Brentzel, Patient/Stakeholder Advisor, University of Pittsburgh
 - Michael Schneider, DC, PhD, University of Pittsburgh
 - Peter Kohler, MD, University of Arkansas for Medical Sciences
 - Mandy Ritok
 - Tung Nguyen, MD, University of California, San Francisco School of Medicine
 - Arcadi Kolchak, MPH, San Francisco State University

Panel Discussion

- Reflecting on your experiences, what have been some of the challenges you encountered and how did you overcome them?
- What approaches to working together have been most effective?
- Additional questions for panelists?

Small Group Discussions

- What did you find most meaningful about the presentation and panel discussion?
- Describe an **"AHA!"** moment from your experiences with engaged research.
- What have been your biggest challenges and what could you have done better or differently to improve your chances for success?
- Think about some of your unresolved challenges. Discuss with your group members to brainstorm possible practical solutions
- What will you do differently with respect to patient and stakeholder engagement in your research moving forward?

Report Back and Wrap-up

- Share significant themes and/or key points from your discussions

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