

Partnering with PCORI: Improving Patient Centered Outcomes Research Through a Multi-Tiered Community Engagement Process

ILIMA KANE, COMMUNITY ENGAGEMENT GRANTS DIRECTOR, COLORADO FOUNDATION FOR PUBLIC HEALTH AND THE ENVIRONMENT

COURTNEY CLYATT, SENIOR PROGRAM ASSOCIATE, PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE (PCORI)

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Overview

- ▶ PCORI's Pipeline to Proposal Awards (P2P)
- ▶ National scope with a local focus leads to partnerships
- ▶ PHIs as fiscal intermediates and technical advisors
- ▶ PHIs role in reducing barriers serves as a bridge into local communities to enhance research efforts
- ▶ CFPHE experience as an Intermediate Funder for the Western US P2P awards

PCORI's Pipeline to Proposal Awards

- ▶ Build partnerships between patients, stakeholders and researchers
- ▶ Build capacity for patient-centered outcomes research
- ▶ Ultimate goal: Improve Comparative Effectiveness Research outcomes

Importance of Patient/Community Engagement in Research

- ▶ Patients, caregivers and stakeholders need evidence-based information to make better-informed health and health care decisions.
- ▶ The evidence-based information must be relevant to patients or it isn't useful.
- ▶ This initiative seeks to shift the research-funding paradigm, allowing patients and stakeholders to engage and partner with researchers to study the issues that are most critical to them.

P2P Tiered Approach

Tier I:

- 9 months, \$15,000
- Pre-engagement, community building projects

Tier II:

- 12 months, \$25,000
- Partnership and infrastructure development projects

Tier III:

- 12 months, \$50,000
- Proposal Development Projects

National Scope, Local Focus

- ▶ Small groups are expected to accomplish great things.
- ▶ Investments at a local level are necessary to support these groups.
- ▶ National leaders have the resources to provide adequate support.
- ▶ Public Health Institutes are the perfect bridge between national resources and local support.

PHI Competencies and P2P Alignment

Fiscal/ Admin. Mgmt.

PHIs Manage Up To
50 Awardees
Regionally

Convening /Partnering

PHIs Encourage
and Support New
Partnerships and
Collaborations

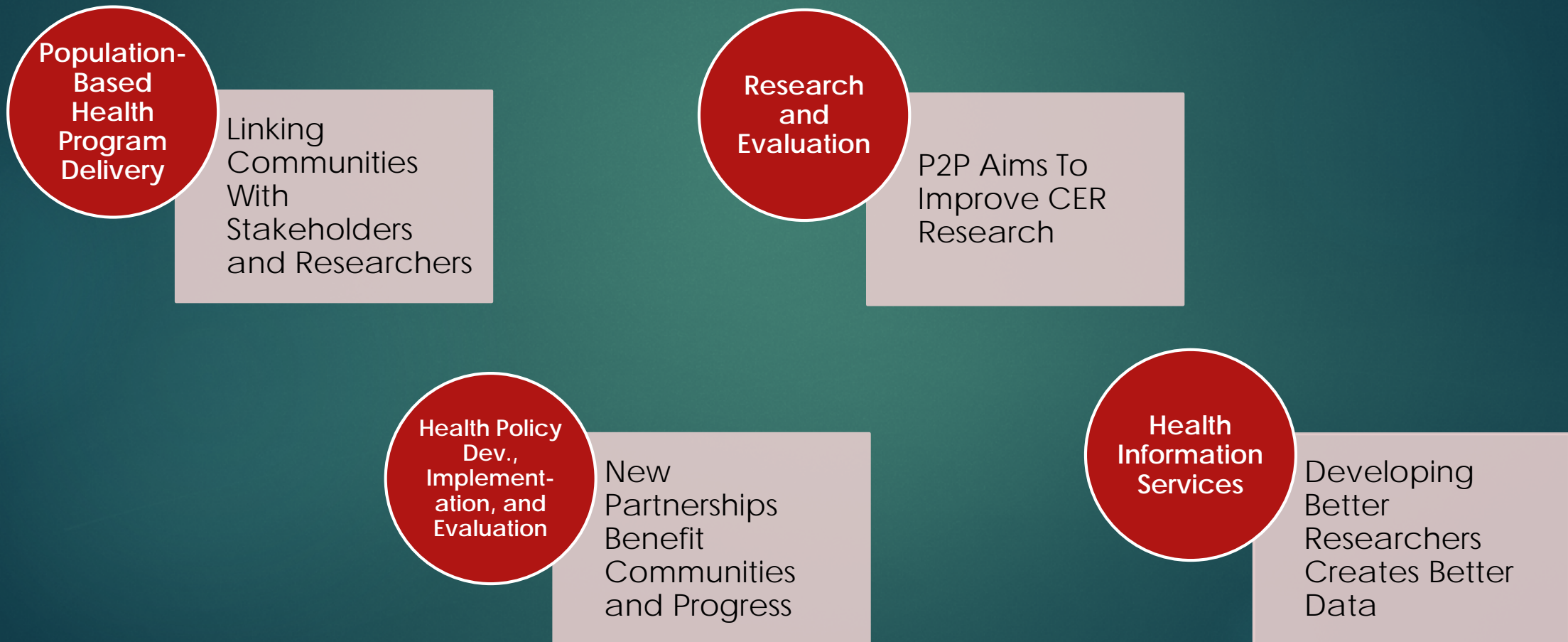
Training and Technical Assistance

PHIs Help
Awardees Become
Successful
Applicants and
Researchers

Health Comm. and Social Marketing

PHIs Publicize the
Work Done in P2P
Through Their
Networks

PHI Competencies and P2P Alignment (cont.)



Colorado Foundation for Public Health and the Environment

- ▶ CFPHE formed in 1993
 - ▶ Provided Fiscal and Administrative Services Only
 - ▶ Grew to Offer Professional and Technical Consultation
- ▶ Projects:
 - ▶ Fiscal and Administrative Services
 - ▶ Limited in Time and Scope
 - ▶ Minimal Strategic Involvement From CFPHE

Colorado Foundation for Public Health and the Environment (cont.)

- ▶ Programs:
 - ▶ Fiscal and Administrative Services
 - ▶ Strategic Consultation
 - ▶ Report to CFPHE Board Regularly
- ▶ PCORI P2P is a program that benefits from experience with a variety of projects.
- ▶ PHIs are uniquely situated to support programs like this.

Fiscal Intermediates & Technical Advisors

- ▶ Fiscal needs of awardees are diverse
 - ▶ Individuals
 - ▶ Advocacy Groups
 - ▶ Universities/Hospitals
- ▶ Technical Assistance needs vary
 - ▶ Researchers
 - ▶ Patients
 - ▶ Stakeholders

Field Notes

- ▶ “As the saying goes, ‘There is no need to reinvent the wheel.’ But it turns out to be harder to locate the old wheels than it seems it should be.”
 - ▶ *Improving Quality of Care Received by People with Parkinson’s in Wyoming*
- ▶ “Don't expect to always meet your goals as a PI [Primary Investigator] particularly in doing CBPR [Community Based Participatory Research]. The community has its own timeline and you have to have lots of flexibility.”
 - ▶ *Mobilizing Community Engagement for Health in a Southern New Mexico Border Region Colonia*

Field Notes (Cont.)

- ▶ “Always find a way to leverage the talent of willing and engaged members of your community. They may not be a perfect fit for what you're looking for right now, but if they have passion, find a place for them.”
 - ▶ *Establishing a Patient-Centered Research Community for Cystic Fibrosis*
- ▶ “By prioritizing the understanding of where we may fit within the institution, we hope that we can focus our future energy on doing effective collaborative work rather than fighting against a structure or operating without an idea for the institutional sustainability of our efforts.”
 - ▶ *Creating the Patient-Centered Primary Care Council in the Highland Hospital Adult Medicine Clinic: Strengthening Primary Care Together*

Bridge Communities & Research

- ▶ PHIs are more than just a fiscal pass through agency
- ▶ Provide assistance to facilitate success in:
 - ▶ relationship building
 - ▶ administration capacity
 - ▶ collaborative research
- ▶ Non biased approach encourages growth over competition
- ▶ Local expertise is essential for quality engagement within new collaboratives

Lessons Learned From an Intermediate Funder

- ▶ Awardees need to be given permission to treat this as a learning experience.
- ▶ Clear expectations up front help the learning experience to be positive and not frustrating.
- ▶ Summarizing reports from all awardees back to awardees provides a sense of community support, not just funder support.

Wrap Up

- ▶ Expertise at a local level supports this national effort by providing contextual, meaningful technical assistance.
- ▶ Fiscal administration is also technical assistance, and a very important part at that.
- ▶ Big ideas are only possible if ample support is provided.