



Community Forum Knowledge Brief

Number 1: Public Deliberation on Health Topics

Public deliberation—a method of public consultation in which members of the public come together to engage in informed dialogue about difficult or complex social issues—has been used to garner insights into the public’s values and views regarding a variety of issues, including public education, the environment, food safety, drug abuse, and economic growth. In the United States, use of public deliberation to address health topics in particular has been of increasing interest over the past decade.

Why Use Public Deliberation in Health?

Public deliberation is an appropriate tool when a topic of public interest involves potentially conflicting values and beliefs. In the context of health care, deliberation among an informed public provides decisionmakers with information about the values of patients, caregivers, and health care consumers. Public deliberation also allows members of the public to participate in shaping policies and programs that potentially affect their own health. Finally, the educational

AHRQ’s Effective Health Care Program and the Community Forum

The Effective Health Care Program was initiated in 2005 to provide valid evidence about the comparative effectiveness of different medical interventions. The object is to help consumers, health care providers, and others make informed choices among treatment alternatives.

The purpose of the Community Forum project, funded initially under the American Recovery and Reinvestment Act (ARRA), is to expand public and stakeholder engagement in health care research supported by AHRQ.

This *Community Forum Knowledge Brief* is the first in a two-part series on public deliberation, based on an extensive review of the literature. Look for the Knowledge Brief on *Methods and Measures of Public Deliberation* (No. 2) and for the full literature review, *Public Deliberation To Elicit Input on Health Topics: Findings From a Literature Review*, at www.effectivehealthcare.ahrq.gov.



Agency for Healthcare Research and Quality
Advancing Excellence in Health Care • www.ahrq.gov

component of deliberation helps participants understand the complexities of constructing health care research programs, public health activities, and other health care plans and policies that address the needs, interests, and values of a diverse nation.

Deeply held values and beliefs often underlie debates on health topics such as the implementation of evidence-based medicine, health care coverage, how care is provided, and who pays for care. Public deliberation has been used to help the public and policymakers identify people's fundamental concerns and elicit public input to inform societal decisions.

The literature on public deliberation identifies four areas in health policy—described in the following sections—where deliberation may be particularly helpful.

Considerations surrounding the generation and use of scientific evidence. Medical evidence alone is seldom a sufficient basis for decisions affecting health care. Evidence may be contradictory or inconclusive; limited evidence may apply to certain population groups but not others; or there may be complex tradeoffs associated with health care decisions. Public deliberation can generate information about the public's values to help shape decisions based on existing evidence.

Learning more about the public's values concerning the risks and benefits of a health care intervention, or concerning the distribution of risks and benefits across the population can inform guidelines regarding the use of the intervention, future research priorities, and efforts to educate the public about the intervention. For example, the Medical Advisory Committee and the Ontario Health Technology Advisory Committee, which are responsible for making evidence based recommendations regarding the use of health technologies in Ontario's health care system, convened a citizens' panel to deliberate on various moral and ethical issues involved in the use of five health interventions, including screening for colorectal and breast cancers (Abelson, Wagner, Levin et al., 2012). The panel's deliberations generated several core values, such as "universal access," "choice," and "quality care" that were then taken into consideration by the advisory bodies when making recommendations regarding these interventions (Abelson, Wagner, Levin et al., 2012).

Public Deliberation on Health Topics: What Have People Been Discussing?

Documented public health deliberations, both in the United States and worldwide, have included a wide range of topics, for example:

- Approaches to childhood obesity
- Coverage for the uninsured
- Cost-effectiveness of treatments for U.S. Medicare coverage
- Fund allocation in health care
- Health care reform
- Pandemic planning
- Personal health responsibility
- Setting priorities for diabetes research
- Prenatal genetic testing
- Regulation and use of biobanks for health research
- Surrogate consent for research with Alzheimer's patients
- The use of telemedicine and telecare

Appropriate use of new technologies.

Advances in technology may give rise to concern and controversy about whether, when, how, and for whom technologies should be used. For example, the fact that new technologies may be available to some population groups and not others because of costs, location, or medical guidelines calls into question the fairness of access to these technologies. New technologies may also fundamentally change health or our expectations of health. In some cases, public deliberation is used to explore public values and moral beliefs related to the use of new technology. This was the case in Australia, where researchers examined the public's ethical principles regarding technologies that extend human life, finding that the participants had concerns such as equity of access to these technologies and the opportunity costs of pursuing life-extension research (Partridge, Underwood, Lucke et al., 2009). In other instances, participants in public deliberation have been asked explicitly to provide guidance to public agencies on the use of technologies (National Institute for Health and Clinical Excellence, 2012).

Public trust concerning health actions. Decisionmaking in public health and health care also involves issues of trust—in science and in scientists, policymakers, and other actors. Public deliberation can be used to assess the level of the public's trust and understanding of decisions that affect the broader community. For example, community members in Southeastern Michigan were engaged in a deliberative process about pandemic planning so that public health officials could learn more about the courses of action, such as closing schools and workplaces, and actors, such as public officials, that were acceptable to the public. Not only did public deliberation provide insights for planners; evidence suggests that participants also emerged from the

deliberative process with a greater understanding and respect for the complexity of health decisionmaking (Baum, Jacobson, and Goold, 2009). Involving the public increases transparency and can promote public buy-in when decisions impose burdens on members of a community.

Addressing health policies where individual interests and societal interests must be balanced. Health care decisions often raise social questions, such as individual responsibility for improving health, the impact of public health programs on vulnerable individuals or on individual freedoms, or the equitable distribution of resources. Deliberative sessions encourage participants to think beyond their own individual perspectives to that of the community, thereby providing helpful insights or guidance regarding these questions. For example, U.S. researchers used deliberative sessions to explore whether participants, acting as insured members of the community, would accept an increase in their premiums to extend coverage to uninsured children and adults, balancing their desire for lower costs against their concern for vulnerable populations (Goold, Green, Biddle et al., 2004). In another example, English-speaking and Spanish-speaking deliberative groups were asked to consider the community in prioritizing socioeconomic and health interventions to maximize health and quality-of-life gains given limited resources, after learning about the role of social determinants in health outcomes; participants prioritized interventions based on their values—such as access to health insurance and safe housing (Pesce, Kpaduwa, and Danis, 2010).

Types of Deliberation on Health Topics

Public deliberations on health topics have been conducted in a variety of countries, including the United States. In the United States, many instances have been research projects sponsored by foundations or academic institutions, while others have been efforts to elicit public input for government sponsors, including the U.S. Environmental Protection Agency and the U.S. Department of Health and Human Services. Sponsorship in other countries has come from a similar mix of foundations, academic institutions, and government agencies, including the Ontario Ministry of Health and Long-Term Care and the United Kingdom's National Food Agency.

Applications of public deliberation to health topics in the literature generally fall into two broad categories: (1) provision of guidance on policy decisions such as what to include in health insurance benefit packages, issues surrounding patient consent, or public health planning; and (2) provision of insights into the values driving public views on these types of issues. The deliberations that focused on developing guidance or recommendations for policy directions were relatively more common outside of the United States, while deliberations focused on gaining insights on the values underlying public views were relatively more common in the United States.

In addition, the issues brought to deliberation in the United States reveal a concern over ethical dilemmas raised in health insurance coverage decisions. Of the health applications of public deliberation in the United States, a substantial portion have dealt with issues of health insurance coverage, including criteria for coverage decisions and strategies for expanding insurance to the uninsured. In contrast, several instances of deliberation outside the United States dealt with how to handle new technologies in health care, whereas few did in the United States.

Deliberations that focused on policy decisions often presented various options or solutions to health policy problems. For example, a citizens' jury in New Zealand, where the public health insurance program covered mammography screening for women aged 45 or older, was asked to weigh scientific evidence and other concerns to decide whether the government should provide free mammography screening to women ages 40 to 49 (Paul, Nicholls, Priest et al., 2008). In a 2012 example, participants who would be potential customers of the California health insurance exchange considered how to align cost-sharing obligations and health needs, with a focus on structuring cost sharing in a way that would maximize equity (Ginsburg, Glasmire, and Foster, 2012). Participants prioritized chronic and catastrophic care for the lowest cost-sharing requirements. Participants in deliberations of this nature often provided recommendations as an output of the process.

Sponsors of deliberations that sought guidance on ethical or values-based dilemmas often presented tradeoffs or conflicts in order to learn more about the public's values and ethical principles. In some cases, the deliberative topic may have explicitly named the values in conflict, such as "freedom of choice." In some instances, core values, such as equity and freedom of choice, were pitted against one another. In one example in the United Kingdom, the NICE Citizens Council was asked to consider whether the National Institute for Health and Clinical Excellence (NICE) should issue guidance that concentrates resources on improving the health of the entire population or on improving the health of the most disadvantaged members of society (National Institute for Health and Clinical Excellence, 2006). In a U.S. issues forum, participants deliberated on four options to address Medicare costs (Furth, Gantwerk, and Rosell, 2009). In deliberations such as these, sponsors often learned about a range of ethical principles and public values that could be used in decisionmaking.

Conclusions

The literature on public deliberation shows that health program and policy decisionmakers, researchers, and others increasingly are interested in having lay people learn about and consider complex issues affecting the broader community in order to contribute to unraveling controversy and identifying common ground. Standing deliberative bodies, such as NICE's Citizens Council and Quebec's Consultation Forum, weigh in on population health and health care issues and play an ongoing role in health decisionmaking processes. Others play a short-term role in shaping

health decisions, such as Canada's Romanow Commission that convened over the course of one and a half years to deliberate on the future of health care in Canada (von Lieres & Kahane, 2006). Still other deliberative gatherings identified in the literature were one-time engagements that were not explicitly tied to decisionmaking processes but that elucidated public views on certain social issues.

Few applications of deliberation in the literature document formal delivery of participants' feedback to policymakers. Many conveners of public deliberation conducted deliberative processes in order to learn more about the public's values and to explore the value of public deliberation. The literature includes a diverse range of health topics that have been addressed via public deliberation. The relevance of public deliberation to decisionmaking about health issues continues to grow, particularly in response to new mandates in the United States for patient and consumer engagement in health care research prioritization, care service delivery, and safety and quality improvement.

For More Information

For more information on AHRQ's work in public deliberation, contact Joanna Siegel in the Center for Outcomes and Effectiveness at Joanna.Siegel@ahrq.hhs.gov. This Knowledge Brief series is based on *Public Deliberation To Elicit Input on Health Topics: Findings From a Literature Review* conducted by the American Institutes for Research under AHRQ Contract 290-2010-00005. Contact Kristin Carman at KCarman@air.org for further information.

Authors: Kristin L. Carman, Ph.D.; Jessica Waddell Heeringa, M.P.H.; Thomas Workman, Ph.D.; Maureen Maurer, M.P.H.; Susan K.R. Heil, Ph.D.

References

Abelson J, Wagner F, Levin L et al. Consulting Ontario citizens to inform the evaluation of health technologies: the citizens' reference panel on health technologies. In: CIHR's Citizen Engagement in Health Casebook: case 12. Canadian Institutes of Health Research; 2012. www.cihr-irsc.gc.ca/e/45358.html#a16.

Baum NM, Jacobson PD, Goold SD. Listen to the people: Public deliberation about social distancing measures in a pandemic. *Am J Bioeth.* 2009;9(11):4-14.

Furth I, Gantwerk H, Rosell SA. Medicare: It's not just another program: Citizen dialogues on paying for health care in retirement. Viewpoint Learning Inc.; December 2009. www.viewpointlearning.com/wp-content/uploads/2011/04/Medicare_its_Not_Just_Another_Program.pdf.

Ginsburg M, Glasmire K, Foster T. Sharing in the Costs of Care: Perspectives from Potential Health Plan Users of the California Health Benefit Exchange. Center for Healthcare Decisions; June 2012. http://chcd.org/docs/hbex_report_6.15.12.pdf.

Goold S D, Green SA, Biddle AK, et al. Will insured citizens give up benefit coverage to include the uninsured? *J Gen Intern Med*. 2004;19(8):868-74.

National Institute for Health and Clinical Excellence. Report on NICE Citizens Council Meeting: Inequalities in Health. June 8-10, 2006.

www.nice.org.uk/niceMedia/pdf/CitizensCouncilHealthInequalitiesReport0806.pdf. Accessed December 2010.

National Institute for Health and Clinical Excellence. Citizens Council. 2012 [cited November 2012]. www.nice.org.uk/aboutnice/howwework/citizenscouncil/citizens_council.jsp. Accessed November 2012.

Partridge B, Underwood M, Lucke J, et al. Ethical concerns in the community about technologies to extend human life span. *Am J Bioeth*. 2009;9(12):68-76.

Paul C, Nicholls R, Priest P, et al. Making policy decisions about population screening for breast cancer: The role of citizens' deliberation. *Health Policy*. 2008;85(3):314-20.

Pesce JE, Kpaduwa CS, Danis M. Deliberation to enhance awareness of and prioritize socioeconomic interventions for health. *Soc Sci Med*. 2011; 72: 789-97.

von Lieres B, Kahane D. Inclusion and representation in democratic deliberations: Canada's Romanow Commission. In: Cornwall A, ed. *Spaces for Change? The Politics of Citizen Participation in New Democratic Arenas*. London: Zed Books; 2006:131-51.



AHRQ Publication Number 13-EHC051-EF
February 2013