

Using Deliberative Methods to Engage Patients, Consumers, and the Public

Agency for Healthcare Research and Quality
Community Forum
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Purpose and objectives

■ Purpose

- Describe deliberative methods
- Explore how deliberative methods can be used in your work

■ At the end of this, you should be able to:

- Identify situations appropriate for deliberative methods
- Develop the questions that can be addressed through deliberative methods
- Understand how deliberative methods can be used

Presenter introductions

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Reason for this work

- Agency for Healthcare Research and Quality's 3-year initiative called Community Forum
- Led by the American Institutes for Research (AIR) with key partners
- Major part of this project is to:
Advance the use of deliberative methods for obtaining input from members of the public on a health research topic

Topics

Overview of deliberative methods

Application to health

Examples from the literature

IOM committee report on essential benefits

Interactive exercise

Discussion and Q & A

Overview of Deliberation

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

Where deliberative methods fit

Intensity of involvement

Opinion
polling

Focus
groups

Deliberative
methods

Informed input

Components of deliberative methods



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

Steps to designing deliberative methods

1. Identify and define issue needing input
2. Engage the decision makers for whom results are intended
3. Set goals for deliberation
4. Determine participant population (e.g., lay public, patient group)
5. Select deliberative process or create hybrid
6. Determine evaluation approaches

Best practices

- Early involvement of audience for participant input
- Diversity
- Balance
- Transparency
- Clarity
- Adapt to context

Applications of deliberative methods to health care



How deliberative methods can help inform health care and health research

Example issues	How deliberation can help
Priority setting comparative effectiveness research topics	Balancing of values, prioritization of topics
Organ shortages for transplantation	Guidance on societal views of ethics involved
Racial/ethnic disparities in maternal and infant mortality	Propose solutions and establish goals for improvement
Quarantine during public health emergencies	Balancing of societal wellbeing vs. individual rights

Real-world applications of deliberative methods

- Two examples from the literature
 - Surrogate consent for research participation
 - Priority-setting social and health interventions
- IOM's Committee on Determination of Essential Health Benefits, Oct. 2011

Examples from the literature



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Effective Health Care Program

Community Forum

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

Deliberative method for prioritization of interventions cont.

- Participants: Spanish or English speakers with income 200% of FPL
- Method: REACH, priority setting game
- 4 rounds of priority setting
 - 1) Self, family
 - 2) Neighborhood
 - 3) Entire city
 - 4) Self, family again

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

Examples of deliberative questions

- What are the characteristics of a medical problem that make it especially critical for coverage?
- Are boundaries like 'pre-approvals' easier to accept than others? Why?
- When treatment effectiveness is minimal, what is a fair approach to coverage?

IOM: using public deliberation to inform coverage decisions

- When public deliberation is recommended
 - Initial coverage details
 - State waivers
 - Updating the benefits package
- The rationale for these inclusions
 - No easy answers
 - Social decisions

Questions, comments?

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