



## ***PCORI and HINTS***

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# PCORI's Mission and Vision

## Mission

The Patient-Centered Outcomes Research Institute (PCORI) helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community.

## Vision

Patients and the public have the information they need to make decisions that reflect their desired health outcomes.

# Research engagement

- **Who determines**
  - The research questions
  - The database to use
  - The variables to examine outcomes, comparators, covariates
  - The analytic methods?
- **Who is on the research team?**
  - Patients or patient advocates?
  - Other stakeholders?
- **What will the research team do with the information?**
  - How will results apply to health decisions?
- **Is there a plan for interaction between researchers and the community?**



# Patient engagement in research

- Improved research recruitment and retention rates  
(Edwards et al. 2011)
- Enhanced trust between researchers and participants  
(Decker et al. 2010; Edwards et al. 2011; Staniszewska et al . 2007)
- Improved content and construct validity of measures  
(Cashman et al. 2008; Cotterell 2008)
- Improved patient understanding of results  
(Chalmers 1995; McCauley et al. 2001; Doyle 2010)
- Increased relevance of research results to patients  
(summarized in Nass et al. 2012)

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- Shared commitment to improving informed health decision making
- Collaboration to develop new items (cycle 3, 4) to assess:
  - The extent to which medical research informs clinical decisions
  - Familiarity with, experience with, and interest in research engagement
  - Perceptions that engagement improves the value of medical research

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- Increase understanding about perceptions of research engagement in the general public
- Explore relationships between other health info search experiences, info needs and views on engagement
- Understand ongoing health info gaps
- Role in filling gaps of
  - Patient-centered comparative effectiveness research
  - Approaches to dissemination
  - Approaches to data collection and study design

# Other PCORI Data Collection

- Surveys of health care stakeholders: patients, clinicians, researchers
- Assessments of engagement in PCORI funded projects and perceived impact
- Surveys of people who interact with PCORI
  - Engagement workshops
  - Merit review