ADVISORY PANEL ON PATIENT ENGAGEMENT MEETING

Via GoToWebinar

Fall 2021 Meeting

November 5, 11:30am-4:00pm EDT

pcori®

PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome

Greg Martin

Acting Chief Engagement and Dissemination Officer

Neely Williams

Chair, Advisory Panel on Patient Engagement

Karen Fortuna

Co-chair, Advisory Panel on Patient Engagement

Housekeeping

- Meeting is available to the public and is being recorded
- Members of the public are invited to listen to this teleconference and view the webinar
- No public comment period is scheduled
- A meeting summary and materials will be made available on PCORI’s website following the meeting
- Visit www.pcori.org/events for more information on future activities

GoToWebinar Housekeeping

- Attendees are in listen-only mode

- Submitting questions/comments (PCORI PEAP)
  - Type “I have a question/comment”

- Panelists (PCORI PEAP) can mute/unmute themselves and turn on/off camera
  - Please keep yourself on mute when not talking

- If you need to leave the meeting early, please send Lisa a note so we aren’t concerned that you are having connectivity issues

Advisory Panel on Patient Engagement

Donald Adams, Jr.

Representing: Patients, Caregivers, and Patient Advocates

Geri Baumblatt

Representing: Patients, Caregivers, and Patient Advocates

Russell Bennett

Representing: Patients, Caregivers, and Patient Advocates

Jen Brown

Representing: Patients, Caregivers, and Patient Advocates

Beth Careyva

Representing: Researchers

Tracy Carney

Representing: Patients, Caregivers, and Patient Advocates

Karen L. Fortuna

Representing: Researchers

Crispin Goytia

Representing: Patients, Caregivers, and Patient Advocates

Advisory Panel on Patient Engagement

Melody Goodman

Representing: Researchers

Una Lee

Representing: Clinicians

Lauren Lessard

Representing: Researchers

Margarita Holguin

Representing: Patients, Caregivers, and Patient Advocates

Alma McCormick

Representing: Patients, Caregivers, and Patient Advocates

Al Richmond

Representing: Patients, Caregivers, and Patient Advocates

Rupa Valdez

Representing: Researchers

Neely Williams

Representing: Patients, Caregivers, and Patient Advocates

Public & Patient Engagement Team

Greg Martin
Acting Chief Engagement and Dissemination Officer

Kristin Carman
Director,
Public and Patient Engagement

Lisa Stewart
Senior Engagement Officer,
Public and Patient Engagement

Meghan Berman
Program Associate II,
Public and Patient Engagement

Tara Lucian
Program Associate,
Public and Patient Engagement

PEAP Chairs

Neely Williams

Chair

Administrator, Community Partners' Network, Inc

Patients, Caregivers, and Advocacy Organizations

neely.williams1@gmail.com

Karen Fortuna

Co-chair

Assistant Professor of Psychiatry, Geisel School of Medicine at Dartmouth College

Researchers

karen.l.fortuna@dartmouth.edu

Agenda

Part I (EDT):

- 11:30 AM – Opening Remarks and Roll Call
- 12:00 PM – Panel Discussion: Increasing the Awareness of PCORI within Communities
- 12:50 PM – Stretch Break
- 12:55 PM – PCORI Strategic Planning Update
- 1:10 PM – Science of Engagement Funding Initiative
- 1:40 PM – Lunch Break

Part II (EDT):

- 2:10 PM – PEAPs in Action: Researching Health Together
- 2:45 PM – Patient-Driven Research Community Learning Network: Overview of Activities
- 3:15 PM – Stretch Break
- 3:20 PM – Achieve Health Equity: Modeling Community-Driven Research Approaches
- 3:50 PM – Announcements and Wrap-Up
- 4:00 PM – Adjourn

Panel Perspectives

Increasing the Awareness of PCORI within Communities

Stretch Break

12:50 – 12:55pm EDT

PCORI Strategic Planning Update

Andrew Hu
Director, Public Policy

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Scope of Strategic Planning Activities

- **National Priorities for Health**
- Research Agenda
- PCORnet® strategic vision for PCORI's next phase
- Methodology Committee focus for PCORI's next phase
- Commitment Planning and strategies to increase funding
- Scenario Planning based on the changes in landscape and environment
- Priorities from reauthorizing law
    - Maternal morbidity and mortality
    - Intellectual and developmental disabilities
    - Full range of outcomes data

Public Input and Public Comment Inform PCORI's National Priorities for Health and Research Agenda

Input

- Stakeholder outreach (e.g., patient/advocacy groups, Congress, clinician forums)
- National Academy of Medicine "Priorities on the Health Horizon" series
- PCORI advisory panels
- PCORI Annual Meeting

Additional Input Opportunities

National Priorities for Health

***Proposed* National Priorities**

June 28- Aug 27, 2021

Public Comment Period

Adopted National Priorities

Research Agenda

***Proposed* Research Agenda**

Public Comment Period

Adopted Research Agenda

Input Gathering Process Reminder

PCORI received input from a range of stakeholders to identify and inform the National Priorities for Health in addition to holding discussion at Board of Governors meetings and several other activities to inform the process.

Summer 2020
- PCORI Advisory Panels
- Board of Governors Meeting
- PCORI Virtual Annual Meeting

Fall 2020
- PCORI Advisory Panels
- Payer Convening
- Health Policymakers & Thought Leaders Panel

Winter 2021
- Clinician Convenings
- Calls with Congressional Offices
- Meetings with Patient Groups
- Priorities on the Health Horizon Meetings

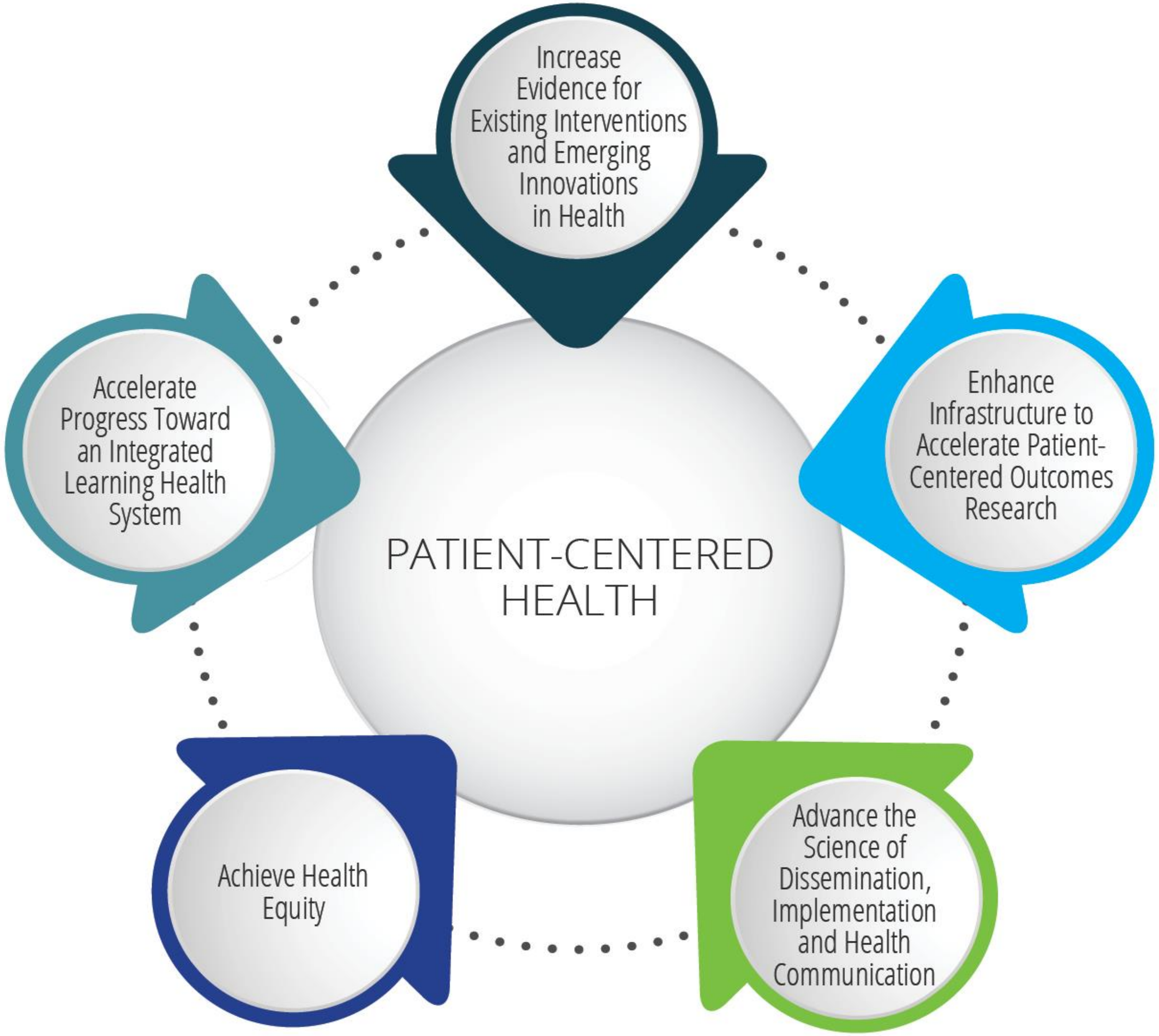
Spring 2021

60-day Public Comment Period

Summer 2021
- Regional Convening

Adopted National Priorities for Health

Creating synergistic opportunities for progress



Increase Evidence for Existing Interventions and Emerging Innovations in Health

Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research

Advance the Science of Dissemination, Implementation and Health Communication

Achieve Health Equity

Accelerate Progress Toward an Integrated Learning Health System

PATIENT-CENTERED HEALTH

Adopted National Priorities for Health

Increase Evidence for Existing Interventions and Emerging Innovations in Health

Strengthen and expand ongoing comparative clinical effectiveness research focused on both existing interventions and emerging innovations to improve healthcare practice, health outcomes, and health equity

Adopted National Priorities for Health

Enhance Infrastructure to Accelerate Patient-Centered Outcomes Research

Enhance the infrastructure that facilitates patient-centered outcomes research to drive lasting improvements in health and transformation of both the research enterprise and care delivery

Adopted National Priorities for Health

Advance the Science of Dissemination, Implementation, and Health Communication

Advance the scientific evidence for and the practice of dissemination, implementation, and health communication to accelerate the effective sharing of comparative clinical effectiveness research results for public understanding and uptake into practice

Adopted National Priorities for Health

Achieve Health Equity

Expand stakeholder engagement, research, and dissemination approaches that lead to continued progress towards achieving health equity in the United States

Adopted National Priorities for Health

Accelerate Progress Toward an Integrated Learning Health System

Foster actionable, timely, place-based, and transformative improvements in patient-centered experiences, care provision, and ultimately improved health outcomes through collaborative, multisectoral research to support a health system that understands and serves the needs and preferences of individuals

Upcoming Discussions

- The ***strategic plan*** centers on achieving the National Priorities for Health, and the Research Agenda is one major component of the plan. The strategic plan aims to describe all the various components and present a cohesive vision for PCORI's future activitites.
- The ***Research Agenda*** provides a framework for achieving progress on the National Priorities for Health specifically through the strategy of funding comparative clinical effectiveness research (CER). The Research Agenda helps guide the development of continuously relevant ***Research Project Agenda*** via an on-going, stakeholder-engaged process.
- PCORI utilizes other strategies in addition to funding CER (for example, Dissemination & Implementation) to achieve the National Priorities for Health, and these will be described in other components of the strategic plan.

Intellectual and/or Developmental Disabilities (IDD)
Maternal Morbidity and Mortality (MMM)

Science of Engagement (SoE) Funding Initiative

Julie Kennedy Lesch
Senior Engagement Officer, Public & Patient Engagement

Rachel Hemphill
Program Officer, Evaluation & Analysis

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Recap and Progress

- We received valuable input from the PEAP, in July, on priorities for studying engagement, including:
  - What does ‘true engagement’ look like?
  - How much engagement is enough?
  - What types of engagement work for specific groups?
  - Outcomes of engagement (ex., on health/wellness of researchers, partners, on uptake of results).
  - Power and equity in engagement.

- We now have a Request for Information (RFI) available on our website to inform the development of a Science of Engagement (SoE) funding initiative

SoE Initiative

- **The new initiative aims to:**
  - Expand the evidence base on the approaches for effectively engaging diverse patients and stakeholders throughout the research process,
  - Identify the ultimate outcomes of engagement or the impact of engagement, and
  - Implement resources and facilitators necessary to successfully support studies that address these research topics.

SoE Potential Topic Areas for Study

What defines successful engagement, and for whom?

How can engagement be measured? What indicates that a study is patient-centered?

What are the approaches that support and achieve successful engagement?

Which approaches should be combined to achieve engagement aims?

Under which conditions do approaches work best and how should they be modified and resourced for different contexts, settings, and communities?

For Discussion Today

- What are the evidence needs of patient advocates/advocacy organizations? What topics would most interest them? What are the evidence needs of other stakeholder types?

- What should PCORI do to ensure that these research opportunities are inclusive and accessible to all types of organizations?

- How can PCORI promote connections between organizations, communities and qualified researchers for this opportunity?

PCORI's Request for Information on SoE

- PCORI has posted a RFI that:
    - Describes SoE,
    - Poses a specific set of questions on both the scientific research topic priorities and the process and resource elements, and
    - Invites responses to questions and general comments.

- Responses to the RFI are due by **November 19, 2021**
- Download the RFI at **www.pcori.org/soe**

Lunch Break

1:40 – 2:10pm EDT

Researching Health Together

A Patient Partner Perspective

Tracy Carney, CPS, CPRP

Senior Recovery Specialist

Community Care Behavioral Health

PCORI Awards

2013–2017

Comparative Effectiveness Research Study

- Optimizing Behavioral Health Homes by Focusing On Outcomes That Matter Most for Adults with Serious Mental Illness

2018–2020

Dissemination & Implementation Award

- Utilizing a Learning Collaborative Approach to Support Behavioral Health Home Dissemination

2019–2021

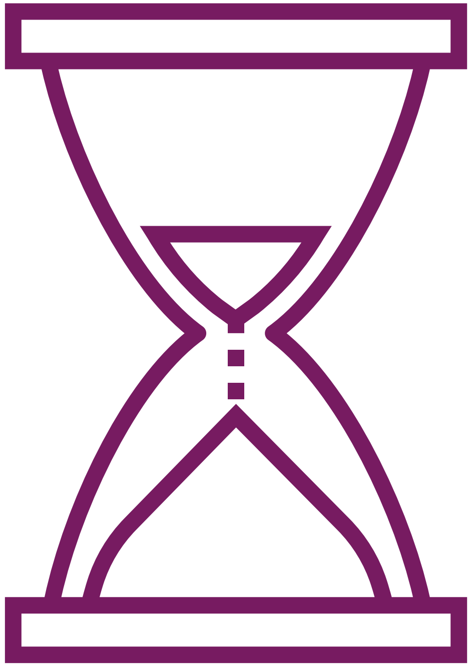
Dissemination, Engagement Award
Rochester Regional Health

- Helping Adults with Serious Mental Illness Improve Their Health and Wellness

Why This Work is Needed

Adults with serious mental illness (SMI) are one of the most medically vulnerable populations.

- 68% of adults with mental health disorders also have medical conditions.
- High rates of undiagnosed, untreated, or poorly treated medical illnesses and difficulty accessing medical care.
- High rates of premature death; dying as much as 15 to 25 years younger than the general population.
- Modifiable lifestyle choices and behaviors may contribute (alcohol & tobacco use, poor nutrition).

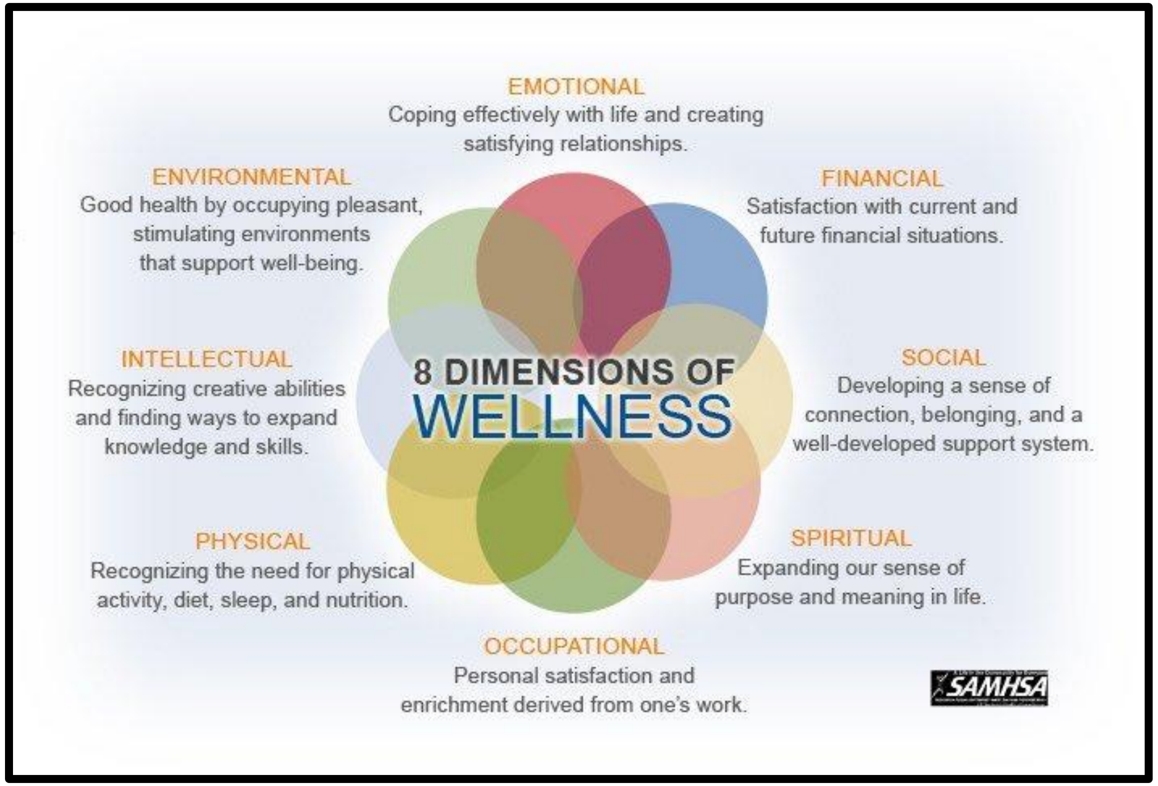


Creating Behavioral Health Home Models to Support Integrated Care Delivery for Members With SMI

- Developed behavioral health home (BHH) model in 2010 that focused on:
  - Enhancing the capacity of rural behavioral health providers to assist individuals with identifying physical health and wellness challenges.
  - Wellness Coaching to activate people to become better informed and more effective managers of their overall health.
  - Service delivery focuses on providing tools, education, and resources to address PH needs.
  - Areas of focus include engagement with primary care providers for hypertension, tobacco cessation, diabetes, and obesity.

8 Dimensions of Wellness Coaching Model

Dr. Peggy Swarbrick



EMOTIONAL
Coping effectively with life and creating satisfying relationships.

ENVIRONMENTAL
Good health by occupying pleasant, stimulating environments that support well-being.

FINANCIAL
Satisfaction with current and future financial situations.

INTELLECTUAL
Recognizing creative abilities and finding ways to expand knowledge and skills.

8 DIMENSIONS OF WELLNESS

SOCIAL
Developing a sense of connection, belonging, and a well-developed support system.

PHYSICAL
Recognizing the need for physical activity, diet, sleep, and nutrition.

SPIRITUAL
Expanding our sense of purpose and meaning in life.

OCCUPATIONAL
Personal satisfaction and enrichment derived from one's work.

SAMHSA

- A strength-based intervention that helps people pursue their individually chosen health and wellness goals.
- Helps people focus on goals that they value and supports them in pursuing goals.
- Short-term goals focused on specific action steps.

Say What?

- What’s a PCORI?
- Why Me?
- Can I make a meaningful contribution?
- Do they need a patient partnership to secure funding?
- Will my participation in the project be meaningful or will it feel like tokenism?
- What is the scope of my role? Time commitment?
- How will I know if I have successfully fulfilled my role as a Patient Co-PI?

Patient Co-PI on a Research Grant Motivation

What's Your Why?

- Discuss as a team what brings you to this work.
- Focus on shared motivations rather differences.

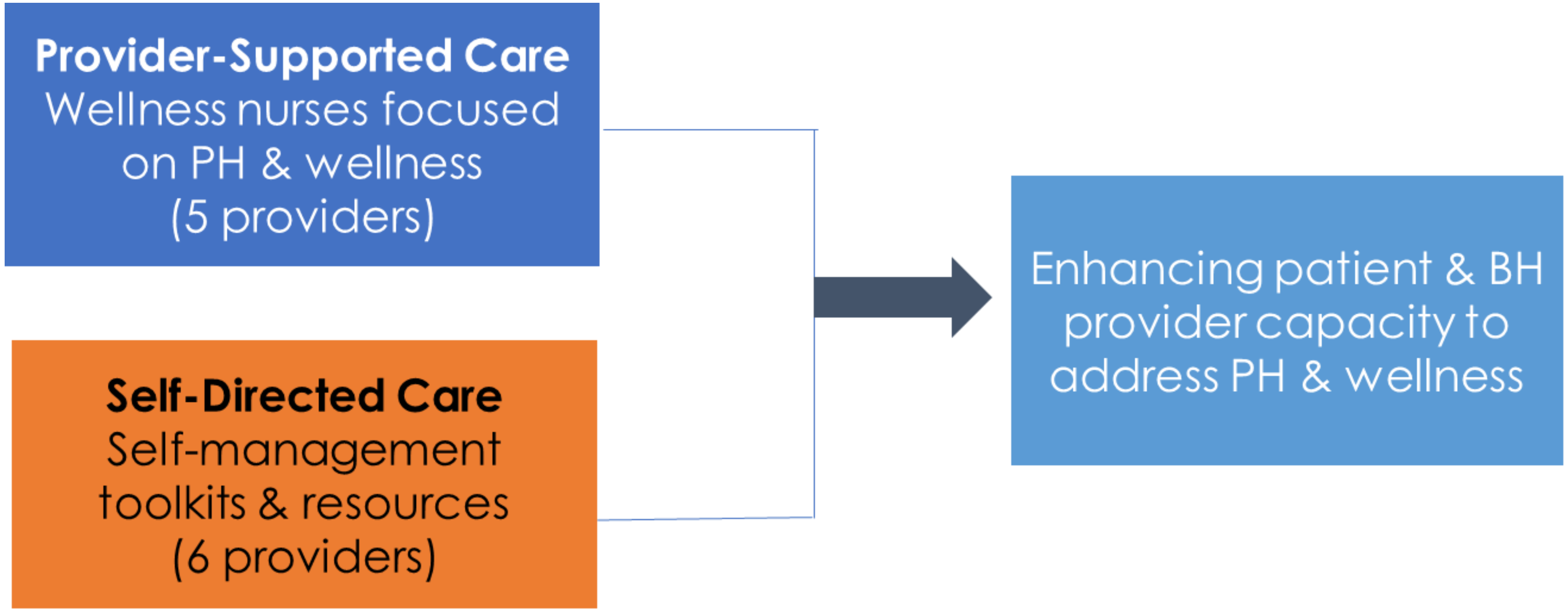
Patient Co-PI on a Research Grant Vulnerability

- No one volunteers to be a patient.
- Patient partners become vulnerable.
- Sharing lived experience is a personal journey.
- Patient partners should be recognized for the value of this work.
- The team should stay sensitive and flexible.
- Shared vulnerability.

PCORI Optimal Health Study

Comparative effectiveness study of two behavioral health home model approaches to **improve the health status of individuals with serious mental illness**, **increase patient activation in care**, and **improve engagement with primary/specialty physical health care.**

1,229 adults with serious mental illness from 11 mental health centers in rural Pennsylvania



Provider-Supported Care
Wellness nurses focused on PH & wellness
(5 providers)

Self-Directed Care
Self-management toolkits & resources
(6 providers)

Enhancing patient & BH provider capacity to address PH & wellness

Optimal Health Results

Patient-Centered Outcomes

↑ Patient Activation

- More rapid increase at provider-supported sites
- Women at provider-supported sites
- Men at self-directed sites

↑ Primary/Specialty

- 40% increase in visits

Unplanned Care & Cost Outcome
(Achieved in year 2)

↓ 15% PMPM total cost
↓ 40% Behavioral and medical inpatient use
↓ 25% Behavioral and medical inpatient cost
↓ 17% PMPM case management cost
↑ 50% Overall physical health service use

Interviews found both models offered support to service-users in achieving positive health and wellness goals

The **Learning Collaborative** led to the integration of model components into routine care delivery at the provider sites

Research Team Strengths

Understood the Place the Work was Done

- What does the community value, need and desire?

Established a Common Goal

- How will the work bring help and value to the community? What happens to the community when the research is over?

Built Trusting Relationships

- Invested Time
- Reciprocal communication, listened, accept/ use input, provide feedback
- Defined roles

Empowerment

- Acknowledged the value of each voice on the Team
- Team vulnerability, learned from each other

Trauma Informed Principles

- **Safety**
- **Trustworthiness + Transparency**
- **Peer Support**
- **Collaboration**
- **Empowerment**
- **Humility + Responsiveness**

SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach

Adapted from the Substance Abuse and Mental Health Services Administration's "Guiding Principles of Trauma-Informed Care.")

BHHP Program Expansion

Behavioral Health Home Plus draws on the unique aspects of both models studied in the Optimal Health Study

Dissemination to additional Community Mental Health Centers (CMHCs)

- Over 50 CMHCs implementing across Pennsylvania

Scaling model to serve other vulnerable populations

- PCORI Dissemination and Implementation award
  - Youth receiving services at residential behavioral health treatment facilities (5 sites)
  - Individuals in opioid treatment programs (7 sites)

Rochester Regional Health

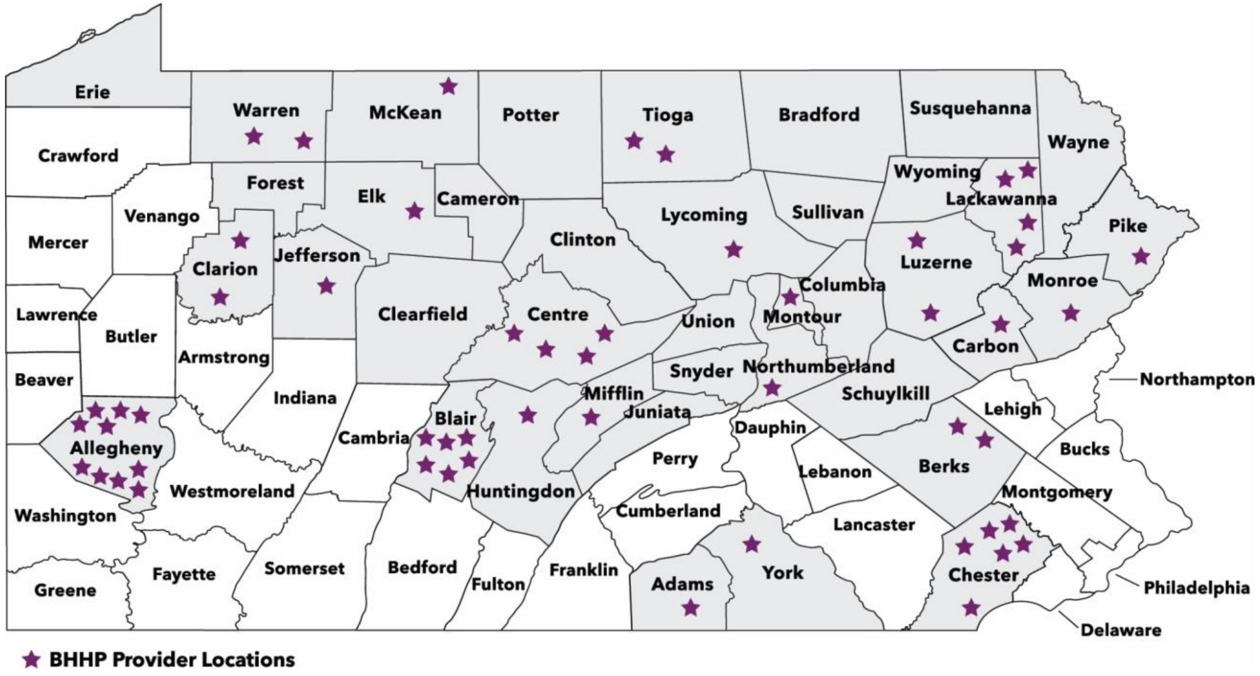
- PCORI Engagement Award to disseminate behavioral health home intervention

Publications and presentations

- Publications: Clinical Trials, Health Affairs, Psychiatric Services (submitted and under review)
- Presentations: Academy Health, Annual PA Association of Psychiatric Rehabilitation Services Conference,
  PA Mental Health and Wellness Conference, etc.

Website

- http://upmcbehavioralhealthhomes.3cisd.com/



UPMC COMMUNITY CARE
Behavioral Health Organization

Cultural Humility

Thank You

Contact Information

Tracy Carney
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Community Care Behavioral Health
carneyta@ccbh.com

Patient-Driven Research Community Learning Network

Overview of Activities

Elizabeth L. Cope
Senior Director, AcademyHealth

Claudia Grossmann
Senior Program Officer, Research Infrastructure

Michelle Johnston-Fleece
Senior Program Officer, Public & Patient Engagement

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Patient-Driven Research Community (PDRC) Learning Network (LN) Background

Research Landscape

- There is a growing role of patient-led communities in research
- Limited understanding of the depth and breadth of patient-led communities and their contributions to PCOR

PDRC Needs

- PDRCs are siloed and seek opportunities for peer learning and further defining their collective role in the research landscape
- PDRCs have interest in collaborating on persistent challenges and topics of shared priority and urgency

PCORI Interests

- Understand PDRC context and how they fit in the research landscape
- Understand how PCORI support of PDRCs may contribute an empowered role for PDRCs in clinical and care delivery research

Working PDRC Definition

A **PDRC:**

Is an organization or group of individuals/organizations that is **led and/or governed by patients/participants and/or caregivers** and for which a ***primary purpose*** **is to enable research** that is a priority to patient/participant or caregiver communities.

PDRCs:

- Have a **shared sense of purpose** related to research
- Ensure that the views of patients/participants and/or caregivers are:
  - **Central** to governance bodies and decision-making
  - **Included** in the health research process
- Are stable entities that engage in research and **maintain relationships** with patient/participant/caregiver communities in governance and research activities over time

PDRC Research Activities

Lead/Collaborate on Research

- Agenda setting, design, & planning
- Study implementation

Collect and Share Data

- Collect & aggregate participant data
- Share data

Connect Research Stakeholders

- To advance PDRC research agendas
- To interpret findings & develop research questions

Fund Research

- Grant awards
- Co-fund with other organizations

Educate/Train to Facilitate Research

- Educate on methods
- Train researchers/clinicians on PDR approaches

Research Advocacy

- Advocate for advancement of a PDR agenda
- Engage policymakers

PDRC LN Members

Participants of the Patient-Driven Research Community Learning Network (PDRC LN)

8 Eugene Washington PCORI Engagement Award Recipients

ABOUT
American BRCA Outcomes & Utilization of Testing Network

COPD FOUNDATION

iConquer MS

PARTNERS
Pediatric Rheumatology Research that Matters to You

ArthritisPower®

IBD PARTNERS

IMPROVECARENOW™

PRIDEnet
CATALYZING LGBTQ HEALTH RESEARCH

Learning Network Activities: Peer-to-Peer Learning and Community Building

Monthly Meetings

- Purpose: Forum for the LN to discuss accomplishments, share lessons, and workshop challenges.

Bimonthly Seminars

- Purpose: Venue for emergent topics, led by experts external to the LN.

Annual Meetings

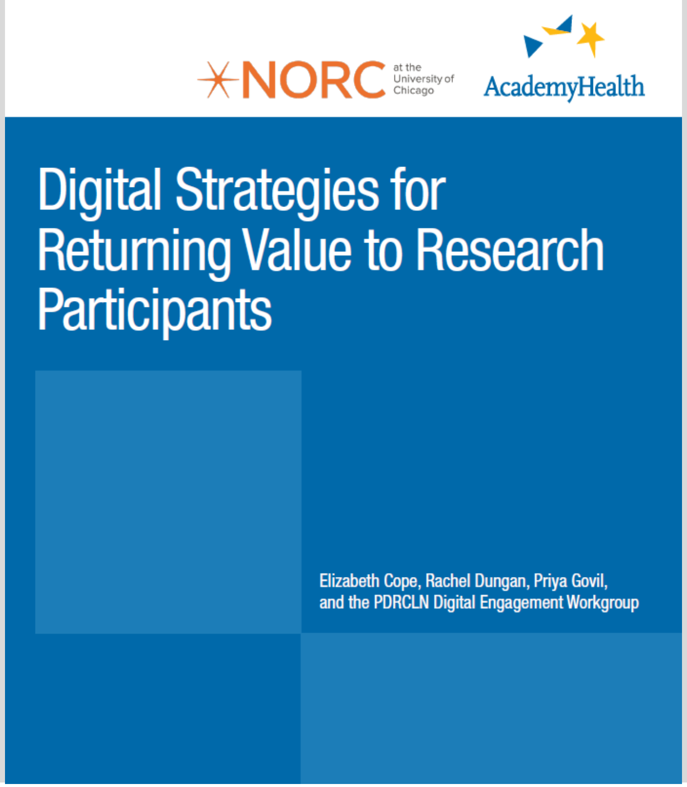
- Purpose: Annual forum for the LN to share progress, signature achievements, and discuss LN member-identified topics of interest.

Workgroups

- Purpose: Provide forums for sharing learnings and extracting generalizable findings to inform the PDRC model and the field more broadly.

Peer-to-Peer Learning: Workgroups

Digital Engagement Workgroup



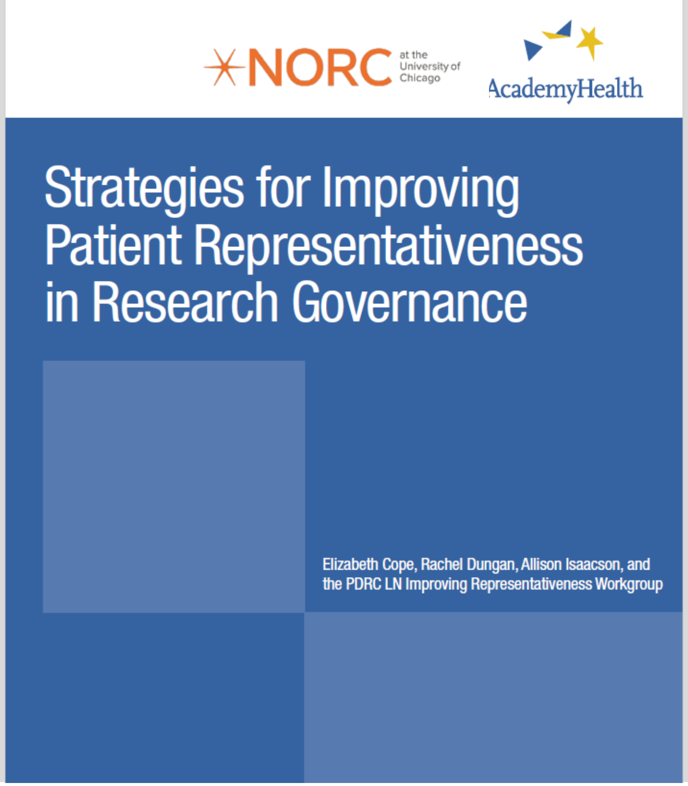
NORC at the University of Chicago

AcademyHealth

Digital Strategies for Returning Value to Research Participants

Elizabeth Cope, Rachel Dungan, Priya Govil, and the PDRCLN Digital Engagement Workgroup

Improving Representativeness Workgroup



NORC at the University of Chicago

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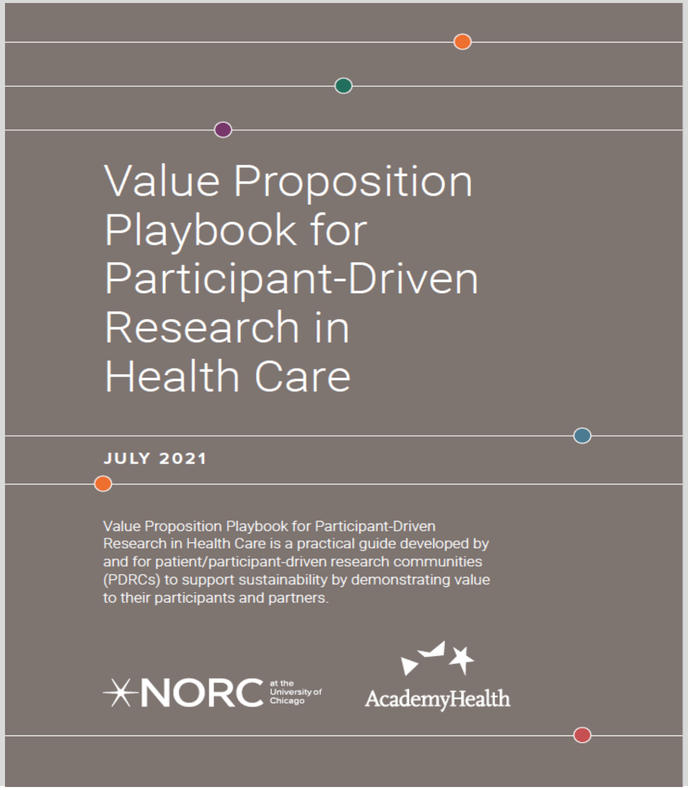
Strategies for Improving Patient Representativeness in Research Governance

Elizabeth Cope, Rachel Dungan, Allison Isaacson, and the PDRC LN Improving Representativeness Workgroup

Sustainability Workgroup



Value Proposition Playbook for Participant-Driven Research in Health Care

JULY 2021

Value Proposition Playbook for Participant-Driven Research in Health Care is a practical guide developed by and for patient/participant-driven research communities (PDRCs) to support sustainability by demonstrating value to their participants and partners.

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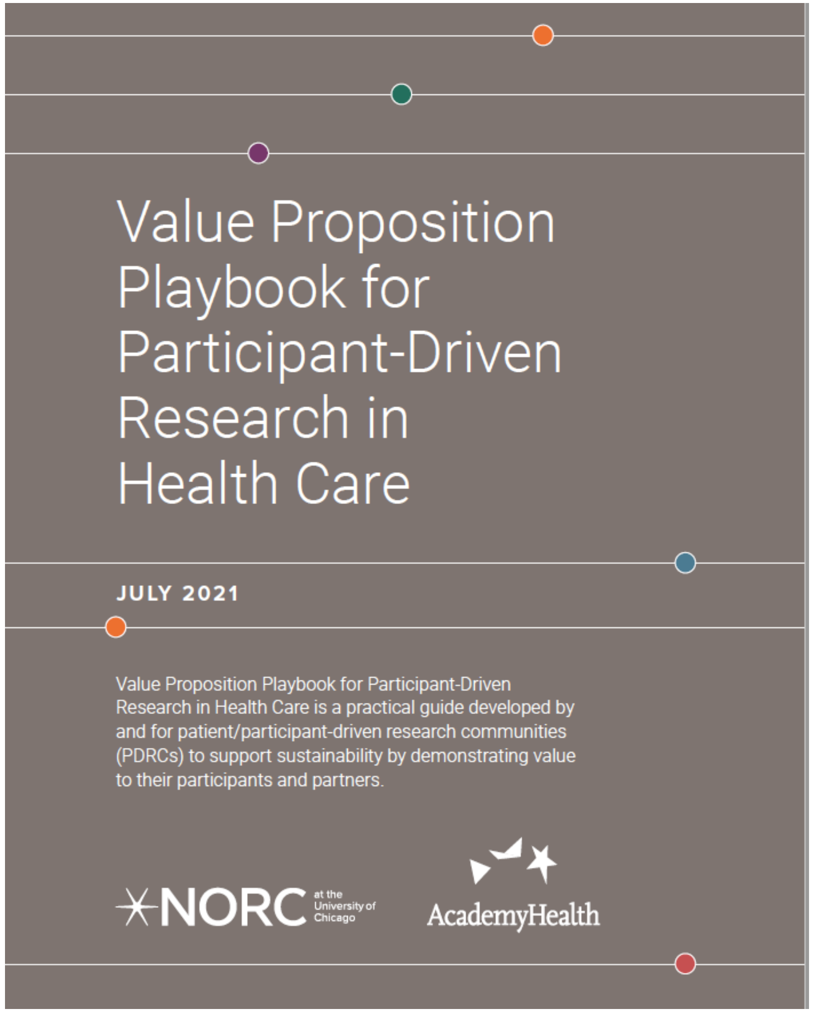
Workgroup Findings: Sustainability



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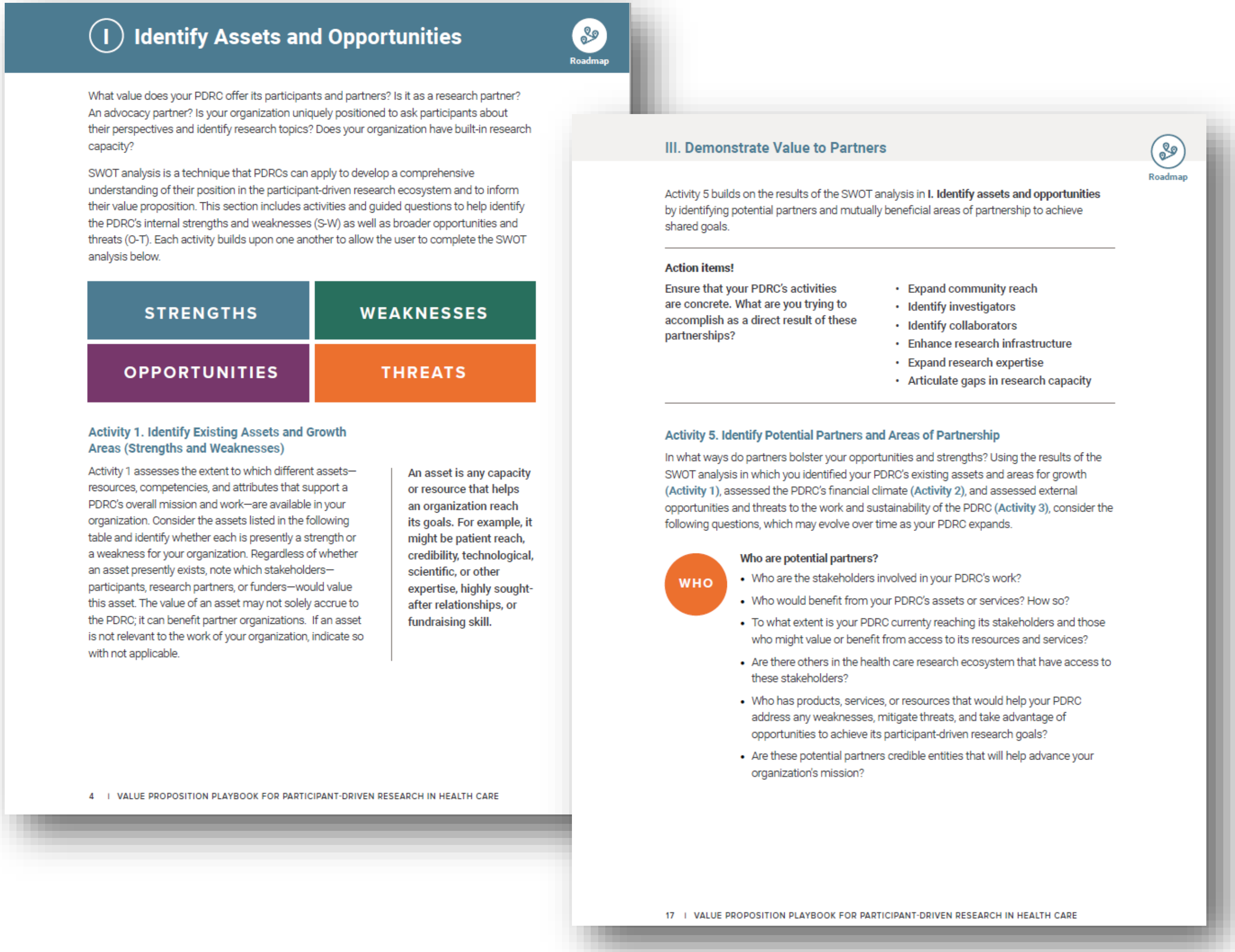


I Identify Assets and Opportunities

Roadmap

What value does your PDRC offer its participants and partners? Is it as a research partner? An advocacy partner? Is your organization uniquely positioned to ask participants about their perspectives and identify research topics? Does your organization have built-in research capacity?

SWOT analysis is a technique that PDRCs can apply to develop a comprehensive understanding of their position in the participant-driven research ecosystem and to inform their value proposition. This section includes activities and guided questions to help identify the PDRC's internal strengths and weaknesses (S-W) as well as broader opportunities and threats (O-T). Each activity builds upon one another to allow the user to complete the SWOT analysis below.

STRENGTHS	WEAKNESSES
OPPORTUNITIES	THREATS

Activity 1. Identify Existing Assets and Growth Areas (Strengths and Weaknesses)

Activity 1 assesses the extent to which different assets—resources, competencies, and attributes that support a PDRC's overall mission and work—are available in your organization. Consider the assets listed in the following table and identify whether each is presently a strength or a weakness for your organization. Regardless of whether an asset presently exists, note which stakeholders—participants, research partners, or funders—would value this asset. The value of an asset may not solely accrue to the PDRC; it can benefit partner organizations. If an asset is not relevant to the work of your organization, indicate so with not applicable.

An asset is any capacity or resource that helps an organization reach its goals. For example, it might be patient reach, credibility, technological, scientific, or other expertise, highly sought-after relationships, or fundraising skill.

4 I VALUE PROPOSITION PLAYBOOK FOR PARTICIPANT-DRIVEN RESEARCH IN HEALTH CARE

III. Demonstrate Value to Partners

Roadmap

Activity 5 builds on the results of the SWOT analysis in **I. Identify assets and opportunities** by identifying potential partners and mutually beneficial areas of partnership to achieve shared goals.

Action items!

Ensure that your PDRC's activities are concrete. What are you trying to accomplish as a direct result of these partnerships?

- **Expand community reach**
- **Identify investigators**
- **Identify collaborators**
- **Enhance research infrastructure**
- **Expand research expertise**
- **Articulate gaps in research capacity**

Activity 5. Identify Potential Partners and Areas of Partnership

In what ways do partners bolster your opportunities and strengths? Using the results of the SWOT analysis in which you identified your PDRC's existing assets and areas for growth (**Activity 1**), assessed the PDRC's financial climate (**Activity 2**), and assessed external opportunities and threats to the work and sustainability of the PDRC (**Activity 3**), consider the following questions, which may evolve over time as your PDRC expands.

WHO

Who are potential partners?

- Who are the stakeholders involved in your PDRC's work?
- Who would benefit from your PDRC's assets or services? How so?
- To what extent is your PDRC currenty reaching its stakeholders and those who might value or benefit from access to its resources and services?
- Are there others in the health care research ecosystem that have access to these stakeholders?
- Who has products, services, or resources that would help your PDRC address any weaknesses, mitigate threats, and take advantage of opportunities to achieve its participant-driven research goals?
- Are these potential partners credible entities that will help advance your organization's mission?

17 I VALUE PROPOSITION PLAYBOOK FOR PARTICIPANT-DRIVEN RESEARCH IN HEALTH CARE

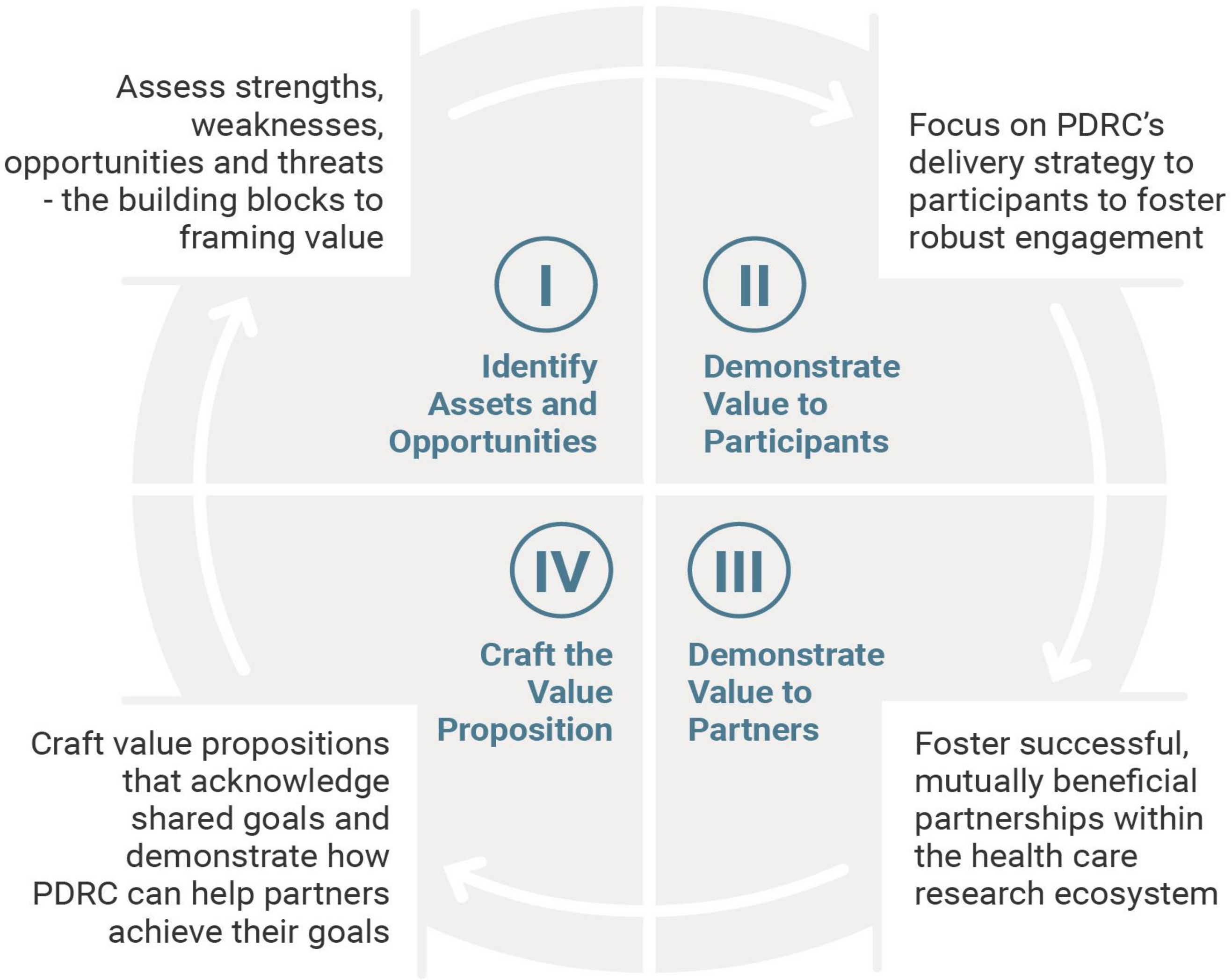
Found in the PCORI Engagement Tool & Resource Repository here.

Workgroup Findings: Sustainability

Key Findings

- PDRCs' sustainability relies on complex business models and partnerships with diverse collaborators
- PDRCs must be able to:
  - Understand goals and needs of partners
  - Identify how PDRC can help partners achieve goals
  - Articulate the value to partners in working with PDRC

Overview of Content



Assess strengths, weaknesses, opportunities and threats - the building blocks to framing value

I

Identify Assets and Opportunities

Focus on PDRC's delivery strategy to participants to foster robust engagement

II

Demonstrate Value to Participants

III

Demonstrate Value to Partners

Foster successful, mutually beneficial partnerships within the health care research ecosystem

IV

Craft the Value Proposition

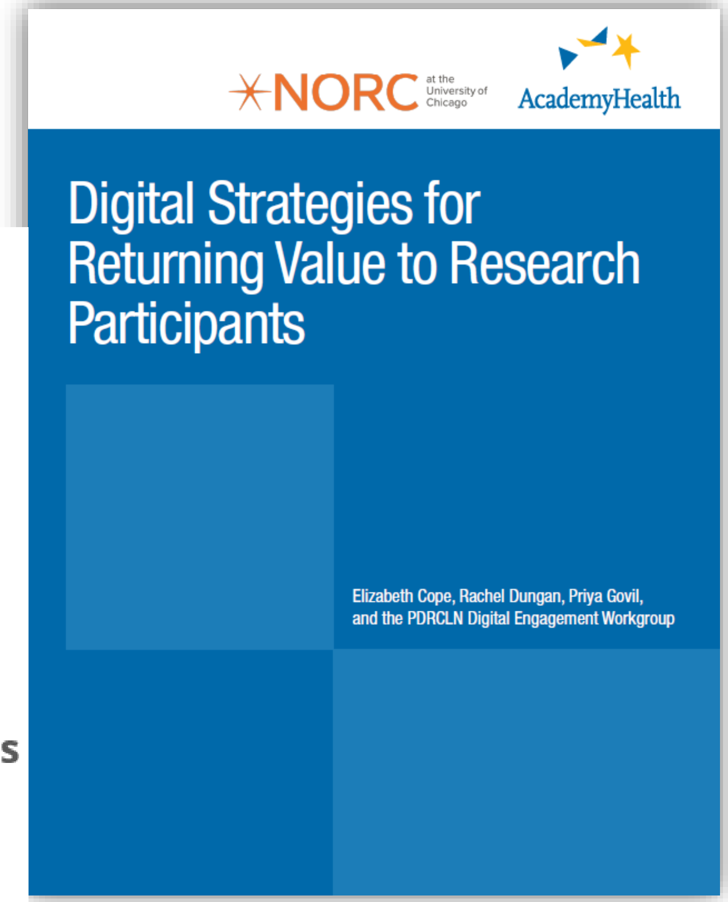
Craft value propositions that acknowledge shared goals and demonstrate how PDRC can help partners achieve their goals

Workgroup Findings: Digital Engagement

A resource about returning value in the context of research participation, and the principles that should guide strategies when using digitally-based methods.

There are many ways to return value

- Returning research results
- **Contextualizing participants' health relative to norms**
- **Offering opportunities to engage in the research process beyond study subjects**
- **Building new skills or capacities**
- **Increasing awareness of influences on participants' health**
- **Providing information about relevant studies in progress**
- **Facilitating connection with others**



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Digital Strategies for Returning Value to Research Participants

Elizabeth Cope, Rachel Dungan, Priya Govil, and the PDRCLN Digital Engagement Workgroup

Found in the PCORI Engagement Tool & Resource Repository here.

Workgroup Findings: Improving Representativeness

A resource for PDRCs about how to better engage partners from traditionally underrepresented groups in research governance.

Structures

Policies

Community-centered Practices

Cultural Competence/ Humility

Education/Training

Supportive Resources

NORC at the University of Chicago

AcademyHealth

Strategies for Improving Patient Representativeness in Research Governance

Elizabeth Cope, Rachel Dungan, Allison Isaacson, and the PDRC LN Improving Representativeness Workgroup

Found in the PCORI Engagement Tool & Resource Repository here.

Workgroup Product Dissemination

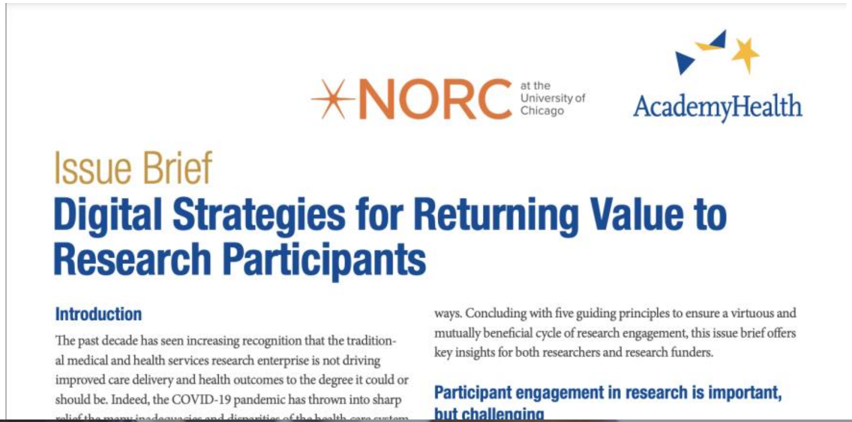
Microproducts

- Issue Briefs
- Case Study Briefs
- Slide Decks
- Dissemination Toolkits

IBD PARTNERS

IBD Partners: Patient Governance Committee Recruitment Strategy

A Case Study on Strategies for Improving Patient Representativeness in Research Governance



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Issue Brief

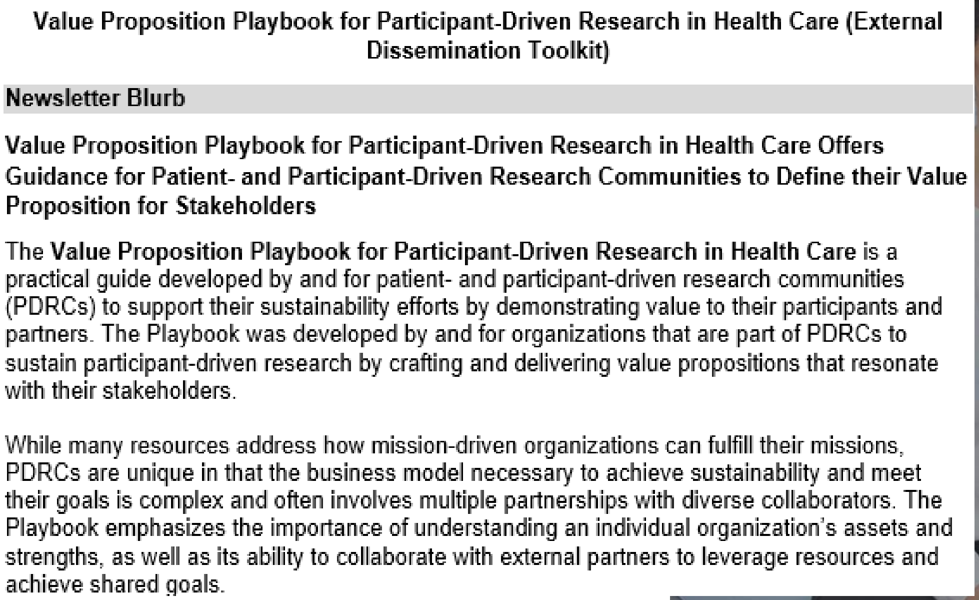
Digital Strategies for Returning Value to Research Participants

Introduction

The past decade has seen increasing recognition that the traditional medical and health services research enterprise is not driving improved care delivery and health outcomes to the degree it could or should be. Indeed, the COVID-19 pandemic has thrown into sharp

ways. Concluding with five guiding principles to ensure a virtuous and mutually beneficial cycle of research engagement, this issue brief offers key insights for both researchers and research funders.

Participant engagement in research is important, but challenging



Value Proposition Playbook for Participant-Driven Research in Health Care (External Dissemination Toolkit)

Newsletter Blurb

Value Proposition Playbook for Participant-Driven Research in Health Care Offers Guidance for Patient- and Participant-Driven Research Communities to Define their Value Proposition for Stakeholders

The **Value Proposition Playbook for Participant-Driven Research in Health Care** is a practical guide developed by and for patient- and participant-driven research communities (PDRCs) to support their sustainability efforts by demonstrating value to their participants and partners. The Playbook was developed by and for organizations that are part of PDRCs to sustain participant-driven research by crafting and delivering value propositions that resonate with their stakeholders.

While many resources address how mission-driven organizations can fulfill their missions, PDRCs are unique in that the business model necessary to achieve sustainability and meet their goals is complex and often involves multiple partnerships with diverse collaborators. The Playbook emphasizes the importance of understanding an individual organization's assets and strengths, as well as its ability to collaborate with external partners to leverage resources and achieve shared goals.

Strategies for Improving Patient Representativeness in Research Governance

The Participant-Driven Research Community (PDRC) Learning Network (LN)

Discussion

- Which of the topics and products resonate with you?

- Do you have ideas about what networks of people would be interested in these products or suggestions for promotion?

Stretch Break

3:15 – 3:20pm EDT

Achieve Health Equity: Modeling Community-Driven Research Approaches

Doing Research Differently

Lisa Stewart
Senior Engagement Officer, Public & Patient Engagement

Kelly Dunham
Senior Manager, Strategic Initiatives

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Expanding Beyond the Individual to Focus on Community Health

- "Health equity and health disparities are intertwined. Health equity means social justice in health (i.e., no one is denied the possibility to be healthy for belonging to a group that has historically been economically/socially disadvantaged). Health disparities are the metric we use to measure progress toward achieving health equity. "

  Braveman P. What are health disparities and health equity? We need to be clear. *Public Health Rep*. 2014

- This requires removing inequitable structures, policies, and practices that impact health

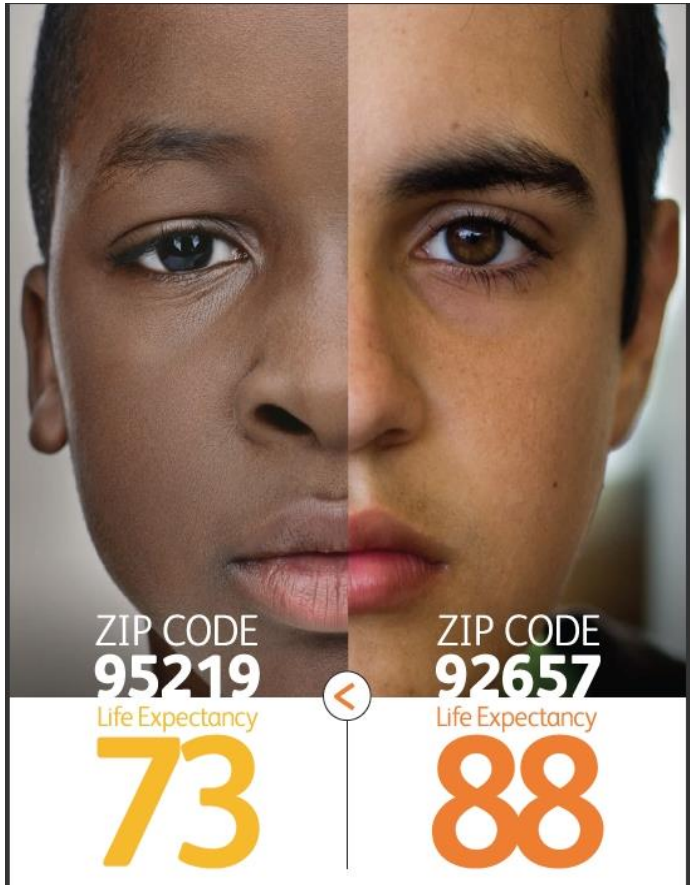


Image from "Health Happens Here" campaign, sponsored by The California Endowment

A Call for Funders to Move Upstream:
The National Academies of Science, Engineering and Medicine (NASEM) Consensus Reports

NASEM Consensus Recommendations:

- Support community capacity building and prioritize equity in the SDOH through **investments in low-income and minority communities**
- Research on the **effectiveness and implementation of social care practices**, including the integration of social care and health care
- PCORI and other funders should encourage payers, providers, and delivery systems to incorporate a **range of study designs and methods that include rapid learning cycles and experimental trials**
- Extend education and **training initiatives to include social care workforce**
- Support **transdisciplinary research approaches**

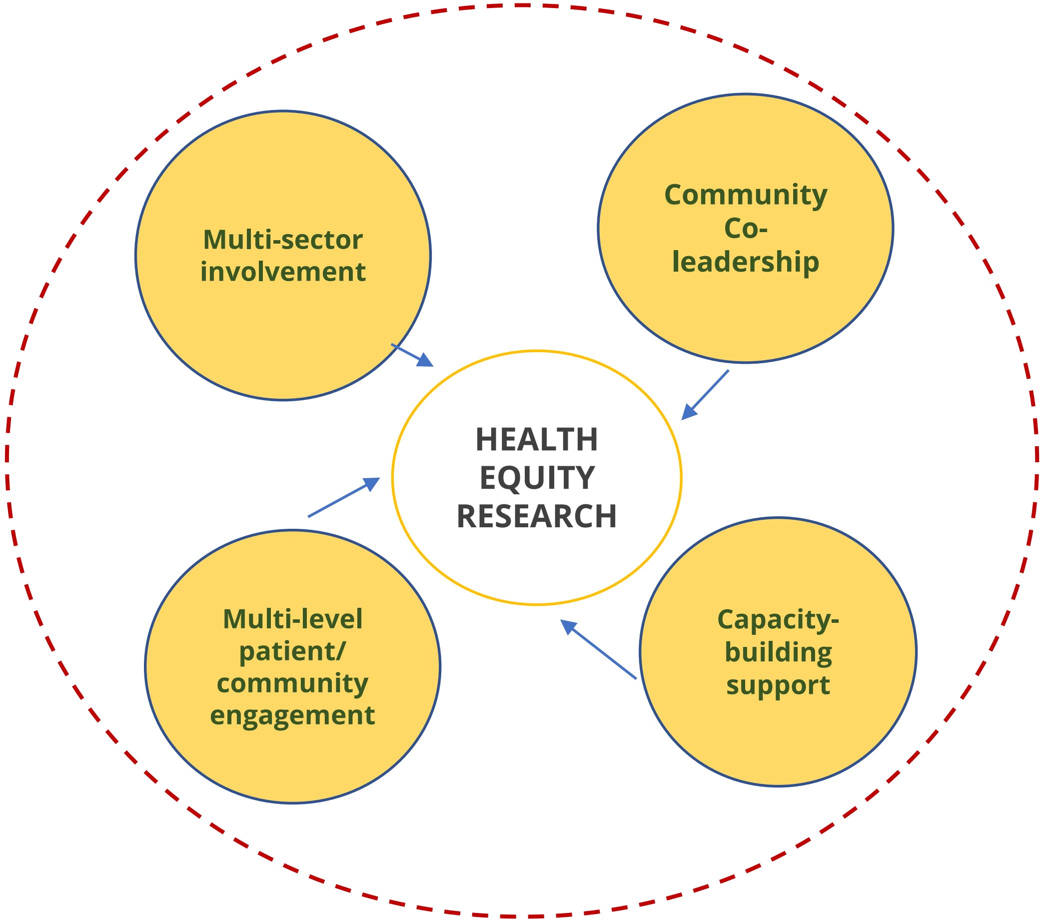
NASEM, *Communities in Action: Pathways to Health Equity* (2017)

NASEM, *Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health* (2019)

Takeaways from Early Stakeholder Discussions

Element	Considerations
Overall Design	• **Geographical context is crucial** – e.g., Appalachia, urban neighborhoods • Incorporate training for researchers and community partners • Foster collaboration and communication across centers- e.g., working groups, frequent meetings, supplemental awards for cross-center projects • Consider follow-on implementation awards for research
Speed and Innovation	• Fund research beyond the traditional model, e.g., pilot funding, feasibility phase, and designs beyond RCTs • Consider rapid funding not tied to cycles and higher risk projects
Partnerships and Balance of Power	• Fund transdisciplinary research which moves beyond discipline-specific approaches • **Consider who is at the table from the start (intersectoral partnerships)** • **Rules, structure, and funding should incentivize partners to effectively collaborate**
Research Focus	• **Guided by community identification of needs and solutions** • Requirement of conceptual model that recognizes multifactorial factors and levels • Consider type of evidence needed to impact policy and community outcomes

What Type of Funding Models are Needed to “Achieve Health Equity” ?



__Examples of potential research topics:__

- Studies that compare ways to increase equitable use of community resources, including exercise facilities, greenspace, biking and walking paths, and healthy food options to improve cardiovascular health
- Studies that compare community-based approaches to increase access to healthy food and social care resources through partnerships to improve diabetes
- Studies that compare approaches to improve healthcare access to youth in low-income neighborhoods through partnerships with schools, FQHCs, nurses, and school-based health centers to address mental health disparities of teens

Model Examples:

Research Centers - Embedded in large organizations; decision-making authority over research agenda and activities traditionally held within the institution

Research Coalitions - A coalition of formal large organizations and informal grassroots organizations, in which larger organization(s) provide infrastructure and staff support; shared decisional authority

How to Ensure Research is Community-Driven?

Discussion Questions:

- Research operations of this scale are traditionally located within research centers of academic institutions or large health systems. Are there **other types of organizations** that you could envision leading efforts like these considering the potential scope, scale and complexity of activities? Can you think of **novel partnership arrangements** between research and non-research organizations that situate community-based organization in leadership?

- Imagine that it was just announced that a donor made a sizeable donation to a nearby university to establish a program that funds research that aims to advance health equity. You've been asked to co-lead it. **What mechanisms would you create to ensure the community drives the direction and research areas of focus?**

- What would you hope a multi-stakeholder, multi-sector research collaborative focused on health equity would accomplish?

Announcements

Studying PCORI's Patient-Centered Approach (PCA) Workgroup

Purpose & Activities

- Advises on PCORI's evaluation agenda, projects that assess effectiveness of PCORI's approach, and projects that build evidence about promising practices for patient-centered research
  - ***Activities include:*** *advising on current projects, helping PCORI staff prioritize questions and projects to pursue, and serving as liaison to the full PEAP*
  - ***Upcoming projects:*** *planning a review of literature on engagement, tracking PCORI's influence on other organizations, and ways of studying diversity, equity, and inclusion at PCORI*

Time Commitment

- Conference calls scheduled on ad hoc basis (about every 2 months) at key phases of project planning, conduct, and/or dissemination
  - *Workgroup members can opt into specific activities throughout the year given availability*

How to Join or Find Out More

- The PCA Workgroup is co-facilitated by**:**
  - **Rachel Hemphill**, *Program Officer, Evaluation and Analysis*
  - **Michelle Johnston-Fleece**, *Senior Program Officer, Public and Patient Engagement*

- **We're recruiting new members!**
  - Please email us if you are interested or have questions about the workgroup (rhemphill@pcori.org; mfleece@pcori.org)

- Follow-up email with more information about the workgroup and how to join

Upcoming Events

Mark your calendars!

- Annual Meeting *(November 17-19)*
- Upcoming Board Meetings *(November 15-16 and December 1-2)*
- PEAP Meeting (*February TBD*)

Adjourn

Post-Meeting Survey

- Don’t forget!
  - Post-meeting survey: https://survey.alchemer.com/s3/6530402/PEAP-Fall-2021-Meeting-Post-Event-Survey

- Your feedback will be carefully considered when planning future meetings

- Feedback incorporated to-date:
  - Shorter presentations from PCORI staff
  - Greater opportunity for input/feedback
  - More time for breaks during virtual meetings