



## Effectiveness of public deliberation methods for gathering input on issues in healthcare: Results from a randomized trial



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### ABSTRACT

Public deliberation elicits informed perspectives on complex issues that are values-laden and lack technical solutions. This Deliberative Methods Demonstration examined the effectiveness of public deliberation for obtaining informed public input regarding the role of medical evidence in U.S. healthcare.

We conducted a 5-arm randomized controlled trial, assigning participants to one of four deliberative methods or to a reading materials only (RMO) control group. The four deliberative methods reflected important differences in implementation, including length of the deliberative process and mode of interaction. The project convened 76 groups between August and November 2012 in four U.S. locations: Chicago, IL; Sacramento, CA; Silver Spring, MD; and Durham, NC, capturing a sociodemographically diverse sample with specific attention to ensuring inclusion of Hispanic, African-American, and elderly participants. Of 1774 people recruited, 75% participated: 961 took part in a deliberative method and 377 participants comprised the RMO control group. To assess effectiveness of the deliberative methods overall and of individual methods, we evaluated whether mean pre-post changes on a knowledge and attitude survey were statistically different from the RMO control using ANCOVA. In addition, we calculated mean scores capturing participant views of the impact and value of deliberation.

Participating in deliberation increased participants' knowledge of evidence and comparative effectiveness research and shifted participants' attitudes regarding the role of evidence in decision-making. When comparing each deliberative method to the RMO control group, all four deliberative methods resulted in statistically significant change on at least one knowledge or attitude measure. These findings were underscored by self-reports that the experience affected participants' opinions.

Public deliberation offers unique potential for those seeking informed input on complex, values-laden topics affecting broad public constituencies.

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Interest in eliciting the public's views, values, and preferences to inform health policy decisions has grown steadily in recent years, as one approach to achieve better, more efficient, and patient-centered care (Abelson et al., 2012; Bolsewicz Alderman et al., 2013; Mitton et al., 2009, 2011). Deeply held values, beliefs, and

attitudes underlie public perceptions and are central to healthcare debates, including what should be covered by health insurance, who pays for care, who should participate in treatment decisions, and who is ultimately responsible for health outcomes. Involving the public in policy decisions can increase the transparency and legitimacy of the decision-making process, make the healthcare system more responsive to public values, and help inform health policy decisions (Bastian et al., 2011; Carman et al., 2013b; Nguyen et al., 2006; Siegel et al., 2013).

In the U.S., efforts to include the perspectives of lay individuals have focused primarily on increasing patients' involvement in their healthcare, rather than in broader health policy questions (Carman et al., 2013a; Gold et al., 2007; Workman et al., 2013). Increasingly, however, efforts to include patients and consumers have extended beyond the clinical setting. For example, many hospitals are partnering with patients and family advisors in organizational decisions (Johnson et al., 2008; Maurer et al., 2012) and the Patient-Centered Outcomes Research Institute (PCORI) includes patients in setting research priorities, evaluating research proposals, and conducting research (Fleurence et al., 2013). Efforts to support broadly improved healthcare quality depend upon the context of decisions as well as public views regarding diverse aspects of decisionmaking (Carman et al., 2010; Dobrow et al., 2004).

Historically, the public's views have been collected through opinion surveys and focus groups that are designed to gather initial and intuitive responses (Fishkin et al., 2004). Such methods are generally designed to measure the prevalence and range of opinions, not their stability or depth. In contrast, public deliberation is an approach designed to capture in-depth and informed public perspectives on complex topics. In public deliberation, members of the public consider an ethical or values-based dilemma and are asked to engage in the careful weighing of alternative—often competing—views. Deliberation emphasizes participant education and engagement in new information, usually provided through written materials or conversations with experts; demands balance, ensuring that all sides of an issue are considered; and encourages participants to become social decision-makers along with considering and speaking from individual points of view (Fig. 1) (Burkhalter et al., 2002; delli Carpini et al., 2004; Jacobs et al., 2009).

Public deliberation has been used on a limited scale in the U.S. in both privately and publicly sponsored projects. Applications of deliberation to health topics have sought to provide guidance on policy decisions such as what to include in health insurance benefits, issues surrounding patient consent, or healthcare priority setting; and insights into the values driving public views on these types of issues (Carman et al., 2013b; Danis et al., 2007; Gold et al., 2007; Goold et al., 2005; Mitton et al., 2009). Although considerable theoretical and case-study literature endorses the value of public deliberation, little empirical research has been conducted

about its effectiveness for health policy and few well-designed studies have compared different deliberative methods (Abelson et al., 2003b; Carman et al., 2013b).

The Deliberative Methods Demonstration, funded by the Agency for Healthcare Research and Quality (AHRQ), sought to expand the evidence base for public deliberation by evaluating its effectiveness in obtaining informed public input and by comparing deliberative methods. The focus of the demonstration was public views about the degree to which medical evidence (or its absence) should be used to determine healthcare choices, a concern central to the agency's mission and research programs. We designed a randomized controlled trial (RCT) to assess the overall effectiveness of deliberation compared to a control group and to compare different deliberative approaches. We selected four distinct previously used methods of deliberation and included core components of successful deliberation identified through literature review (Carman et al., 2013b). These methods varied on important aspects that have implications for cost and feasibility for policymakers. This paper reports on one of two aims of this research: to evaluate whether public deliberation is an effective way to obtain informed public input regarding complex health questions and identify the most feasible deliberative methods. Findings summarizing the input about appropriate and acceptable ways to use evidence are reported separately (Carman et al., 2014).

## 1. Methods

### 1.1. Measuring effectiveness

Based on an extensive literature review and input from a Technical Expert Panel, we chose to measure the effectiveness of deliberation using four outcomes (Carman et al., 2013b, 2014). The first is increase in participants' *knowledge* of the deliberative topic—specifically, of medical evidence and comparative effectiveness research. The intent of deliberation is to obtain *informed* public opinion; improvement in knowledge is thus a necessary—although insufficient—indicator of whether effective deliberation occurred. The second measure, *shift* in participants' *attitudes* about the use of evidence in decision-making, reflects the core assumption of public deliberation that information, discussion, and understanding of others' perspectives will alter participants' views as they reach a more informed judgment on a topic. The third measure of effectiveness is participants' *self-report of the impact* of deliberation, i.e., whether the participants believed that deliberation affected their views and that participating in the processes had value. Studies of deliberative processes frequently assess these outcomes as measures of deliberation effectiveness (Abelson et al., 2003a, 2007; Deng and Wu, 2010; Timotijevic and Raats, 2007). The final measure of effectiveness in our study is whether the deliberative process can elicit from the public main themes and values regarding

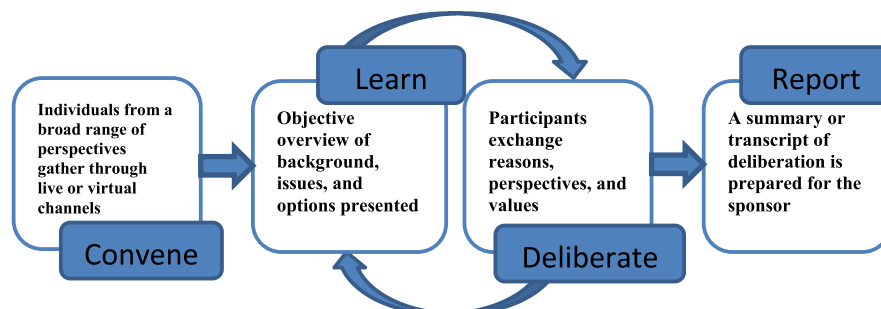


Fig. 1. Public deliberation: process and core elements.

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