

Using Deliberative Methods to Engage the Public

IOM Evidence Communication Innovation Collaborative
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Reason for this work

- Agency for Healthcare Research and Quality's 3-year initiative called Community Forum
 - Centers for Outcomes and Evidence (COE)
 - Jean Slutsky, PA, MSPH, Director of COE
 - Joanna Siegel, ScD, Project Officer
- Led by the American Institutes for Research (AIR) with key partners
- Major focus of this project is to:
 1. Obtain evidence to guide AHRQ in the use of deliberative methods to obtain informed public input
 2. Gather public views on how evidence of the effectiveness of medical interventions should be used, to inform AHRQ research programs and strategies

What is deliberation

- Convening of “mini publics” (Fishkin 2009) ...
- ...“to weigh carefully the consequences of various options for action and the views of others” (Matthews 1994)
- Provides opportunity to weigh the “principles and values involved as well as the circumstances and consequences” of the topic of debate (Gracia 2003)

Goals of deliberative methods

- To provide decision makers with understanding of public values relevant to complex issues
- To influence change at policy or program level
- To expand participants' knowledge and insight on an issue
- To increase participants' civic engagement and willingness to participate

Components of deliberative methods

Opinion
polling

Focus
groups

Deliberative
methods

Convening of groups

Discussion

Education

Reason-giving and debate

Societal perspective

Characteristics of deliberative topics

- Values-based or ethical dilemmas
- Social/affecting common good
- Cannot be resolved through technical or scientific information alone
- Controversial but opportunity for common ground
- Timely and relevant

How deliberative methods vary

- Length, duration
- Group size, participant sample
- Recruitment method
- Structure (e.g., breakout groups, interrupted)
- Education, use of experts
- Mode (online, in-person)
- Facilitation
- Consensus as goal

Applications of deliberative methods to health care

IOM Committee Report on Essential Benefits: Identifying principles and criteria

- Coverage elements to consider in determining ‘essential benefits’
 - Extent of medical conditions and treatments
 - Types and circumstances of patient cost-sharing
 - Pre-approvals and other clinical oversight
 - Limits on quantity of services
 - Standards of clinical effectiveness

IOM Committee: the role of societal values

Deliberative method for assessing surrogate consent

- Issue: Can family members provide surrogate consent for research participation for individuals with dementia?
- Researchers: led by University of Michigan with funding from National Institute on Aging
- Goal of deliberation:
 - Assess how participants view surrogate consent for research participation for individuals with dementia
- Evaluation: Determine whether deliberation affected caregivers' views of surrogate consent

Deliberative method for prioritization of interventions

- Issue: How would you decide which social or health services to provide to improve health?
- Researchers: National Institutes of Health, Howard University, and D.C. Department of Health
- Goals:
 - Learn how participants prioritize social or health services to improve health and understand their reasoning
- Evaluation: Assess whether deliberation affected participants' knowledge on the determinants of health

California Health Benefit Exchange: Using public deliberation to inform health plan design (forthcoming)

- Participants are potential Exchange consumers
 - Uninsured
- Deliberative topic is cost-sharing
 - Consider the financial impact of different approaches to cost-sharing and their effects on patients with a variety of medical needs
- Mode
 - Ten (12) in-person groups, including two (2) in Spanish
- Identify principles for the Exchange to consider to implement cost-sharing in health plans in the “fairest way possible”

Community Forum experiment

■ Background

- Started in August 2010
- Literature review, Technical Expert Panel, formative research to inform approach

■ Objectives

- Expand the evidence base on public deliberation
 - Obtain public input on the use of evidence in healthcare decision-making
- ## ■ Assist AHRQ in developing research programs that address priority health care concerns and disseminating evidence in ways acceptable and useful to the public

Overview of experiment

- RCT comparing multiple deliberative methods
 - 4 locations: DC, Chicago, Sacramento, Raleigh-Durham
- Participants
 - Inclusion of AHRQ's priority populations: aged Medicare, African American women, and bilingual Latino
 - Education level diversity sought
- Evaluation
 - Knowledge of CER, quality of care, generation of medical evidence
 - Attitudes on appropriate roles of providers, patients, purchasers, and government regarding using evidence in healthcare decision-making; boundaries around the use of evidence
 - Motivation to participate in civic activities

Next steps and resources

■ Next steps

- Implement experiment: summer - fall 2012
- Analysis: summer 2012 - summer 2013
- Report of findings: fall 2013

■ Information to look for on the EHC Program website

— Webinars

- Using Deliberative Methods to Engage the Public: How to Design and Implement an Effective Deliberative Session (April 2012)
- Using Deliberative Methods to Engage Patients, Consumers, and the Public (December 2011)

— Literature Review (coming soon)

<http://www.effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/how-to-get-involved-in-the-effective-health-care-program/>

What can the ECIC learn from the Community Forum experiment?

■ Methods

- What, if any, is the effect of public deliberation?
- What methods are most efficient?
- What are the most effective ways to reach disadvantaged populations?

■ Findings

- What and how does the public think about applying medical evidence?
- What matters most to the public?
- How can public input be used to inform CER?

Key contacts

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AHRQ's Effective Health Care Program site:

<http://www.effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/>

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