PCORI Update

2020 Science of Patient Engagement Symposium
National Health Council

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PCORI COVID-19 Response

COVID-19 Targeted Funding
- Adaptations to healthcare delivery
- Impact on vulnerable populations
- Healthcare workforce well-being, management and training

COVID-19 Enhancement Projects
- Dissemination & Implementation (13)
- Engagement (53)
- Research (50)

As of September 22nd, 2020

www.heroesresearch.org
PCORI’s Early Belief in Engagement

Engagement leads to research that:

- Better reflects the needs and values of patients, caregivers, clinicians, and other stakeholders
- Improves the feasibility of conducting studies in real-world settings
- Improves the relevance, and encourage uptake and use, of research results
## Science of Engagement: Engagement Impacts

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>User-Orientation &amp; Acceptability:</strong></td>
<td>studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs</td>
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<tr>
<td><strong>Feasibility:</strong></td>
<td>interventions, enrollment, and data collection that are more doable in real-world settings</td>
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<tr>
<td><strong>Study Quality:</strong></td>
<td>study rigor, comprehensiveness, and quality of materials and products</td>
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<tr>
<td><strong>Relevance:</strong></td>
<td>results applicable and important for decision-making</td>
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<tr>
<td><strong>Engagement Scope &amp; Quality:</strong></td>
<td>engagement processes are effective, and stakeholders are well equipped</td>
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Science of Engagement: **Engagement Takes Many Forms**

**Levels of partners’ decision-making authority for study design and implementation**

**Input**
- Focus Groups, Town Halls, Crowdsourcing

**Consultation**
- Advisory Committee

**Collaboration**
- Patient Co-I or Multi-Disciplinary Executive Team

**Shared Leadership**
- Patient Co-PI, Patient-led tasks

Adapted from:
Research Partners Can Contribute Throughout the Research Process

Percent of projects that reported engaging partners at each study phase

STUDY PHASES

- Research topics and/or research questions: 61%
- Interventions and/or comparators: 75%
- Outcomes and/or measurement: 71%
- Other aspects of study design: 65%
- Recruitment and/or retention: 74%
- Data collection: 59%
- Data analysis and/or results review: 64%
- Sharing study information and/or results: 66%

Note: Data from awardee reports collected through 12/31/19; n=513 awardees (by percent of projects)
Engagement Priority: 
**Resources that Support Engagement**

**Research Fundamentals**

**Building Effective Multi-Stakeholder Research Teams**

Start

Coming soon!
Research Fundamentals Learning Package

Five Interactive Learning Modules

Developing Research Questions

Designing the Research Study

Planning Patient-Centered Consent and Study Protocols

Sampling, Recruiting, and Retaining Study Participants

Understanding and Sharing Research Findings

Module 2: Designing the Research Study

The Steps in Designing a Research Study

- Identify the research question
- Choose a research method
- Identify where the information, or data, will come from
- Collect the necessary data
- Analyze the data and determine the results
- Share the results with others

Module 4: Sampling, Recruiting, and Retaining Study Participants

Sampling: Inclusion and Exclusion Criteria

- Inclusion criteria: women who have had breast cancer

Five Interactive Learning Modules
Engagement Priority: Practices that Support Inclusion and Health Equity

Trust and Trustworthiness:

- Trustworthiness of Study Team
- Trustworthiness of Clinicians
- Trustworthiness of Institutions
- Trustworthiness of Science
- Trustworthiness study recruiters
**Trust moves local**

Trust has moved from a top-down vertical model, dependent on traditional leaders, to to a horizontal one, in which people rely more on friends, family, and “a person like me.”

**Top-down trust**
People trust or distrust in response to the decisions and messages of authority figures

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**Horizontal trust**
People trust or distrust based on their interaction with a peer, or “a person like me”

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**Local trust**
People trust or distrust based on their interaction with others who are personally close to them in their community, workplace, or family

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Partnering with Community Leaders

Meet People Where They Are

Image credits: COMPPARE (left); Daily Mountain Eagle (top right); Olivia Anderson/Washington Post (bottom right)
Reducing Bias in Recruitment

Unexpected findings in the exploration of African American underrepresentation in biospecimen collection and biobanks.


Abstract

Racial/ethnic minorities are underrepresented in current biobanking programs. The current study utilized community-based participatory research to identify motivating factors and barriers that affect older African Americans' willingness to donate biospecimens. The standardized phone survey was administered to 78 African Americans who are 55 years old or older and live in the metropolitan Detroit area to assess their overall willingness to donate biospecimens and what factors were associated with it. The majority of the participants were willing to...
PCORI Strategic Planning: National Priorities & Research Agenda

Strategic Planning:
- Engaging Stakeholders & the Public
- Identifying National Priorities
- Establishing & Updating Research Agenda
- Commitment Planning & Related Discussions

Related Discussions:
- Summer 2020: Public Engagement
- Fall 2020: Framing PCORI 2.0
- Winter 2020-2021: Developing Key Components
- Spring 2021: Public Engagement Cont’d, Formal Public Comment
- Summer 2021: Bringing it Together, Drafting Strategic Plan
- Fall 2021: Finalizing Strategic Plan

National Priorities
Research Agenda
Strategic Plan
Call for Public Comment (open until November 13)
“Principles for the Consideration of the Range of Outcomes Data”

Changes from reauthorization

New directive to capture, as appropriate, the full range of outcomes data, including cost and economic related to the utilization of health care services. Examples:
  • Medical out-of-pocket costs
  • Non-medical costs to patients and families (i.e. caregiving, absenteeism, future care)

Principles for implementation

The draft principles are a high-level framework of PCORI’s interpretation of the new mandate and will serve as a reference point when developing guidance and standards for future research applicants.

Webinars
Monday, October 5
• Patient Advocates
• Condition Specific Organization
• Caregivers
• Consumer Groups

Tuesday, October 6
• Payer
• Purchaser
• Life Sciences Industry
• Provider
• Health System
Thank you!

Shout out to PCORI PEAPs!
Contact Information

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