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POLICY FORUM

Public Deliberation in Decisions about Health Research

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The idea of “patient-centeredness” receives much attention in today’s health care environment. Increased patient engagement in health care decision making is posited as a promising path toward better quality, efficiency, and health. Importantly, this emphasis has extended beyond the setting of patient care to medical and health services research. Many, if not most, health research agencies and organizations have developed new ways to include patients and other members of the public in developing research agendas, identifying research priorities, and evaluating research proposals, and to support their involvement in all steps of the research process (e.g., the National Cancer Institute Director’s Consumer Liaison Group, the Department of Defense Congressionally Directed Medical Research Programs, the Food and Drug Administration’s Patient Representative Program, and the Agency for Healthcare Research and Quality Stakeholder Support [1]).

The views, preferences, and values of the public shape many of the most important determinants of health and the effectiveness of health care. Public perceptions determine the impact of programs ranging from obesity prevention to the success of immunization programs and cancer screening and from the use of new technologies to the design of insurance. Recently, interest has increased in the use of structured forums for eliciting public input on specific health care issues, particularly when—as is often the case—the problems faced cannot be resolved by technical information alone and involve values-based or ethical tensions. Public deliberation, a form of public consultation, is often central to these forums.

The literature on public deliberation offers a rich set of ideas and chronicled experiences about its goals, benefits, uses, and expected outcomes. This paper provides a brief overview of public deliberation and describes its emerging role in health and health care research.

Overview of Public Deliberation

Public deliberation is based on the premise that many of the important decisions faced by a society—particularly those that involve competing values and complex trade-offs—are best made by decision makers in partnership with the public [2-6]. In the practice of public deliberation, citizens are brought together to engage in a process of learning about, debating, and discussing an issue. Throughout the process, participants have the opportunity and are encouraged to describe their perspectives and articulate the reasoning behind their views [2, 5, 6, 7-12].

Deliberative methods encompass a range of approaches including citizens' juries or councils, deliberative focus groups, issues forums, deliberative polling, and others. These methods vary considerably in intensity, with sessions lasting anywhere from a few hours to several days; they may convene once or periodically over the course of a term. However, all of these methods contain four core elements of public deliberation. First, a *sponsor convenes* a group of people, either in person or using online technologies that connect people in remote locations [8, 13]. The active interest of the sponsor is essential for framing the questions of interest, motivating participants, and ensuring the effective implementation of the deliberative sessions.

Second, participants are *informed* about the relevant issue(s) through educational materials and/or the use of content experts. Education is critical to the thoughtful discussion that is central to deliberative methods [7, 10, 11]. Third, participants *deliberate* the issues presented. Participants are asked to give reasons for their opinions and preferences with the goal of clarifying underlying values; they are encouraged to listen and respond to the perspectives of others [2, 6, 8-10, 12].

Finally, the content of the deliberation is *reported* to assist a sponsor in understanding public perspectives and incorporating them into decisions. Public deliberation thus assembles a diverse group of people who learn about and debate issues surrounding a social topic and describe their perspectives and reasoning to one another. The result is a record of underlying values and ethics, public reasoning, and options for consideration by decision makers.

Public deliberation is on one end of a continuum of public consultation methods that is defined by the intensity of participants' engagement. Information obtained through public deliberation differs from that collected through public surveys, polls, and other public opinion research methods that obtain "top-of-mind" responses and reactions to public issues [4, 14]. Similarly, public deliberation methods differ from town hall meetings, which focus on informing the public and answering questions but do not require participants to examine and clarify their values.

The fundamental attributes that characterize public deliberation and distinguish it from other methods stem from its roots in theories of deliberative democracy. Democracy is predicated on the idea that an informed public shapes the policies and decisions that affect citizens' lives and well-being. The ideal of public deliberation, in use since ancient Greece, is grounded in philosophies of the social contract and bonds among individuals and institutions that shape political and social life. Such deliberation is a means to bolster democratic life, include underrepresented groups, and promote moral reasoning and mutual understanding.

Amy Gutmann and Dennis Thompson define deliberative democracy as "a form of government in which free and equal citizens (and their representatives) justify decisions in a process in which they give one another reasons that are mutually acceptable and generally accessible, with the aim of reaching conclusions that are binding in the present on all citizens but open to challenge in the future" [5].

Deliberative democracy is distinguished from a “minimalist democracy,” which relies solely upon traditional voting and tallying of votes in service of electing a leader. As Robert E. Goodin describes,

> All [that a minimalist democracy] asks of citizens is to cast a ballot from time to time: in most places, if and only if they feel like it… [it] does not ask them to pay attention to public debates on the issues of the day. It does not ask them to get together with others to discuss the issues. It does not ask them to justify their voting decision to anyone else. Still less does it ask people to… persuade others that they should vote the same way [11].

Public deliberation has a number of outcomes, the relative importance of which depend on the goals of the sponsor. These range from changes in the individual participant’s knowledge and civic-mindedness to increased public acceptance of policy decisions and improved societal decision making [2, 4, 5, 13, 15-17]. Deliberation can uncover, articulate, and foster shared values as well as diverging perspectives. Further, public deliberation aspires to give voice to underserved groups by providing a shared forum in which majority and minority perspectives are equally encouraged—a goal dependent on the sponsor’s commitment and willingness to support and engage participants from diverse backgrounds. This goal ultimately reinforces deliberative outcomes involving both individual participants and social decision-making [4, 5, 13, 18, 19]. Finally, deliberation is an inherently transformative process—designed to alter not only participants who go through the process but also the sponsors and other decision-making entities that seek public input.

Use of Public Deliberation in Health care

The literature describes five general tasks for which deliberation has been used in health care applications. These include (1) developing policy guidance or recommendations, (2) setting priorities, (3) providing guidance on ethical or values-based dilemmas, (4) assessing risks, and (5) determining who should have decision-making authority. Although emphasis varies, these objectives are consistent in U.S. efforts as well as internationally.

In the U.S., recent deliberation projects have included efforts to explore and develop guidance on such topics as childhood obesity, health care reform, health insurance coverage for the uninsured, coverage priorities for Medicare and Medicaid plans, and state-level pandemic planning. For example, in June 2012, potential users of the California Health Benefits Exchange participated in deliberations in seven California locations regarding how to establish fair cost-sharing to address the health needs of a broad population [20]. The primary purpose of the deliberations was to learn how the public prioritizes health needs for affordable coverage in order to inform the design of the health benefits offered through the exchange [20]. Participants prioritized chronic illness and catastrophic losses for higher levels of coverage.

In 2008, Washington, D.C. residents participated in a deliberative exercise, prioritizing socioeconomic and health interventions as part of a hypothetical benefit package of social programs for the purposes of maximizing health. Participants gave priority to health insurance, housing, job training, and dental care [21]. Community members in Michigan were engaged in a deliberative process about pandemic planning to inform public health officials about the courses of action, such as closing schools and workplaces, that would be acceptable responses [22].

In several other countries, deliberative processes have become a more widespread and sometimes institutionalized approach to incorporating public input into health care decisions. In Canada, citizen engagement exercises have taken place in all provinces as well as at a national level and have been used to address a variety of concerns. In New Brunswick, a provincewide initiative engaged the public in establishing priorities for primary care, acute/supportive care, and systemwide concerns [23]. In Ontario, public consultation was used to prioritize services at a community hospital that was facing budget deficits, with citizens acting to identify core services to be maintained at the hospital as well as noncore services (including, for example, a diabetes complication prevention clinic, complex continuing care, and outpatient rehabilitation) that would be closed [24, 25]. In Quebec, a consultation forum met over a 3-year period to provide input about the performance of the health care system and to discuss specific social and ethical dilemmas submitted to it by the Health and Welfare Commissioner [26].

In the United Kingdom, the National Institute for Health and Clinical Excellence (NICE), an independent “arm’s length body” funded by the Department of Health, founded a standing 30-member Citizens Council to assist with its work, which includes developing guidance for public health and health care, evaluating new technologies, and establishing quality standards, among other activities [27]. NICE’s Citizens Council represents possibly the most formalized version of a deliberative panel in health care, with ongoing governmental support, in contrast to more local and ad hoc efforts. The explicit role of the Citizens Council is issuing social value judgments—judgments that “take account of the ethical principles, preferences, culture and aspirations that should underpin the nature and extent of the care provided by a health service” [14].

The first Citizens Council convened in 2002 to discuss NICE’s top priority topic—identifying the factors NICE should consider when making decisions about clinical need of patients with a particular disease or condition. NICE asked the council to think specifically about the most important features of conditions and of patients (apart from their conditions) that should be considered and the weight to give the views of various stakeholders (e.g., patients, health care professionals, family and caregivers, or patient advocates) in determining clinical need. Some of the important features the participants generated included the severity of the pain caused by a condition, whether a condition was potentially fatal or contagious, the availability of alternative treatments, and the patient’s age and ability to undergo treatment [28]. Since this initial report, the Citizens Council has deliberated and released reports on

15 topics. Citizens Council reports summarize the social values and principles that are involved in each topic they consider; NICE's advisory committees and guideline development groups are expected to adopt the public's principles in issuing guidance [14].

Deliberation and Health Care Research

Public deliberation in the area of health research is as yet quite limited. Deliberation has been used to (1) address principles for the conduct of research, (2) explore priorities for research, and (3) consider how research evidence should be applied in health decisions.

In addressing research *principles,* deliberative projects have focused on consent and the use of health information. For example, participants in southeastern Michigan deliberated on whether society should allow surrogate consent for research participation for persons with dementia [9]. Participants supported development of a societal policy covering surrogate consent. A citizens' jury in New Zealand deliberated on the use of personal health data for studying drug safety, concluding that identifiable health data could be used for research purposes without consent as long as relevant laws and ethical principles were followed [29]. Similarly, a citizens' panel in Denmark deliberated about using data derived from electronic health records (EHR) in research [30]. The panel recommended that patients be informed of the uses of their data and that a formal policy governing the use of EHR data be developed.

One of the first deliberative projects to address *priorities* for research took place in Bristol, England, where a 20-member citizens' jury identified broad areas important for research and then priority questions in each area [31, 32]. For example, in the area of prevention, high-priority research questions included whether preventive measures provided through local primary care (immunizations, mental health, lifestyle advice) were effective and how to maximize the impact of preventive health strategies for high-risk groups. A citizens' jury in Alberta, Canada identified 13 criteria for setting priorities for health technology assessment [33]. Among the criteria they identified were a technology's potential to benefit many people, to extend length of life while maintaining quality, and to improve quality of life.

Addressing the *application* of health research, deliberative initiatives have engaged the public to elucidate ethical and social values related to the introduction of new technologies into health care practice. A 14-member Citizens' Reference Panel on Health Technologies in Ontario developed a set of social values and ethical principles that should be taken into account in technology assessments of such health technologies as colorectal and breast cancer screening [34]. In the U.S., Gold and colleagues explored the acceptability of cost-effectiveness information as a supplement to evidence on medical effectiveness in determining the priority for Medicare's coverage of treatments [35]. Currently, the U.S. Agency for Healthcare Research and Quality (AHRQ) is sponsoring a large demonstration of public deliberation to obtain public input regarding the appropriate ways to use medical evidence to guide health care practice. Findings from the demonstration are expected in 2013, and will be used to inform the comparative effectiveness research enterprise in AHRQ's Effective Healthcare (EHC) Program.

Conclusions

The role of health care research in health care decisions is complex. Evidence from medical research is often less than conclusive, and policies based on evidence may imply tradeoffs regarding the distribution of risks and benefits across society, tensions between short-term and long-term outcomes, and a range of effects on quality of life, among other considerations and consequences [15, 36]. Recommendations and guidelines designed to improve health care based on research may conflict with public perceptions of quality care and meet with suspicion [37]. Effective use of health care research depends on understanding and consideration of public values and perceptions, in addition to the development of scientifically valid research results.

Public deliberation aims to facilitate meaningful and inclusive public engagement in policy and social issues. As efforts to include patients in the design and execution of research studies continue to expand, public deliberation offers a means for the general public to become involved with the broader social context that determines the impact of research, from the identification of research priorities to the use of research results to shape health care policy and practice. As a result, deliberation offers a means to enhance the value of research in improving the health of the public.

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