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*Today’s webinar is being recorded and will be posted on PCORI’s website.
Welcome & Introductions

Courtney Clyatt, MA, MPH
Program Officer
P2P Awards Program

Lia Hotchkiss, MPH
Director
Eugene Washington Engagement Awards Program

Julie K. Lesch, MPA
Engagement Officer
Public & Patient Engagement

Krista P. Woodward, MPH, MSW
Senior Program Associate
Public & Patient Engagement
Agenda

• What is Engagement Sustainability?
• PCORI Portfolio Observations & Lessons Learned
• Project Investigator & Team Reactions
  • Joseph A. Greer, PhD, MS & Noriko Burke
  • Anda Kuo, MD; Megumi Okumara, MD; Baylee Decastro, MPP; & Juno Duenas
• Discussion / Q&A
Where We Engage Partners:
Engagement in Research

HELPING DETERMINE
Research Partnerships and Capacity
Research Priorities
Conduct of Research
Dissemination and Implementation
Policy and Practice

INVOLVED HOW?
Relationship and PCOR Skill Building
Topic Solicitation and Input, Advisory Panels, and Workshops
Research Teams
Sharing and Uptake of Findings
Impacting Institutional Policies and Clinical Practice
Engagement Sustainability in the Literature

Challenges and Facilitating Factors in Sustaining Community-Based Participatory Research Partnerships: Lessons Learned from the Detroit, New York City and Seattle Urban Research Centers

Sustaining patient and public involvement in research: A case study of a research centre

Public-Academic Partnerships

Evidence-Based Implementation: The Role of Sustained Community-Based Practice and Research Partnerships

Participatory evaluation of a community-academic partnership to inform capacity-building and sustainability.
Engagement Sustainability
Current Questions

• What does engagement sustainability look like across different contexts, populations, and engagement structures?
• What are the practices that will lead to engagement sustainability throughout the duration of a research project?
• What are the mechanisms for effecting institutional policy or research practices to shift towards a patient-centered culture?
The Value of Engagement Sustainability

1. Research that has sustained engagement *may* increase the patient-centeredness, quality, and trustworthiness of evidence available to support healthcare decision-making.

2. Institutional infrastructure that support patient-centered approaches *may* lead to sustained engagement in research projects.

3. Sustained partnerships beyond time-limited research projects *may* shift the culture of research to more quickly adopt patient and stakeholder engagement standards.
<table>
<thead>
<tr>
<th>Program</th>
<th>Details</th>
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<tbody>
<tr>
<td>Pipeline to Proposal Awards</td>
<td>• Fund a nationwide foundation of patients, stakeholders, and researchers equipped to participate in patient-centered outcomes research (PCOR) by focusing on topic prioritization and proposal development that address questions from their community.</td>
</tr>
<tr>
<td>Eugene Washington Engagement Awards</td>
<td>• Fund projects that build communities prepared to participate in patient-centered outcomes research (PCOR) and comparative clinical effectiveness research (CER), as well as to serve as channels for disseminating study results.</td>
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<tr>
<td>Comparative Effectiveness Research Awards</td>
<td>• Fund comparative effectiveness research projects with an emphasis on patient and stakeholder engagement that will provide reliable, useful information to help people make informed healthcare decisions and improve patient care and outcomes.</td>
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Setting the Stage

• The data and information presented in this webinar is practice-based and exploratory.

• Portfolio-level observations and trends have allowed us to speculate on potential engagement strategies that will lead to sustained partnerships.

• We expect your experiences and knowledge will broader and even challenge our understanding of engagement sustainability.
Developing Sustainable Partnerships: Pipeline to Proposal Awards Program (P2P)

Courtney Clyatt, MA, MPH
Program Officer, Pipeline to Proposal Awards Program
Engagement in Research

HELPING DETERMINE

Research Partnerships and Capacity

Research Priorities

Conduct of Research

Dissemination and Implementation

Policy and Practice

INVOLVED HOW?

Relationship and PCOR Skill Building

Topic Solicitation and Input, Advisory Panels, and Workshops

Research Teams

Sharing and Uptake of Findings

Impacting Institutional Policies and Clinical Practice
Pipeline to Proposal Program

Objective: To build a national community of patient, stakeholder, and researcher partnerships with the goal of developing high-quality research proposals to address the health issues affecting their communities.

Reciprocal Relationships ~ Co-learning ~ Partnership ~ Trust ~ Transparency ~ Honesty
### Key Components of a Business Plan

<table>
<thead>
<tr>
<th>Key Components</th>
<th>Pipeline to Proposal Deliverables</th>
<th>What Happens</th>
</tr>
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</table>
| Management and personnel | Partnership | • Identify partners – stakeholder mapping  
• **Strategize partnership engagement**  
• Expand partnership to include state, regional and national organizations  
• Identify individual strengths to help with work  
• Formalize relationship |
| Business description and structure | Governance Document | • Develop a mission statement and vision  
• Identify and develop infrastructure  
• Define roles and expectations  
• Decide how decisions are made |
| Executive Summary | Recruitment & Communication Plan | • Create a five-minute elevator pitch, why others should join your partnership and the benefit to them |
| Market research and strategies | Research Question Development and Prioritization | • Conduct a landscape assessment  
• Identify research question and why and how your team is best posed to answer this question |
| Financial documents | Sustainability Plan | • Create a shared understanding of sustainability  
• **Identify potential funders**  
• Look at risks to partnership funding and additional opportunities for funding |
Level the Playing Field
• Project teams addressed the power dynamics among members and language/jargon barriers by:
  • establishing ground rules and meeting norms to create a safe space
  • acknowledging that everyone was an equal contributor and brings their own set of experiences
  • maintaining a first name policy and making sure no titles were used

Understand Partners’ Culture and Needs
• Veteran’s Suicide Protection Advisory Group initially offered gift cards to military families; however, this was seen as soliciting and it was questionable whether or not this was allowed on base
  • Instead of paying Advisory Group members for their participation, they received a challenge medal, which was more consistent with military culture
• Advisory Group members would often bring their support animals to meetings
  • In order to support animals’ attendance at the meeting, the project team modified their budget to cover the cost of dog food and chew toys

“Partnership building requires patience and empathy. I use the word empathy to specifically describe the ability to look at the project from your partners’ perspectives. That will help facilitate progress.”
Organizational Structure for Sustainability

Align the Team
- All partners must share the same base knowledge of the project, and goals must be clearly defined and understood by all partners upfront
  - This creates a sense of informed and shared vision for the project and allows everyone’s opinions and voice to be heard and weighed with the same importance
- Project team developed fact sheets around 6 potential research questions, which were used at meetings
  - Allowed patients, their family and other members of the project team to have rich discussions about the research topics/questions

Prepare for Change
- Projects with leadership transitions have used the roles identified in the governance document
  - Teams were able to parcel out the project lead’s duties to other members of the team, and the projects were able to move forward without interruption

“The governance document really helped partners purposely think of the kind of structure they wanted. This document was helpful for ensuring the patient voice was incorporated into any decisions ... The governance document also was a mechanism to be purposeful on recruiting and onboarding any new members”
Sustaining Engagement: Eugene Washington PCORI Engagement Award Program

Lia Hotchkiss, MPH
Director, Engagement Award Programs
Engagement in Research
Engagement Awardees: Sustaining Engagement

Empowering stakeholders to continue active roles and pursue additional opportunities

Creating tools for sharing information with stakeholders

Building stakeholder networks to support ongoing and future efforts
Empowering Stakeholders

Stakeholder partners have developed new skills and are empowered to seek leadership roles on research projects, advisory boards, and PCOR initiatives.

• **Improving Care for Critically Ill Patients and Families** (Society of Critical Care Medicine)
  - ICU teams from project are publishing manuscripts based on their own experiences implementing patient and family engagement initiatives
  - Team members continuing to serving on functioning advisory councils
  - In future projects, several ICU teams will serve as mentors to new teams

• **Latino Health Riverside** (Regents of University of California, Riverside Campus)
  - Steering Committee elected to continue to meet even after completion of the project; currently organizing a series of training programs in mental health for local clergy

• **Healthcare Decision Making of Adults Living in Rural Communities with Acquired Neurologic Conditions** (University of Kentucky Research Foundation)
  - Project stakeholders continue to help formulate research questions for future research
Creating Tools and Sharing Information

Engagement Award teams have sustained stakeholder engagement by providing informational updates, with several creating tools to share information with wide audiences

- These tools have been used during and post-project to engage with the patient and stakeholder community

- At the urging of project stakeholders, Global Healthy Living Foundation developed webpage about the BeTTER SAID project and created resources on joint replacement

- Public website provides contact information, so researchers from other institutions can gain access to trained patients who are ready to partner on research in this area
Building Stakeholder Networks and Coalitions

Engagement Awards have facilitated the formation of stakeholder networks and coalitions that keep stakeholders engaged beyond the initial project.

Examples

- **Establishing Community-Based Research Networks (CBRN)** (Penn State College of Nursing)
  - CBRN was established across 8 Penn State campuses and now represents over 15 PA counties, with continued growth anticipated.
  - Coalitions poised to address some of the state's biggest healthcare challenges.
  - Community stakeholders actively involved with Coalitions and pursuing collaborations with Penn State researchers.

- **Patient Support Conference & Health and Research Ambassador (HARA) PCOR/CER Training Program** (National Alopecia Areata Foundation)
  - HARA was created by a stakeholder engaged in the first NAAF project; it has grown to include 30 ambassadors who have trained more than 600 patients in PCOR/CER.
Sustaining Partnerships Within Study Conduct & Beyond

Julie Kennedy Lesch, MPA
Engagement Officer,
Public and Patient Engagement
Sustainability of Partnerships Within Study Conduct and Dissemination

Strategies

1. Goal setting for engagement
2. Training for what’s next
3. Clear communication of roles and expectations
4. Closing the feedback loop
Goal Setting for Engagement

- Defining study teams’ engagement goals and the key activities that align with those goals
- Separate study team goals from partners’ individual goals

To meaningfully influence the approach and implementation of Advanced Care Planning in clinics by giving real feedback (not theoretical) based on personal medical experiences and experiences as a caregiver or legal guardian

--Caregiver

To ensure the implementation is successful and potentially replicable in real-life primary care settings and that the implementation considers what patients need to prepare for initial and follow-up conversations

—Awardee
Training for What’s Next

- Defining study teams’ engagement goals and the key activities that align with those goals
- Separate study team goals from partners’ individual goals
- Orienting, training and offering ongoing capacity-building opportunities

“We have learned 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

“We would like more training in understanding research, reading journal articles, and writing journals articles, how to analyze data.”
—Patient/Consumer
Roles and Expectations

- Defining study teams’ engagement goals and the key activities that align with those goals
- Separate study team goals from partners’ individual goals
- Orienting, training and offering ongoing capacity-building opportunities
- Clarifying evolving roles and expectations

“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
Feedback Loop

Defining study teams’ engagement goals and the key activities that align with those goals
Separate study team goals from partners’ individual goals
Orienting, training and offering ongoing capacity-building opportunities
Clarifying evolving roles and expectations
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
Engagement in Research
Sustainability Beyond Study Conduct

In some instances, exemplary engagement during capacity building, study conduct, and dissemination can:

• Translate to institutional adoption of mechanisms to support engaged research

• Translate to partners who continue to partner and mentor other patient partners

• Translate to investigators who continue to conduct engaged research & serve as mentors to peers
Beyond Study Conduct to Paradigm Shift…

PCORI is credited with inspiring a *cultural shift* towards engagement in research at Children’s Hospital of Philadelphia (CHOP) Research Institute

- PCORI projects at CHOP have increased recognition of the need to engage patients, families, and other stakeholders in research
- CHOP developed a Research Family Partners Program, to integrate the patient and family voice into every aspect of healthcare
- CHOP started with 3 research family partners during the PCORI pilot projects and have grown to over 30 trained families participating with a variety of research teams

Researchers are seeing from PCORI that patients and families can really make a difference.
—Amy Kratchman, Former PCORI Advisory Panel Member, Children’s Hospital of Philadelphia, August 2016
A PCORI-funded project (PI: Peter Kohler) has inspired **policy changes and capacity building efforts** at the University of Arkansas for Medical Science (UAMS).

- **Policy changes:**
  - **Hiring policy:** Redefining the classification and necessary qualifications for research coordinators, interpreters, and community health workers representing the communities of research focus.
  - **IRB Dissemination policy** on returning results to the community and study participants (*forthcoming*)

- **Capacity building:**
  - Implementation of a **training on the responsible conduct of research** for non-academic research partners
  - Bolstered services offered through **Community Engagement** component of the UAMS Translational Research Institute to mentor ~25 UAMS researchers

Peter Kohler, MD & Pearl McElfish, Ph.D; University of Arkansas for Medical Sciences
[July 2017]
Research Study Team Lessons Learned

Joseph Greer, PhD
Program Director, Center for Psychiatric Oncology & Behavioral Sciences
Associate Director, Cancer Outcomes Research Program, Massachusetts General Hospital Cancer Center

Noriko Kameda Burke
Patient Partner
A PCORI-funded project (PI: Joseph Greer) influenced the establishment of a Patient and Family Advisory Council (PFAC) for the Cancer Outcomes Research Program (CORe) at Massachusetts General Hospital.

...Born out of the desire to have long-standing relationships with research partners beyond a given study

- **PFAC Mission:** To help advance the mission of cancer care anchored in patient perspective in a clinically meaningful way.
- **Goal:** To heighten the community’s understanding and appreciation of cancer research and increase stakeholder involvement in supportive care research efforts.
The PFAC members and CORe investigators meet quarterly in person to discuss new and ongoing supportive care studies such as the:

- Use of telemedicine for delivering early palliative care for patients with advanced cancer
- Development of mobile apps to support adherence to oral cancer therapy; coping for patients hospitalized for leukemia; sexual health in survivors of bone marrow transplantation
- Delivery of cognitive-behavioral interventions to treat anxiety in patients with incurable cancers and their caregivers

PFAC involvement consists of:

- Brainstorming and generating study ideas with CORe investigators
- Providing feedback about all aspects of CORe studies (hypotheses, design, implementation)
- Reviewing proposed study interventions to enhance patient-centeredness
- Participating in CORe’s annual workshop to train junior investigators in supportive care research
- Networking with broader community to increase awareness and philanthropy for supporting studies in the CORe Program
Engagement Award Team
Lessons Learned

Anda Kuo, MD
Professor, Department of Pediatrics, University of California San Francisco

Megumi Okumura, MD, MAS
Associate Professor, University of California San Francisco

Baylee Decastro, MPP
Senior Manager of Health Equity Partnerships, University of California San Francisco

Juno Duenas
Executive Director, Support for Families of Children with Disabilities
PCORI Eugene Washington Engagement Award: Transforming Research As Usual (TRU)

Megumi Okumura, MD, MAS, Associate Professor, UCSF
Baylee Decastro, MPP, Senior Manager of Health Equity Partnerships, UCSF
Juno Duenas, Executive Director, Support for Families of Children with Disabilities
UCSF Child Health Equity Institute: All children have an equal opportunity to be healthy

Problem Statement: Despite the persistence of child health inequities, direct engagement with research by families and communities most impacted by disparities remains limited.

TRU: Sustainable partnerships with underserved Bay Area families to strengthen child health equity research and improve real-world application of research to policy and practice.

- Formal network of researchers, community groups and providers to advance CCER
- Research community advisory board for families to partner with UCSF researchers
- Research and advocacy training program created with and for families
Obj 1: How TRU Conceptualizes and Operationalizes Engagement Sustainability

Conceptual questions:

- What is the value of family voice in CCER?
- What challenges sustaining family research engagement? How can we address them?
- What is the role of established family research engagement efforts as we seek to leverage these efforts toward engagement sustainability?

Operational issues:

- Programmatic sustainability
- Operational sustainability
- Family Voice
- Engagement Authenticity
Objective 2: How TRU leveraged PCORI portfolio towards planning and implementation of engagement sustainability practices

- Thought partnership with PCORI program officer
- Networking and linkage with other PCORI projects
- Incorporating promising practices
- Sustainability research project
Obj 3: How TRU sustained engagement throughout the project and informed institutional policy and practice.

- **Partner at every step of the process.** Don’t let “deadlines” and “deliverables” undermine equitable partnership or limit community building time.

- **Share decision making.** Majority rules and consensus are not the same thing. Agree on how decisions will be made and stay in a place of integrity with the process you define.

- **Leadership development.** Importance of the 1-minute personal story and advocating for your needs within a broad, systemic context. Identify the right leadership development training for your community members.

- **Resource family and community partner engagement.** Create conditions for families and community partners to step fully into the work (e.g. stipends, childcare, meals, partner funding, two-way translation).
Discussion Questions

• What additional lessons learned do you have?
• Have we drawn the right lessons learned?
• Are these lessons transferable to your context?
• What more information might you need? In what form?
Commitment to Understanding & Facilitating Engagement Sustainability

- Commitment to studying engagement in real-world contexts
- Addressing methodological challenges and investing in new approaches
- Distinguishing the necessary and/or sufficient conditions to support engagement throughout the lifetime of a project
- Clarifying when and how engagement tactics can lead to sustained partnerships
- Revising sustainability models and frameworks based on new learnings
Thank You

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Engagement Resources

- Pipeline to Proposal Awards
- Eugene Washington PCORI Engagement Awards
- Ambassadors Program
- Engagement Rubric
- Budgeting for Engagement Activities
- Compensation Framework for Engaged Research Partners
- Sample Engagement Plans
- Methodology Report
- PCORI in Practice Webinar Series