

2

Deliberative Engagement of Communities in Decisions About Research Spending (DECIDERS)

—Susan Dorr Goold, Zachary E. Rowe, and Karen Calhoun

The DECIDERS Project, a statewide project in Michigan, engaged communities in deliberations about health research spending priorities using a community-based participatory research (CBPR) approach. Key engagement strategies including project direction by academic and community co-directors, a Steering Committee composed of community leaders from medically underserved communities and populations, and regional advisory groups. The project used a participatory approach to adapting an existing simulation exercise, CHAT (CHoosing All Together), to facilitate deliberations about health research priorities constrained by limited resources. The project convened 47 CHAT groups across the state and evaluated project outcomes and the project partnership.

Introduction

A major contributor to health disparities is the relative lack of resources—including resources for research—allocated to address the health problems of those with disproportionately greater health needs (Davey, 2004; Viergever & Hendriks, 2016). Health research priorities do receive attention and influence from scientists, clinicians, advocacy groups, the private sectors of health care and health research, and other influential groups (Pierson & Millum, 2017). But allocating scarce resources for health research requires attention to justice as well as science (Callahan, 1999; Resnik, 2001). Engaging and involving underrepresented communities when setting research priorities can make the scientific research agenda more equitable, more just, and more responsive to their needs and values (Fleck, 2001; Goold, 1996; Vayena, 2014). Listening to communities can also enhance trust in researchers, research institutions, and funders. Further, research funders are increasingly looking for input from patients, the public, and/or

stakeholders (James Lind Alliance, n.d.; Lomas, Fulop, Gagnon, & Allen, 2003; National Institute for Health Research, n.d.; Patient-Centered Outcomes Research Institute, n.d.; Selby, Beal, & Frank, 2012)

Yet how best to engage minority and underserved communities when setting priorities for research remains a challenge. Traditional methods of engagement, like polling or focus groups, may not be very useful for a topic like health research, which is outside of normal life experience (Solomon & Abelson, 2012). Community consultations or *town halls* do not usually emphasize reflection and may lead communities to question whether their input will affect decision making. To remedy this, political scientists, philosophers and other scholars have justified deliberative strategies based on expectations that they could develop a more informed public (Fishkin, 1997), create decisional legitimacy (Cohen, 1997), and perhaps claim that constituents have consented to informed decisions (Patient-Centered Outcomes Research Institute, n.d.). With the intention of forming a policy recommendation, deliberative procedures gather nonprofessional members of the public to learn about a topic and reason through various positions (Solomon & Abelson, 2012). Deliberative procedures are most appropriate when (1) nonexperts' informed opinions provide important information that experts do not have, (2) informed opinions are difficult to obtain, (3) individual opinions will benefit from group discussion and insight, and/or (4) group judgments are relevant (Solomon & Abelson, 2012). All these conditions apply to setting health research priorities. Combined with trusting partnerships—in which communities contribute expertise, influence priorities, and decide how best to pursue research goals—informed deliberations provide an avenue for minority and underserved community members to share their opinions about what research is most important to pursue.

This chapter describes the DECIDERS Project, a statewide project in Michigan that engaged minority and underserved communities in deliberations about health research spending priorities using a community-based participatory research (CBPR) approach. CBPR emphasizes “the participation and influence of nonacademic researchers in the process of creating knowledge,” including identifying research needs and priorities (Israel, Schulz, Parker, & Becker, 1998, p.177). Existing community-academic partnerships provided the foundation for this project and its conceptualization, led by community and academic co-directors. Mr. Rowe, Executive Director of Friends of Parkside, a community-based organization (CBO) in Detroit, has served on the Board of the Detroit Urban Research Center since its founding, has longstanding and deep ties with many community-based organizations in Michigan, and expertise and experience in CBPR. Ms. Calhoun has been a community leader in CBPR for many years, is a Community-Engaged Research Program Officer at the Michigan Institute for Clinical and Health Research, and has been an editor at *Progress in Community Health Partnerships*. Dr. Goold, a professor at the University of Michigan Medical School and School of Public Health, brings expertise in social science research and public deliberation about health priorities. Dr. Goold and Mr. Rowe served as co-directors of the DECIDERS project. Ms. Calhoun served on the Steering Committee and also as a trained facilitator of deliberations.

In keeping with the principles of CBPR (Box 2.1), we took a participatory approach to adapting an existing simulation exercise (“**serious game**”¹), CHAT (CHOosing All Together, formerly Choosing Healthplans All Together), to facilitate deliberations about health research priorities constrained by limited resources. CHAT, which is described

¹ Serious games are games that have another purpose than just pure entertainment, usually for education, training, or helping make decisions.

BOX 2.1 PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH

1. CBPR recognizes community as a unit of identity.
2. CBPR builds on strengths and resources within the community.
3. CBPR facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.
4. CBPR promotes co-learning and capacity building among all partners.
5. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners.
6. CBPR emphasizes the local relevance of public health problems and ecological perspectives that attend to the multiple determinants of health inequities.
7. CBPR disseminates findings to all partners and involves them in the dissemination process.
8. CBPR requires a long-term process and commitment to sustainability.
9. CBPR addresses issues of race, ethnicity, racism, and social class and embraces cultural humility.

Source: Israel, B., Schulz, A., Coombe, C., Parker, E. A., Reyes, A. G., Rowe, Z., & Lichtenstein, R. (2019). Community-based participatory research: An approach to research in the urban context. In S. Galea, C. Ettman, & D. Vlahov (Eds.), *Urban health* (pp. 272–282). Oxford, UK: Oxford University. Adapted from Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health, 19*, 173–202. <https://doi.org/10.1146/annurev.publhealth.19.1.173>

later in detail, promotes, in an inclusive and engaging manner, informed, reasoned dialogue among ordinary persons about complex and value-laden allocation decisions. Serious games use attractive media and the motivational features of game design, such as curiosity, collaboration, and competition, to engage players in what might otherwise be considered uninteresting or difficult to understand (Hofstede, de Caluwé, & Peters, 2010). Iteration (e.g., using *rounds*) helps players learn and become comfortable with the topic and the task. Serious games have been used in education and business for teaching and training; budgeting games have been used in policy domains (Mayer, 2009). Those engaged in serious games are often in positions of decision-making power. While the potential of *gamification* for civic engagement has received some recognition (Mayer, 2009), policy gaming rarely emphasizes the voices of minority and low-income communities.

Project Leadership and Engagement Strategies

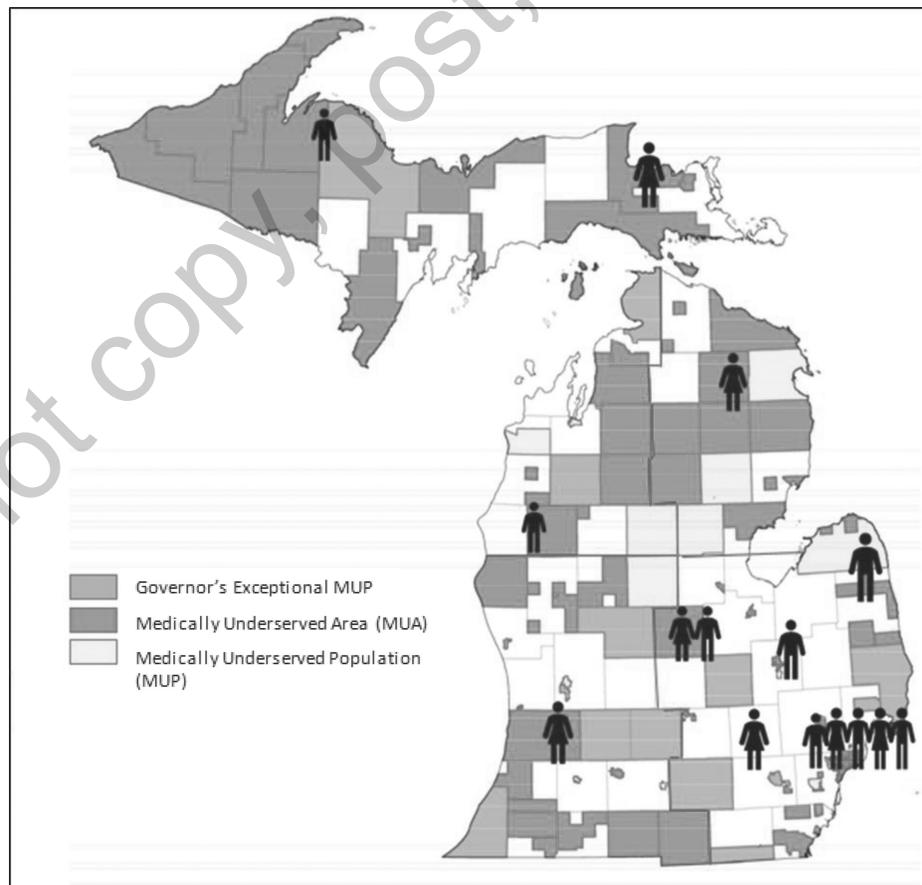
DECIDERS Steering Committee

We convened the DECIDERS Steering Committee (SC) with the aim of uniting diverse communities and community partners to increase their voices in priority setting for health research. The rationale for involving varied underserved communities included acknowledging that health research priorities, like health priorities, could be quite different for rural than for urban communities, Native American compared to African American communities, and established Hispanic and/or Latinx communities compared to migrant farm worker communities, for example. Deliberation about tradeoffs between competing needs for limited, shared resources should, to enhance fairness, include consideration of diverse needs. Our communities were geographically dispersed, culturally diverse, and without a unifying health need. The project's

goal could be undermined if only some voices were included, since fair allocation of resources requires considering the needs, preferences, and values of all those who could be affected by allocation decisions. While blending different communities of identity into a single, statewide project pose challenges, collective engagement might also strengthen the sense of statewide community (Israel et al., 1998).

We identified community leaders in or near medically underserved counties and populations in Michigan (see Figure 2.1). Since we were developing a process for deliberations about health research priorities, we searched for community leaders with some knowledge and/or experience with CBPR or health research, who worked for or with an organization that had some impact on community health. Project co-directors met with each prospective member in person or by phone (for distant members) to describe the project, answer questions, and discover their interest in and ability to serve on the SC. Initially, the SC included 15 members from minority and underserved communities throughout Michigan, with representation from all regions of the state and a wide range of experiences and perspectives, still keeping the size of the committee small enough for high-quality dialogue and decision making. SC community members included ten women and five men, and at least one member identified as Hispanic or Latinx, non-Hispanic white, black or African American, Native American, Arab American, other, and multiracial. Community members constituted over two thirds of the SC to ensure decisions would reflect community needs. The SC also included four members from

FIGURE 2.1 ● Steering Committee Members' Locations



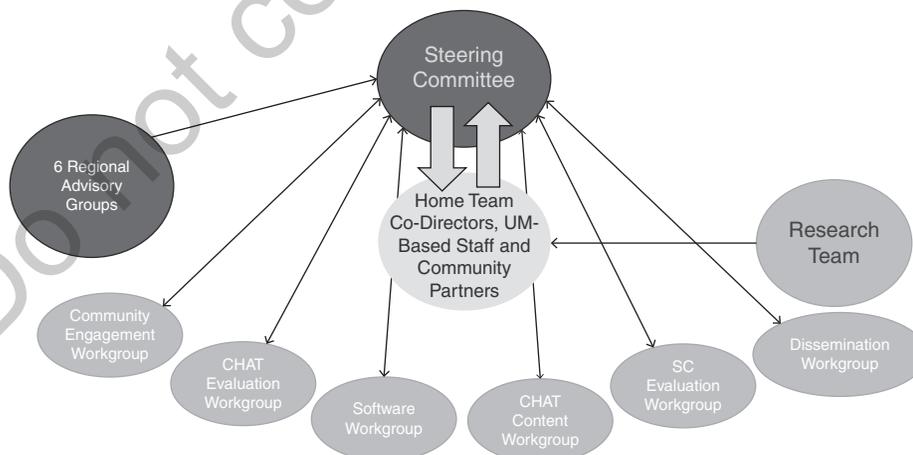
organizations that fund and/or conduct health research in Michigan to help ensure results would be actionable by research decision-makers. SC members were expected to attend 1- to 2-hour meetings by phone or in person every one to two months, and day-long retreats held every 1 to 2 years. They were asked to help with identifying individuals for regional advisory groups, with convening and leading those groups, and with dissemination of results to community groups. They were encouraged (but not required) to participate in workgroups (see Figure 2.2). Community members were paid an hourly rate, including, with some limits, for time spent preparing for meetings, participating on workgroups, reviewing materials or reports, and disseminating results.

Given the importance of face-to-face contact for relationships and the need to have norms and expectations in place, the SC charged co-directors and staff early on to organize a day-long retreat. At the retreat, the SC made several important decisions that would guide the project for the next 5 years. They established group operating norms and identified the state of Michigan as their focus area (community), which they later limited to minority and underserved Michigan communities due to the those communities' lack of voice in health research priority setting (and other health policy decisions). They established a common purpose of enhancing the voice of their communities. All SC members either had previous experience conducting CBPR and/or community leadership expertise working with group processes responsible for designing and implementing community interventions, programming, and decision making on behalf of their community. Thus, there was no need to train members on CBPR; however, we discussed the principles for consensus on an operating framework to guide how the group will operate.

Regional Advisory Groups

The SC identified the need for *regional advisory groups* to help provide more local voice and input into the project and decision making. SC members developed a list of organizations and persons in their own regions serving vulnerable communities whose role affected community health, such as organizations working with prisoners, addressing rural health care, or serving older adults. Organizations and persons in six

FIGURE 2.2 • Project Leadership Structure



Note: UM = University of Michigan; SC = Steering Committee; CHAT = CHoosing All Together

Michigan regions (Upper Peninsula, Northeast Lower Peninsula, Northwest Lower Peninsula, Thumb, Southwest, and Southeast) were identified, and invitations were sent for introductory meetings in each region. Regional Advisory Group (RAG) meetings were convened and led by SC members with help from research staff once or twice a year. RAGs helped with planning and implementation, and helped inform and review project materials (e.g., drafts of the priority setting exercise, interpretation of results, dissemination materials). Their feedback was brought to SC meetings. Attendees received a gift card for their effort.

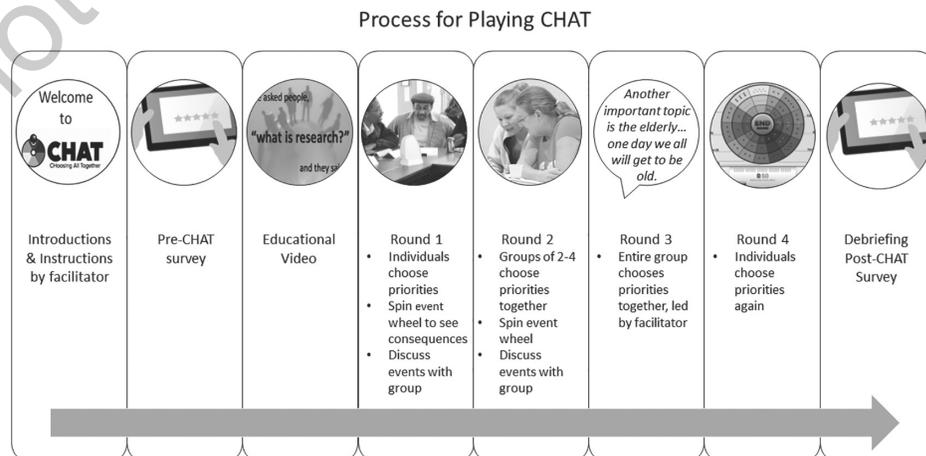
The SC further identified a need to engage tribes. A SC member from American Indian Health and Family Services facilitated an opportunity for the co-directors to meet with tribal health ministers about the project. Although these efforts did not lead to active tribal collaboration (since decisions to collaborate must be made by tribal leadership), they helped engage some members of the tribal community in RAGs and CHAT sessions and facilitated developing relationships with tribal leaders.

The CHAT (CHoosing All Together) Exercise

CHAT was originally developed as a “serious game” for deliberations about the design of health insurance plans (Goold, Biddle, Klipp, Hall, & Danis, 2005). CHAT aims to promote informed, reasoned dialogue about allocation decisions among ordinary persons (Burkhalter, Gastil, & Kelshaw, 2002), and it has been used to inform health and health care priorities in a number of different settings in the United States and other countries, engaging a wide range of individuals and communities (Danis, Ginsburg, & Goold, 2006; Dror, Panda, May, Majumdar, & Koren, 2014; Ginsburg, Goold, & Danis, 2006; Goold et al., 2005; Goold, Green, Biddle, Benavides, & Danis, 2004; Myers, Gordon, Kim, Rowe, & Goold, 2018). A number of studies in these settings have concluded that CHAT facilitates high-quality deliberation, changes individual preferences and opinions, and increases knowledge (Danis, Ginsburg, & Goold, 2010; Goold et al., 2005). There is some evidence that CHAT leads participants to take a more public-spirited view of resource allocation decisions; for example, a 2004 study found that participants in CHAT were willing to give up some benefit coverage to increase coverage of the uninsured (Goold et al., 2004).

The CHAT session (see Figure 2.3) starts with introductions and some initial instructions by the facilitator, then participants complete a pre-CHAT survey. A brief

FIGURE 2.3 • The CHAT Process



video provides participants, who have different levels of basic knowledge about health research, an introduction to health research goals, methods, costs, funders, and uses. The video was iteratively designed and revised by RAGs and the SC to translate complex biomedical information into layman's terms and encourage equity among all participants on background information useful for the game. Participants are then led by the facilitator through how to complete round 1, and instructed that their task is, during later group priority setting, to provide input to decision makers about how to spend limited resources for health research.

The CHAT game is played on tablet devices, presenting participants with an interactive game board resembling a pie chart (see Figure 2.4). Each wedge of the circle represents a category of health research spending, and each wedge has different levels of spending (including the option of no spending at all). Each of 16 categories of health research offers up to three cumulative spending levels that could be selected, with the higher levels (toward the center of the wheel) investing in more research at a higher cost. The costs assigned to different levels of spending within the categories reflected the assumption that there would be fixed costs associated with funding research within a category, so the first (lowest) level of spending in every category would need the largest marginal increase. In other words, moving from no spending in a category to any spending (Level 1 in CHAT) requires more markers than increasing funding from a lower level to a higher one (e.g., from Level 1 to Level 2). Full descriptions of categories and levels are available from the authors.

Participants choose the level of funding for each category by allocating the markers required for that level. However, participants are given a limited number of markers (50 markers with 92 open spaces) so they must make tradeoffs. If they select a high level of funding in one category, they have to choose less or no funding in another.

The CHAT game includes four rounds; iteration helps participants learn and become comfortable with the topic and the CHAT process.

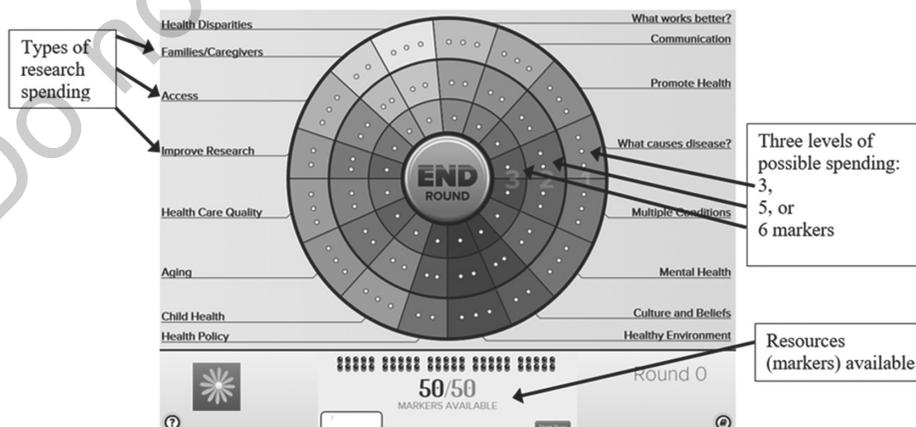
Round 1: Participants set priorities as individuals.

Round 2: Participants set priorities in groups of two to four.

Round 3: Participants set priorities with the entire group (up to 15).

Round 4: Participants again set priorities as individuals.

FIGURE 2.4 • CHAT Screenshot



After Rounds 1 and 2, the group hears and discusses scenarios (events), selected through a spinning wheel (to frame the events as happening by chance) that illustrate the consequences of their choices. In all the rounds, trained facilitators ask deliberators to make fair decisions about potential public health research expenditures on behalf of their fellow community members and to explain the reasons for their priorities. Facilitators also encourage participants who were not contributing to share their views.

After all rounds of the game have been completed, the group is debriefed by the facilitator to learn what participants thought of the exercise, what surprised them, and what they learned.

Adapting Chat for Setting Health Research Priorities

To adapt CHAT to the unique needs and objectives of research priority setting for minority and underserved communities, we engaged community partners in its design, informed by the following resources:

1. Documents describing research priorities from governmental organizations, foundations, and research institutions
2. Key informant interviews with
 - organizations that conduct and/or support research*—how they categorize types of research and set priorities, how they present options and assess relative costs, and what public input they would find valuable;
 - physicians practicing in underserved areas*—what health research they need to inform patient care;
 - community leaders with experience collaborating in research*—whether and how they would frame and present those types of research identified by organizations and clinicians, and what other options they would include in a priority-setting exercise.

Our research team, the SC, and RAGs collaboratively authored the instructional video and CHAT content to be credible and comprehensible to a lay audience. Consistent with CBPR principles, they also helped develop the process, research questions, and analysis of the key informant interviews. After several iterations and revisions, spending options (the *menu*) were designed to reflect the current priorities of industry and government, as well as other options, to yield decisions that could be actionable by decision makers but not constrained by the status quo. The final content of the exercise (which included definitions and explanations of a number of scientific terms) had a Flesch-Kincaid readability score of 55, about the same as *Time* magazine. All the content was translated into Spanish.

The use of CHAT (or similar deliberative structured exercises) presents challenges and limitations. Anytime there is a need to convene people for face-to-face, language-based activities, representation will be suboptimal for those with limited mobility, cognitive abilities, or facility with the language(s) used. A structured exercise, while it can facilitate learning and well-distributed dialogue, may not be as open to disparate points of view or experiences. CHAT requires significant investment of time and effort to make it reflect the broad range of possible points of view, make it accessible to those more comfortable with other languages and those of limited literacy, and, importantly, provide active outreach and accommodation for those with limited mobility. Besides these limitations, few studies have examined the impact of CHAT-based deliberations on actual allocation decisions, or compared this approach to other forms of deliberative public input.

Deliberately Engaging Communities

Project Participants

With help from SC and RAG members, and their organizations, we recruited participants from minority and medically underserved communities in Michigan (Health Resources & Services Administration, n.d.). We used flyers and a variety of local advertising (e.g., newspapers, craigslist, radio, libraries) in English and Spanish. Additional recruitment occurred through personal contacts, the University of Michigan website, and UMHealthResearch.org. We aimed to recruit equal numbers of men and women, with disproportionate representation of minority and low-income residents.

We convened 47 CHAT groups of four to 15 participants across the state of Michigan from February 2015 to November 2015. Most of the groups (89.4%) contained at least eight participants. The deliberators ranged from 18 to 88 years old, with 20% over age 65 (see Table 2.1). About two thirds were women, and about one third resided in a rural area. About 45% identified as white, 30% black or African American, 8% Hispanic, 6% Native American, and 4% Arab American, Arab, or Chaldean. Most of the participants

TABLE 2.1 • Participant Characteristics

Participant Characteristics	<i>N</i> (% , except as noted)
Female	351 (67.6)
Age in years (<i>n</i> = 509), mean (SD, range)	48.3 (17.6, 18–88)
Self-identified race (<i>n</i> = 505)	
White	252 (49.9)
Black or African American	158 (31.3)
Other, including multiracial	95 (18.8)
Native American	32 (6.1)
Arab American	23 (4.4)
Hispanic (<i>n</i> = 481)	35 (7.3)
Education (<i>n</i> = 510)	
High school/GED or less	140 (27.5)
Some college	192 (37.7)
Bachelor's degree or more	178 (34.9)
Region (<i>n</i> = 519)	
South east	230 (44.3)
South west	102 (19.7)
North	109 (21.0)
Upper	58 (11.2)
Thumb	20 (3.9)

TABLE 2.1 • (Continued)

Participant Characteristics	N (% , except as noted)
Urbanity (n = 494)	
Urban	298 (60.3)
Suburban	25 (5.1)
Rural	171 (34.6)
Income (n = 490)	
Less than \$15,000	165 (33.7)
\$15,000 to \$34,999	144 (29.4)
\$35,000 or more	181 (36.9)
No. of people in household (n = 503), mean (SD; range)	2.7 (1.5; 1–9)
At or below 100% federal poverty level (n = 481)	157 (32.6)
At or below 200% federal poverty level (n = 482)	257 (53.3)
Living alone (n = 502)	118 (23.5)
Perceived health status (n = 511)	
Fair or poor	87 (17.0)
Good	179 (35.0)
Very good or excellent	245 (48.0)
Work or worked in health care or health research (n = 510)	193 (37.8)
Currently work in health care or health research	77 (15.1)
Health care	72 (13.7)
Health research	3 (0.6)
Missing	3 (0.6)

(63%) had incomes of less than \$35,000, and at least 157 (32.6%) had incomes less than the federal poverty level. The groups met in locations familiar to and convenient for participants (e.g., community centers, libraries) to encourage an open and frank dialogue. Two group meetings (4.3% of all the meetings) were conducted in Spanish.

Results²

Research priorities selected by individuals before deliberation

Table 2.2 shows the percentage of participants selecting each possible funding level for each research category before (Round 1) and after deliberation (Round 4).

²Some results were previously published in Goold et al., 2016; Goold et al., 2018; and Goold et al., in press.

TABLE 2.2 • Individual Priorities Before and After Group Deliberation

	Before Deliberation				After Deliberation				Change ^b [%]	Mean Change ^c
	Selected Level ^a (%)				Selected Level ^a (%)					
	None	1	2	3	None	1	2	3		
What Causes Disease?	14.6	32.7	20.7	32.0	15.2	28.6	27.6	28.6	40.6	-.01
Promote Health	17.3	39.0	24.0	19.7	21.5	33.3	24.7	20.5	39.3	-.03
Communication	35.3	38.0	16.6	10.1	34.9	37.5	20.1	7.5	39.6	.00
What Works Better?	38.4	33.1	14.6	13.8	41.4	29.4	18.3	11.0	41.0	-.07
Health Disparities	40.2	34.5	16.8	8.6	44.0	26.6	18.7	10.8	40.6	.04
Families/Caregivers	28.5	39.4	18.9	13.3	24.7	31.8	27.6	15.8	37.9	.17 ^d
Access	23.0	36.6	22.8	17.5	16.0	32.3	31.2	20.5	34.2	.22 ^d
Improve Research	32.6	34.5	20.7	12.3	46.5	26.4	16.4	10.8	36.5	-.21 ^e
Health Care Quality	17.3	36.5	26.7	19.5	19.9	39.4	25.4	15.4	34.0	-.15 ^e
Aging	19.1	35.1	24.4	21.4	16.8	28.6	29.2	25.4	42.4	.14 ^e
Child Health	10.7	28.8	28.7	31.6	10.3	19.7	32.9	37.1	41.4	.15 ^e
Health Policy	35.5	39.4	17.9	7.2	48.5	29.2	15.4	6.9	41.8	-.17 ^e
Healthy Environment	18.9	34.1	24.6	22.4	18.1	30.2	27.8	23.9	38.9	.09
Culture and Beliefs	44.4	30.6	14.6	10.3	54.0	29.0	9.9	7.1	50.0	-.20 ^f
Mental Health	9.4	30.6	25.5	34.5	6.9	19.9	27.6	45.6	42.0	.28 ^f
Multiple Conditions	25.3	39.4	17.7	17.5	25.6	32.3	23.7	17.4	37.7	.03

Note: Cell values are percentages unless otherwise specified in column headings.

^a Percentages are calculated out of those who prioritized health research in each Round; $n = 513$ Before Deliberation, $n = 493$ After Deliberation.

^b Percentage of participants who changed their selected level from before to after deliberation; restricted to those with data in both Rounds.

^c Calculated as the mean of the priority levels after deliberation (Round 4) minus before deliberation (Round 1); positive values correspond to greater allocation after deliberation. Multilevel regression models adjusted for within-CHAT group clustering.

^d $p < 0.05$, ^e $p < .01$, ^f $p < .001$

None refers to not selecting that category for any funding. Before deliberation, most of the individuals selected, at least at the minimum level, *mental health* (90.6%) and *child health* (89.3%) research, and about one third invested at the highest possible level in each of those categories. The next most commonly selected categories prior to group deliberations were *what causes disease* (85.6%), *promote health* (82.7%), *(e)quality (equity and quality)* (82.7%), *aging* (81.1%), and *healthy environment* (81.1%). About three quarters of the individuals selected the *access*, *families/caregivers*, and *multiple conditions* categories before deliberations, at least at the minimum level. Before deliberations, individuals were least likely to choose *culture and beliefs*, *health disparities*, *what works better (comparative effectiveness)*, *health policy*, *communication*, and *improve research*.

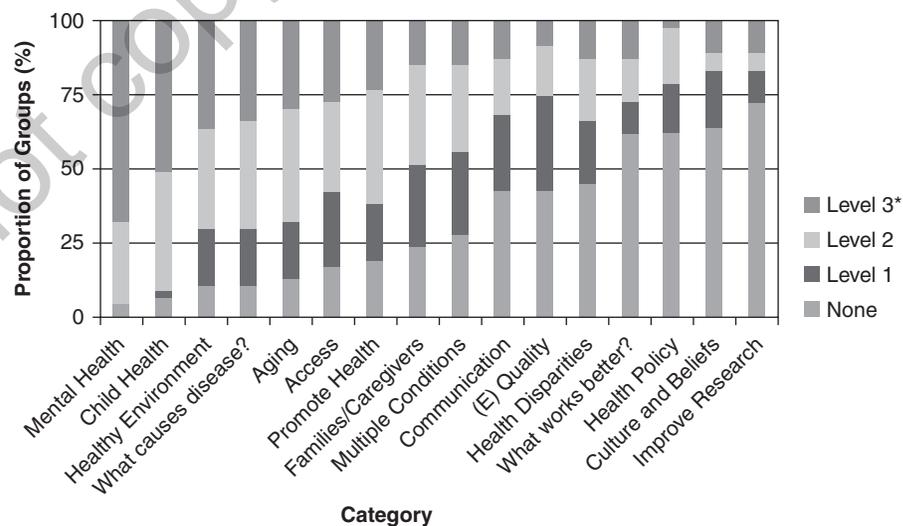
Research priorities selected by groups

During the full group deliberations in Round 3, nearly all the groups selected *child health* and *mental health* research (93.6% and 95.7%, respectively), and most chose the highest possible level of investment (Level 3) for those two categories, which required using almost one eighth of their resources on each category (see Figure 2.5). The next most likely categories to be selected by groups were *healthy environment, what causes disease, aging, access, and promote health*, and at least 25% of the groups selecting those categories also chose to invest at the highest possible level. The categories *what works better, health policy, culture and beliefs, and improve research* were not selected at any level by more than 50% of the groups. However, with the exception of *health policy* research, at least 10% of groups chose to invest at the highest possible level in each of those categories.

Research priorities selected by individuals after deliberation

Table 2.2 shows both the percentage of participants who changed their level of selection after deliberation and the mean difference in the level of selection. The level of investment in many categories changed after the group deliberations. The deliberators increased their investment in *mental health* research (within-participant mean increase in level = 0.28, $p < .001$), *access* research (.22, $p = .002$), *families/caregivers* research (.17, $p = .002$), *child health* research (.15, $p = .03$), and *aging* research (.14, $p = .049$). They decreased their investment in *improve research* (within-participant mean decrease = -.21, $p = .02$), *culture and beliefs* (-.20, $p < .001$), *health policy* research (-.17, $p = .01$), and *(e)quality* research (-.15, $p = .02$). However, regarding whether they selected at all, versus not, the only category significantly more likely to be selected by individuals after group deliberations (77.0 vs. 84.0%, OR = 1.63, $p = .005$) was *access*, whereas *improve research, health policy, and culture and beliefs* were significantly less likely to be selected after group deliberations (all, $p < .001$; ORs are available upon request).

FIGURE 2.5 ● Group Priorities



* Level 3 is the highest possible level of spending.

Mental health and *child health* research were high priorities for individuals both before and after group deliberations.

Predictors of priority selection

After deliberations, older age was modestly associated with a greater likelihood of selecting *aging* research (Adjusted Odds Ratio [aOR] = 1.03, $p < 0.01$) and a lower likelihood of selecting *child health* research (aOR = 0.98, $p < 0.05$). Those identifying as black or African American were more likely to prioritize *communication* research (aOR = 1.95, $p < 0.05$). Blacks were less likely than whites to choose *mental health* (aOR = 0.15, $p < 0.05$) and *what works better* (aOR = 0.52, $p < 0.05$), and those of other races (compared with whites) were more likely to select *(e)quality* (aOR = 2.60, $p < 0.05$) and *culture and beliefs* (aOR = 4.06, $p < 0.01$). Hispanics were less likely to prioritize *aging* research (aOR = 0.27, $p < 0.05$). Rural residents were more likely than urban residents to prioritize *child health* research (aOR = 3.57, $p < 0.05$) and less likely to choose the *culture and beliefs* (aOR = 0.38, $p < 0.05$) and *improve research* (aOR = 0.27, $p < 0.01$) categories. Those living under the federal poverty level were more likely to select *health policy* (aOR = 2.04, $p < 0.01$) and *improve research* (aOR = 2.13, $p < 0.01$). More education was associated with greater priority for *healthy environment* research (aOR = 1.82, $p < 0.01$) and lower priority for *improve research* (aOR = 0.66, $p < 0.05$), *multiple conditions* (aOR = 0.71, $p < 0.05$), and *(e)quality* research (aOR = 0.66, $p < 0.05$). Better health status was associated with a greater tendency to select *what causes disease* (aOR = 1.45, $p < 0.05$), *promote health* (aOR = 1.59, $p < 0.05$), and *mental health* (aOR = 2.03, $p < 0.05$). Gender was not predictive of any priority selection.

Results were disseminated to participants, community organizations, and leaders of scientific and funding organizations. Below, we describe whether and how these audiences used or responded to results.

Evaluating Engagement

Evaluating CHAT

While the goal of deliberation could be construed as *better* decisions, or outcomes, evaluating solely the outcomes of deliberations misses the normative argument that deliberative democratic procedures can have value as fair processes, and that they can be justifiably criticized if they fail to meet certain standards. Theories of deliberative democracy, despite important differences, share an emphasis on a process in which political actors listen to each other with openness and respect, provide reasons and justifications for their opinions, and remain open to changing their points of view. Therefore, we evaluated CHAT deliberations using a framework that examines the formal *structure* of deliberation (how it is organized), the *process* of deliberation (how it transpires), and the *outcomes* produced (Blacksher, Diebel, Forest, Goold, & Abelson, 2012; De Vries, Stanczyk, Ryan, & Kim, 2011; Goold et al., 2012; Myers & Mendelberg, 2013; Neblo, 2007). Structural elements can include information and choices, materials, tasks and exercises, sampling, and group composition (Knobloch, Gastil, Reedy, & Cramer Walsh, 2013). Examples of procedural aspects of quality include respectful treatment, civility, and reason-giving. Outcomes can include changes in participants' knowledge or opinions, decisions made, and participants' views of the group decision. These domains may interrelate; for instance, representation (one element of structure) could influence the quality of deliberations (process) and/or participants' views of the groups' discussions (outcome).

Methods

Data collection to evaluate deliberations included tablet-based surveys completed by CHAT participants before and after CHAT sessions, dialogue during deliberations recorded and transcribed, observation during CHAT sessions by research staff, and follow-up interviews with participants, SC members, and those to whom results were presented and/or disseminated (see Table 2.3).

TABLE 2.3 • Evaluating Deliberative Community Engagement

Domain	Elements	Data	Analysis
Structure	Representativeness	Survey Demographics	Descriptive
	Information, Materials	Survey Views of information and choices	Descriptive, with subgroup analyses
Process	Perceptions of deliberations	Survey Views of deliberation	Descriptive, with subgroup analyses
	Support for way decision of group was reached	Survey Trust process like this Support using to inform decision makers	Descriptive, multivariate analysis of predictors
	Equality of participation by deliberators	Staff observed, counted contributions of deliberators	Herfindahl-Hirschman index
Outcomes	Deliberator knowledge and understanding	Survey Knowledge about research Knowledge of health disparities	Descriptive, pre-post, with subgroup analyses
	Deliberators' trust in medical research, researchers	Survey Trust in medical researchers Willingness to participate in research Likelihood of participating in future research	Descriptive with subgroup analyses
	Perceived and desired input on setting research priorities	Survey Perceived and desired input	Descriptive with subgroup analyses
	Longer-term impact on deliberators	Interview 6–12 months after CHAT Recall of exercise Recall/views of results Any conversation, action related to their experience	Descriptive, exploratory
	Impact on community leaders and organizations, research and funding organizations, influencers	Interviews 3–12 months after dissemination of results about knowledge of results and whether and how those results had informed or led to action	Descriptive, exploratory

Structure

Representativeness has a role in CBPR, which encourages inclusion of voices not typically involved in decision making. CBPR recognizes community members as experts in their own right and as key participants in knowledge creation (Eder et al., 2018). Representativeness seeks to accurately reflect characteristics of a larger group. We measured representativeness using participants' demographic characteristics, which, given our goal to engage minority and underserved communities, needed to disproportionately include racial and ethnic minority and lower-income individuals. We calculated poverty level using the upper portion of the income range that participants selected and the number of people living in the household. It represents a conservative (under) estimate of the number and proportion of participants living under the federal poverty level. We included six questions in the post-deliberation survey to measure deliberators' views of the quality of information and the choices available, another element of structure (Blacksher et al., 2012; De Vries et al., 2011; Goold et al., 2012; Myers & Mendelberg, 2013; Neblo, 2007).

Process

We measured a number of elements of the deliberative process. Based on previous experience with the CHAT exercise, we hypothesized that participants would find the deliberative process fair, and that they would express willingness to abide by their groups' decisions (Danis et al., 2006; Dror et al., 2014; Ginsburg et al., 2006; Goold et al., 2004, 2005; Myers et al., 2018). To measure deliberator's perceptions of the quality of discussion, we included a series of 13 questions measuring various dimensions of deliberative quality, including being treated with respect, perceiving the opportunity to contribute their point of view, and the kinds of arguments offered in deliberation (Danis et al., 2010; De Vries et al., 2011; Goold et al., 2005, 2012; Myers & Mendelberg, 2013; Neblo, 2007). We also included two items asking whether deliberators supported using their group's decision to inform decision makers, and whether they would trust a process like this to inform decision makers; while these are not direct measures of the quality of deliberation, we would expect deliberators would only support using this process to inform policy if they felt that the process was high quality.

In addition to survey measures of process quality, equality of participation by deliberators was measured by members of the research team who were present at each session. Using a diagram of the table and deliberators, they placed a mark on the diagram each time that person spoke. To examine the distribution of participation in deliberations, we calculated the Herfindahl-Hirschman index (HHI). While the HHI is commonly used as a measure of market concentration, it can be used to measure the degree to which one or a few actors dominate any setting (U.S. Department of Justice, n.d.). In this case, we use it to measure the degree to which discussion was dominated by one or a small number of people. Since the possible range for HHI depends on the number of participants in a group, results need to be interpreted with the possible range for each group.

Outcomes

We hypothesized that participants' knowledge and understanding about research and health disparities would increase and that participation might increase trust in medical researchers and willingness to participate in research (Danis et al., 2006; Dror et al., 2014; Ginsburg et al., 2006; Goold et al., 2004, 2005; Myers et al., 2018).

Knowledge of health research was measured using two new instruments, after a search revealed no validated measures available in the literature. One instrument

presented three vignettes and asked participants whether or not the vignette was research. The other instrument presented statements about research and research funding and asked respondents to rate them true or false, for example, “Results from research need to be repeated to make sure they are believable,” and “The federal government funds a great deal of health research.” Both measures of knowledge about research were cognitively pretested. Knowledge of health disparities was tested using a single item asking them to choose the best definition. Post-deliberation surveys also measured trust in medical researchers (Hall et al., 2006), willingness to participate in research (Goold et al., 2005), the likelihood of becoming a participant in health research in the future (Goold et al., 2005), and their perceived and desired input on setting research priorities. We examined relationships between participants’ demographic characteristics, views of the deliberation, and their overall trust in or support for using this process to inform policy using multivariate models.

We also aimed to explore, after disseminating results, the impact of the project. To do this, we interviewed SC members, decision makers, and influencers for research and funding, and leaders of community organizations asking about their knowledge of results and whether and how those results had informed or led to action. We also explored the impact on CHAT participants 6 to 12 months after their participation by randomly selecting one participant from each CHAT group and asking them to participate in an interview about what they recalled about their experience and the results they received, whether and to whom they had spoken of their experience, and how they would suggest using results. Of the 47 participants who were randomly selected to be interviewed from each CHAT group, 37 participants were interviewed, one participant refused to participate, and nine could not be reached after several attempts. Since interviews were semi-structured, not every interview included responses to every question.

Results

The age range of deliberators, the proportion from minority communities and low-income households (see Table 2.1), and the proportion from rural areas achieved our goals for representation, although women were overrepresented. Mean item and scale scores (see Table 2.4) describe generally favorable views of the information and choices provided. Those with a high school education or less had lower scores on the favorable views of information and choices and scale (see Table 2.5). No other demographic characteristic predicted those scale scores in multivariate models.

Mean item and scale scores described generally favorable views of deliberations (see Table 2.4). The highest rated item in the “views of deliberation” scale (“During the exercise, I was treated with respect”) had a mean score of 3.4 (possible range, 0–4 where 0 = Strongly Disagree). The lowest rated item in the scale (“A few people dominated the discussions”) had a mean score of 2.3, still on the favorable side. Participants, on average, agreed they would “support using their group’s decision to inform decision makers” (Mean = 3.1) and “would trust a process like this to inform funding decisions” (Mean = 3.0).

Those with a high school education or less had lower scores on the views of deliberation scales (see Table 2.5, Appendix). No other demographic characteristic predicted those scale scores in multivariate models. In multivariate analyses, favorable views of “information and choices” and “views of deliberation” were positively associated with support for “using our group’s decision to inform decision makers” (beta coefficients 0.289 and 0.742 respectively, $p < .001$). Favorable views of “information and choices” and “deliberation” were also positively associated with “trust in a process like this to inform funding decisions” (beta coefficients 0.387 and 0.476 respectively, $p < .0001$).

TABLE 2.4 • Participants' Views of Information, Choices, and Deliberation

Indicator	Mean (SD, Range) (n = 519)
Sufficient Information and Choices Scale¹	2.9 (0.7, 0.0–4.0)
The information given to us was believable.	3.0 (0.9, 0.0–4.0)
The choices offered in the exercise were realistic.	2.9 (0.9, 0.0–4.0)
The choices in the exercise included the choices I could have wanted.	2.8 (0.8, 0.0–4.0)
There was a wide selection of choices.	2.9 (0.8, 0.0–4.0)
Insufficient Information and Choices Scale²	2.3 (0.8, 0.0–4.0)
We did not have enough information to make good decisions. (-)	2.5 (1.0, 0.0–4.0)
There were choices I would have liked to have seen but didn't. (-)	2.0 (1.0, 0.0–4.0)
Views of Deliberation³	2.8 (0.5, 0.9–4.0)
A few people dominated the discussions. (-)	2.3 (1.1, 0.0–4.0)
The way in which the group reached its decision was not fair. (-)	3.0 (0.9, 0.0–4.0)
The discussions were superficial. (-)	2.8 (0.9, 0.0–4.0)
There was too little time to discuss. (-)	2.5 (1.0, 0.0–4.0)
People in the group argued by referring to what would be best for themselves. (-)	2.4 (1.1, 0.0–4.0)
Our discussion included responding to each other's arguments.	2.8 (0.8, 0.0–4.0)
I gained understanding of the arguments that opposed my own.	2.9 (0.7, 0.0–4.0)
My views were considered and taken into account.	3.1 (0.7, 0.0–4.0)
I had lots of chances to share my views.	3.1 (0.7, 0.0–4.0)
The participants in the group argued by referring to what would be best and most fair for all people.	2.6 (1.0, 0.0–4.0)
All positions were considered with equal respect.	3.1 (0.7, 0.0–4.0)
The arguments of the other participants were useful in forming my own position.	3.0 (0.7, 0.0–4.0)
During the exercise, I was treated with respect.	3.4 (0.6, 0.0–4.0)
I would support using our group's decision to inform decision makers.	3.1 (0.8, 0.0–4.0)
I would trust a process like this to inform funding decisions.	3.0 (0.8, 0.0–4.0)

Note: (-) Denotes reverse-scored items

¹ Mean of 4 items; each 5-point item can range from 0 to 4. Cronbach's $\alpha = .81$.

² Mean of 2 items; each 5-point item can range from 0 to 4. Cronbach's $\alpha = .43$.

³ Mean of 13 items; each 5-point item can range from 0 to 4. Cronbach's $\alpha = .80$.

The HHI ranged from a low of 805 to a high of 2,852 and tended to be near the lower possible bound of the Index for each group size, indicating broad, well-distributed dialogue (Goold et al., 2018).

Results with regard to participants' changes in knowledge and views of research and researchers were mixed. Participants were more likely to correctly identify the definition of health disparity after CHAT than before (aOR = 2.2, $p < .001$). Their knowledge of health research, as measured by agreement with statements about research, did not change after participation. Their proportion correct of three vignettes had a statistically significant decrease, although the change was small (−2.9% out of 100, $p < .05$). Participants were more likely to say they had some or a great deal of input in setting research priorities after participation, compared to before (aOR = 3.7, $p < .001$), and were also more likely to say they *should* have some or a great deal of input in setting research priorities (aOR = 2.3, $p < .05$). The proportion willing to take part in a research study, high at baseline, did not significantly change. Trust in health researchers declined slightly after participation (mean score change = −0.7, $p < .001$).

Later impact on deliberators

When asked if they remembered CHAT, about half of participants were able to recall aspects of their deliberation and/or group deliberations. Many recalled the need to prioritize. Some mentioned specifically encountering other points of view, the need to work out differences, and changing their selections after the group deliberations (see Box 2.2).

More than half (11/21), talking about the process of working together, mentioned hearing other points of view. Some found that experience eye-opening, and some acknowledged the difficulty that it presented (see Box 2.3).

BOX 2.2 CHAT PARTICIPANTS' RECOLLECTIONS OF THE DELIBERATIVE PROCESS

"We were expressing our agendas as to how public dollars should be spent."

"I remember it was really difficult to prioritize because the more we got into assessing our selections, the more you could see everybody's point of view."

"I remember the process was kind of challenging like trying to prioritize what we wanted ... because everyone had to kind of put away their own individual biases and just think as a group."

"After the discussion, I changed the way that I answered."

BOX 2.3 CHAT PARTICIPANTS' COMMENTS ON WORKING TOGETHER

"So it was frustrating to have to have a conversation with somebody that maybe didn't ... not only didn't share my viewpoints, but didn't ... I felt like I wasn't being heard. So that was a frustrating part, but I felt like then when we got back as a bigger group we were able to discuss things more."

"When we did CHAT, we were still new to the town, and so it was ... It was enlightening to see what the other people in our small town thought ... how they felt."

"It made you think beyond yourself and beyond your friends and family, and it made you think for your entire state, and to think of, you know, what things matter to you and why they matter to you, and then how would you go about making a difference and making a change in each area?"

"It made me a little more open to looking at different angles of an issue. That it's not just my point of view that matters."

Many participants remembered sharing their views in deliberations, or staying quiet, and some mentioned the importance of being heard either way (see Box 2.4).

Others mentioned the importance of community involvement, and some felt included in decision making (see Box 2.5).

After participation, most said they had spoken about their participation in DECIDERS, typically to family or friends, sometimes to other participants, and on a few occasions to community groups or organizations. For example, one participant said:

“I had actually talked to my director in reference to the ... to the use of the CHAT and how it helped to pull team members out, and actually did kind of minimize the voice of some of the really strong ones and allow the others to be able to speak.”

Asked about any changes they attributed to participation, most did not identify any. A few talked about being more attentive to their health, and a few mentioned being more open to and encouraging of other points of view. One participant stated:

“I think we tried to make sure that we’re staying true to that word and be much more collaborative and work together with existing organizations in the community, and I think in my role as [redacted] I tried to be a little more disciplined in evaluating cares and concerns brought to me ... whether it’s the public or staff. I think that’s an important part of leadership, and I think I got a lot of that out of the CHAT process.”

Fourteen of 33 participants who were asked whether they looked for opportunities to get involved in their communities had not done so since playing CHAT. Just under one third (10 of 33) said they were already involved in their communities, and nine said they became more involved (see Box 2.6).

Most interviewees had not acted on or used the report they received describing results. A few people asked about how they could use them. Some had plans to share the results, for instance with employers or agencies, while others planned to use results in advocacy work (see Box 2.7).

When asked how results could or should be used, almost all thought the results should be shared with decision makers. For example,

“... But certainly on a national level, they would be of help for politicians to know what their general public feels about certain issues.”

Others thought it would be beneficial to share results with communities and thought the CHAT tool was beneficial for engaging communities in research (see Box 2.8).

BOX 2.4 CHAT PARTICIPANTS’ COMMENTS ON SHARING THEIR VIEWS

“It ... provided a way to be able to have my voice heard without actually speaking and then waiting for someone else to speak. It just provided a different type of avenue to be heard, and I liked that ... I think the thing that I remembered most was that my vote counted. That meant a lot.”

“I know the goal was to have all folks participate, but ... I’m kind of an outspoken person anyway. So I do recall that I shared my opinions.”

BOX 2.5 CHAT PARTICIPANTS' COMMENTS ON COMMUNITY INVOLVEMENT AND INCLUSION

"You know, it made me aware that there's only so much money available for research ... and that ... And it made me aware that yeah, if you get a representation of the community together to make the decisions, you know, it might help the true funders to be more aware of what people want."

"It actually made me feel like ... like I was a part of ... decision making, of helping with decision making in the future."

BOX 2.6 CHAT PARTICIPANTS' COMMENTS ON COMMUNITY INVOLVEMENT AFTER CHAT

"I started volunteering with different mental disability groups within my community, and that wasn't really something that I was, you know, in before, and once I came home and realized how prevalent it was just in my community, I started volunteering for mental disabilities."

"I think it motivated me. I thought I was going to retire and sit up here and read books and ... take up

knitting, look out at the beautiful lake and whatnot, but I have ... I have certainly gotten a lot more involved in local, county, and state issues because everybody that I meet that's into that sort of stuff has some other group that they want me to get involved with."

BOX 2.7 CHAT PARTICIPANTS' COMMENTS ON ACTING ON CHAT RESULTS

"No. It is on my list of things to share though with leadership here at our agency, but I haven't acted on it yet."

"We talk about child health and mental health and the whole stress there is right now about school closings. You know, that's a big priority in low-income communities."

BOX 2.8 CHAT PARTICIPANTS' COMMENTS ON THE VALUE OF CHAT

"I think it could be helpful if it was brought more into the communities and more people could learn more about it."

"... there's been an adversarial relationship with the Indian Health Service because it started out as an Army

program. So something like this where we're ... You're open about bringing that information back to the tribe, you know that you're ... It's clear that you're working with us, not to us or on us ... We need more things like that."

Impact on leaders, decision makers, and influencers

After disseminating results throughout the state and, to some extent, nationally, our final, exploratory phase explored whether and how results might influence decisions about priorities. Research funders, decision makers, and influencers, including SC members, easily recalled results of the project, and often found those results, particularly the priority given to mental health research, consistent with priorities they had identified in other ways (see Box 2.9). They were sometimes surprised at lower priorities like *culture and beliefs*. Many of these interviewees spoke about the need to hear from minority and underserved communities (e.g., "I think,

BOX 2.9 LEADERS AND DECISION MAKERS RECALL PRIORITIES FROM DECIDERS

"... in redoing needs assessment back in 2015, mental health had really come up on the scale. So I found that it was interesting that you guys found the same results... You guys were looking at areas of research. We're looking at priority areas to take action. Child health being up there as well."

"I guess I'm not surprised by the top five.... I'm not surprised that certain things like policy research and improving research are at the bottom. It is interesting that in, you know, underserved communities, culture

and beliefs is so low, although I don't know exactly what that entails or what the questions around that looked like."

"So I was surprised that they would choose mental health ... that that was the highest priority... That was surprising because we always hear about cuts to mental health. We hear about the stigma of mental health, and I was surprised ... This was a grassroots audience, correct? So that's even more surprising to me is that the general public was that focused on mental health."

for our board, ... particularly when you're talking about underserved communities, minorities, to think that way. To view and just open up their minds a little bit about how their organizations serve.") to inform their understanding of the needs of those they serve. Some spoke about the CHAT process ("a handy tool") and its ability to keep people engaged ("it keeps people's interest a little bit more").

Most had not done anything substantial with the results yet but found the CHAT process valuable for making an impact in the future, contingent on reaching the right people and availability of funding and other resources (see Box 2.10). Some had presented results to other actors in health and human services. Some stated that the results confirmed their current priorities or ones they plan to address, especially mental health priorities. One CBO shared the results with staff, and they plan on using parts of the results in their future endeavors such as needs assessments. One scientific leader talked about the difficulty of aligning community priorities with funders' priorities. A few mentioned the value of the DECIDERS network, and some mentioned other possible uses for the CHAT tool ("different ways you could use the same modeling to ... use it with the state budget").

BOX 2.10 LEADERS AND DECISION MAKERS ABOUT IMPACT

"Those folks at the top, you know, and in our legislature in Lansing needs to know that this is an issue, not just in one county, but in a good majority of our counties ... we probably need to look at putting some money and resources behind getting folks the help that they need."

"We saw how it fit in with what we're doing. As I said, if anything it reinforced ... It reinforced what we're doing."

"When are we gonna quit looking at all this stuff and do something about it?"

"I sent [results] to staff, but we haven't had the chance to sit down and ... sort of talk about it in any detail. You know, just have more conversation about what it means for us, especially around the issue of mental health. And then also, the issue around child health because we're ... because we're involved with other projects like asthma,

like childhood asthma ... So we're already doing that kind of work So it is gonna ... continue."

"... we tend to follow the priorities that are identified by the people giving us money to do the research rather than sort of the direct community input. So I think leveraging the connection between ... the output of these kinds of things and funding agencies could probably be a more ... an impactful way of approaching it.... Well, I think we've acted on it."

"We've now helped to build in the DECIDERS network into our future plan for trying to enhance community-driven research networks. In terms of the specific health priorities, we do have children's health as a priority as one of a number of underrepresented populations in health research."

In summary, representation and participant views of the information and choices appeared to be consistent with the structural goals of the deliberative project. Participation in deliberations was, as hoped, distributed widely in each group. Participant views of the deliberative process were generally favorable; in fact views of the deliberations strongly predicted a willingness to use or trust the process to inform decision makers, which did not vary by race, ethnicity, age, gender, income, or educational level. Participants' changes in knowledge and views of research and researchers showed mixed outcomes. Our exploration of the impact of the project found some modest impact on decision makers, leaders, participants, and SC members.

Evaluating the Project Partnership

Besides evaluating the priority-setting process (CHAT sessions), the SC decided to evaluate the partnership itself. A participatory evaluation (Coombe, 2012) was led by an external evaluator and a workgroup composed of four SC members, the co-directors, and the project manager, who were involved in all aspects of design, analysis, interpretation, and feedback to the full SC. Mixed methods (Johnson, Onwuegbuzie, & Turner, 2007) included data collected from:

1. Project documentation (e.g., meeting minutes, decisions, attendance, SC member participation in activities);
2. Periodic closed-ended surveys to assess CBPR process and effectiveness (e.g., participation, trust, group dynamics, communication, satisfaction);
3. Semi-structured, focused evaluation discussions with the SC and home team (see Figure 2.2); and
4. Direct observations by an external evaluator.

The evaluation found that SC members generally agreed that appropriate members were around the table (mean of 4.4 on a 5-point scale with 1 = Strongly Disagree and 5 = Strongly Agree), the SC adequately represents state diversity (4.1), and RAGs bring voices that would not otherwise be heard (4.6). Attendance at monthly online webinars averaged 49%, with some members joining online (e.g., comments typed during discussions) and some by telephone, with electronic or hard copies of materials at hand. In surveys, 83% said SC webinars were an effective means to share new ideas and make important decisions. A majority of SC members participated in the project in other ways as well, for instance in workgroups (see Figure 2.2). While technology can help strengthen communication, we found face-to-face meetings of the SC essential at least once per year for in-depth discussion of important decisions. We also found smaller face-to-face meetings (workgroups, RAGs) and informal, nonworking time helped develop strong relationships. Others with dispersed community partners have found multiple modes of communication useful, and they also highlight the value of face-to-face meetings and visits to communities (Burhansstipanov, Christopher, & Schumacher, 2005; Sánchez, Carrillo, & Wallerstein, 2011).

Although many community-academic partnerships confront issues about representation, the size and heterogeneity of the community selected by the SC created an unusually important challenge. In DECIDERS, the SC recognized a shared vision of increasing voice for minority and underserved communities in health research priority setting. The SC recognized the multiple and diverse communities in the state, discussed different cultures, and who they themselves represented.

They used this knowledge to identify missing perspectives and crafted the RAGs to include those voices.

Bringing diverse community leaders together presented opportunities along with challenges. Community leaders from underserved rural areas learned about the health needs of urban underserved communities, and vice versa. Leaders from organizations serving particular racial or ethnic groups (e.g., the Arab Community Center for Economic and Social Services, Detroit Hispanic Development Corporation) learned about other communities' needs and values. Leaders of scientific and funding organizations learned from community leaders, and community leaders learned about research organizations. Each member brought important capacities to the partnership and enabled the creation of new relationships. For example, those with less health research experience brought perspectives of distant and diverse communities (e.g., rural Northern Michigan). These relationships bore fruit beyond the project both informally (e.g., advice from one community leader to another) and formally (e.g., some community leaders were asked by a research institution leader to join a grant proposal). Many communities characterized as *medically underserved* are also underserved by health researchers. Such communities expressed surprise ("You came over the bridge!") and often great interest in collaborating with researchers. Community leaders new to CBPR have enhanced their own and community capacity for research by helping form and lead RAGs. Several members of the SC received training in facilitation and served as facilitators (in English and Spanish) for project data collection.

The SC, individually and as a group, voiced an interest in sustaining the relationships and the statewide network developed for DECIDERS. Since the DECIDERS project concluded, most of the DECIDERS partners continue working on projects to enhance the voice of minority and low-income communities in decisions about limited health resources. For example, another statewide project engaged low-income community members in deliberations about priorities for Medicaid (also using CHAT) (Myers et al., 2018). That project, and an evaluation of the Medicaid expansion, benefit from oversight of the SC. Similarly, a project in three locales in Michigan will engage communities in deliberations about community health benefit spending to influence implementation strategies of not-for-profit health care organizations for meeting community health needs.

Conclusions

Engaging and involving underrepresented communities when setting research priorities can make the scientific research agenda more equitable, more just, and more responsive to their needs and values (Fleck, 2001; Goold, 1996; Vayena, 2014). Research funders increasingly look for input from patients, the public, and/or stakeholders (James Lind Alliance, n.d.; Lomas et al., 2003; National Institute for Health Research, n.d.; Patient-Centered Outcomes Research Institute, n.d.; Selby et al., 2012). In DECIDERS, the approach we tested for engaging communities in deliberations about health research priorities shows many strengths. This includes not just the CHAT tool itself but the community-based, participatory approach to project and tool design, implementation, and evaluation. Participants in CHAT deliberations found the process fair, contributed relatively equally, and supported using results to inform decision makers. Participatory design doubtless contributed to the favorable experiences of CHAT deliberators. Participatory evaluation of the community-academic partnership also revealed many strengths, and most partners have elected to continue in the DECIDERS network.

Our exploration of the impact of this project and the paucity of literature about the impact of deliberative approaches (personal communication, Jodyn Platt) strengthens our recommendation that community engagement (including this and other approaches) needs further research measuring its impact to demonstrate full respect for the time, effort, and wisdom of communities. That is, as we practice community-based research methods, we must also study them.

We have followed similar methods for engaging communities in deliberations about community health priorities and Medicaid spending priorities. We hope to disseminate this process to other sites with partnerships to foster engagement of communities in decisions about how best to use limited resources. What do we think would be required for successful application? First, academic-community partnerships that, whether longstanding or new, commit to sharing power and resources. Second, tailoring CHAT content (e.g., options for spending limited resources) requires some training and the availability of information about costs. Sessions require facilitators trained in basic facilitation who also become familiar with CHAT. Perhaps most important, community deliberations about how best to use limited resources need to influence decisions about those resources. How best to accomplish that translation, of results into policy, remains unknown and would benefit from future investigation.

A network of minority and underserved communities partnered with an academic institution to create a statewide community to provide voice to minority and underserved communities about how best to spend limited health research resources through a CBPR process. Having started with the identification of health research priorities, we hope to continue to strengthen our relationships, build capacity for CBPR throughout the state, and connect community partners with researchers capable of engaging equitably and competently to meet their needs. We will continue to provide robust, inclusive, and accessible opportunities for communities to add their voices to resource allocation decisions related to health.

Resources

CHAT

<https://usechat.org>

DECIDERS

<https://deciders-project.med.umich.edu/>

Discussion Questions

1. How have you or others involved communities in setting research priorities or agendas?
2. Why use a “serious game” to engage communities about research priorities? What are some other potential applications of a tool such as CHAT?
3. One of the community leaders said “When are we gonna quit looking at all this stuff and do something about it?” What do you think the next steps should be for the partnership in DECIDERS?
4. How did the CHAT tool contribute to this partnership? What aspects of CHAT enriched the partnership, and how did the partnership employ the tool successfully?
5. The authors advocate for studying community engagement as well as practicing it. Do you agree with this imperative? What are some advantages and disadvantages to studying community-academic partnerships?

References

- Blacksher, E., Diebel, A., Forest, P.-G., Goold, S. D., & Abelson, J. (2012). What is public deliberation? *Hastings Center Report*. <https://doi.org/10.1002/hast.26>
- Burhansstipanov, L., Christopher, S., & Schumacher, S. A. (2005). Lessons learned from community-based participatory research in Indian country. *Cancer Control: Journal of the Moffitt Cancer Center*, 12(Suppl. 4), 70–76. <https://doi.org/10.1177/1073274805012004S10>
- Burkhalter, S., Gastil, J., & Kelshaw, T. (2002). A conceptual definition and theoretical model of public deliberation in small face-to-face groups. *Communication Theory*, 12(4), 398–422. <https://doi.org/10.1111/j.1468-2885.2002.tb00276.x>
- Callahan, D. (1999). Shaping biomedical research priorities: The case of the National Institutes of Health. *Health Care Analysis*, 7(2), 115–129. <https://doi.org/10.1023/A:1009401507982>
- Cohen, J. (1997). Deliberation and democratic legitimacy. In J. Bohman & W. Rehg (Eds.), *Deliberative Democracy: Essays on Reason and Politics* (pp. 67–92). Cambridge, MA: MIT Press.
- Coombe, C. (2012). Participatory evaluation and other approaches for evaluating community engagement and coalition building. In M. Minkler (Ed.), *Community Organizing and Community Building for Health and Welfare* (3rd ed., pp. 346–370). New Brunswick, NJ: Rutgers University Press.
- Danis, M., Ginsburg, M., & Goold, S. (2010). Experience in the United States with public deliberation about health insurance benefits using the small group decision exercise, CHAT. *Journal of Ambulatory Care Management*, 33(3), 205–214. <https://doi.org/10.1097/JAC.0b013e3181e56340>
- Danis, M., Ginsburg, M., & Goold, S. D. (2006). The coverage priorities of disabled adult Medi-Cal beneficiaries. *Journal of Health Care for the Poor and Underserved*, 17(3), 592–609. <https://doi.org/10.1353/hpu.2006.0103>
- Davey, S. (2004). *The 10/90 Report on Health Research 2003–2004*. Geneva, Switzerland: Global Forum for Health Research.
- De Vries, R., Stanczyk, A. E., Ryan, K. A., & Kim, S. Y. H. (2011). A framework for assessing the quality of democratic deliberation: Enhancing deliberation as a tool for bioethics. *Journal of Empirical Research on Human Research Ethics*, 6(3), 3–17. <https://doi.org/10.1525/jer.2011.6.3.3>
- Dror, D. M., Panda, P., May, C., Majumdar, A., & Koren, R. (2014). “One for all and all for one”: Consensus-building within communities in rural India on their health microinsurance package. *Risk Management and Healthcare Policy*, 7, 139–153. <https://doi.org/10.2147/RMHP.S66011>
- Eder, M., Evans, E., Funes, M., Hong, H., Reuter, K., Ahmed, S., ... Wallerstein, N. (2018). Defining and measuring community engagement and community-engaged research: Clinical and translational science institutional practices. *Progress in Community Health Partnerships: Research, Education, and Action*, 12(2), 145–156. <https://doi.org/10.1353/cpr.2018.0034>
- Fishkin, J. (1997). *The Voice of the People*. New Haven, CT: Yale University Press.
- Fleck, L. (2001). Healthcare justice and rational democratic deliberation. *American Journal of Bioethics*, 1(2), 20–21. <https://doi.org/10.1162/152651601300168852>
- Ginsburg, M., Goold, S. D., & Danis, M. (2006). From the field: (De)constructing “basic” benefits: Citizens define the limits of coverage. *Health Affairs*, 25(6). <https://doi.org/10.1377/hlthaff.25.6.1648>
- Goold, S. D. (1996). Allocating health care: Cost-utility analysis, informed democratic decision making, or the veil of ignorance? *Journal of Health Politics, Policy, and Law*, 21(1), 69–98.
- Goold, S. D., Biddle, A. K., Klipp, G., Hall, C. N., & Danis, M. (2005). Choosing Healthplans All Together: A deliberative exercise for allocating limited health care resources. *Journal of Health Politics, Policy and Law*, 30(4), 536–602. <https://doi.org/10.1215/03616878-30-4-563>
- Goold, S. D., Green, S. A., Biddle, A. K., Benavides, E., & Danis, M. (2004). Will insured citizens give up benefit coverage to include the uninsured? *Journal of General Internal Medicine*, 19(8), 868–874. doi:10.1111/j.1525-1497.2004.32102.x
- Goold, S. D., Myers, C. D., Danis, M., Abelson, J., Barnett, S., Calhoun, K., ... & Kim, H. M. (2018). Members of minority and underserved communities set priorities for health research. *Milbank Quarterly*, 96(4), 675–705. doi:10.1111/1468-0009.12354
- Goold, S. D., Myers, C. D., Rowe, Z., Danis, M., Gornick, M., Szymecko, L. A., ... Abelson, J. (in press). Evaluating deliberations about health research priorities. *Health Expectations*.
- Goold, S. D., Neblo, M. A., Kim, S. Y. H., Vries, R. De, Rowe, G., & Muhlberger, P. (2012). What is good public deliberation? *Hastings Center Report*, 42(2), 24–26. <https://doi.org/10.1002/hast.29>
- Goold, S. D., Rowe, Z., Szymecko, L., Coombe, C., Danis, M., Hammad, A., ... & Salman, C. (2016). The state as

- community in community-based participatory research. *Progress in Community Health Partnerships: Research, Education, and Action*, 10(4), 515–522. doi:10.1353/cpr.2016.0059
- Hall, M. A., Camacho, F., Lawlor, J. S., DePuy, V., Sugarman, J., & Weinfurt, K. (2006). Measuring trust in medical researchers. *Medical Care*, 44(11), 1048–1053. https://doi.org/10.1097/01.mlr.0000228023.37087.cb
- Health Resources & Services Administration. (n.d.). Medically Underserved Areas and Populations (MUA/Ps). Retrieved February 16, 2018, from https://bhw.hrsa.gov/shortage-designation/muap
- Hofstede, G. J., de Caluwé, L., & Peters, V. (2010). Why simulation games work-in search of the active substance: A synthesis. *Simulation and Gaming*, 41(6), 824–843. https://doi.org/10.1177/10468781110375596
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202. https://doi.org/10.1146/annurev.publhealth.19.1.173
- Israel, B., Schulz, A., Coombe, C., Parker, E. A., Reyes, A.G., Rowe, Z., & Lichtenstein, R. (2019). Community-based participatory research: An approach to research in the urban context. In S. Galea, C. Ettman, & D. Vlahov (Eds.), *Urban Health* (pp. 272–282). Oxford, UK: Oxford University.
- James Lind Alliance. (n.d.). About the James Lind Alliance. Retrieved February 16, 2018, from http://www.jla.nihr.ac.uk/about-the-james-lind-alliance/
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research*, 1(2), 112–133. https://doi.org/10.1177/1558689806298224
- Knobloch, K. R., Gastil, J., Reedy, J., & Cramer Walsh, K. (2013). Did they deliberate? Applying an evaluative model of democratic deliberation to the Oregon Citizens' Initiative Review. *Journal of Applied Communication Research*, 41(2), 105–125. https://doi.org/10.1080/00909882.2012.760746
- Lomas, J., Fulop, N., Gagnon, D., & Allen, P. (2003). On being a good listener: Setting priorities for applied health services research. *Millbank Quarterly*, 81(3), 1583–1584.
- Mayer, I. S. (2009). The gaming of policy and the politics of gaming: A review. *Simulation and Gaming*, 40(6), 825–862. https://doi.org/10.1177/1046878109346456
- Myers, C. D., Gordon, H. G., Kim, H. M., Rowe, Z., & Goold, S. D. (2018). Does group deliberation mobilize? The effect of public deliberation on willingness to participate in politics. *Political Behavior*, 1–24. https://doi.org/10.1007/s11109-018-9507-z
- Myers, C., & Mendelberg, T. (2013). Political deliberation. In L. Huddy, D. O. Sears, & J. S. Levy (Eds.), *The Oxford Handbook of Political Psychology* (2nd ed., pp. 699–734). Oxford, UK: Oxford University Press.
- National Institute for Health Research. (n.d.). *Patient and Public Involvement*. Retrieved February 16, 2018, from https://www.nihr.ac.uk/patients-and-public/
- Neblo, M. A. (2007). Family disputes: Diversity in defining and measuring deliberation. *Swiss Political Science Review*, 13(4), 527–557. https://doi.org/10.1002/j.1662-6370.2007.tb00088.x
- Patient-Centered Outcomes Research Institute. (n.d.). *What we mean by engagement*. Retrieved February 16, 2018, from http://www.pcori.org/funding-opportunities/what-we-mean-engagement
- Pierson, L., & Millum, J. (2017). The limits of research institutions in setting research priorities. *Journal of Medical Ethics*, 43(12), 810–811. https://doi.org/10.1136/medethics-2016-103998
- Resnik, D. B. (2001). Setting biomedical research priorities: Justice, science, and public participation. *Kennedy Institute of Ethics Journal*, 11(2), 181–204. https://doi.org/10.1353/ken.2001.0017
- Sánchez, V., Carrillo, C., & Wallerstein, N. (2011). From the ground up: Building a participatory evaluation model. *Progress in Community Health Partnerships: Research, Education, and Action*, 5(1), 45–52. https://doi.org/10.1353/cpr.2011.0007
- Selby, J. V., Beal, A. C., & Frank, L. (2012). The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA*, 307(15), 1583–1584. https://doi.org/10.1001/jama.2012.500
- Solomon, S., & Abelson, J. (2012). Why and when should we use public deliberation? *Hastings Center Report*, 42(2), 17–20. https://doi.org/10.1002/hast.27
- U.S. Department of Justice. (n.d.). *Herfindahl-Hirschman Index*. Retrieved from https://www.justice.gov/atr/herfindahl-hirschman-index.
- Vayena, E. (2014). The next step in the patient revolution: Patients initiating and leading research. *BMJ*, 349, g4318. doi:10.1136/bmj.g4318
- Viergever, R. F., & Hendriks, T. C. C. (2016). The 10 largest public and philanthropic funders of health research in the world: What they fund and how they distribute their funds. *Health Research Policy and Systems*, 14(1), 12. https://doi.org/10.1186/s12961-015-0074-z

• Appendix •

TABLE 2.5 • Relationships Between Demographics and Views of Deliberation

Dependent Variables →	I would support using our group's decision to inform decision makers ^a	I would trust a process like this to inform funding decisions ^b	Sufficient information and choices ^c	Insufficient information and choices ^d	Views of deliberation ^e
Independent Variables ↓	Beta Coefficient	Beta Coefficient	Beta Coefficient	Beta Coefficient	Beta Coefficient
Age	.002	.001	.000	.001	.001
Gender	.111	.034	.142 [†]	.256 [†]	.075
Race					
White	-.233	-.315	-.047	-.122	.012
Black	-.072	-.308	-.010	-.048	.015
AmerIndNatAl	-.123	-.160	-.066	-.494	-.077
ArabArAm	-.222	-.387	-.116	.106	.146
Other	.092	-.202	-.056	-.279	-.134
Hispanic	.052	-	-.156	-.059	-.123
Education					
HS or less	-.044	-.018	-.345 [†]	-.080	-.174 [†]
Some College	.012	-.073	-	-	-
College Degree	-	-	-.024	-.017	.100
Income					
Less Than \$15,000	.005	-	-	-	-
\$15,000 to \$34,999	.022	-	-	-	-
Rural	-	-	.122	.120	-
Sufficient Info and Choices	.289 [†]	.387 [†]	-	-	-
Insufficient Info and Choices	-.026	-.006	-	-	-
Views of Discussion	.742 [†]	.476 [†]	-	-	-

Dash (-) indicates variable not included in model based on bivariate analyses

[†]p < 0.05; [‡]p < .0001

^a Dependent variable = Favorable views of information and choices (scale score); independent variables included age, gender, educational attainment, race, Hispanic, rural residence

^b Dependent variable = Unfavorable views of information and choices (scale score); independent variables included age, gender, educational attainment, race, Hispanic ethnicity, and rural residence

^c Dependent variable = Views of Deliberation (scale score); independent variables included age, gender, race, Hispanic ethnicity and educational attainment

^d Dependent variable = I would support using our group's decision to inform decision makers (5-point Likert scale); independent variables included age, gender, race and educational attainment, views of information and choices, views of deliberations

^e Dependent variable = I would trust a process like this to inform funding decisions (5-point Likert scale); independent variables included age, gender, Hispanic ethnicity, income and educational attainment; views of information and choices, and views of deliberations