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## Public Deliberation: What is it and why do it?

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# INTRODUCTION

The New York Academy of Medicine (the Academy) has a rich history of partnering with community-based organizations and engaging community members to inform the design and development of programs and policies that promote good health. We have used multiple methods in this work, including community member surveys, in-depth interviews, focus groups, and PhotoVoice—each of which has proved informative for gathering information on particular questions. This report describes “public deliberation,” a method we utilized recently in collaboration with Maimonides Medical Center, a South Brooklyn hospital serving an extremely diverse community. Public deliberation is unusual in its intensity, significant educational component, and focus on providing guidance around a specific—often value-laden—question. We describe it here, as it represents an important option for community engagement in public health.

# BACKGROUND

The importance of engaging community members in public health and health care decision-making processes is gaining increased attention,<sup>1</sup> with concerted efforts to include community perspectives in medical research,<sup>2-4</sup> the assessment of community health needs,<sup>5,6</sup> policy,<sup>7</sup> and program planning.<sup>8</sup> A growing number of federal agencies support and promote community engagement, including the Research Centers in Minority Institutions program of the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ), and the Patient-Centered Outcomes Research Institute (PCORI).<sup>1</sup> Furthermore, national health care reform as directed by the Patient Protection and Affordable Care Act (ACA) has made community engagement a key element of its efforts to improve the accountability of hospitals to the communities they serve.<sup>9</sup> Under the ACA, not-for-profit hospitals must conduct a community health needs assessment (CHNA) every three years in order to maintain their tax-exempt status with the Internal Revenue Service. They are also required to implement activities that address the priorities revealed through the CHNA.<sup>1</sup>

Research examining the value of community engagement suggests that it facilitates effective and sustainable population-based health interventions<sup>6,9</sup> and that it can play an important role in efforts to improve the health outcomes of disadvantaged groups.<sup>8,10</sup> Although less frequently examined, a small number of studies indicate that community engagement can have a positive impact on the individuals who participate in the engagement process—in addition to its impact on the population addressed by the research or intervention itself.<sup>10</sup>

There is a clear logic behind the engagement of community members in health-related efforts: community members can articulate their values, attitudes and perceptions related to the topic in question. Input from the community is exceptionally valuable given that many aspects of health are socially rooted and community members bring knowledge and experience regarding what is likely to be desirable, effective, and appropriate, given local socioeconomic, cultural and environmental conditions.<sup>1,11</sup> A key concern within community engagement efforts is the inclusion of those who bring the perspectives of medically underserved populations. The inclusion of their perspectives is important to understanding and

addressing the social and cultural context driving health disparities, and to ensure that perspectives and guidance from those who have been disempowered are incorporated into policy and programming going forward.<sup>1,11</sup>

While it is widely recognized that community perspectives are important to include in the planning and design of new initiatives, meaningful and effective community engagement can be challenging.<sup>3,10</sup> They may, for example, elicit responses from a limited and non-representative portion of the target population or they may lack the breadth, depth and opportunities for debate and disagreement required to elicit thoughtful contributions from community members.<sup>12</sup>

## PUBLIC DELIBERATION DESCRIBED

Recognizing the challenges of more common approaches, public deliberation is a method of engaging community members in informed discussion to provide advice to institutions and/or policy makers that are considering a complex, value-laden decision.<sup>13,14</sup> This methodology differs from other forms of community engagement in that it allows community members to delve deeply into the decision at hand—providing ample time and information, as well as a framework in which to learn from others, clarify their own values,<sup>15</sup> and arrive at a more meaningful, community-centered response to the deliberative question.<sup>12</sup> As part of the deliberative process, participating community members receive relevant background information including balanced and/or neutral presentations from individuals with expertise relevant to the decision-making context. Participants spend time interacting with the facilitators, the presenters, and—most importantly—with one another as they consider case studies and/or exercises developed to facilitate discussion that will elucidate preferences, priorities and recommendations for the sponsoring institution or policy maker.<sup>7</sup>

An essential component of public deliberation is an inclusive recruitment process to select demographically and geographically representative individuals—or those considered representative based on the issue in question. In other words, individuals

who participate in public deliberation intentionally reflect the average citizen, rather than solely those who are moved by circumstance or personality to make their voices heard.<sup>16</sup>

Deliberative sessions typically pose specific, closed-ended, questions to participating community members, which articulate the decision the sponsoring institution or policy maker is considering. The method has been used to address a range of questions within the health care field, many of which center on ethical issues that arise in addressing the health of the public. Some topics addressed through public deliberation include triage protocol in the event of an emergency,<sup>17</sup> genetic testing, placebo use, bio-banks, resource allocation, setting research priorities, and health system reform.<sup>16</sup>

Deliberations can and do play an important role in addressing questions that arise with respect to reshaping the health care system. As indicated above, the Academy carried out a public deliberation sponsored by Maimonides Medical Center in New York City. This work was done to expand upon the hospital's ACA mandated CHNA and elicit community priorities regarding how the hospital should approach chronic disease prevention in the neighborhoods it serves. More detail about this deliberation—titled *Prioritize Health!*—can be found on page 5. In another example, community members in California were asked to participate in a deliberation that would help the state reduce unnecessary, harmful and/or wasteful medical care.<sup>18</sup> This deliberation resulted in a range of recommendations from the community, including greater oversight of physicians and guidance regarding the balance of ethics and evidence that should be used to make decisions about care.

Health care policy and practice continue to raise questions without easy answers, particularly as efforts are made to address and redress the expense, inefficiency, and inequity in the existing system. Decision-makers have smartly recognized the value of community engagement in formulating effective solutions that best match the needs of the communities affected, and multiple methods can effectively engage community members. However, it is essential that the methodologies employed toward this end match the complexity, and the values, at the heart of the questions asked.

## CASE STUDY

# PRIORITIZE HEALTH!

### Background

In late 2014, Maimonides Medical Center in Brooklyn, New York completed an ACA-mandated community health needs assessment. The undertaking—which included focus groups with community members and interviews with local stakeholders—helped the hospital to identify chronic disease prevention as a priority area on which to focus its population health efforts. Faced with the challenge of identifying and implementing approaches to address this issue within its catchment area, Maimonides elected to sponsor a public deliberation carried out by The New York Academy of Medicine. **The purpose of the deliberation was to elicit community values and informed perspectives on chronic disease prevention in order to guide the hospital in prioritizing approaches.**

### Methods

Three, two-day deliberative sessions took place over the course of four weeks in the fall of 2015. Each deliberative session involved 21–24 participants, diverse according to age, race, ethnicity, educational attainment and neighborhood—and reflective of the communities Maimonides serves. To ground the discussion, the deliberation focused on two central questions:

1. Should Maimonides' efforts to improve health focus primarily on:
  - a. Improving prevention services delivered by medical staff in the hospital's clinics;
  - b. Community interventions that decrease risk factors for disease; or
  - c. Working to change policies (e.g., of the government, of employers, of schools) that make it easier for people to stay healthy?
  
2. Should Maimonides concentrate its efforts to prevent disability and disease primarily on:
  - a. Children;
  - b. Working age adults;
  - c. Older individuals; or
  - d. People who have the highest risk for early disability or death due to social circumstances?

Throughout the deliberative process, participants were provided in-depth information and ample opportunity to discuss and consider evidence relevant to the deliberative questions. Information provided was tailored to the Brooklyn context.

- **Presentations** were given on topics such as the burden of diseases in Brooklyn, risk factors for poor health (both behavioral and sociodemographic), and community resources (e.g., green space), or lack thereof (e.g., food deserts).
- **Content experts** in the broader determinants of health, as well as clinical, community, and policy approaches to preventing chronic disease, provided information and held dynamic discussions with participants.
- **Case studies** provided examples of potential approaches to preventing chronic disease and evidence of intervention effectiveness modeled for the Brooklyn context.
- **Facilitated small and large group discussion** of the deliberative questions and case studies occurred throughout the sessions to allow for in-depth exploration of participant values and perspectives.

## Findings

- Support for an expanded focus on community and policy based approaches to preventing chronic disease.
- Interest in seeing hospital efforts focus on people who have the highest risk of disease due to social circumstances.
- Positive response to the experience—public deliberation perceived as a valuable tool that should be utilized by hospitals in the future.

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**“How do you learn about the community or what the community needs or wants if not by gleaning information from actual residents and people who utilize the hospital facilities? So yes, it’s very important. It’s something that I never even thought existed, really... I think it’s a definite positive, something to add to Maimonides’ credentials.”**

– *PRIORITIZE HEALTH! PARTICIPANT*

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*The views presented in this publication are those of the authors and not necessarily those of The New York Academy of Medicine, its Trustees, Officers or Staff.*

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