



Agency for Healthcare Research and Quality

Advancing Excellence in Health Care www.ahrq.gov

Communicating Evidence for Health Care Decisions in a Charged Environment

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What are We Talking About?





Excellence & Mediocrity



“A society which scorns excellence in plumbing simply because it is plumbing, but rewards mediocre philosophy simply because it is philosophy will soon become a society in which neither its pipes nor its theories will hold water.”

John W. Gardner (1961)



Donald Schön, 1983

- “In the varied topography of professional practice, there is a high, hard ground, where practitioners can make effective use of research-based theory and techniques, and there is a swampy lowland where the situations are confusing ‘messes’ incapable of technical solution. **The difficulty is that the problems of the high ground, however, great their technical interest, are often relatively unimportant to clients or the larger society while in the swamp are the problems of greatest human concern.**”



Differences in perspective and values may mask as debates over evidence

- Importance of pathophysiologic model
 - Intermediate vs. clinical endpoints
- When is evidence “good enough”?
 - Risks of inaction vs. risk of premature action
 - “Evangelists vs. snails”
- How important are harms vs. benefits?
 - Specialist vs. primary care perspective
- How important are costs (and opportunity costs)?



Obama, iPad, and the value of information in 21c democracy (and business)

- “What Jefferson recognized [is] ... that in the long run, their improbable experiment — called America — wouldn’t work if its citizens were uninformed, if its citizens were apathetic, if its citizens checked out, and left democracy to those who didn’t have the best interests of all the people at heart. It could only work if each of us stayed informed and engaged, if we held our government accountable, if we fulfilled the obligations of citizenship.”



Comparative Effectiveness Research

- An initiative to expand and systematize citizen and stakeholder engagement in AHRQ's Effective Healthcare Program.
 - Citizen Input
 - Stakeholder Input



Can we Communicate Better Than This?





Definitions

- **Citizens** - Members of the general public identified without regard to medical background or experience.
- **Stakeholders** - Persons or groups who have a vested interest in a clinical, research or health policy decision.



Community Forum Components

- **Develop and demonstrate deliberative methods** and tools for obtaining informed public opinion as an input to decisions related to the conduct of comparative effectiveness research (CER), as well as the application of research results in policy and practice.



Deliberative Methods

- Public engagement in important decisions
 - allows decisions to reflect public values;
 - improves decisions by bringing multiple perspectives to bear;
 - allows decision-makers to gauge public response;
 - educates the public;
 - provides legitimacy for decisions;
 - builds support for decisions.



Meaningfully Engaging the Public

- Deliberative approaches require:
 - Access to information
 - Exposure to multiple perspectives
 - Opportunities to reflect, discuss, question, ponder
 - Time to reason, enlarge opinions, change or revise views



Public engagement in health care decision making

Processes that emphasize deliberation and its principles of providing information as a basis upon which to come to reasoned public judgments have become popular instruments for eliciting public values in complex, contentious, and ethically controversial areas of public policy.

Abelson 2007



Deliberative processes are well suited to the health field because they can meet the broader objectives of stimulating debate, improving public understanding of complex issues, and encouraging consensus about health service priorities.

Abelson 2003



Especially Now



Patient-Centered Outcomes Research Institute

- Identify research priorities and establish and implement research agenda overseen by 19 member Board of Governors, including the Directors of AHRQ and NIH
 - expert advisory panels and methodology committee
 - Cannot “mandate coverage, reimbursement, or other policies for any public or private payer”
 - Government may use findings in coverage “if such use is through an iterative and transparent process which includes public comment and considers the effect on subpopulations” and subject to other constraints



DO NOT TOUCH THE EDGES OF THIS SIGN



ALSO, THE BRIDGE IS OUT AHEAD



In Summary

- Common ground is challenging
- We're a lot closer than we think
- We are truly at a "fork in the road" where we can begin to agree on certain issues

