PCORI in Practice Webinar Series

Engagement Challenges, Strategies, and Resources

December 5, 2017

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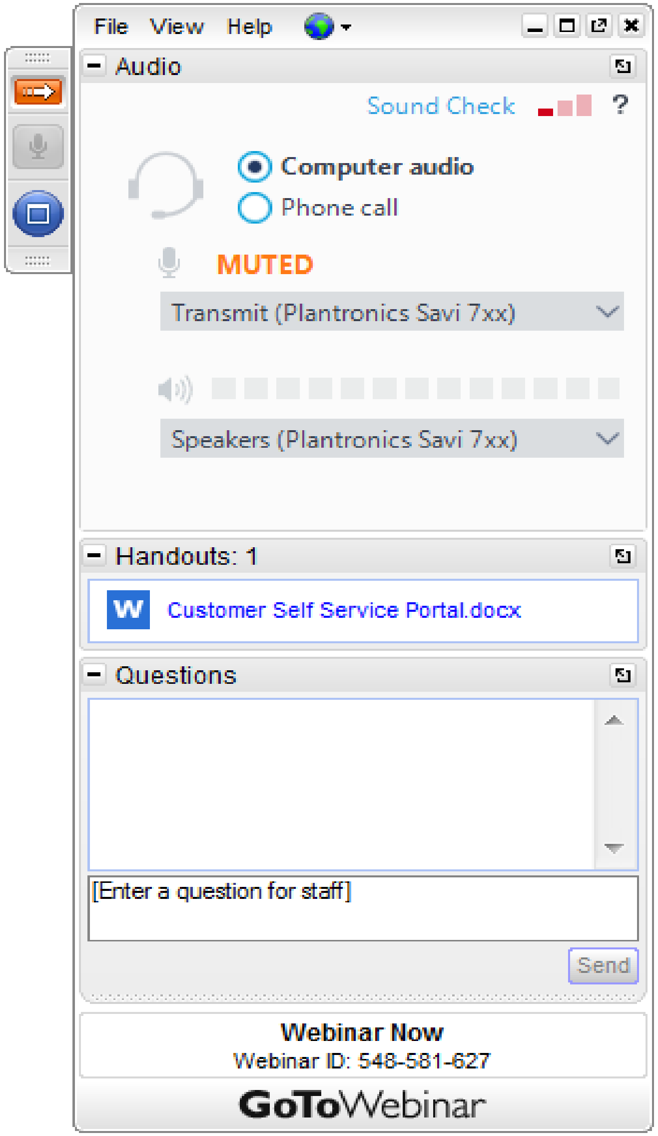

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PCORI in Practice Webinar Series

Engagement Challenges, Strategies, and Resources

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PCORI Staff Introductions

Lisa Stewart, MA
Engagement Officer
Public & Patient Engagement

Andrea Heckert, PhD, MPH
Program Officer
Evaluation & Analysis

Courtney Hall, MPH
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Evaluation & Analysis

Today's Agenda

- Introduction to PCORI
- Key findings from PCORI awarded projects: engagement challenges and strategies
- Presentations by PCORI awardees and partners:
  - Dr. Michelle Salyers and Tim Gearhart
  - Dr. Elizabeth Cox and Jean Benzinger
- Discussion

Learning Objectives

At the conclusion of this webinar, attendees will be able to:

- Describe some of the common challenges and strategies related to engagement in PCORI's portfolio of funded research projects
- Identify useful resources for patient and stakeholder engagement in research

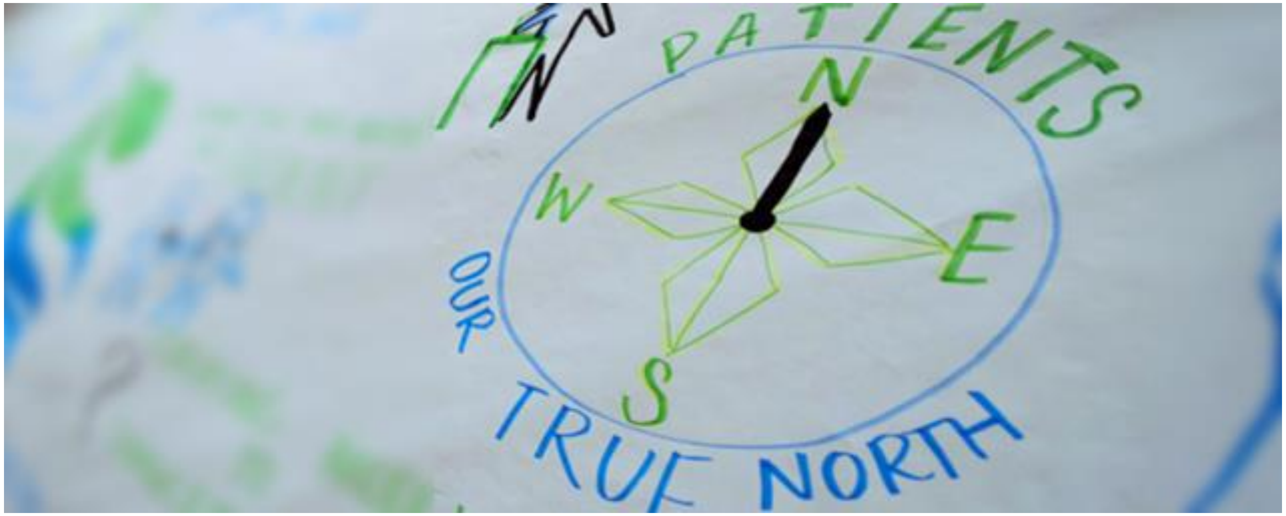
Introduction to PCORI

Lisa Stewart, MA
Engagement Officer
Public & Patient Engagement

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

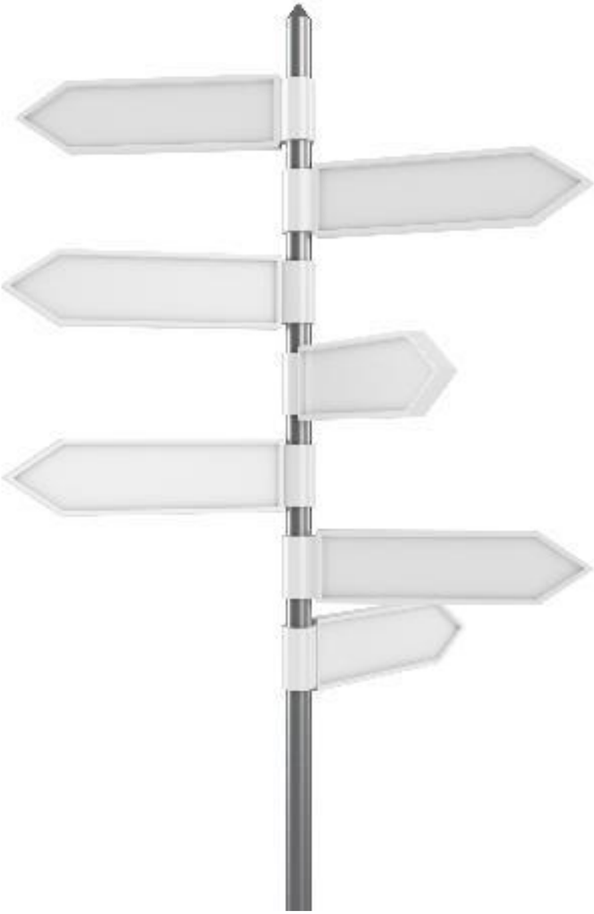
About Us

- An independent research institute authorized by Congress in 2010 and governed by a 21-member Board of Governors representing the entire healthcare community
- Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process
- Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns



How Is Our Work Different?

- We fund research on which care options work, for whom, under which circumstances.
- We focus on answering questions most important to patients and those who care for them.
- We aim to produce evidence that can be easily applied in real-world settings.
- We engage patients, caregivers, clinicians, insurers, employers, and other stakeholders throughout the research process.
- This makes it more likely we'll get the research questions right and the study results will be useful and taken up in practice.



PCORI's Approach to Research

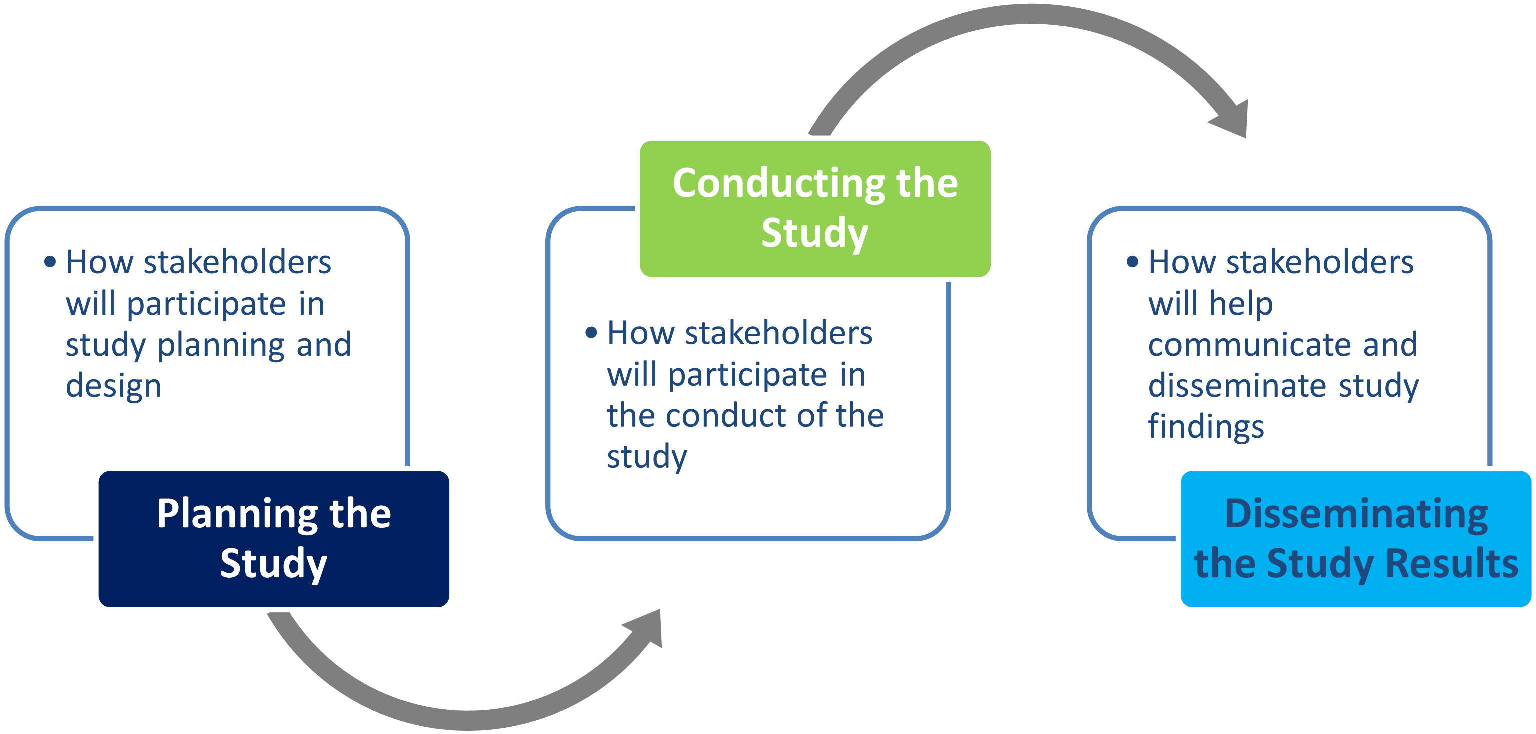
Patient-centeredness

- The project aims to answer questions or examine outcomes that matter to patients within the context of patient preferences
- Research questions and outcomes should reflect what is important to patients and caregivers

Patient and stakeholder engagement

- Patients are partners in research, not just "subjects"
- Active and meaningful engagement between scientists, patients, and other stakeholders
- Community, patient, and caregiver involvement already in existence or a well-thought-out plan

Our Engagement Rubric: A Valuable Resource



- How stakeholders will participate in study planning and design

Planning the Study

Conducting the Study

- How stakeholders will participate in the conduct of the study

- How stakeholders will help communicate and disseminate study findings

Disseminating the Study Results

Reciprocal relationships

Co-Learning

Partnership

Trust

Transparency

Honesty

Key findings from PCORI awarded projects: engagement challenges and strategies

Andrea Heckert, PhD, MPH
Program Officer
Evaluation & Analysis

Courtney Hall, MPH
Program Assistant
Evaluation & Analysis

OUTLINE

☐ Research engagement activities and effects among PCORI-awarded projects*

☐ Common research engagement challenges

☐ Common strategies and suggestions to overcome research engagement challenges

**For more information, please see links at the end of this webinar to the related PCORI webinar from September 2017 and associated publications*

Information sources and methods

Awardee Engagement Report

PCORI Research Awardees

N=305 awardees

Ways of Engaging-ENgagement ACtivity Tool (WE-ENACT)

Patient & Other Stakeholder Partners

N=260 partners

Communities engaged in PCORI research projects

(by percent of projects)

91%
PATIENTS/
CONSUMERS

62%
ADVOCACY ORGS

56%
CAREGIVERS/
FAMILY MEMBER

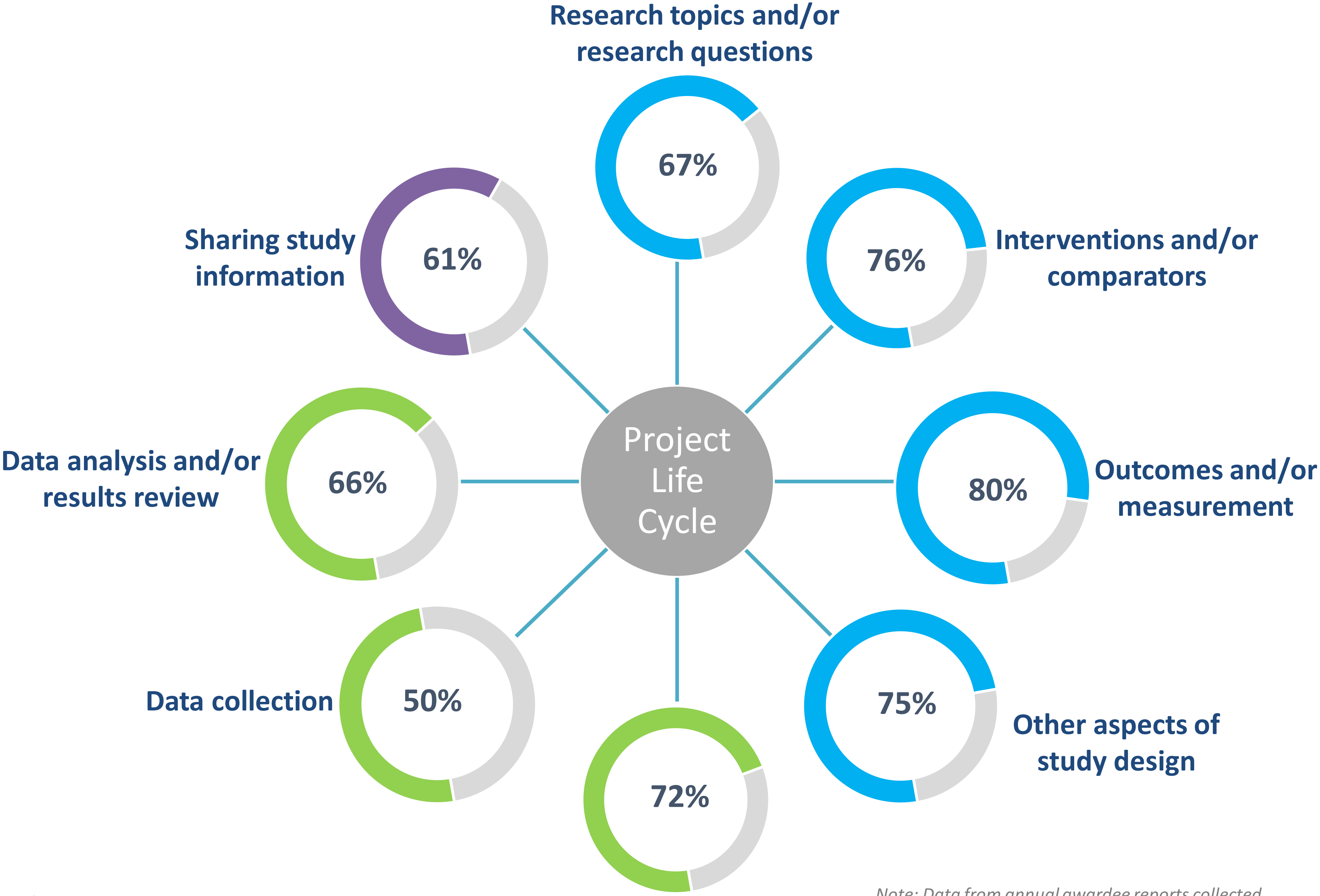
92%
CLINICIANS

61%
HEALTH SYSTEMS

96% of projects engage with at least one of these communities

PCORI projects also engage with subject matter experts (56%), representative of community-based organizations (36%), policymakers (19%), payers (17%), training institutions (17%), industry (7%), and purchasers (3%)

Note: Data from annual awardee reports collected through 6/30/17. N=305 awardees (134 projects at project year 1, 205 projects at project year 2, 119 projects at project year 3)



Project Life Cycle

Research topics and/or research questions 67%

Interventions and/or comparators 76%

Outcomes and/or measurement 80%

Other aspects of study design 75%

Recruitment and/or retention 72%

Data collection 50%

Data analysis and/or results review 66%

Sharing study information 61%

Note: Data from annual awardee reports collected through 6/30/17. N=305 awardees (134 projects at project year 1, 205 projects at project year 2, 119 projects at project year 3)

What do partners do in the research projects?

- **Share personal perspectives**
  (*e.g., priorities, experiences*)
- **Provide guidance and share in decision-making** for research project design, processes, and materials
  (e.g., outcomes studied, recruitment strategies)
- **Actively participate in study conduct**
  (e.g., recruiting participants, collecting data, sharing study information or results)

How do partners impact the research projects?

- **Better understanding** of patient and other stakeholders’ personal perspectives
  (*e.g., priorities, experiences*)
- **Enhance patient-centeredness of study process and outcomes**
- **Enhance study design, conduct, or efficiency**

Note: Data from annual awardee reports collected through 6/30/17
N=305 awardees (134 projects at project year 1, 205 projects at project year 2, 119 projects at project year 3) and partner reports collected through 6/30/2016
N = 260 partners

Challenges in engaged research

Awardees

- Identifying and inviting partners
- Integrating diverse partner perspectives
- Additional time & effort
  to manage engagement

Partners

- Research jargon
- Perspective is understood and valued
- Impact of one's contributions to the study
- Project delays
- Limited connection to others

Partners & Awardees

- Scheduling logistics
- Maintaining consistent partner participation

Data from annual awardee reports and partner WE-ENACT collected through 6/30/16 (N = 261 awardees; N = 260 partners). Data also from all available reports for 50 purposively selected projects.

Partner & Awardee Challenges

- **Scheduling logistics**
- **Maintaining consistent partner participation**

> Because I am the primary caregiver of my son, **being able to schedule time to meet has been my greatest challenge**.
> – *Caregiver/family member*
>
> We've continued to face challenges associated with **engaging patients with serious illness**. **These patients are often in frail health and it is difficult for them to come to meetings on a regular basis**.
> – *Awardee*
>
> Another **challenge** with patient/stakeholder engagement is **finding a common meeting time**… since these are **busy individuals with varying priorities**.
> – *Awardee*

Partner & Awardee Challenges

- Scheduling logistics
- Maintaining consistent partner participation

Strategies from Partners & Awardees

- Dedicating staff to manage engagement
- Integrating partner input for scheduling
- Being adaptable and flexible

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

Awardee Challenges

- **Identifying and inviting partners**
- **Integrating diverse partner perspectives**
- **Additional time & effort to manage engagement**

> **Disparities in education can interfere with ability to engage all relevant stakeholders** to the same extent.
> *–Awardee*
>
> One of the largest challenges has been **accommodating differing opinions**… Striking the right balance is challenging.
> *-Awardee*
>
> “There were times I felt all of us **couldn't understand each other clearly,** which **led to a little bit of frustration**, from both sides.”
> *-Representative of patient, consumer, or caregiver advocacy organization*

Partner Challenges

- **Research jargon**
- **Perspective is understood and valued**
- **Impact of one’s contributions to the study**
- **Project delays**
- **Limited connection to others**

> Sometimes folks on **our committee use acronyms or abbreviations for terms or establishments that I am not familiar with** and **by the time the discussion pauses I'm lost**. I might have a vague idea but **I don't want to disrupt the momentum of the conversation for a definition**.
> – *Patient/Consumer*
>
> The **researchers need to let the partners know that no question is stupid**, and need to **be patient with the partners** (e.g., if someone is answering slowly).
> – *Representative of patient, consumer, or caregiver advocacy organization*
>
> Sometimes, I am **not sure that my contribution is helpful or hitting the ‘target’** for the researchers.
> – *Patient/Consumer*

- **Dedicating staff to manage engagement**
- **Engaging partners early and consistently**
- **Meeting and/or communicating frequently**

Strategies from Partners & Awardees

> During the first six months, **we met with patient stakeholders prior to each conference call to make sure they felt comfortable with all of the information and had a strong voice**. We no longer need to do this as they are truly part of our stakeholder advisory committee.
> *-Awardee*
>
> We have **learned the lesson** that we need to **communicate earlier and more often** to **help research team members internalize the key points** of the study. **We have developed project 'roadmaps' to continually cover where we are in the project and where we are going.**
> *–Awardee*

Strategies from Partners & Awardees

- Dedicating staff to manage engagement
- Engaging partners early and consistently
- Meeting and/or communicating frequently
- **Orienting, training and offering ongoing capacity-building opportunities**
- **Clarifying evolving roles and expectations**

> [We would like] **more training in understanding research**, **reading journal articles**, and **writing journals articles**, how to **analyze data**.
> – *Patient/Consumer*
>
> **Define the purpose, the role, the input you're hoping to receive**…If the team lead doesn't want a patient in the room, then don't waste the time of either the researcher or the advocate.
> *-Representative of patient, consumer, or caregiver advocacy organization*

Strategies from Partners & Awardees

- Dedicating staff to manage engagement
- Engaging partners early and consistently
- Meeting and/or communicating frequently
- Orienting, training and offering ongoing capacity-building opportunities
- Clarifying evolving roles and expectations
- **Improving group facilitation skills**
- **Using plain language**
- **Being sensitive to partners' needs**
- **Creating a supportive and respectful environment**

> **Youth involvement was a bit difficult** in the first Parent & Youth Advisory Group meeting so the **structure of the meeting was changed** so that **youth were given an opportunity to speak before adults could.**
> –*Awardee*
>
> Round table discussions where **every person's 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*

Strategies from Partners & Awardees

- Dedicating staff to manage engagement
- Engaging partners early and consistently
- Meeting and/or communicating frequently
- Orienting, training and offering ongoing capacity-building opportunities
- Clarifying evolving roles and expectations
- Improving group facilitation skills
- Using plain language
- Being sensitive to partners' needs
- Creating a supportive and respectful environment
- **Communicating with partners on how their contributions have shaped the study**

> **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*

The Impact of Burnout on Patient-Centered Care: A Comparative Effectiveness Trial in Mental Health

Michelle P. Salyers, PhD

Professor of Psychology

Indiana University Purdue University Indianapolis (IUPUI)

Tim Gearhart, MSW

Vice President of Clinic Operations

Pulaski Memorial Hospital

(Formerly Four County Counseling Center, one of the partner agencies)

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PCORI project origins

- Prior work in community mental health services
- High rates of burnout, developing approaches

- Meeting with new CEO of Four County

“I believe the well-being of our service providers is directly linked to well-being of our consumers and I would like to study that”

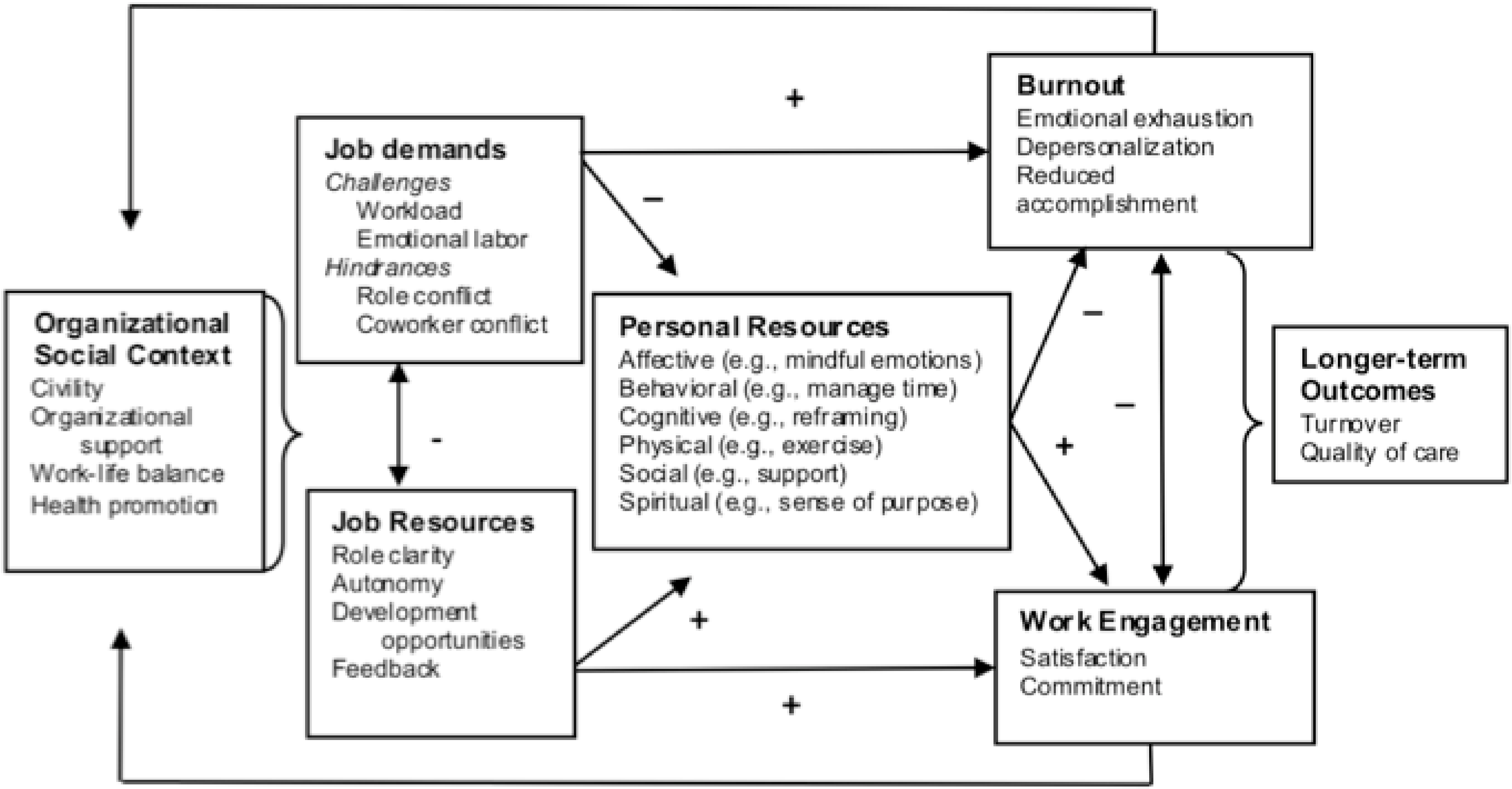
- Partner with 2 Community Mental Health Centers (Four County and Places for People in St Louis)
- Team of researchers includes clinicians, administrators, “patients”/consumers

Burnout in mental health

- Maslach’s conceptualization:
  - Emotional exhaustion
  - “Depersonalization” (negative, cynical attitudes and feelings about consumers)
  - Diminished work accomplishment/reduced sense of job efficacy

- High levels of burnout (20-67%; Morse et al, 2011)

Figure 1. Differentiated job demands and resources within an organizational social context.



Demerouti, et al., J Appl Psychol. 2001; Crawford et al., J Appl Psychol. 2010

BREATHE:
Burnout Reduction: Enhanced Awareness, Tools, Handouts and Education

- Focus on personal resources
  - Burnout is like other stress/mental health concerns
  - Help people be more aware
  - Learn skills to address it -- applying many of the same treatments we use with consumers
  - Relapse prevention framework
- Coping/renewal and wellness approaches
  - Burnout prevention principles
  - Practices
  - Personal plan/toolkit

Modules to address personal resources

- Core contemplative practices (breathing/mindfulness/imagery)
- Cognitive practices (e.g., reconnect with meaning/values)
- Physical strategies (e.g., sleep, yoga)
- Time management approaches
- Building social support and right relationships
- (Integrating into daily work life)

PCORI project aims:

1. **Understand the patient experience of clinician burnout.**
   - Focus groups
     - clinicians (3 groups, 27 participants)
     - patients (5 groups, 45 participants)
2. **Test the BREATHE intervention using a randomized, comparative effectiveness design.**
   - 206 clinicians randomly assigned: BREATHE or Motivational Interviewing
   - Randomly select about 4 adult patients for each (n = 469)
   - Follow over 12 months
3. **Test a conceptual framework linking clinician burnout to patient-centered processes, engagement, and outcomes.**

Our stakeholder engagement

- Co-investigators included clinicians, administrators, patients, and university-based researchers
  - Met monthly for project management, adapt methods as needed
  - Subset met weekly for recruitment
  - Involved from initial research question through analysis and write-up
- Focus groups with clinicians and patients
- Open-ended questions in surveys for clinicians and patients
- Qualitative interviews with clinicians

- We did not have a separate advisory board

How stakeholders shaped the project - Planning

- Initial research question (administrative partner)
  - Aligned with research interests -> Perfect match!
- *Aim 1: Understand the patient experience of clinician burnout*, suggested we add clinician focus groups (patient partner)
  - Expanded our understanding, led to a new paper that could incorporate both perspectives
- Interest in quality of supervision, we added specific measures of supervision (clinician partner)
  - These ended up being strong predictors of burnout and turnover. Planning a new study with them.

How stakeholders shaped the project - Conducting

- Partners led planning on when and how to recruit participants (clinicians and patients)
- Partners did the recruiting and interviewing at each site
- Pancake breakfast with matching t-shirts for researchers and clinician/administrators (missed photo op’s, though!)

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Partnering to
Serve
YOU!

How stakeholders shaped the project - Disseminating

- Teams to analyze focus group data (admin, clinician, patients, researcher)
  - Reading transcripts, meeting to discuss
  - Some involved in writing a paper
- Reviewing preliminary data, ideas for secondary analyses
  - Working overtime – administrators discussing new regulations led to new paper, involved in writing
  - Supervision quality – clinician interest, added measure, now analyzing
- Input on final report and “main” paper
  - Ongoing

Challenges

- Longer time to do most things
  - scheduling multiple people with busy schedules
  - more time to understand ways of doing things/training
  - revisions in methods– new IRB amendments
  - analyzing qualitative data with other job responsibilities
- Identifying and engaging patient partners at sites (health concerns and turnover)

Joys

- Meetings were fun, time to get to know each other (e.g., appreciative check-ins)
- Research felt more meaningful
- New ideas to better understand the study
- New ideas for future research

Project ACE: Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources

Elizabeth Cox

Principal Investigator

Jean Benzinger

Parent Advisory Board Member

December 5, 2017

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MEDICAL
COLLEGE
OF WISCONSIN

School of Medicine
and Public Health
UNIVERSITY OF WISCONSIN-MADISON

Diabetes Self-Management Challenges

- For over 50% of youths with Type 1 diabetes, control is not optimal

- Each family experiences unique challenges
  - Staying motivated
  - Parent and child working together as a team
  - Having needed knowledge and skills

- Diabetes control and quality of life are influenced by these challenges

Limited Uptake of Existing Interventions

- Families often don’t access self-management resources
  - Typical interventions have many sessions over 6-9 months
  - <30% agree to participate, even when paid $200
  - Lack of buy in and inconvenient scheduling
- What if these resources were “family-centered”
  - Respected families’ wants, needs, and preferences
  - Solicited their input on the education and support needed

Family-Centered Tailoring

- Self-management resources delivered in coordination with routine clinic visits for groups of ~6 families who have same survey-identified self-management barrier

- Addresses families' challenges to uptake
    - Creates family buy-in by addressing their specific needs
    - Coordinates delivery with routine clinic visit
    - Allows limited workforce to serve many families

Research Question and Participants

- Can family-centered tailoring of diabetes self-management resources improve outcomes that matter to youth/parents?

- Outcomes: A1c, quality of life for youth and parent

- Participants
  - 200 children who are 8-16 years of age and their parents
  - Receiving routine diabetes care at two Wisconsin clinics
  - 100 usual care and 100 intervention

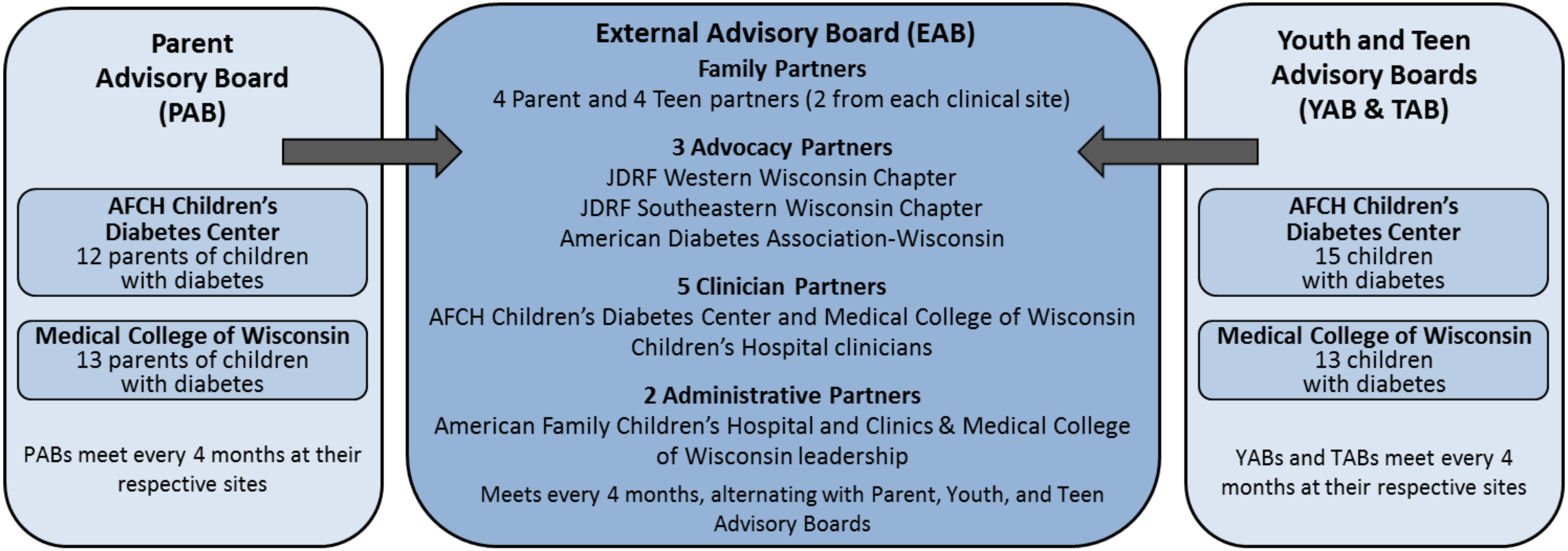
Stakeholders: Our Problem Solvers

- Recruiting and retaining “hard to reach” populations
  - Youths
  - Rural/inner city families

- Implementing the intervention in two different clinics
  - Different patient populations, staffing and workflow

- Developing/evaluating the intervention to optimize potential for dissemination to care systems broadly

Project ACE Stakeholder Engagement



Parent Advisory Board (PAB)

AFCH Children's Diabetes Center
12 parents of children with diabetes

Medical College of Wisconsin
13 parents of children with diabetes

PABs meet every 4 months at their respective sites

External Advisory Board (EAB)

Family Partners
4 Parent and 4 Teen partners (2 from each clinical site)

3 Advocacy Partners
JDRF Western Wisconsin Chapter
JDRF Southeastern Wisconsin Chapter
American Diabetes Association-Wisconsin

5 Clinician Partners
AFCH Children's Diabetes Center and Medical College of Wisconsin Children's Hospital clinicians

2 Administrative Partners
American Family Children's Hospital and Clinics & Medical College of Wisconsin leadership

Meets every 4 months, alternating with Parent, Youth, and Teen Advisory Boards

Youth and Teen Advisory Boards (YAB & TAB)

AFCH Children's Diabetes Center
15 children with diabetes

Medical College of Wisconsin
13 children with diabetes

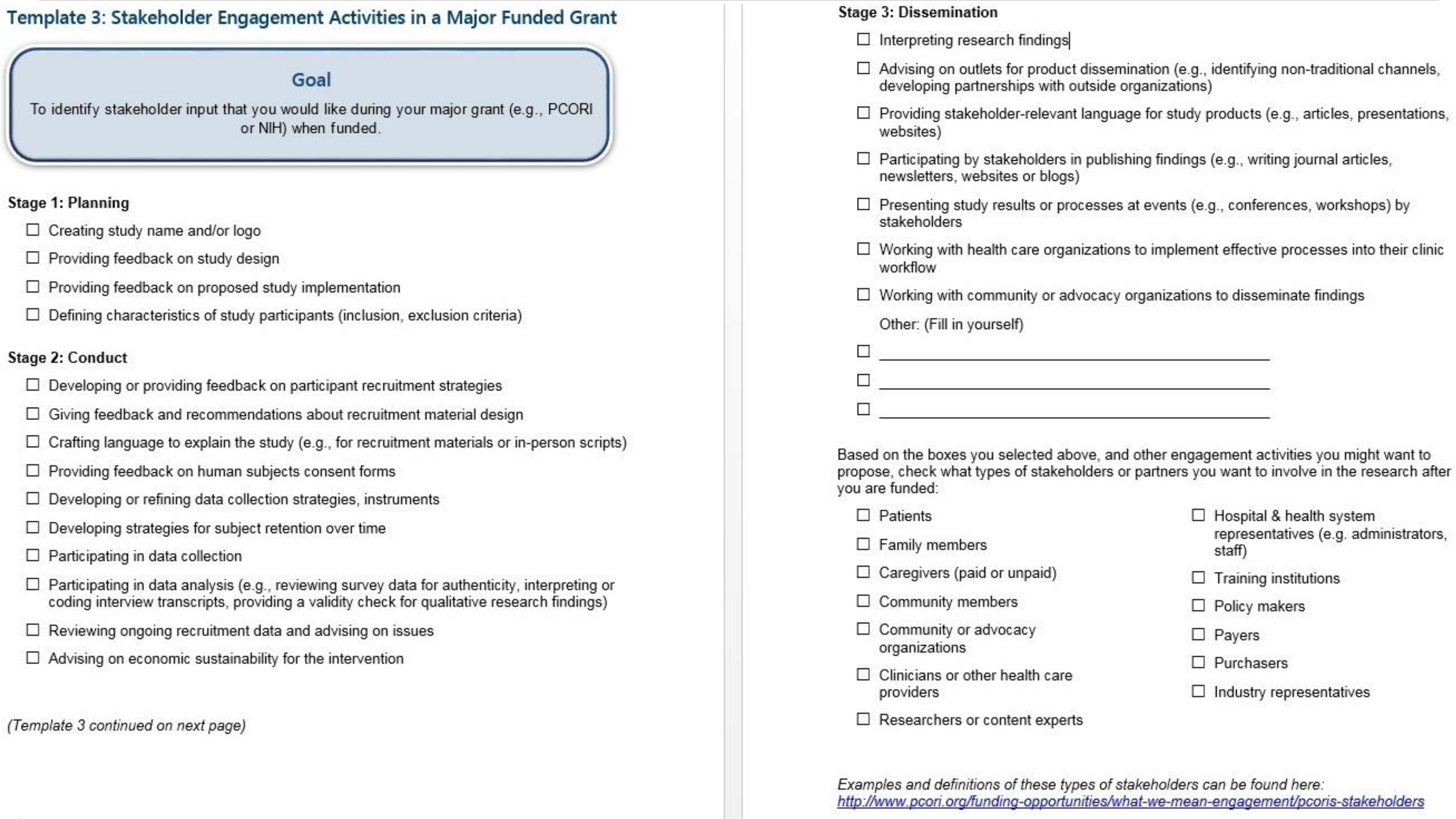
YABs and TABs meet every 4 months at their respective sites

Identifying and Engaging Partners

- What do you need from your stakeholders?

- Who can provide that?

Stakeholder Engagement Activities



Template 3: Stakeholder Engagement Activities in a Major Funded Grant

Goal

To identify stakeholder input that you would like during your major grant (e.g., PCORI or NIH) when funded.

Stage 1: Planning

- ☐ Creating study name and/or logo
- ☐ Providing feedback on study design
- ☐ Providing feedback on proposed study implementation
- ☐ Defining characteristics of study participants (inclusion, exclusion criteria)

Stage 2: Conduct

- ☐ Developing or providing feedback on participant recruitment strategies
- ☐ Giving feedback and recommendations about recruitment material design
- ☐ Crafting language to explain the study (e.g., for recruitment materials or in-person scripts)
- ☐ Providing feedback on human subjects consent forms
- ☐ Developing or refining data collection strategies, instruments
- ☐ Developing strategies for subject retention over time
- ☐ Participating in data collection
- ☐ Participating in data analysis (e.g., reviewing survey data for authenticity, interpreting or coding interview transcripts, providing a validity check for qualitative research findings)
- ☐ Reviewing ongoing recruitment data and advising on issues
- ☐ Advising on economic sustainability for the intervention

(Template 3 continued on next page)

Stage 3: Dissemination

- ☐ Interpreting research findings
- ☐ Advising on outlets for product dissemination (e.g., identifying non-traditional channels, developing partnerships with outside organizations)
- ☐ Providing stakeholder-relevant language for study products (e.g., articles, presentations, websites)
- ☐ Participating by stakeholders in publishing findings (e.g., writing journal articles, newsletters, websites or blogs)
- ☐ Presenting study results or processes at events (e.g., conferences, workshops) by stakeholders
- ☐ Working with health care organizations to implement effective processes into their clinic workflow
- ☐ Working with community or advocacy organizations to disseminate findings

Other: (Fill in yourself)

- ☐ ____
- ☐ ____
- ☐ ____

Based on the boxes you selected above, and other engagement activities you might want to propose, check what types of stakeholders or partners you want to involve in the research after you are funded:

- ☐ Patients
- ☐ Family members
- ☐ Caregivers (paid or unpaid)
- ☐ Community members
- ☐ Community or advocacy organizations
- ☐ Clinicians or other health care providers
- ☐ Researchers or content experts
- ☐ Hospital & health system representatives (e.g. administrators, staff)
- ☐ Training institutions
- ☐ Policy makers
- ☐ Payers
- ☐ Purchasers
- ☐ Industry representatives

Examples and definitions of these types of stakeholders can be found here: http://www.pcori.org/funding-opportunities/what-we-mean-engagement/pcoris-stakeholders

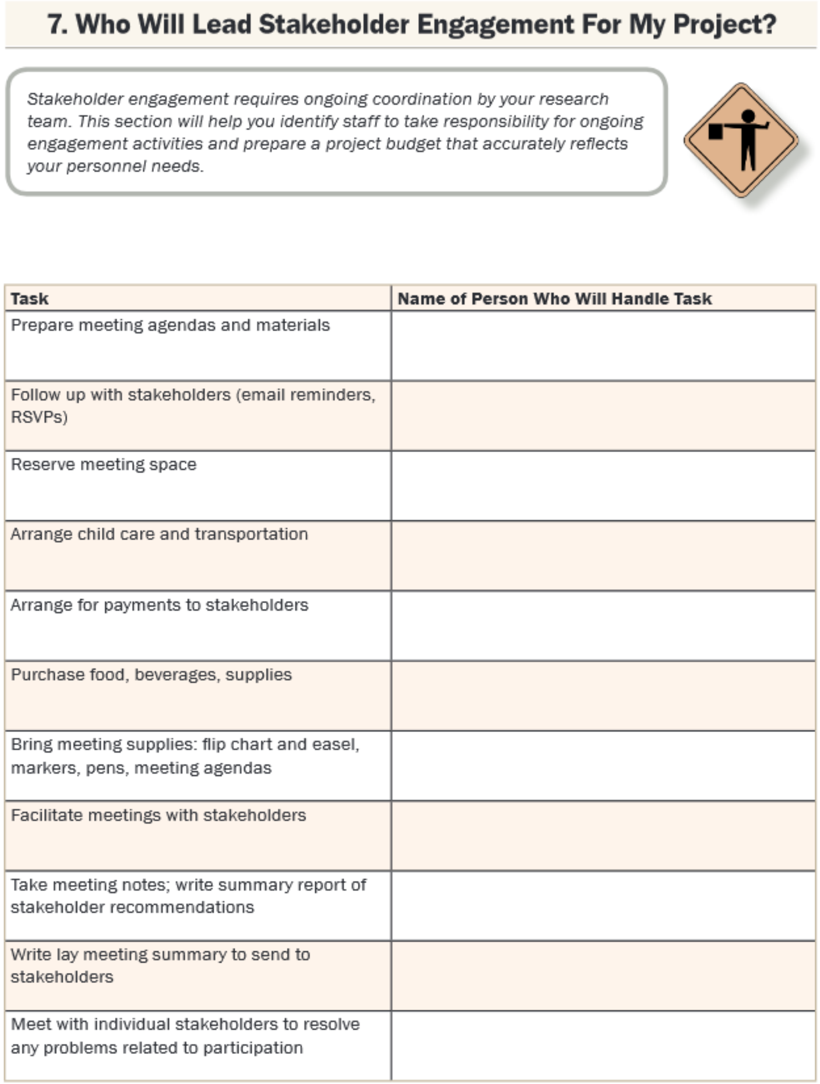
Logistics Require Dedicated Resources

- Scheduling needs to be flexible to meet partners' other commitments and needs

- Purposefully planned environment helps support engagement

- Communication is key! (and time consuming)

Coordinating Logistics

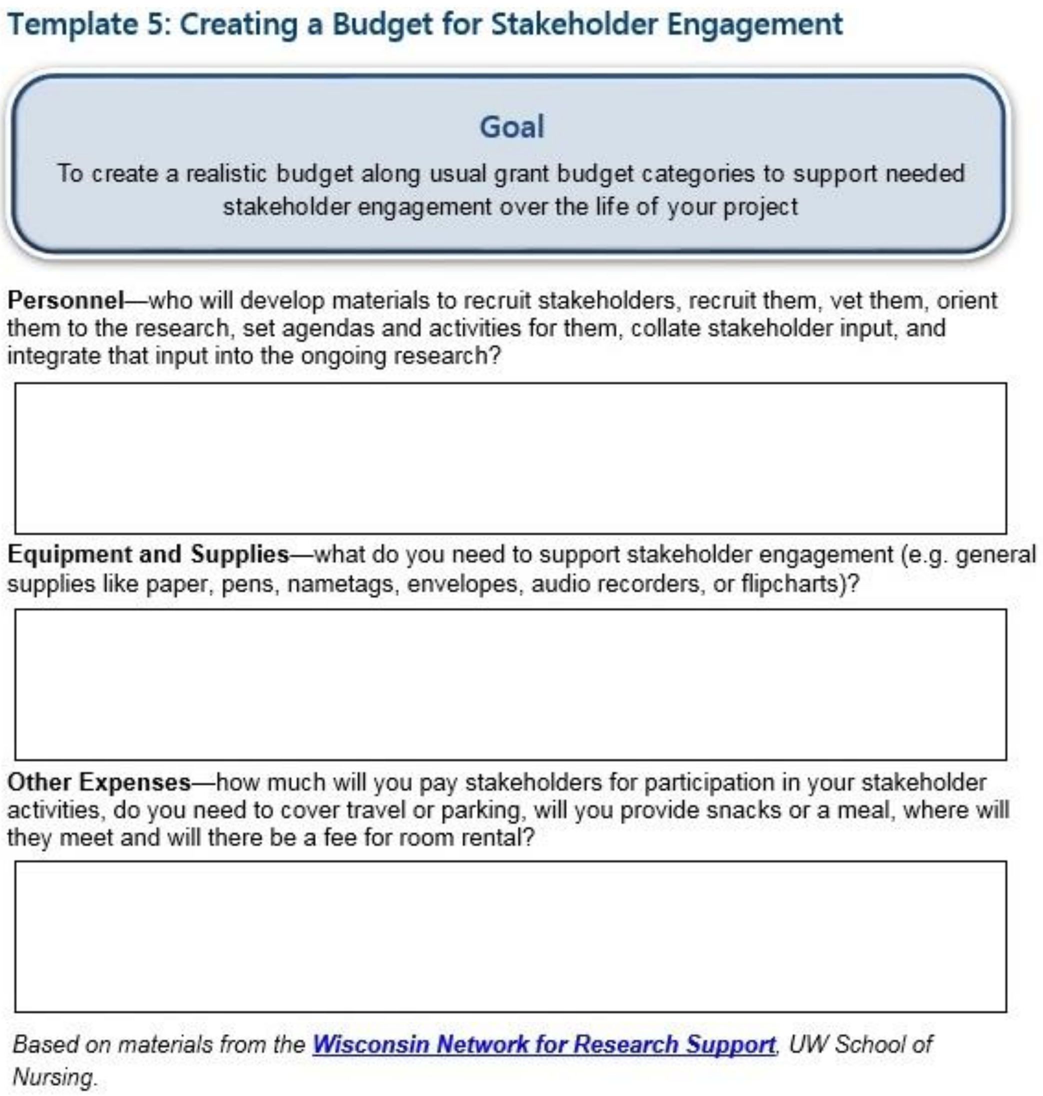


7. Who Will Lead Stakeholder Engagement For My Project?

Stakeholder engagement requires ongoing coordination by your research team. This section will help you identify staff to take responsibility for ongoing engagement activities and prepare a project budget that accurately reflects your personnel needs.

Task	**Name of Person Who Will Handle Task**
Prepare meeting agendas and materials	
Follow up with stakeholders (email reminders, RSVPs)	
Reserve meeting space	
Arrange child care and transportation	
Arrange for payments to stakeholders	
Purchase food, beverages, supplies	
Bring meeting supplies: flip chart and easel, markers, pens, meeting agendas	
Facilitate meetings with stakeholders	
Take meeting notes; write summary report of stakeholder recommendations	
Write lay meeting summary to send to stakeholders	
Meet with individual stakeholders to resolve any problems related to participation	

How Much Money Do I Need to Engage Stakeholders?



Template 5: Creating a Budget for Stakeholder Engagement

Goal

To create a realistic budget along usual grant budget categories to support needed stakeholder engagement over the life of your project

Personnel—who will develop materials to recruit stakeholders, recruit them, vet them, orient them to the research, set agendas and activities for them, collate stakeholder input, and integrate that input into the ongoing research?

Equipment and Supplies—what do you need to support stakeholder engagement (e.g. general supplies like paper, pens, nametags, envelopes, audio recorders, or flipcharts)?

Other Expenses—how much will you pay stakeholders for participation in your stakeholder activities, do you need to cover travel or parking, will you provide snacks or a meal, where will they meet and will there be a fee for room rental?

*Based on materials from the **Wisconsin Network for Research Support**, UW School of Nursing.*

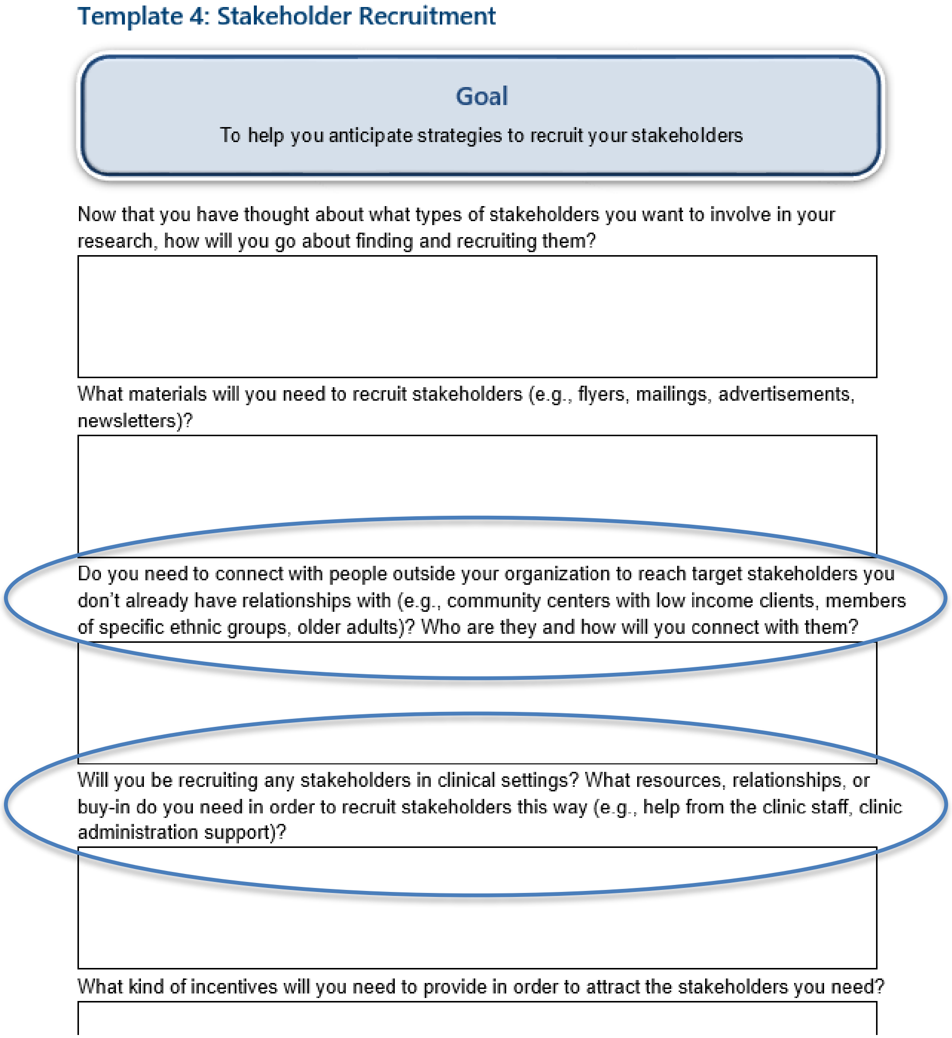
Ensuring and Engaging Diverse Partners

- Partner diversity allows perspectives from many vantage points to inform the research

- What diversity is crucial for your work?
  - Families from both inner city and rural areas
  - Role diversity—patient, parent, provider, advocate, healthcare organizational leadership

- Who can help to reach these diverse partners?

Recruiting Stakeholders



Template 4: Stakeholder Recruitment

Goal

To help you anticipate strategies to recruit your stakeholders

Now that you have thought about what types of stakeholders you want to involve in your research, how will you go about finding and recruiting them?

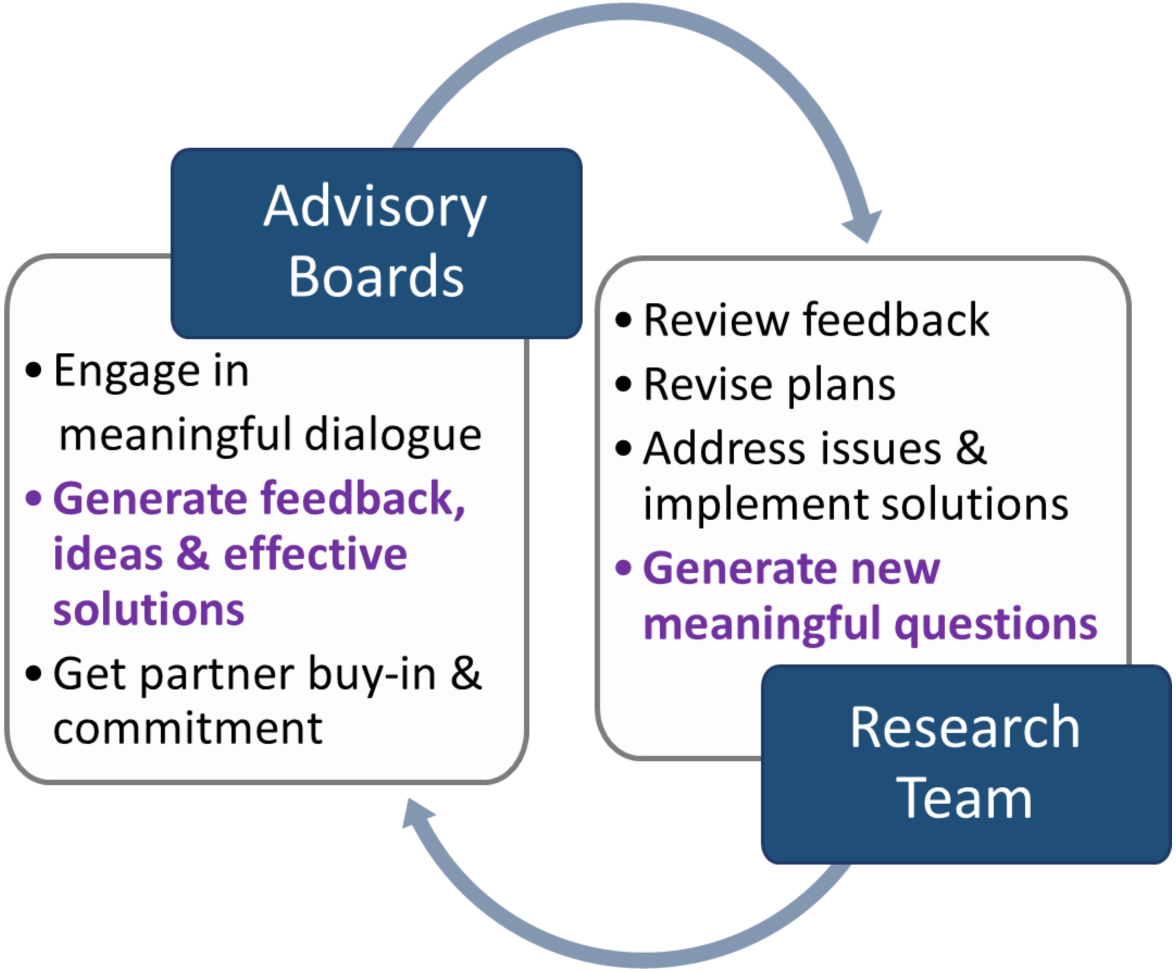
What materials will you need to recruit stakeholders (e.g., flyers, mailings, advertisements, newsletters)?

Do you need to connect with people outside your organization to reach target stakeholders you don't already have relationships with (e.g., community centers with low income clients, members of specific ethnic groups, older adults)? Who are they and how will you connect with them?

Will you be recruiting any stakeholders in clinical settings? What resources, relationships, or buy-in do you need in order to recruit stakeholders this way (e.g., help from the clinic staff, clinic administration support)?

What kind of incentives will you need to provide in order to attract the stakeholders you need?

Acknowledging Contributions with Iterative Collaboration



Advisory Boards

- Engage in meaningful dialogue
- **Generate feedback, ideas & effective solutions**
- Get partner buy-in & commitment

- Review feedback
- Revise plans
- Address issues & implement solutions
- **Generate new meaningful questions**

Research Team

Engagement Impacted Recruitment and Retention

- 73% of eligible families agreed to participate, took less time, matched population demographics

- Intervention group was planned as 4 group sessions
  - 69% of participating families attended at least 3 of the 4 intervention group sessions; 82% attended at least 2
  - Rescheduled only 4 of 128 group sessions!

Engagement Informed Data Collection

- Decided process and timing for data collection and reminders
  - Phone reminder references email
  - 3 weeks before and 3 days before

- Over 24 mo, A1c lab every 3 mo, surveys every 6 mo
  - 82% of A1c values were collected
  - 84% of surveys were completed; <1% missingness

Engagement has Helped our Work…

- Recruit and retain participants
- Be engaging and accessible for hard to reach populations
- Balance the needs of participating families with the clinical constraints
- Collect high quality, complete data

Stakeholder Experience of Engagement

- Safe place

- Unexpected benefits
  - Conversations with teenage son before/after
  - Networking with others/friendships
  - Feel part of something

Engagement Resources

Toolkits:

- Sustaining Engagement of Blended Stakeholder Boards
  https://www.hipxchange.org/SustainingEngagement
- Hard-to-Reach Patient Stakeholders: An Engagement Guide (HARPS)
  https://www.hipxchange.org/HARPS
- Toolkit on Patient Partner Engagement in Research (TOPPER)
  http://www.hipxchange.org/TOPPER

Other Resources:

- Patient-centred outcomes research: brave new world meets old institutional policies. Chung JS, Young HN, Moreno MA, Kliems H, Cox ED. Fam Pract. 2017 Jun 1;34(3):296-300. PMID: 28122843
- PCORI 1st Annual Meeting Plenary Panel Highlights videos
  https://www.youtube.com/playlist?list=PL2i6nTuOk4qAS6kHCB8546Yw8PNXrg-ka

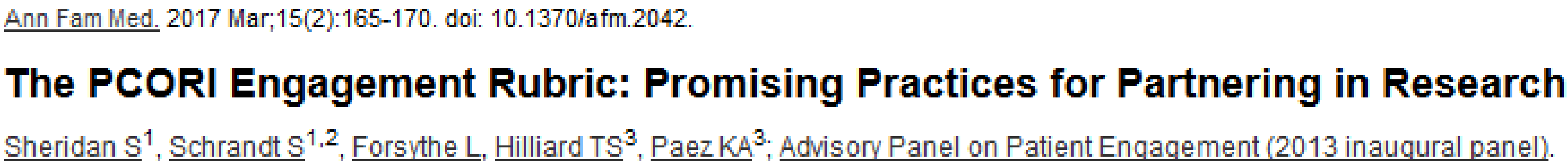
Upcoming Event!

- June 2018 – Stakeholder Engagement in Clinical Trials Short Course
  2017 Course Information: http://conferences.union.wisc.edu/translational/

Discussion

- Which aspects of today’s webinar are most meaningful to you?
- What else would you like to learn?
    - Effects of engagement on partners
- How does today’s webinar resonate with your own work?
- How do these strategies and resources to prevent and overcome engagement-related challenges add to the growing body of promising practices?

Resources

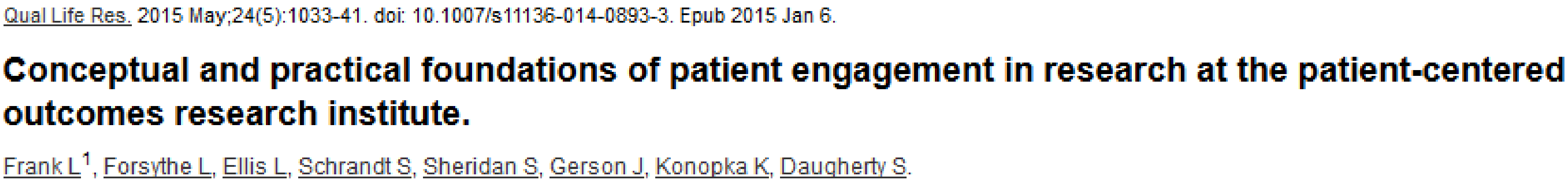


Ann Fam Med. 2017 Mar;15(2):165-170. doi: 10.1370/afm.2042.

The PCORI Engagement Rubric: Promising Practices for Partnering in Research.

Sheridan S[1], Schrandt S[1,2], Forsythe L, Hilliard TS[3], Paez KA[3]; Advisory Panel on Patient Engagement (2013 inaugural panel).

https://www.ncbi.nlm.nih.gov/pubmed/28289118

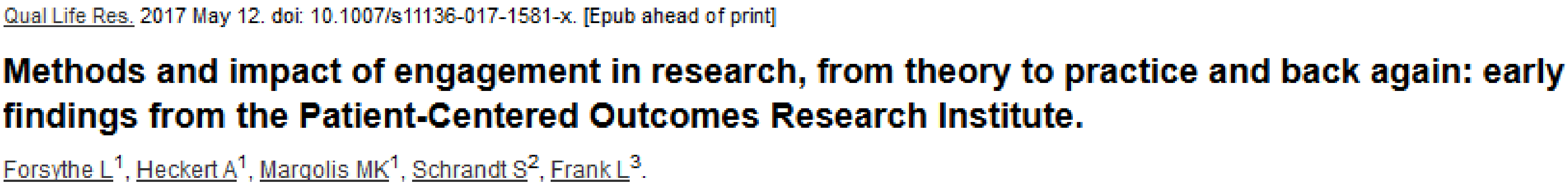


Qual Life Res. 2015 May;24(5):1033-41. doi: 10.1007/s11136-014-0893-3. Epub 2015 Jan 6.

Conceptual and practical foundations of patient engagement in research at the patient-centered outcomes research institute.

Frank L[1], Forsythe L, Ellis L, Schrandt S, Sheridan S, Gerson J, Konopka K, Daugherty S.

https://www.ncbi.nlm.nih.gov/pubmed/25560774



Qual Life Res. 2017 May 12. doi: 10.1007/s11136-017-1581-x. [Epub ahead of print]

Methods and impact of engagement in research, from theory to practice and back again: early findings from the Patient-Centered Outcomes Research Institute.

Forsythe L[1], Heckert A[1], Margolis MK[1], Schrandt S[2], Frank L[3].

https://www.ncbi.nlm.nih.gov/pubmed/?term=FOrsythe+HEckert

PCORI Engagement Rubric

Info Sheet on Patient and Stakeholder Partner Roles

Previous *PCORI in Practice* webinars

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

- webinar information
- archived webinar

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

- webinar information
- archived webinar

Community Engagement in Research: Practical Tips for Researchers and Community-based Organizations

- webinar information
- archived webinar

See other resources for the
Webinar Series on How PCORI Is Advancing Patient-Centered Outcomes Research

Thank You!

Acknowledgements

- Dr. Salyers, Tim Gearhart
- Dr. Cox, Jean Benzinger
- Awardees and partners

- Following this event, the slides, a recording, and additional materials for this webinar will be posted to https://www.pcori.org/events/2017/patient-and-stakeholder-engagement-research-engagement-challenges-strategies-and

- Send any questions or comments about today's webinar to surveys@pcori.org

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