Principles and Practices for Engagement in Research

Lori Frank, PhD
PCORI
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Steering Committee

PCORI Methodology Committee Co-chairs:
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Kim Wittenberg, AHRQ
Mary Kay Margolis and Lori Frank, PCORI
Engagement in research

Passive  Engaged
Subject  Respondent  Participant  Stakeholder  Consultant  Partner  Researcher

Engagement as a path to useful, high-quality research

- Involve all healthcare stakeholders in topic selection
- Improve study recruitment and retention
- Engage stakeholders in application review
- Ensure outcomes matter to healthcare stakeholders
- Speed dissemination and uptake of findings


Research engagement is growing worldwide

**UK**
All National Institute for Health Research (NIHR) grants must include a patient or public involvement (PPI) component.

**Canada**
The Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) provides infrastructure for patient engagement and patient-centered research.

**US**
History of community-based participatory research but engagement not a widely used research requirement beyond the Patient-Centered Outcomes Research Institute (PCORI).
Examples of engagement: Dementia care and services research

- **James Lind Alliance**
  - Dementia Priority-Setting Partnerships
  - Generates top priorities for dementia research in UK

- **DeNDRoN**
  - UK focus groups on trial recruitment challenges, study experience
  - Input of persons with dementia and caregivers on study materials
  - Oversight of study design, outcomes, implementation, dissemination

- **Canadian Institutes of Health Research**
  - Established Strategy for Patient-Oriented Research
  - Infrastructure for patient engagement and patient-centered research

- **Alzheimer's, Dementia, Patient & Caregiver-Powered Research Network**
  - PCORI funded as part of PCORnet
  - Multi-site network to connect patients, caregivers, and researchers and support clinical research

Dementia Methods Pre-Summit

Five areas of recommendations emerged:

- **Scientific**
- **Research infrastructure**
- **Regulatory**
- **Administrative**
- **Financial**
Dementia Methods Pre-Summit:
Recommendations for engagement in research

- Address skepticism about the feasibility and value of engaging people with dementia in research.
- Fund new research on best methods for engaging people with dementia and caregivers.
- Apply existing engagement models to dementia care and services research.

Commit to “research done differently” and focus on engagement.

Dementia Methods Pre Summit:
Recommendations for engagement in research

Commit to “research done differently” and focus on engagement.

Apply existing engagement models to dementia care and services research.

- Engage people living with dementia and caregivers in development of interventions.
- Address inclusion of people living with dementia and caregivers in governance for research.
- Value and seek out diversity to ensure novel perspectives and ideas inform research.
With thanks to Pre-summit participants and the Persons Living with Dementia Stakeholder Group

Dementia Methods Pre-Summit materials can be found on PCORI’s website: https://www.pcori.org/events/2017/dementia-methods-pre-summit

www.pcori.org
info@pcori.org