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Community-Based Dialogue: Engaging Communities of Color in the United States' Genetics Policy Conversation

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Abstract

Engaging communities of color in the genetics public policy conversation is important for the translation of genetics research into strategies aimed at improving the health of all. Implementing model public participation and consultation processes can be informed by the Communities of Color Genetics Policy Project, which engaged individuals from African American and Latino communities of diverse socioeconomic levels in the process of "rational democratic deliberation" on ethical and policy issues stretching from genome research to privacy and discrimination concerns to public education. The results of the study included the development of a participatory framework based on a combination of the theory of democratic deliberation and the community-based public health model which we describe as "community-based dialogue."

Introduction: Why Is It Important to Engage Communities of Color in the Genetics Conversation?

Throughout the history of the United States, the science of heredity has been used to provide "scientific" support for discriminatory practices and racist social policy. For example, during the eugenics movements of the late-nineteenth and early-twentieth centuries, racist and discriminatory propaganda was touted as empirically justified, resulting in state and federal policies which supported and exacerbated race-based inequalities (Paul 1998). Later, when sickle-cell disease was first characterized, it was thought to be a "race-specific disease," exclusively present in blacks and thus a biological identifier of race (Editorial Comment 1947). Armed with this false assumption, certain researchers claimed that interracial marriage should be outlawed for the health of the public, arguing that miscegenation could "directly

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The authors honor their deceased colleague Marian Gray Secundy, PhD, coprincipal investigator of the Communities of Color and Genetics Policy Project for her scholarship in the field of bioethics and leadership in engaging minority communities in public deliberation in addressing the racial and ethnic health inequities in the United States.

endanger the white race by the transmission of the sickle trait" (Gamble 1999). The most well-known example of harms done to communities of color in the name of science was the United States Public Health Service Syphilis Study, enduring from 1932 to 1972 (Brandt 2000; Jones 1993). These incidents, mingled with everyday experiences of racism, have left communities of color questioning the trustworthiness of the biomedical research industry, the federal government, and the U.S. health care system (Gamble 1997).

Realizing the benefits from genetics and genomics research[1] depends in part upon who is involved in shaping the policies that determine how the science proceeds. If these policies are shaped exclusively by the interests of the biotech industry, research institutions, and special interest groups, and if genetic knowledge is disseminated with the distortions that have typified some popular media (Lynch and Condit 2006;Lezemore 2002;Peterson 2001), the benefits of genomics are likely to broaden the gap between the health care haves and have-nots, and the public's misunderstanding of genetics may increase discrimination against and stigmatization of communities of color. Several examples of past, current, and proposed genomics research initiatives point out the need for broad public engagement, especially among communities of color, in the process of developing policies to guide the conduct and application of genomics research.

Genetic Developments and the Issues They Pose

Uncovering the Human Genome

In April 2003, the International Human Genome Sequencing Consortium declared that it had successfully sequenced the human genome, fulfilling the principal goal of the Human Genome Project (HGP) (NHGRI, DOE 2003). This landmark accomplishment received great fanfare, particularly within the scientific community, as a major step toward identifying the genetic contributions to many common diseases. Accompanying the initiation of the Human Genome Project in 1990, the National Institutes of Health (NIH) and its National Center for Human Genome Research set aside 5 percent of its budget for the exploration of ethical, legal, and social implications (ELSI) of genomic research and technologies. With new genetic research discoveries emerging, biotech companies, clinicians, and policy makers began to contemplate the creation of new screening programs for cystic fibrosis, familial breast cancer, and cholesterol-related ApoE, among others. As a result, issues such as testing safety, adequacy of consent, privacy and ownership of information, and group discrimination received intense attention.

Race, Ethnicity, and Human Genetic Variation Research

Today, an intense effort is under way to catalog human genetic variation and understand its role in the differences in health between individuals. With more than 3 million single nucleotide polymorphisms charted, the journal *Science* declared "Human Genetic Variation" the 2007 breakthrough of the year (Pennisi 2007). While most of the relatively small amount of genetic variation that does exist between individuals is shared among the world's populations, 3 to 5 percent of it is attributable to differences between human population groups (Rosenberg et al. 2002).

Researchers have reported using genetic markers to classify individuals into four to six racial or ethnic groups (Barbujani and Belle 2006; Tang et al. 2005). Recent research has reported different distributions of gene variants or polymorphisms related to risk for myocardial

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[1] Genetics is the study of genes and their effects. Genomics is the integrated study of the functions of genes, their regulatory signals, and their interactions with the environment and other genes.

infarction (Helgadottir et al. 2006), prostate cancer (Freedman et al. 2006), and pre-term birth (Wang et al. 2006) by populations linked to racial and ethnic groups.

The renewed interest in and controversy about the relationship between socially constructed racial and ethnic categories and genetics has resulted in numerous scholarly meetings (MIT Center for the Study of Diversity in Science, Technology, and Medicine 2007; Center for Race and Ethnicity at Rutgers University 2008; Wolf 2006; Genetics and Public Policy Center 2004; National Human Genome Center 2003); written academic discourse (Cho 2006; Anderson and Nickerson 2005; Cooper, Kaufman, and Ward 2003); and coverage in the news media, including opinion pieces in major newspapers (Katz 2006; Leroi 2005). The controversy has encompassed the development and marketing of the first race-based pharmaceutical (Bibbins-Domingo and Fernandez 2007; Harty, Johnson, and Power 2006; Duster 2005; Temple and Stockbridge 2007) and genetic tests used to determine ancestry (Bolnick et al. 2007).

Genomics and Racial and Ethnic Health Disparities Research

Racial and ethnic differences in health outcomes are recognized as important health policy issues (U.S. Congress 2007a; Frist 2005; Kennedy 2005). Scholars have described racial and ethnic health disparities as an issue of distributive justice (Gamble 2006). A call has been made for the federal government, together with researchers, to set an outcome-oriented national agenda to reduce racial and ethnic health disparities (Gibbs et al. 2006). However, racial and ethnic health disparities may be exacerbated if researchers assume that the basis of these disparities is solely genetic and thus conduct studies in a manner that appears to affirm a genetic basis for racial differences in disease prevalence (Sankar et al. 2004). Even well-meaning policy makers who take these studies at face value could create policies that harm rather than benefit racial and ethnic minority groups' health. Harms may result from concentrating on genetic contributions to disease and health without attending to systemic social contributions to health. The gap in health outcomes among racial and ethnic groups may also be widened by lack of universal access to genetic clinical services and new therapies. In spite of the aim of leaders in genomics research to develop genome-based tools that improve the health of all, access to the benefits of the genomic revolution may not be shared equally, and people of color may not receive the benefits at the same level as white Americans and high socioeconomic status groups. Importantly, the next phase of scientific inquiry into the human genome and human genetic variation is likely to have profound social and political impacts, with special relevance for communities of color (Bonham, Warshauer-Baker, and Collins 2005).

Future Directions in Genomics Research

In March 2007 the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) issued a report looking at policy issues associated with a possible national longitudinal cohort study to understand the major environmental and genetic contributors to common illnesses. With other countries creating national biobanks and gathering genetic, clinical, and environmental information, a conversation within the scientific community has continued to build. It is envisioned that a longitudinal cohort study would analyze environmental exposures, genetic risk factors, lifestyle, and medical experiences of a cross section of America (Collins 2004). To have maximal benefit, such an initiative requires that research participants reflect the diversity of the United States' population (SACGHS 2007).

Need for Engagement

The benefits and social implications for people of color[2] (ibid.) of current genomic research, including genetic variation research, require their engagement. While issues of race and genetics have been discussed at a number of scholarly meetings, rarely has the lay public been involved. The few discussions engaging the public on the topic of race and genomic policy, while valuable in their own right, have been dominated by researchers and health professionals or have been only minimally successful in recruiting individuals of color. Many members of communities under-represented in the scientific discourse do not recognize the social and political significance of the sequencing of the human genome and its subsequent use and research initiatives. The Secretary's Advisory Committee on Genetics, Health, and Society has concluded that there is a need for public conversation about the undertaking of the proposed large population gene-environment study (SACGHS 2007). Focus groups (Kaufman et al. 2008) and critical analyses (Chaufan 2007) have begun to articulate the associated ethical and risk-benefit issues, but it is important that conversations reflect the outlooks of diverse U.S. communities, including different racial and ethnic groups.

Federal Legislative Initiatives

The importance of establishing models to engage of communities of color in genomics policy making has been recently reinforced by several federal legislative initiatives focusing on genetics. On March 23, 2007, then Senator Barack Obama introduced Senate Bill S. 976, the Genomics and Personalized Medicine Act, with the goal of improving access to the validated benefits of genomics research and the promise of personalized medicine for all Americans (U.S. Congress 2007a). This bill is a reintroduced version of the 109th Congress Senate Bill 3822, which contained language focused on the study of race, genomics, and health. Obama first called for public input regarding the inclusion and designation of racial and ethnic populations in genomics research in Senate Bill S. 3822 and later provided similar language as an original cosponsor to Senate Bill S. 1576, the Minority Health Improvement and Health Disparity Elimination Act, introduced by Senator Edward Kennedy on June 7, 2007. Senate Bill S. 1576 contained provisions to: (1) track cultural competency training in the health professions; (2) establish a plan for funding grants and contracts for research to improve the health of racial and ethnic minorities; and (3) ensure that genomics research focuses on genetic variation within and between populations, with a focus on racial and ethnic minority populations. Senate Bill S. 1576 called for a summit to provide guidance in these areas, requiring representation by leaders of community organizations working to reduce disparities (U.S. Congress 2007b). The effective implementation of such legislation would require that, as a country, we develop effective models of engaging communities of color in the genetics policy development process.

The above legislative activity demonstrates that we are at a moment in history where members of the public must be participants in the social, scientific, and political conversation with scientists, ethicists, policy makers, and those who make their livings from the study of the human genome. What do the findings to date mean for individuals, their families, and communities? How should information regarding people of color be interpreted by scientists, media, and policy makers? Will the public, particularly communities of color, feel comfortable participating in large-scale genomic studies and a national longitudinal cohort study of genes and the environment? How should we go about identifying the models of public participation contemplated in Senate Bill S. 1576?

Background: Developing a Framework for Community Dialogue

Literature on the process of working with communities to establish models of genetics education and policy development is limited. This article proposes a framework for the engagement of communities of color in genetics education and the development of genetics policies, and it describes one successful project that may serve as a model for such engagement.

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[2] "People of color" is a term that varies in use and context; for the purposes of this study it is defined as individuals who self-identify as African American, black, Hispanic, or Latino.

First, we introduce participatory democracy as a means of developing social policy. Second, we outline a community-based public health model for disease prevention and health promotion interventions. Third, we show how the fusion of these two theoretical frameworks, one from political philosophy and the other from public health, can be combined to create a new model, which we call community-based dialogue. Fourth, we demonstrate the usefulness and feasibility of community-based dialogue by providing details of the design and implementation of the Communities of Color and Genetics Policy Project (CCGPP). Last, we discuss the lessons that we learned from the process, unexpected project outcomes, and limitations of the process.

Participatory Democracy

Rational Democratic Deliberation

Participatory democracy is a means of generating public policy that is both factual and value-laden. The values that should count include those representing and expressed by everyone affected by the policy, not just a subset (Dryzek 1990). Democratic deliberation, or democratic discourse,[3] is a major form of participatory democracy from political philosophy in which participants are free and equal. First, social status, wealth, occupation, gender, ethnicity, religion, race, and other group characteristics may not exert any restrictions on participation. Second, participants are bound by the outcomes of the deliberative process. Third, they are required to use only those rational arguments that they reasonably believe their fellow participants will find convincing (Fleck 2008: chapter 5). Participants in democratic deliberation are then able and called upon to “consider the arguments offered on their merits. They listen and participate with openness to the reasons given on one side or another” (Fishkin 1993: 37).

Limitations of Rational Democratic Deliberation

While democratic deliberation benefits from representativeness of viewpoints, it also suffers from limitations. In restricting public discourse to rational argument, advocates of democratic deliberation essentially claim that there are no other forms of expression that are legitimate in policy making. This particular restriction favors those who both can and wish to articulate their concerns through reasoned analysis, skewing the conversation to be more suited to some members of the polity than others. As Iris Marion Young argues, “the norms of deliberation are culturally specific and often operate as forms of power that silence or devalue the speech of some people” (Young 1996: 123).

The types of communication that individuals feel most comfortable employing in policy conversations and find most appropriate for expressing their concerns may vary. There are many ways in which people can and do communicate meaningfully, aside from the traditional Western philosophical ideal of providing and defending reasons. Expressions of assumptions, fears, hopes, beliefs, and concerns may or may not fit into a strictly reason-based framework, but may more authentically convey legitimate issues that are relevant to policy decision making.[4]

Democratic deliberation has also given limited attention to the context within which the policy conversation takes place. Context includes who organizes the discourse, when and where it

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[3] While some scholars may make a distinction between democratic deliberation and democratic discourse, we feel they share enough relevant features for us to group them together here.

[4] While the role of reason should not be overemphasized in public deliberation, it should not be underemphasized either. Ultimately, public policies need to be justified and legitimated to all who are affected by those policies. The work of justification is necessarily the work of reason. That same appeal to reason and balanced judgment can govern community deliberations regarding the uses of the new genetic technologies.

takes place, who leads or moderates, the format, and who else participates. Some individuals may feel comfortable coming to a hospital or government building and having the conversation led by a public health official, for example. Others may feel more comfortable meeting in a church, while others may rather meet in a secular community center. Undergoing political discourse in a poorly matched context may impede individuals' willingness or ability to participate fully.

Community-Based Public Health and Community-Based Participatory Research

The community-based public health (CBPH) model for disease prevention and health promotion interventions has gained increasing attention by public health officials and academically based scholars during the past fifteen years. Rather than applying health programs in a top-down manner, with health professionals carrying out interventions *on* a community, the CBPH model involves forming partnerships *between* public health professionals and community-based organizations (CBOs). Through these partnerships, the community whose health is the focus of the intervention identifies and assumes ownership of the health problem by actively working together with health professionals throughout the various project phases. This partnership model of public health is particularly effective in dealing with the chronic diseases that currently account for the highest levels of mortality and morbidity, the prevention of which require committed changes in individual behavior and community modifications to the social and physical environment (Institute of Medicine [IOM] 2002).

A parallel process of CBPH, community-based participatory research (CBPR), has also developed, involving mutual partnerships between academic institutions and CBOs sharing in the identification of the problem to be studied, the design of the research, and the application and dissemination of its findings (Israel et al. 2006, 2005; Kieffer et al. 2005).

CBPR both recognizes the community as a primary unit of identity demanding collective attention and follows an asset- rather than a deficit-based model. Asset-based models start with the discovery of communities' capacities and assets rather than needs and deficiencies. Strengths and talents of individuals, organizations, and institutions are empowered to utilize the assets of the community. The health services, community advocacy, and church-related organizations involved in the CCGPP exemplify this approach.

Community-based engagement often focuses its primary attention to social inequalities within the community. In this project, participants were keen to point out instances where access inequalities and discrimination might arise, leading to constructive policy recommendations. Mutual benefit is an important principle and essential ingredient in community-based efforts (Israel et al. 2006). For this project, community organization leaders and project investigators and staff held policy meetings with legislators and staff in Alabama and Michigan as well as with congressional members and staffers in Washington, DC, to convey project materials and make sure community voices reached policy makers.

Community-Based Dialogue in the Context of Participatory Research

Community-based dialogue, used by the CCGPP, draws from the theoretical frameworks of democratic deliberation and community-based public health. It incorporates some of the features of democratic deliberation and seeks to avoid its limitations by incorporating principles of community-based public health participatory research and practice. The goal of community-based dialogue, unlike the goal of democratic deliberation, is not to reach the best *reasoned* decision; it is instead to use a community structure to situate a policy-oriented conversation in which fellow citizens truly appreciate each other's needs. In dialogue, citizens see themselves as equals, situationally empathize, and bring their underlying feelings, thoughts, and motivations to the fore (Yankelovich 2001). Context is seen as important, and all forms of expression that do not undermine the building of mutual respect are legitimate.

Community-based dialogue is a process of recognition of a social problem or issue where there is a shared concern among members of a community. The methodologic hypothesis behind the CCGPP was that awareness of a problem is based on a shared racial, ethnic, religious, geographic, or social structure with which the participants of an organized dialogue group can identify. A common “code” exists based upon common experiences of striving against real structural obstacles.

The Communities of Color and Genetics Policy Project

Project Design

The CCGPP used this fusion of participatory democracy and community-based participatory research to develop a set of recommended policies to guide the use and application of genetic knowledge in ways that would avoid harms and maximize benefits for communities of color. The project sought to engage African American and Latino communities of diverse socioeconomic levels in the process of community-based dialogue on moral and political issues relating to genomic research and technology.

The project consisted of a series of linked phases to: (1) identify community-based organization partners that would convene the dialogue groups; (2) recruit the participants in the dialogues; (3) convene focus groups to identify issues of concern from their communities; (4) develop education- and issues-oriented materials relating to the topics; (5) train dialogue facilitators; (6) convene the community-based dialogues to select issues of concern to the groups and carry out a series of dialogue sessions; (7) analyze the output of the dialogue and identify the common themes and recommendations of the fifteen groups; and (8) disseminate the findings of the project, including convening policy meetings at the state and federal levels (see figure 1).

Two hundred and thirty-eight individuals participated in the dialogues. The dialogue sessions were held in seven different geographic areas in two states (Michigan and Alabama) over a seven-month period, from November 1999 to June 2000. Half of the ten African American dialogue groups were based in Tuskegee, Alabama; two in Flint, Michigan; two in East Lansing, Michigan; and one in Ann Arbor, Michigan. Due to demographics (three major Michigan cities >10 percent Latino; Tuskegee, 0.7 percent Latino), all five of the Latino dialogue groups were held in Michigan, with two in Grand Rapids, one in Saginaw, one in Lansing, and one in Ann Arbor. Each of the dialogue groups met for a total of six two-hour sessions (five theme-driven plus one recommendation summation session). The sessions took place independently of any other preexisting organizational activities. Compensation of participants varied by organization, with some groups offering stipends (range: $25–125); others, meals. The median sex ratio of the Michigan African American groups was 47 percent male to 53 percent female. The Tuskegee groups were all predominantly female, with the sex ratio varying from 0 percent male/100 percent female to 35 per cent male/65 percent female. The majority of participants in all but five of the fifteen dialogue groups reported a household income of $45,000 or less per year (Singer et al. 2001: 4). (See tables 1, 2a, and 2b for a more detailed description of the demographics of each dialogue group.)

The CCGPP research team was diverse by discipline, gender, race, and ethnicity. The team included both African American and Latino researchers in key roles in the project. The project involved investigators from three different research universities, all of which had collaborated in the former “Genome Technology and Reproduction” genetics policy project — the University of Michigan, Michigan State University, and Tuskegee University — the latter a historically black university. Bringing a diverse group of ethics researchers, social scientists, and experts in the field of genetics together to analyze the outcomes of the dialogue process and policy consensus processes was important to achieving the project aims.

The project also established a national advisory board of experts with diverse backgrounds and disciplinary perspectives, including expertise in community dialogue, issues of race and genetics, and bioethics. Two joint meetings of this National Advisory Board (NAB) and the Community Advisory Board (CAB) were held for the research team to draw upon input from both. The NAB included representatives from the Hastings Center for Bioethics, the Division of Community and Minority Programs of the Association of American Medical Colleges, and the National Conference of State Legislatures, among others.

The Role of Community-Based Organizations

Community-based organizations in communities of color can raise the awareness of their constituents and the larger community to public policy issues. CBOs serve as what Robnett (1997) refers to as “bridge organizations,” intermediaries between rank-and-file members of their organizations and the larger community on the one hand, and external actors (e.g., researchers, policy makers) who are not indigenous to the communities where the research activity is taking place.

A critical element in the design and implementation of the CCGPP was the role played by fifteen preexisting community-based organizations (ten African American CBOs; five Latino — see table 1) who partnered with the academic team of researchers. The groups convened by CBOs included affiliates of national service organizations (fraternal and advocacy organizations, such as the National Urban League), local community service organizations (support groups, advocacy groups, and health organizations, such as the Tuskegee Support Group of Individuals with Disabilities and Clinica Santa Maria of the St. Mary’s Mercy Medical System), and faith-based organizations (churches and faith-based service agencies, such as Bethel AME Church and Flint Faith Access to Community Economic Development). Project faculty of the three universities had previously established relationships with these CBOs. The Detroit Urban Research Center (URC) was also helpful in the CBO identifying process. CBOs were each offered $5,000 from principal project funding and the chance to create recommendations that would be passed directly to policy makers and the public.

The CBOs were represented collectively by the project’s Community Advisory Board (CAB), a group that proved to be at least as important to securing the project’s desired outcomes as the academic research team itself. As figure 2 describes, the CAB was established as an organized group composed of a representative of each of the organizations that participated in the project. It served as a liaison between the project team and the CBOs. The CAB consisted of a group of people reflecting diversity of background, social status, and educational level. CBOs were asked to choose for themselves the representative to attend and one alternate. Some representatives held high-ranking positions in their organizations. Others were members who did not hold any formal leadership roles.

Even though most of the CAB representatives were otherwise employed full time, they were expected to carry out a number of responsibilities as partners in the study. These included participating in project team meetings, relaying concerns and pertinent information between the project team and the CBOs, developing recruitment strategies to ensure the participation of CBO members in the dialogue sessions, reviewing proposed educational materials and draft reports, and participating in the writing of dialogue summaries and project reports intended for dissemination. CAB representatives received a modest compensation for their involvement in this project.

Being knowledgeable about the needs and characteristics of the communities they served, CAB leaders were invaluable in helping to shape the design of the project to assure the acceptability of the dialogue process by community members. For example, the community-based organizations in Tuskegee proposed that the research team first hold informal sessions with CBO members. This allowed a member of the project team (usually the project director) to describe the project and propose opportunities for collaboration. More importantly, it allowed the CBO members to have a face-to-face meeting with one of the lead investigators of the project before the design of the project was finalized. CBOs were thus able to emphasize to their constituents that the project was “owned” mutually, in terms of design, conduct, and outcomes, by the community and its academic partners rather than being carried out *on* the community by the universities.

Recruitment and Project Implementation

Recruiting by investigators can lead to less commitment on the part of those contacted, and less success in participant enrollment, than recruitment efforts from within the community. The advantages of utilizing CBOs in participant recruiting are several: (1) CBOs are recognized by their membership as having the members’ true interests in mind; (2) CBOs can recommend changes to make community projects relevant to the community’s interests; and (3) they have an established membership network that can facilitate recruiting. For the CCGPP, CAB leaders (CBO spokespeople serving as project Community Advisory Board members) were critical in successful recruiting of African American and Latino participants, each applying their own individual stamp to how recruiting was conducted. CAB leaders attended church meetings, contacted community colleges, made phone calls, distributed written materials, broadcast via media and the Internet, and invited groups to restaurants with culturally oriented cooking to describe the project. CAB leaders were also responsible for choosing dialogue sites (e.g., the CBOs’ meeting places and organizational spaces, churches, community organizational facilities) and timing along with deciding on provision of food, transportation, and child care.

CAB members worked in tandem with the research team to select facilitators, many coming from within the community. Criteria for selecting facilitators (language fluency, influence in the community, conversational flexibility) were provided by CAB members at their second meeting. Creation of facilitators’ guides was a collaborative effort between the research team and CAB members, resulting in guides of reasonable length that gave discretion to facilitators in the directions they chose for dialogue. CAB members simplified the educational materials used and brought in material from news and popular magazines. Restructuring the facilitator’s guide format and revising the project’s educational materials were viewed by CAB members as good examples of how their input was incorporated (Caldwell 2000: 8).

Topics chosen for dialogue discussion were a melding of themes decided on by the dialogue groups, by the recommendations of the preceding focus groups from the same communities, and the research team. Recognizing their responsibility to constituents, CBOs worked with their academic partners to assure that written materials emerging from the project accurately reflected the voices of the community rather than being diluted through translation. When the dialogues were finished, each dialogue group with its facilitator wrote a report of the areas it covered and its recommendations. CAB members chose coauthors from within their ranks and, together with the project team, consolidated the group reports into two collective pieces — an interim Grid Report (CCGPP 2000a) and a final Summary Dialogue Report — reformulating the latter into position papers for policy makers (CCGPP 2001: www.sph.umich.edu/genpolicy). Policy recommendations covered seven topic areas: access to genetic testing and services; education; playing God and creating perfect children; the right to genetic privacy; genetic research; genetic testing; and trust and distrust. To assure faithfulness to what was verbalized in the dialogues, dialogue participants helped formulate recommendations and wording at each stage (CCGPP 2000b: 4).

Project Outcomes

Substantive Recommendations and Their Relevance to Current Policy Debate

CCGPP recommendations relate to current policy issues that society faces in the field of genomics, including regulatory, research, and clinical translation. For example, in the commercial sector, the number of genetic tests (chronic conditions, nutrigenomics, paternity, and ancestry) offered direct to consumers (DTC) on the Internet has been skyrocketing, with very little regulation to assure safety of consumer use (Hudson et al. 2007; Javitt 2006). While CCGPP participants recommended "strong regulations to protect genetic information," the popularity of DTC tests in spite of their lack of regulation may be due to the strong preference, articulated by CCGPP participants, "to make genetic testing anonymous" (CCGPP 2001, rpt. 3: 17). One participant even suggested that home genetic test kits be developed in order to prevent the possibility of others' accessing one's personal genetic information. Other safety-related recommendations, however, emphasize the need for external oversight of private companies involved in genetic research and development. In addition, a clinical practice recommendation emphasizes the importance of personal physicians ordering genetic testing since they can inform the individual about the pros and cons of a specific test (ibid.: 17, 21). These recommendations reflect the tenor of a Government Accountability Office report that documented troubling marketing practices by some DTC companies as well as a Federal Trade Commission consumer alert advocating caution about claims made by some companies (Hudson et al. 2007). These issues were addressed in a bill introduced in 2007 by Senator Edward Kennedy, S. 736 — the "Laboratory Test Improvement Act," bringing all laboratory-developed tests, including those offered directly to consumers, under FDA supervision (U.S. Congress 2007c).

The Summary Dialogue Report offered twelve recommendations specific to genetic research, including genetics and aging research, chronic disease, and research with human embryonic stem cells. Communities were concerned about the participation of their members in this research. As one group suggested, "If heart disease is more prevalent among African Americans than other groups, then research connected to heart disease should include a higher ratio of African Americans to reflect that fact" (CCGPP 2001, rpt. 3: 24). Likewise, dialogue members indicated that risks associated with genetic research, such as group labeling or unauthorized disclosure of information, should be equally borne by all the groups involved.

The communities also discussed mandated disclosure of personal genetic information to family members. The majority of dialogue participants felt such a requirement would be inappropriate since it violated the patient's privacy. A significant minority argued that such a law, requiring disclosure, would be a good thing to put in place since it could help family members in a preventive or preparatory way. Others felt the information could equally burden family members, who might feel their insurability jeopardized. Participants having heard each other's points of view, the final recommendation was worded in terms of an overall majority opinion, with the minority opinion appearing below it (ibid.: 15).

A significant dialogue occurred about genetics research oversight and the need for ethical protections. Both the SACGHS report and CCGPP recommendations also stress the importance of some form of independent oversight to insure adequate protections. The CCGPP recommendations clarify that oversight should extend beyond the individual level, e.g., adequacy of informed consent, to the societal level to establish that communities are adequately educated in the details of the effort, allowing an informed and genuine commitment. The SACGHS report recognizes that population gene-environment research is likely to have material spinoffs, particularly in the areas of toxicogenomics and pharmacogenomics (SACGHS 2007). Underserved racial/ethnic communities are frequently located in urban environments with elevated levels of lead, asthma- provoking contaminants, and factory pollutants (Olden and White 2005). Health services associated with genetic testing, whether for environmental susceptibilities or drug toxicities, should be affordable for all.

Scientists and policy makers currently display a lack of unanimity on the cost-benefit analysis for genetic projects that are national in scope. Population studies could be used to pinpoint the environmental and biological mechanisms underlying breast and prostate cancer mortality in African Americans, but will this knowledge translate into effective public health policies (Chaufan 2007; Hayanga and Newman 2007)? Participants recommended avoidance of policies that would mandate racially or ethnically based genetic testing, but they maintained openness to testing policies that might benefit minority health (CCGPP 2001, rpt. 3: 21). The CCGPP Summary Report correspondingly recommends an increase through training in the number of genetics-related scientists and researchers representing communities of color (ibid.: 30).

An omnipresent backdrop to the use of genetic tests is the possibility of genetic discrimination. The Genetic Information Nondiscrimination Act (GINA) was passed by the U.S. Senate (95–0 vote) and House (414–1 vote) and signed into law by President Bush on May 21, 2008 (Genetic Information Nondiscrimination Act, Pub. L. No. 110–233, 122 Stat. 881 [final passage May 21, 2008]). GINA provides uniform federal protection for health care consumers from genetic discrimination by insurers and employers and is the fruit of more than a decade of effort by many advocates. CCGPP participants were in full support of GINA, having recommended federal laws and regulations to prevent insurers and employers from requiring DNA testing and using genetic test results to discriminate against the individual (CCGPP 2001, rpt. 3: 14).

Community Voices

Development of these recommendations and many others required a large amount of time and significant buy-in from community members. Was involvement in a series of genetic dialogues worth it for them, and how did the above recommendations comport with people’s individual feelings? Views expressed by dialogue participants showed the project’s perceived relevance. Dialogue participants expressed a personal interest in health care avenues that could benefit their well-being. Between 20 and 50 percent of dialogue participants reported the presence of a genetic illness in a family member (this number rose to 92 percent for participants in the Tuskegee Support Group for Individuals with Disabilities) (Singer et al. 2001: 5). One dialogue group discussed diseases affecting ethnic groups, focusing on diabetes and its prevalence in Latino communities (CCGPP 2000a: 11). Likewise, a large number of focus group participants voiced hope that genetic advancements could bring relief to family members with diabetes, sickle-cell disease, and high blood pressure. “I am very interested in this topic personally because in my family there is a genetic problem. It is very important to be more knowledgeable” (Schulz, Caldwell, and Foster 2003: 157). The frequent mention of personal hopes and concerns over heritable family conditions pointed to the value of the dialogues.

Twinned with hope were concerns, especially relating to privacy, discrimination, and access to services. One dialogue group noted the plethora of hospital workers other than trained physicians who might have access to patients’ personal information. “With personal health history at their fingertips — who’s to stop them from using this information in a way for which it was not intended?” (CCGPP 2000a: 102). A second major concern was that African Americans and Latinos tested might not receive the same support for their conditions as others, or might suffer genetic discrimination for confirmation of a condition or predisposition by a genetic test. The theme of access to services was discussed:

> P1: At a very broad level, everyone should benefit from genetic technology, especially those who have a specific need for this type of technology. I would hope the benefits are made available to all human kind and not just for the benefit of a specific population (e.g., those who can afford to pay for it, those who have insurance, etc.). It should benefit people irrespective of gender, social economic status, political affiliation, etc.
>
> P2: I'm having trouble with the moral aspect of this. I don't think we should interfere with the human ecostructure as it exists. I'm not against curing disease or helping people who have specific needs that can be corrected through genetic therapy or genetic research…. Once you start tampering with the natural process of life, it becomes problematic. Also, looking at the global community, it's not reasonable to assume that the benefits of genetic technology will be made available to everyone.

In eliciting the moral issues involved from the group, the facilitator noted three kinds of concerns: 1) access to genetic technology; 2) interference with natural processes; and 3) slippery slope in adaptation of newer and possibly more dehumanizing technologies. Noting the expansiveness of the technologies being contemplated, one person suggested:

> P3: I think we need to narrow the scope (of the technology). It's one thing to try to cure breast cancer and another to come up with the perfect child.

This suggestion provoked the following:

> P4: Okay, let's narrow the scope. For example, there's a new treatment for breast cancer but the only way to be eligible for it is to go through some type of genetic screening process. Who should have access to this? Those on Medicare/Medicaid? Those with private insurance? If hypothetically a treatment is available for breast cancer, and someone is found eligible for this treatment via genetic testing, then I don't think factors like ability to pay should play any part in receiving the treatment. (CCGPP 2000a: 16)

This last statement moved the conversation from moral issues to policy. The individual's comment reflects that participants did not view access to health insurance as being exclusive to either genetic or nongenetic conditions, but more a combination. Concerns about health insurance came up as point six for discussion in the dialogue one week later. The group developed a recommendation in that session to establish a federal law preventing insurance company genetic discrimination, a recommendation which was later incorporated into the project Summary Dialogue Report (CCGPP 2001, rpt. 3: 14).

Participants also frequently voiced concerns over impacts of genetic technologies used for specific groups, foreshadowing the first race-based therapeutic, BiDil. Members of a Tuskegee dialogue group voted research abuses "like the U.S. Public [Health] Service Study of Syphilis" among their top three concerns (the other two relating to military and private sector uses) (CCGPP 2000a: 10). Possible repeats of the Tuskegee syphilis study, which denied 399 African American sharecroppers treatment for the condition in order to study its natural course, surfaced as a serious trepidation in all the groups. Some believed the government could not be trusted to protect their racial or ethnic group. Fear of becoming "guinea pigs" for genetic experiments was voiced by both African American and Latino participants. Concern also existed over private institutions "sequencing the whole entire genome, base by base… [and] using it to a disadvantage" (CCGPP 1999, Tuskegee Support Group: 1). Many attendees voiced a desire to hold dialogues that might mitigate the possibility of a repeat of the Tuskegee event: "But what we have to do, is make sure that we have people in all aspects of this who are community minded people that make sure that we don't get taken advantage of and who are looking out for people in African, Hispanic, Latino people, in the community. That we aren't taken advantage of again, like we did 30, 40 years ago in the Tuskegee syphilis study" (ibid., Omega Psi Phi/Alpha Kappa Alpha: 7).

> People naturally wanted to see to it that their overall needs are addressed:
>
> P1: We don't have any policy in place to meet the health care needs of the population as it is, so I don't think genetic technology should take precedence.
>
> P2: It's like any other benefit. What's needed at the time? If emergency dictates, then yes. But I'd rather see kids getting their immunizations, for example, first. (CCGPP 2000a: 22)

The upshot of this prioritization was the recognition in the final report that basic health care should come before genetic services (CCGPP 2001, rpt. 3: 26).

At the same time, participants referred to the opportunity for genetic discoveries to address complex social and economic problems relating to health and human welfare. Wrote one dialogue group note taker, "They saw the project as having significant personal relevance for them,… [and] the Genome project as offering tremendous potential benefits for the unborn" (CCGPP 2000a: 159). Multiple groups mentioned the need to assure that financing of genetic testing benefits all racial and ethnic groups equally. One individual stated, "I believe that if the governments that have a lot of money will subsidize people in order to clone animals that have a lot of meat, or that have a lot of milk, much of the poverty in the world would end" (Schulz, Caldwell, and Foster 2003: 157).

African American and Latino dialogue participants were acutely aware of past violations of their rights by health researchers, but this recognition prompted them to want to be part of future policy making. "Make sure that we know who the policy makers are and what their views are on all these issues, and to invite them into our groups, into our organizations, into our churches, into wherever we are to make sure that we generate enough discussion in the African American community so that it's in the light, and it's not we going along with just another level of trust that somebody else is taking care of the problem — I think all of us can do something" (ibid.: 164). Involvement allowed a say in what emerged and engendered a sense of ownership in the project recommendations and the process leading to them: "We [African Americans] must go into the community and let people know what is going on. We are slowly losing our rights. A collective voice and effort is the only way to make a difference, and to have an impact" (CCGPP 2000a: 57).

Just where do five genetics dialogue sessions fall on the radar screen of a busy person focused on supporting a family? Looking back on the dialogues, one CAB member mused, "Many people indicate interest but do find life's other concerns can easily take the priority spot when a decision about participation is necessary…. Overall the project is much more time consuming than initially understood, but extremely important to our future. [We] must continue" (Caldwell 2000: 11).

Community Impact

The planned outcome of the CCGPP was a series of policy recommendations reflecting the communities' views on how best to assure that genetics will be used in ways that provide benefit and minimize harms for communities of color (CCGPP 2001). But perhaps the most significant outcomes of the project were the empowerment of the community members and their active engagement in using dialogues to consider the communities' needs related to genetics. The project energized the communities' call for education in genetics and their participation in policy advocacy.

The participants in CCGPP expressed strong enthusiasm for dialogue as a viable procedure for engaging communities of color and encouraging them to advocate for policies that are likely to be debated by policy makers and practitioners involved in genomic research and practice. Since many of the partner CBOs had a long history of involvement in policy advocacy and policy making, they were in a position to further the policy agenda according to the expression of their community constituents.

Beyond the project proper, CAB leaders participated in a number of outside community consultations — independently organized gatherings of policy makers and public representatives — that helped assure the communities' voices would be heard. These events included "Public Meeting: A Consultation on Genetic Testing," hosted by the Secretary's Advisory Committee on Genetic Testing in Baltimore in January 2000 (Secretary's Advisory Committee on Genetic Testing [SACGT] 2000); the "First Community Consultation on the Responsible Collection and Use of Samples for Genetic Research," hosted by the National Institute of General Medical Sciences in Bethesda, Maryland, in 2001 (National Institute of General Medical Sciences [NIGMS] 2001); and the "Hispanic/Latino Genetics Community Consultation Summit," hosted by the Hispanic/Latino Genetics Community Consultation Network (HLGCCN) in Washington, DC, in 2003 (HLGCCN 2003). CAB leaders relayed community concerns and recommendations regarding genetic research, the need for minority representation on institutional review boards and trust building between researchers and communities, and the desire for government to provide funding to support culturally relevant community outreach activities and education in genetics.

CBOs in two Michigan cities engaged community members in dialogues outside the CCGPP to identify genetics education needs. The "Michigan Demonstration of the Genetics Education Needs Evaluation" project, part of the March of Dimes GENE Project, was established to improve community access to genetic information (March of Dimes 2006). The effort fostered an educational needs assessment process, engaged the school systems in one district in exploring best methods for translating a genetics curriculum for school children, and in another enacted a community educational needs assessment connected with the "Improving Cancer Outcomes in Children of African Americans" effort.

Heath advocates at Flint-based Faith Access to Community and Economic Development (FACED), an organization situated in a high-unemployment Michigan city, were particularly interested in the role of genetics in chronic disease. These individuals were supplied written information and references to Internet sites. Two lessons were absorbed: (1) community activity can breed curiosity and the desire for more information, and (2) partnership building must go beyond consultation to actual community engagement.

In conducting the CCGPP, the Community Advisory Board and members of the community-based organizations played roles akin to community organizers and grassroots activists. The community engagement model developed for the project incorporated characteristics in its recruitment strategies and dialogue sessions similar to characteristics of initiatives used to mobilize blacks in the civil rights movement.

Before recruiting for participation in the dialogues, the investigators created partnerships with both traditional and "invisible" leaders who recognized the value of hearing the voices from the grassroots community. The community leaders that participated in the project have a natural connection to the grassroots community, being able to connect the project with people whose voices would not have otherwise been heard. Additionally, the community leaders and participants ultimately drove the project in the direction that represented their communities' needs and interests.

As CAB meetings concluded in September of 2002, members argued that advocacy efforts should continue beyond the life of the project. Discussion of a coalition led to the formation of the Genetics Equity Network (2006), which held its first meeting at Howard University in Washington, DC, in October 2006. The network has created multiple partnerships promoting genetics policies to reduce health disparities.

Evaluative Results

What are the measures of success for such a project? Pure cognitive measures are one indicator — "Did participants learn new information?" In our project, both African American and Latino participants showed knowledge increases between weeks two and five (72.1 to 77.0 percent and 52.4 to 68.8 percent, respectively) in strongly agreeing with the item "I have learned things that help me make better judgments" (Singer et al. 2001: 31). Comments from participants suggest this learning came about because of the exposure to new ideas and information presented, as well as interactions with each other throughout the dialogues.

Success is also measured in terms of the quality of interaction between participants (Fleck 2006). The dialogues included a Participant Process Evaluation at weeks two and five that provided suggestive evidence the goal of mutual listening and understanding was being achieved. African American groups showed increases in "Strongly Agree" on two items ("Members talk as equals" − 72.5 percent (week two) to 83.2 percent (week five) of participants; and "Members respect each other's opinions" − 76.1 to 78.2 percent) over this interval, and African American and Latino groups showed increases on the statement "My opinion is listened to" (72.5 to 75.0 percent, and 62.7 to 68.8 percent, respectively) (Singer et al. 2001: 29, 30).

The process evaluation further suggests that active identification with others' views was taking place. Latino participants showed an increase in "Strongly Agree" with the statement "I have a better understanding of others' views" (54.9 to 62.5 percent; African Americans showing an insignificant 0.4 percent dip) over the three-week interval (ibid.: 31). African Americans showed a similar increase for the statement "I have a greater tolerance for others' policy choices" (42.3 to 51.8 percent). These results indicate greater understanding and appreciation of others' views forming over time. We also found that in an open dialogue setting, a small number of vocal individuals tend to be outspoken from one session to the next. This occurrence should be considered in future dialogue projects.

Engagement in a project is another measure of success. Past national efforts are known for having attracted disproportionate numbers of white middle- to upper-income participants (Garland and Hasnain 1990). This shortcoming was overcome in the CCGPP by use of community-based organizations in many different locales reflective of a range of racial/ethnic and socioeconomic categories. Three hundred seventy-four people volunteered to participate. Of these, 216 individuals attended dialogues on week one; 207 attended on week five (table 3). CBO involvement was critical in recruitment and retention efforts.

If brought no further than the report writing stage, any effort — focus group, community dialogue, community consultation — will have little more than an academic impact. The CAB members interacted with legislators and relayed their concerns and recommendations that were anticipatory of legislation cited in this article. Community-based research is concerned with benefits sharing to the participating communities. Local advocacy efforts, community educational projects, and the establishment of a national equity network have fulfilled this goal.

The CCGPP shows that models of deliberation, when fused with community participatory research methods, can be culturally tailored to suit the unique concerns of the community engaged in the process; that through collaboration, individuals from varied cultural, racial, and ethnic communities can be empowered to generate policy recommendations that reflect their collective values.

Project Limitations

The CCGPP provided an opportunity to learn about the difficulties and limitations inherent in the community-based dialogue process. The Latino and African American communities that participated in this project considered the limited number of investigators sharing the racial and ethnic characteristics of those communities problematic. However, not every investigator had to share the community's racial and ethnic background in order to establish trust and conduct successful community-based research. Conducting community-based policy research requires honest relationships that are built on trust. That trust can only be gained through time and personal and professional commitment. The dialogue process itself requires a significant time commitment by both researchers and community members. To obtain community consensus from a cross section of the public when most members of the public do not have the time, energy, or immediate interest in the policy issue creates an obstacle in establishing a true community dialogue to reach common community opinions.

Working with CBOs in communities of color provided an opportunity for voices lost in the broader public to be heard. The earlier, NIH-ELSI–sponsored "Genome Technology and Reproduction: Values and Public Policy" community dialogue project included proportional representation from African American and Latino groups. But that proportional representation translated into small absolute numbers of African Americans and Latinos, limiting the ability to detect anything distinctive about their concerns or perspectives. A challenge of working with a select group of predetermined CBOs is the potential limitation of reducing the diversity of opinions represented in the dialogue process.

In addition, restricting participation to certain communities risks what Cass Sunstein (2001) refers to as the "cascade effect," which results in a socially corrosive form of group polarization. But Sunstein sees this possibility as a risk to be skillfully managed, and not a necessary outcome of such deliberative forums. Further, he notes particular advantages of "enclave deliberation," one being that "[enclave deliberation] promotes the development of positions that would otherwise be invisible, silenced, or squelched in general debate" (Sunstein 2001). The experience of the two projects bears this out.

Moving from community engagement to dialogue to advocacy and finally to policy action can take years. A traditional research project does not have the funding and time to move from engagement to action. To be effective in influencing genetics policy, the community must sustain its efforts. Community leadership will need to match its advocacy activities to the political process and timetable.

A major limitation of this model is that engagement is only at the beginning of the process of policy making. The political power of these communities is subject to many other factors. Is there a champion to lead the policy making? Is that champion in a position to move policy? Without corresponding interest on the part of the policy makers, community voices can fall on deaf ears.

Conclusions

The Human Genome Project and its resulting research initiatives have great potential to improve the health of humankind. However, they also have the potential to stigmatize groups of people when social and political categories of race and ethnicity are used inappropriately as scientific categories representing "genetic population groups."

Today, perhaps more than ever, it is vital that members of communities of color are truly empowered to participate in providing guidance for genomics research and the policy-making process for science and biomedical research. Community-based participatory research (CBPR) has been recognized as a valuable model of conducting research to improve health and reduce health disparities. Developing models of community engagement to educate, build consensus, and empower the community in policy making is extremely important in the field of genomics.

The future of genomics research will require recruitment of individuals of diverse backgrounds to both lead and participate in large cohort studies to better understand the genetic and environmental basis of diseases (Collins 2004). These studies will undoubtedly measure differences in disease between groups, including groups defined by race, ethnicity, geography, and gender. For this reason, the study of "difference" requires the public to be engaged in the process to protect against racism and other forms of discrimination (Mittman and Secundy 1998; King 1992). There is no universally appropriate model for engaging the public in this country. The model of engaging communities of color described in this article is rooted in the rich history of community mobilization and the role of the church, social organizations, and community leadership in addressing the civil rights of their communities.

What has a new importance is the need for models to engage communities of color to address access to the benefits of the genomic revolution and the use of genetic information in society. By moving from engagement to advocacy, there is hope for sustained participation of communities of color in genomics research and the policy-making process.

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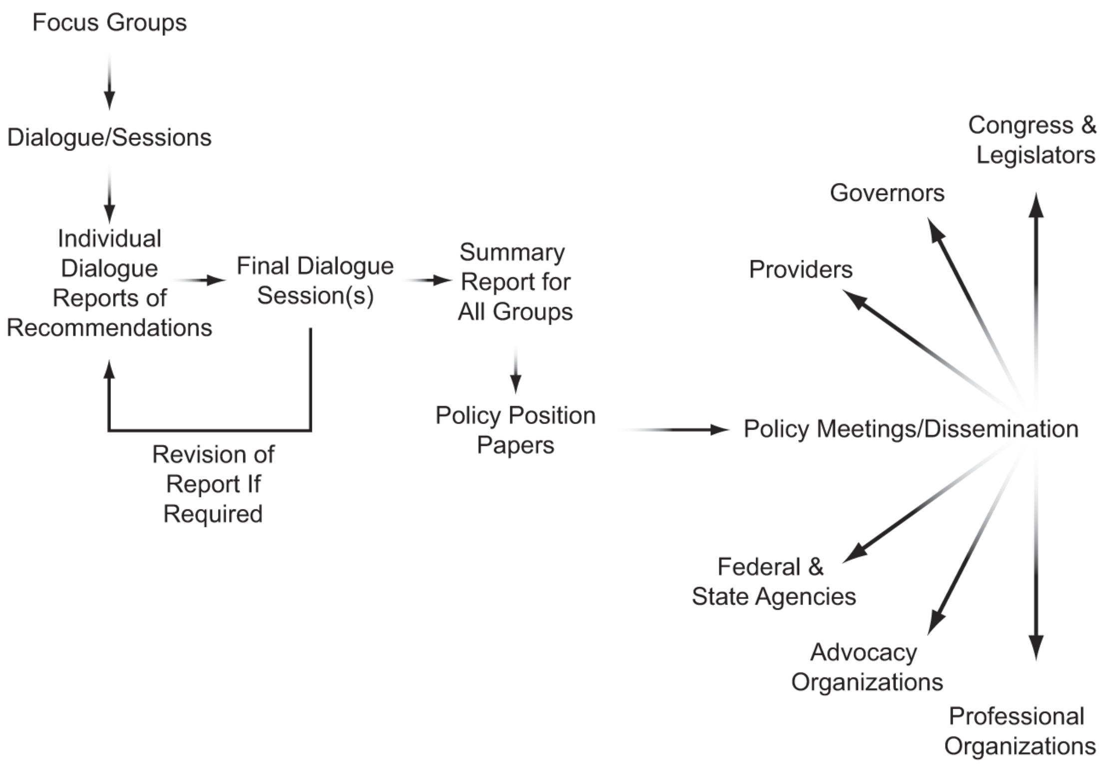

Figure 1.
Communities of Color and Genetics Policy Project: Dialogue and Dissemination Framework

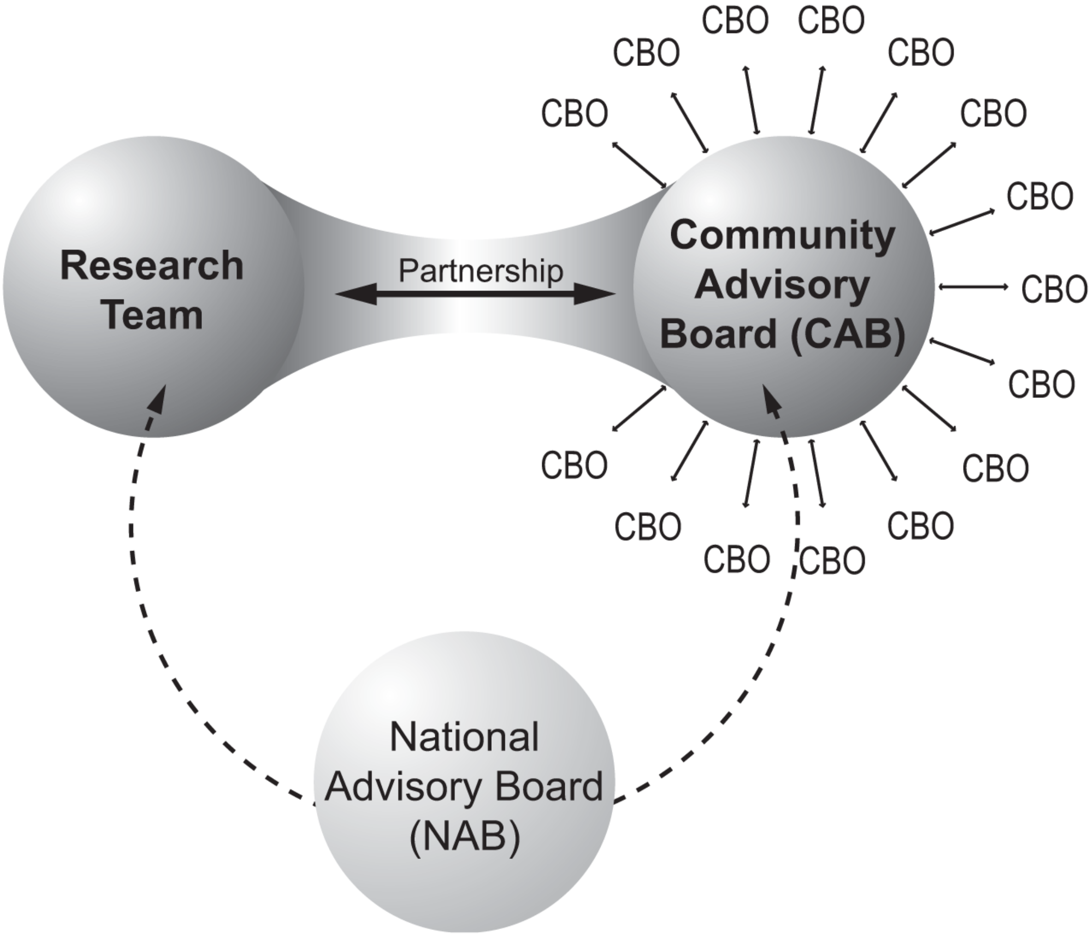

Figure 2.
Community-Based Genetics Participatory Research Partnership

Table 1

Community-Based Organizations

Organization	Location	Abbreviation[a]
Faith-Based:		
Bethel AME Church	Ann Arbor, MI	AME
Faith Access to Community Economic Development	Flint, MI	FACED
Church of Christ	Tuskegee, AL	ChCh
St. Andrew’s Episcopal Church	Tuskegee, AL	StAndr
Clinica Santa Maria	Grand Rapids, MI	Clinica
Affiliate of National Service:		
Urban League of Flint	Flint, MI	ULF
Alpha Kappa Alpha Sorority	Lansing, MI	AKA
Omega Psi Phi Fraternity	Lansing, MI	OPP
Local Service:		
The Orchid Club of Tuskegee	Tuskegee, AL	Orchid
Tuskegee Housing Authority Resident Council Executive Board	Tuskegee, AL	Resd
Support Group for Individuals with Disabilities	Tuskegee, AL	Support
La Salud Student Organization	Ann Arbor, MI	LSalud
Latino Family Services	Detroit, MI	LFS
Tri-City SER Jobs for Progress	Saginaw, MI	SER
Castillo and Associates	Lansing, MI	Castillo

[a] Abbreviations used in Tables 2a, 2b, and 3

Table 2

Table 2a. Demographic Characteristics of Dialogue Groups by Percent

Organization	AME (*N* = 19)	FACED (*N* = 16)	ULF (*N* = 17)	AKA (*N* = 25)	OPP (*N* = 23)	ChCh (*N* = 17)	Orchid (*N* = 11)	Resd (*N* = 12)	StAndr (*N* = 13)	Support (*N* = 12)	LSalud (*N* = 22)	LFS (*N* = 16)	Clinica (*N* = 17)	SER (*N* = 18)	Castillo (*N* = 15)
Race/Ethnicity															
African American	100	100	100	96	100	100	100	100	84.6	91.7	0	0	0	0	0
Latino	0	0	0	0	0	0	0	0	0	8.3	90.9	93.8	94.1	94.4	80
Other	0	0	0	4	0	0	0	0	15.4	0	9.1	6.3	5.9	5.6	20
Gender															
Male	47.4	31.3	58.8	40	65.2	35.3	0	0	23.1	8.3	36.4	18.8	29.4	38.9	73.3
Female	52.6	68.8	41.2	60	34.8	64.7	100	100	76.9	91.7	63.6	81.3	70.6	61.1	26.7
Age															
Under 30	10.5	18.8	11.8	28	26.1	17.6	0	33.4	0	16.7	95.5	50	47.1	11.1	33.3
31–50	36.9	31.3	58.8	32	52.2	29.4	0	66.7	7.7	8.3	4.5	43.8	41.2	27.8	46.6
51–60	21.1	31.3	5.9	16	8.7	17.6	27.3	0	7.7	58.3	0	0	0	27.8	13.3
61+	31.6	18.8	23.5	24	13	35.3	72.7	0	84.6	16.7	0	6.3	11.8	33.3	6.7
Education															
Less than h.s.	5.3	12.5	0	0	0	11.8	0	25	0	0	0	18.8	41.1	0	0
12 years	10.5	31.3	46.7	0	0	17.6	0	33.3	0	16.7	0	50	29.4	0	0
Some college	31.6	18.8	46.7	16	0	41.2	0	41.7	16.7	16.7	63.6	25	29.4	37.5	14.3
College grad	31.6	18.8	6.7	28	30.4	5.9	9.1	0	33.3	16.7	18.2	6.3	0	25	57.1
Some grad school	21.1	18.3	0	56	69.6	23.5	90.9	0	50	50	18.2	0	0	37.5	28.6

Table 2b. Demographic Characteristics of Dialogue Groups by Percent

Organization	AME (*N* = 19)	FACED (*N* = 16)	ULF (*N* = 17)	AKA (*N* = 25)	OPP (*N* = 23)	ChCh (*N* = 17)	Orchid (*N* = 11)	Resd (*N* = 12)	StAndr (*N* = 13)	Support (*N* = 12)	LSalud (*N* = 22)	LFS (*N* = 16)	Clinica (*N* = 17)	SER (*N* = 18)	Castillo (*N* = 15)
Income															
< $15,000	0	14.3	18.8	10	4.3	41.7	0	88.9	0	18.2	47.6	33.3	52.9	8.3	0
$15,000–45,000	40	42.8	56.3	45	21.7	33.3	33.3	11.1	50	27.3	38	41.6	29.4	33.3	46.7
$45,000–60,000	13.3	28.6	18.8	0	17.4	8.3	11.1	0	30	18.2	0	16.7	11.8	8.3	13.3
> $60,000	46.7	14.3	6.3	45	56.5	16.7	55.6	0	20	36.4	14.3	8.3	5.9	50	40

Table 2b. Demographic Characteristics of Dialogue Groups by Percent

Organization	AME (*N* = 19)	FACED (*N* = 16)	ULF (*N* = 17)	AKA (*N* = 25)	OPP (*N* = 23)	ChCh (*N* = 17)	Orchid (*N* = 11)	Resd (*N* = 12)	StAndr (*N* = 13)	Support (*N* = 12)	LSalud (*N* = 22)	LFS (*N* = 16)	Clinica (*N* = 17)	SER (*N* = 18)	Castillo (*N* = 15)
[Missing]	[4]	[2]	[1]	[5]	[1]	[5]	[2]	[3]	[3]	[1]	[1]	[4]		[6]	
Primary Activity															
Employed	78.0	37.5	46.7	62.5	60.9	29.4	45.5	50	41.7	75	0	50	58.8	50	85.7
Retired	16.7	13	20	16.7	13	17.6	54.5	0	58.3	16.7	0	0	0	18.8	7.1
Other	5.3	49.5	33.4	20.9	26.1	52.9	0	50	0	8.3	100	50	41.1	31.2	7.1
[Missing]			[2]	[1]					[1]					[2]	[1]
Marital Status															
Married/Partner	63.2	50.1	56.3	52	65.2	25	81.8	16.7	53.8	33.3	18.1	56.3	37.5	68.8	80
Widowed	0	12.5	12.5	8	0	12.5	0	0	15.4	16.7	0	0	0	0	0
Divorced/Separated	21.1	12.5	18.8	16	4.3	18.8	18.2	33.3	30.8	25	0	25.1	12.5	12.0	0
Never married	15.8	25	12.5	24	30.4	43.8	0	50	0	25	81.8	18.8	50	18.8	20

Notes: Valid %—based on the number of people who answered the question on the particular form. *N* reflects the number of people who filled out the form and may not equal the number of people actually attending the session or answering a particular question.

Table 3

Number Attending Each Dialogue Session by Group

Organization	AME (*N* = 23)	FACED (*N* = 16)	ULF (*N* = 18)	AKA (*N* = 25)	OPP (*N* = 24)	ChCh (*N* = 18)	Orchid (*N* = 12)	Resd (*N* = 16)	StAndr (*N* = 15)	Support (*N* = 14)	LSalud (*N* = 22)	LFS (*N* = 24)	Clinica (*N* = 17)	SER (*N* = 18)	Castillo (*N* = 17)
Session 1	21	15	15	10	11	16	10	12	9	11	22	16	17[a]	18	13
Session 2	18	15	17	12	17	17	8	7	10	13	21	21	11	17	14
Session 3	19	14	16	17	21	12	9	9	10	11	21	21	N/A	14	11
Session 4	15	11	10	13	16	12	5	7	9	11	21	14	N/A	15	11
Session 5	17	12	15	19	17	13	8	6	11	10	20	22	12	14	11

Note: N reflects the total number of people attending at least one session for a particular group. N/A = Not assessed.

[a] Attendance not taken. Data based on number of questionnaire forms handed in.