

# Principles and Practices for Engagement in Research

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PCORI  
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#DementiaCareSummit

## Dementia Methods Pre-Summit, June 7-8, 2017 Steering Committee

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### **PCORI Methodology Committee Co-chairs:**

**David Meltzer**, University of Chicago

**Brian Mittman**, Veterans Affairs Greater Los Angeles Healthcare System; Kaiser Permanente

**Arlene Bierman**, Agency for Healthcare Research and Quality (AHRQ)

**Chris Callahan**, Indiana University-Purdue University Indianapolis

**Elena Fazio**, National Institute on Aging (NIA)

**Laura Gitlin**, Johns Hopkins School of Nursing; Johns Hopkins School of Medicine

**Lisa Gwyther**, Duke University

**Lee Jennings**, University of Oklahoma Health Sciences Center

**Ian Kremer**, LEAD Coalition

**Katie Maslow**, Gerontological Society of America

**Darby Morhardt**, Northwestern University

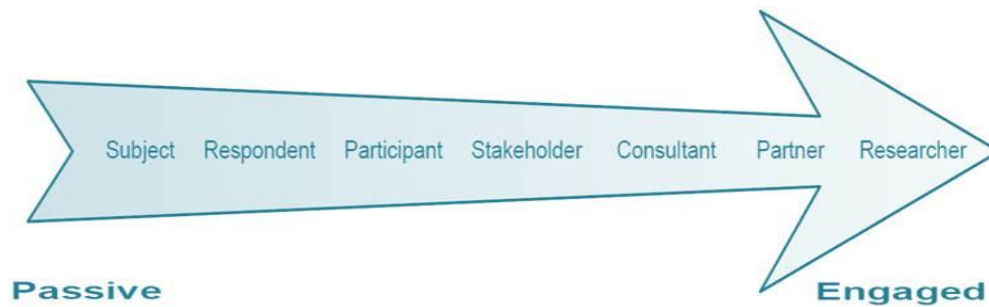
**David Niebuhr**, AHRQ

**Kim Wittenberg**, AHRQ

**Mary Kay Margolis and Lori Frank**, PCORI

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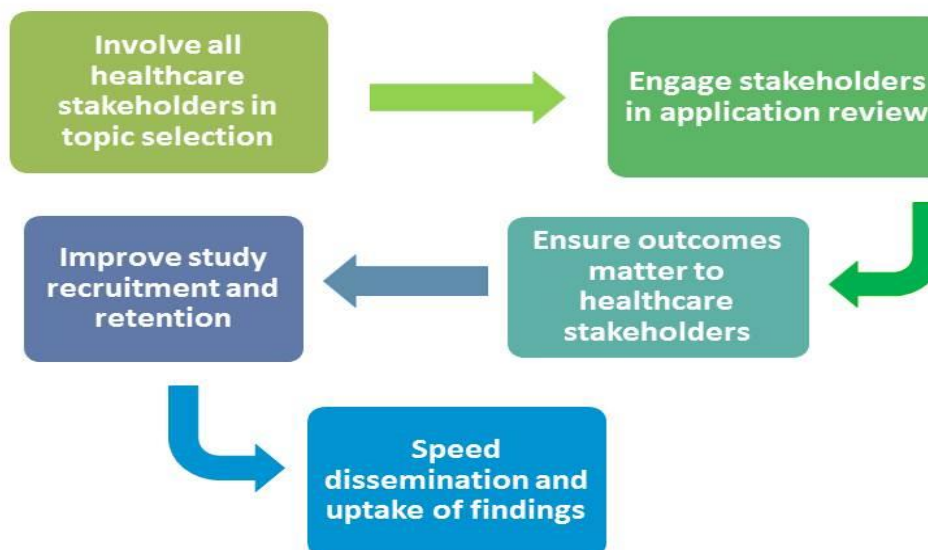
## Engagement in research



From Domecq JP, Shippee N, Murad MH. *Eliciting Patient Perspective in Patient-Centered Outcomes Research: A Meta Narrative Systematic Review*. PCORI Workshop on Incorporating the Patient Perspective into Patient-Centered Outcomes Research. March 2012; Washington, DC. <https://www.pcori.org/events/2012/workshop-incorporating-patient-perspective-patient-centered-outcomes-research>  
Adapted from Arnstein SR. A Ladder Of Citizen Participation. *Journal of the American Planning Association*. 1969; 35(4): 216-224.

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## Engagement as a path to useful, high-quality research



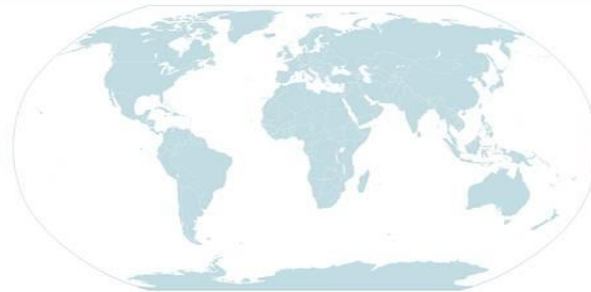
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## Research engagement is growing worldwide

### 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

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## Dementia Methods Pre-Summit

Five areas of recommendations emerged:



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## Dementia Methods Pre-Summit: Recommendations for engagement in research

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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.**

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## Dementia Methods Pre Summit: Recommendations for engagement in research

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

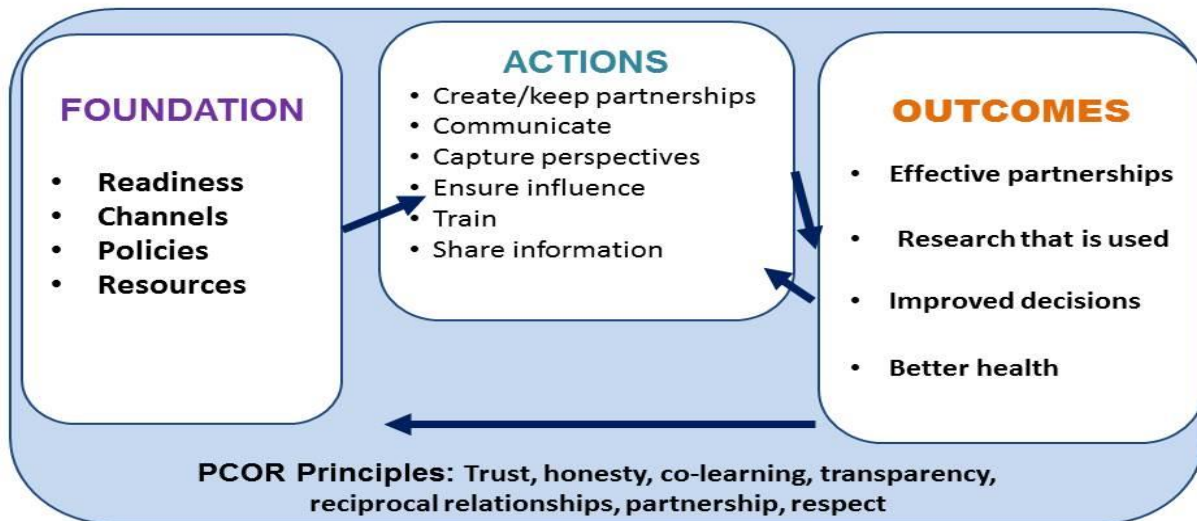
### **Apply existing engagement models to dementia care and services research.**



- 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.

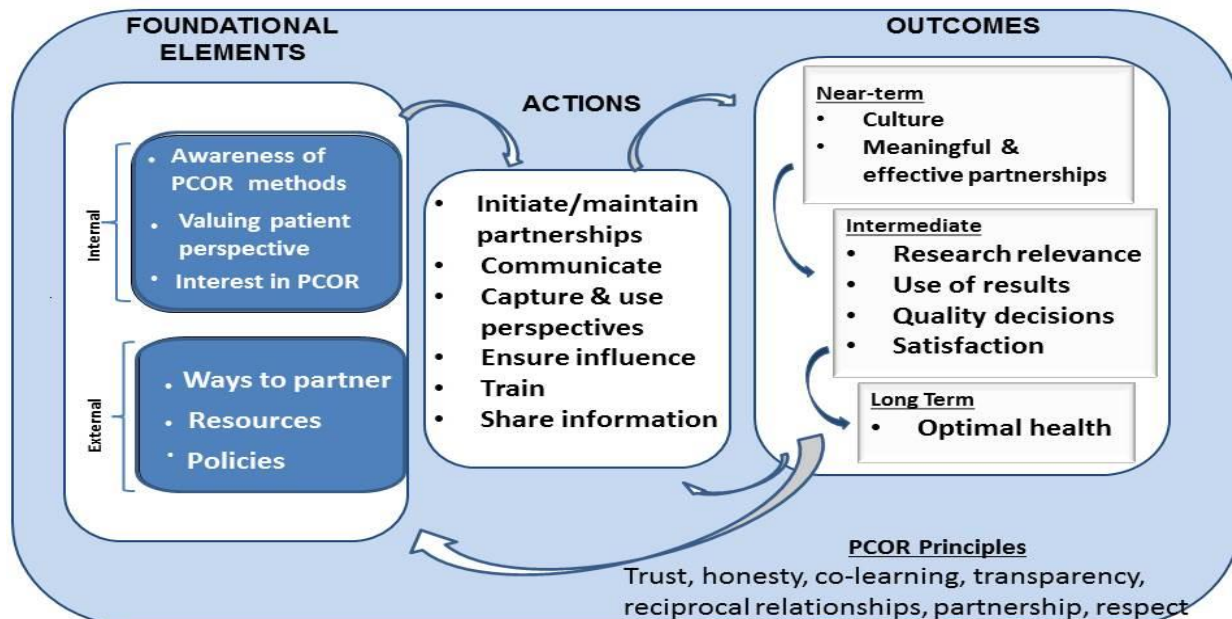
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## Conceptual Model of PCOR



Frank L, Forsythe L, Ellis L, Schrandt S, Sheridan S, Gerson J, Konopka K, Daugherty S. Conceptual and practical foundations of patient engagement in research at the Patient-Centered Outcomes Research Institute. *Quality of Life Research* 2015. 24(5):1033-1041 DOI 10.1007/s11136-014-0893-3

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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>

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