Chapter 4

INFRASTRUCTURE FOR EQUITABLE DECISION MAKING IN RESEARCH

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Calls from national governments, including the United States, for community participation to achieve health for all are not new. For example, the Alma Ata Declaration of 1978, which was ratified by 134 member nations of the World Health Organization (WHO), is considered a major public health milestone of the twentieth century (Rosato et al., 2008). A core principle of the declaration was that “people have a right and duty to participate individually and collectively in the planning and implementation of their health care” (WHO, retrieved 2011).

In the United States, the Economic Opportunity Act of 1964, which was the centerpiece for the nation’s declared War on Poverty, mandated “maximum feasible participation” by the poor in planning programs, such as Community Health Centers and Head Start (Public Law 88–452). In reference to the mandated “maximum feasible participation,” Sherry Arnstein (1969), chief adviser on Citizen Participation for the U.S. Department of Housing and Urban Development at the time, defined community participation as citizen power in decision making. In her eight-rung Ladder of Citizen Participation (Figure 4.1), Arnstein outlined the gradation of citizen power—from “manipulation” to “citizen control”—that she observed occurring in Community Action Agencies and the Model Cities Program.

More recently, a gradation for community participation in medical research has emerged in the second edition of Principles of Community Engagement, coauthored by the Clinical and Translational Science Award Consortium and the Community Engagement Key Function Task Force on the Principles of Community Engagement (United States Department of Health and Human Services, 2011). This Continuum of Community Involv...
FIGURE 4.1: Ladder of Citizen Participation


ment: Impact, Trust, and Communication Flow (Figure 4.2) describes five stages—from “outreach” to “shared leadership”—through which research collaborations involving researchers and communities are likely to move toward increasing community involvement. Different from Arnstein’s Ladder, which is anchored in decision-making power, this continuum is anchored in several different dimensions, including level of community involvement, types of communication and information flow (that is, one-way versus bidirectional), and outcomes.

As heuristic tools, both the Ladder of Participation and Continuum of Community Involvement offer insights into the range and complexity of ways in which research
partnerships can promote or undermine equitable sharing of decision-making power and responsibilities between academic and community partners. Systematic reviews of articles on CBPR projects (Catalani & Minkler, 2009; Chen, Diaz, & Lucas et al., 2010; Cook, 2008; Viswanathan et al., 2004) as well as “conceptual” pieces on CBPR (Ahmed & Palermo, 2010; Cornwall & Jewkes, 1995; Hawe, Schiell, Riley & Gold, 2004; Rifkin, 1996; Trickett, 2011) have noted both the challenges and wide variation in activities to initiate, achieve, and sustain equitable participation between community and academic partners in the research enterprise. Community norms, institutional inertia, and internalized expectations all can enable more powerful partners; however well-intentioned, to determine what level of community participation is most valuable at which stage of research and for whom (Argyris et al.,

<table>
<thead>
<tr>
<th>Model</th>
<th>Community Engagement</th>
<th>Description</th>
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<tbody>
<tr>
<td>Outreach</td>
<td>Some Community involvement, which is described as follows: Communication flow is from one to the other to inform. Provides community with information. Entities co-exist</td>
<td>Increasing Level of Community Involvement, Impact, Trust, and Communication Flow</td>
</tr>
<tr>
<td>Consult</td>
<td>More Community involvement, which is described as follows: Communication flow to the community and then back around seeking. Gails information or feedback from the community. Entities share information, and outcomes: Develops connections.</td>
<td></td>
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<tr>
<td>Involve</td>
<td>Better Community involvement, which is described as follows: Communication flow both ways, participation forms of communication. Involves more participation with community on issues. Entities are cooperating with each other, and outcomes: Visibility of partnership established with increased cooperation.</td>
<td></td>
</tr>
<tr>
<td>Collaborate</td>
<td>Community involvement, which is described as follows: Communication flow is bidirectional. Forms partnerships with community on each aspect of project from development to solution. Entities form bidirectional communication channels, and outcomes: Partnership building, trust building.</td>
<td></td>
</tr>
<tr>
<td>Shared Leadership</td>
<td>Strong bidirectional relationship, which is described as follows: Final decision making is at community level. Entities have formed strong partnership structures, and outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.</td>
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Source: [http://www.casdr.cdc.gov/communityengagement/images/figure4.2.png](http://www.casdr.cdc.gov/communityengagement/images/figure4.2.png)
Moreover, external policies and institutions that govern how research is organized, such as institutional review boards (IRBs), can dictate the level or form of community participation (Ar requisite, 1985; Downe & Gottrell, 2001; Flicker, Skinner, & Veinot, 2005; Israel, Schulz, Parker, & Becker, 1998; Schnarch, 2004).

In this chapter, we focus on explicit mechanisms and structures for equitable decision making for CBPR partnerships to create an infrastructure for integrating diverse expertise in decision making that anticipates and manages conflict, and is transparent and accountable to all research partners. These structures and mechanisms are:

*Undoing Racism* training for developing a common language and framework on health equity and social justice to address openly the power differences and historical challenges facing community-academic partnerships;

*Full value contract* for stating the specific set of values, affirmed by each member of the partnership, for investing time in, sharing experience with, giving and receiving open and honest feedback, and committing to the success of the partnership;

*Research ethics training and certification* for community partners, as an alternate to the conventional online Collaborative Institutional Training Initiative training modules;

*Partnership bylaws* for explicitly stating long-term principles and procedures to build the relationship among partners and governance of decision making;

*Managing and addressing conflict* that can be as formal as including a “conflict committee” in bylaws or as informal as a “pinch moment” group norm; and
Publications and dissemination guidelines for ensuring co-ownership and control of how, when, and where findings and lessons learned are communicated.

This chapter draws on the experiences of the North Carolina Community-Based Public Health Initiative Consortium and the Greensboro Health Disparities Collaborative to highlight the impetus, process, and application of these six structures and mechanisms.

BACKGROUND ON THE CBPR PARTNERSHIPS

The structures and mechanisms discussed here were developed by two CBPR partnerships in North Carolina (NC): The NC Community-Based Public Health Initiative Consortium (referred to as “the Consortium”) and the Greensboro Health Disparities Collaborative (referred to as “the Collaborative”). The Consortium was established in 1992 by 11 partners in four contiguous counties with funding from the W.K. Kellogg Foundation, which included four local health departments, three African American community-based organizations (CBO), a county housing authority, a primary care center with satellite clinics in two counties, a university School of Public Health, and a regional Area Health Education Center (Margolis et al., 2000; Margolis, Parker, & Eng, 1999; Parker et al., 1998; Parker, Margolis, Eng, & Henriquez-Roldan, 2003). Since that time, one county’s 400% growth in its Latino population caused the Consortium to add partners from this county that served Latino communities. The 11 current partners are concentrated in three of the four original counties and include two academic institutions, three CBOs, and six health agencies. CBPR projects include the CDC-funded Men As Navigators for Health and Project DIRECT (http://www.cdc.gov/diabetes/projects/direct.htm), and the Kate B. Reynolds Trust-funded Project SELF (Smoking, Exercise, Lifestyle and Fitness) Improvement (http://www.kbr.org/initiative-archive.cfm) (Engelgau et al., 1998; La Verne et al., 2003). The Consortium’s mission is:
To improve the health of minority and/or high-risk populations in selected communities by establishing collaborative structures and processes that respond to, empower, and facilitate communities in defining and solving their own problems. (WKF, 1992, p. 1)

The “Collaborative” (http://www.greensborohealth.org) was established in 2004 through a planning grant from the Moses Cone-Wesley Long Health Foundation. The 35 members represent community, academic, and health professional organizations. The geographic focus of the Collaborative is Guilford County, North Carolina. The county seat of Greensboro has a population of nearly 270,000, and black or African American residents comprise more than 40% of the total population (U.S. Census, American Fact-Finder, 2011). CBPR projects include the NCI-funded Cancer Care and Racial Equity Study. The Collaborative’s mission (Greensboro Health Disparities Collaborative, n.d.) is:

To establish structures and processes that respond to, empower and facilitate communities in defining and resolving issues related to racial disparities in health. Thus, the results of the work of the Collaborative will be used to reduce the racial disparities experienced by disadvantaged populations when interacting with healthcare institutions.

The vision and leadership for the Collaborative to examine and address institutional racism and disparities in health was initiated by the Partnership Project, an anti-racism training organization in Greensboro, North Carolina, who approached the University of North Carolina (UNC) at Chapel Hill to identify a faculty research partner. After interviewing a number of faculty, the Partnership Project Board selected Dr. Eugenia Eng, which marked the beginning of this community-academic partnership. They were able to secure an 18-month planning grant from a local health care foundation to establish a health disparities task force of community leaders, academic and health professionals to explore the presence and nature of disparities in health and health care in Guilford County, North Carolina. Through support of the planning grant, the Collaborative was developed with a commitment to design and seek research funding to study how complexities in systems of health care, including historical and institutional racism, may help explain race-based differences in treatment and their potential association with racial disparities in health care treatment outcomes.
This chapter uses the experiences of the Consortium and the Collaborative to describe and analyze the application of the six structures and mechanisms (listed above) aimed at ensuring equity in decision making, power sharing, and transparency in community-academic partnerships.

INFRASTRUCTURE FOR CBPR PARTNERSHIP DEVELOPMENT

The following sections provide illustration and history associated with the utilization of participatory decision-making structures and tools for cultivating and sustaining CBPR partnerships.

Structure 1: Undoing Racism Training

To address the complex relationships of power differences and historical challenges among representatives of the academic, medical and wider communities, the Collaborative began its work with Undoing Racism training by the People's Institute for Survival and Beyond (PISAB, 2011), an anti-racism organization that has been recognized by the Aspen Institute (Fulbright-Anderson, 2004) as one of the top ten anti-racist training groups in the United States. This 2.5-day training was identified by the Collaborative as an essential element in cultivating research to examine and address persistent and chronic racial disparities in health, as described in the Institute of Medicine report, Unequal Treatment (Smedley et al., 2003). To address such disparities, the Collaborative believed that it would be essential to come to an understanding of the history of the development of a race- and class-based health system that was a part of a social culture which is hundreds of years old. The primary purpose of having each member of the Collaborative complete the Undoing Racism training was to cultivate a common language and shared framework as a foundation for constructive dialogue associated with the dynamics of race, racism, and institutional culture in this country (Aronson et al., 2008a; Aronson et al., 2008b; Yonas et al., 2006).

PISAB's Undoing Racism training addresses controversial and emotional concepts such as racism, prejudice, privilege, institutional power, and internalized racism through a series of facilitated presentations, interactive dialogue, role playing and structured small-group activities. These are aimed at assessing, decon-
structing, and generating a common awareness of power and privilege and their impact upon health disparities and health equity (Aronson et al., 2008a; Aronson et al., 2008b; Barnes-Josiah, 2004; Yonas et al., 2006). The five core objectives of the PISAB Undoing Racism training include (Aronson et al., 2008a):

- Defining racism and its different forms (individual, institutional, linguistic, and cultural);
- Recognizing the presence of institutional racism and its impact;
- Understanding why people are poor and the role of institutions in maintaining inequality;
- Understanding the historical and contemporary purpose and context for racial classifications within the United States; and
- Understanding how community organizing principles and strategies and multicultural coalition building are utilized as tools for Undoing Racism.

This formal and required training served as the foundation for the Collaborative's education about systems of power+race and how this dynamic affects all organizations at all levels. Members of the Collaborative came to understand collectively that the way people and organizations think about race and poor communities strongly influences the kinds of questions they ask and the solutions they seek. Although race is a biological myth, it is a political and institutional reality that continues to have consequences throughout our society, including in our health care system.

Using the Undoing Racism training as the central mechanism for the development of a common understanding of race and racism allowed for the development of a partnership to address health disparities with a unified focus. The training itself assisted in the production of the Full Value Contract (see Structure 2 below) based on the principles of mutual respect which are necessary for an in-depth discussion of race and racism. Though exceptionally challenging personally and collectively, participating together in the Undoing Racism training provided the unique and valuable opportunity to mutually explore our personal histories and develop a common language for learning how to address disparities. Throughout the life of the Collaborative, members have repeatedly referred back
to the principles of Undoing Racism to facilitate understanding of the systems within which they are working.

**Structure 2: Full Value Contract**

The Full Value Contract (FVC) is a formal “living” document developed by a partnership, similar to a memorandum of understanding, to remind members of the guiding principles overseeing the CBPR project. For the Collaborative, the FVC was developed and signed by all members as an established set of beliefs and values which would guide the Collaborative’s work together. Central to the FVC was the assumption that every member has equal worth (regardless of their diverse disciplines, expertise, and levels of power), and by the virtue of that worth, has a right and responsibility to give and receive open and honest feedback. In essence, the FVC helped to shape and codify a newly integrated identity for a group of individuals, each accountable to specific constituencies (for example, university, community organizations, and churches) and dedicated to understanding and addressing institutional racism in health and health care.

The Collaborative’s one-page FVC (see Appendix B), developed through consensus and incorporating input from community and academic partners, affirmed the stated values of trust, mutual respect, accountability, confidentiality, active listening, integration of humor and patience, sharing of personal experience, and acknowledgment of everyone’s strengths. To ensure that members would commit to maintaining trust, open communication, and shared power in decision making to achieve the goals of the Collaborative, each member agreed to sign the FVC as the foundation from which he or she would work. (For a description of other similar processes and tools for identifying operating norms and guidelines, see Chapter Three.)

Given the Collaborative’s focus on understanding and addressing persistent inequities in health and health care through the systems-level framework of Undoing Racism, the FVC was used to inform the creation of collective decision-making expectations and structures and processes associated with research ethics training, partnership bylaws, and dissemination guidelines, as described in the following sections. In sum, the FVC has been essential throughout the Collaborative’s history as a touchstone for why and how the partnership works collectively and with a common understanding grounding the purpose and process of research.
INFRASTRUCTURE FOR CONDUCTING RESEARCH

Structure 3: Research Ethics Training and Certification

The past two decades have witnessed an increasing number of major federal initiatives and funding opportunities for CBPR and community engagement in research (Catalani & Minkler, 2009; Chen et al., 2010; Cook, 2008; Viswanathan et al., 2004). With this growing support from the scientific sector for engaging communities in research, CBPR investigators and observers have noted that the values, guiding principles, and procedures of equitable participation can become entangled with the laws, regulations, and policies for protecting human subjects (Flicker et al., 2007).

Human subjects are people who participate in research, and whose rights and welfare are paramount. For universities, research involving human subjects is not a right, but a privilege. Any research proposed by faculty, staff, or students that involves human subjects must be reviewed and approved by an institutional review board (IRB) before studies may begin, and before related grants may be funded. Investigators and study personnel are required by their university to complete proper training in the ethical and regulatory aspects of research with human subjects. Processes and procedures differ from university to university as to how these training and regulatory aspects are handled in relationship to CBPR. In some instances, such as was the case with both the Consortium and the Collaborative, this requirement can be a “double-edged sword for CBPR studies.” On the one hand, training in the ethical conduct of research to protect the rights and welfare of participants would be beneficial for community members who, for example, serve on CBPR steering committees; are hired by community and academic partners as project coordinators, recruiters, interviewers, or data managers; or fulfill a lay health adviser role in the intervention. On the other hand, because community members of the research team may not be affiliated with an institution that has an IRB, they may not be eligible to receive such training. Although human subjects training was an issue for both the Collaborative and Consortium as we describe in this section, we recognize that for other institutions, there may be other IRB-CBPR related issues that are problematic, or there may be no issues at all.

In the case of the Collaborative, we wanted all Collaborative members to be able to complete human subjects’ research certification, regardless of whether or not they were listed as key personnel on the grant. If an IRB will not permit
nonidentified personnel who are not affiliated with the institution to complete the training, in order to move forward with beginning the study, a CBPR partnership is forced to limit community partners’ direct interaction with participants and access to identifiable data. In this section, we describe a mechanism established by the IRB of the University of North Carolina at Chapel Hill (UNC) for research ethics training and certification of community partners as nontraditional investigators. As an alternative to the more conventional online Collaborative Institutional Training Initiative (CITI) training modules (https://www.citiprogram.org/Default.asp), this mechanism not only can enable CBPR partnerships to fulfill the requirement for IRB approval, but also can build the capacity of community representatives to gain insights into the academic view on ethical conduct of research, the challenges of protecting the rights and welfare of participants, and their roles and responsibilities as community partners of the research team.

In the Collaborative, research ethics training for nontraditional investigators has been used to ensure their equitable participation into the research process at all phases, including data collection, data analysis, and to inform the ethical dynamics throughout the entire research process. Modeled after the traditional online CITI research ethics training, this 1.5- to 2.0-hour alternate training (see downloadable supplement for this chapter) is conducted in person and in a facilitated format using scenarios relevant to the specific research project. Comprising thirty PowerPoint slides with detailed inclusive notes pages, this interactive training uses historic photographs and a storyline to cover the same content found in the conventional CITI training:

- What it means to be a research participant;
- History of unethical research with examples of experiments conducted in Nazi Germany and the resulting Nuremberg trials and creation of the Nuremberg Code; a study of hepatitis A conducted at Willowbrook State School in New York; the establishment of the Declaration of Helsinki; the Tuskegee syphilis study and the resulting Belmont Report;
- Guiding principles of research ethics, which are respect for persons, protection from harm, and justice; and
- Rules guiding the ethical conduct of research, such as informed consent, training to protect participants in research, privacy protections, and requirement of IRB approval.
The trainer was required to be a senior university investigator from UNC. Questions and scenarios are built into the slides and notes pages for the trainer to trigger discussion about why participants may feel like “guinea pigs,” and to critically examine ethical dilemmas that community and academic research partners may face while conducting their studies.

In short, by making this alternate research ethics training available for nontraditional investigators such as community partners, four issues that could undermine equitable participation and equitable decision making when using the CBPR approach are minimized: accessibility, format, tailoring, and literacy. Accessibility refers to the community-oriented presentation of the alternate research ethics training that is not dependent on access to the Internet and can be implemented in almost any community setting with an electrical power source for an LCD projector and laptop. If electricity is not available, paper copies of the PowerPoint slides can be substituted. The format in which the training is delivered is not one of sitting alone in front of a computer monitor and clicking response items on a test page. Rather, the format is a facilitated small-group discussion for exchanging interpretations, asking questions, and probing false assumptions with the trainer, project staff, and community partners. The alternate training also enables tailoring to the roles, interactions, and content that is specific to the study being conducted by the research partners receiving training. Finally, with regard to literacy, the alternate training is not dependent on either literacy levels or English language fluency of community partners. Guided by cues provided to the trainer in the PowerPoint slides and notes pages, oral comprehension is maximized and the slides can be translated into the language of participants. Upon completion of the alternate research ethics training, documentation of completion is certified by the senior university investigator, and then submitted to the IRB for entry into the database of nontraditional investigators who completed project-specific research ethics training. We describe below a case example of the effects from this alternate training on a CDC-funded study within the Consortium.

The Consortium was awarded funding from CDC to conduct a CBPR project, called Men as Navigators (MAN) for Health at three community sites (urban African American, rural African American, and rural Latino). An academic partner served as the fiscal agent, and three community partners each received a subcontract to hire a full-time project coordinator, form a community advisory group, and recruit and enroll “navigators” (male lay health advisers). The Consortium’s steering committee served as the decision-making body for...
all aspects of the study, which included designing the intervention and evaluation instruments, and writing the application for funding. As a complex research intervention study, not only were skills in qualitative and quantitative research methods required, but also in the procedures and protocols for protecting the men who were participating in the research.

Given the newness of this training and certification in research ethics for nontraditional investigators, those who developed it also designed a brief evaluation form for all participants (that is, 4 project coordinators, 23 navigators, and 22 members of the MAN steering committee and 3 community advisory board members) to complete immediately after the training. MAN staff translated the form into Spanish for the Latino navigators. The training was conducted in community-chosen locations of convenience and facilitated primarily by the academic principal investigator.

With regard to who benefits from research, it is important to note that not one participant agreed with the statement, "Research will not help you, it will only help the researcher." About half agreed that research will help people outside their community. Whereas 70% of African American navigators and project coordinators agreed that research will help their own community, only 20% of the Latino counterparts did. Latino navigators and the project coordinators were still less sure than their African American counterparts, after training, about asking questions, or that the rules for people to follow will make research safe.

As an indicator of the relevance of this training to their role as coinvestigators with MAN, it is important to note that about three-quarters of both African American and Latino navigators and project coordinators felt better about the safety of research after undertaking the training. All but two of the African American and Latino investigators, respectively, felt that other lay health advisor studies should include this training.

To enable MAN's community partners, their community advisory board members, project coordinators, and navigators to be equitably involved as coinvestigators, they needed to understand, follow, and be certified in the principles of ethical research. University faculty, research staff, and graduate student research assistants were required to complete the online CITI course on the Protection of Human Research Subjects. For all coinvestigators, academic and community alike, training in research ethics was an essential component for the study to facilitate equitable decision making through a clear understanding of the history and ethics associated with research involvement.
Structure 4: Partnership Bylaws

Partnership bylaws have been found by some partnerships to serve as a useful tool in the governance of partnerships. The process of bylaws development and revision over time is as important as the content of the bylaws themselves. We describe two examples.

Development of Bylaws in Response to Funding Requirements

The Consortium was one of 15 selected from across the United States to participate in the W.K. Kellogg Foundation Leadership Model Program, a one-year preproposal period in 1991. During this year, the Consortium developed principles for collaboration, which included a commitment to move forward with implementing the proposed work even if the application was not funded. The full set of principles was stated in a written memorandum of understanding and signed by each partner organization’s director, dean, or board president.

After funding was awarded in 1992, the Consortium established a steering committee that worked for more than nine months to complete the bylaws. During the time required for developing and receiving final adoption of the bylaws through consensus, the Consortium followed its initial principles of collaboration for equal partner participation, conflict management, and equitable distribution of resources to move forward with the tasks as planned and to address unplanned events that are inevitable during implementation.

The Important Role of Structure of the Consortium’s Bylaws

The Consortium’s bylaws mandated representation on the 24-member steering committee that would amplify the voice of community partners. The steering committee was comprised of 12 community representatives; 6 health agency representatives, including one from each of the four participating counties and two appointed by the Consortium chair; and 6 academic representatives. In addition, the bylaws designated specific roles and responsibilities for Consortium officers, the steering committee, county coalitions, university partners, and other partners. For example, the bylaws specified the responsibilities of the steering committee for handling administrative concerns and holding partners accountable for following
the appropriate chain of communication, in all matters (see Appendix C for an example of bylaws).

The bylaws also specified a structure for shared leadership with the Consortium, for example, the president position rotated between a community partner and a health agency partner. University partners would hold the office of secretary-treasurer due to their responsibilities as the grant’s fiscal agent. With regard to monitoring and revising protocols and procedures for making decisions and handling finances, the Consortium's bylaws established a resource panel. The resource panel was also charged with planning and recommending strategies to the steering committee in the areas of sustainability, policy development, and state expansion. Finally, the bylaws provided a specific mechanism for anticipating and managing conflict through the establishment of a conflict resolution committee (see Structure 5 below).

Development of Bylaws for Group Identity Development

Our second bylaws example was not driven by a funding agency requirement, but by a CBPR partnership’s need to define and operationalize a unified sense of identity. In the case of the Collaborative, the development of the group as an entity (and later the development of the bylaws) was influenced by the shared principles, language, and framework for understanding racism gained through participating in the Undoing Racism training. The group developed through a process that evolved over two years during which time a grant proposal had been submitted and was funded by the National Cancer Institute (Yonas et al., 2006). When the process of securing the first research grant was complete and the Collaborative had begun to mature, it became clear that documents designed to sustain and maintain the Collaborative’s mission through personnel and activity changes were needed. The organization had established group norms and expectations for membership, but these had not yet been codified in a formal document.

The Important Role of Process in the Development of the Collaborative’s Bylaws

The first meeting at which the bylaws were proposed included a discussion emphasizing that the bylaws should not focus only on the currently funded study, but rather be broadly fashioned so as to apply to other funding mechanisms
expected in the future. In addition, members emphasized that the bylaws should not hinder the leadership structure and that they should “incorporate humanistic approaches” toward accomplishing the work of the organization. Since the inception of the Collaborative, the “Full Value Contract,” and the principles of Undoing Racism have been essential core values uniting all members. All activities of the Collaborative have maintained those principles, and the members, acting as a corporate body, have relied on each other to apply those principles to inform decision making, preparation of documents, planning of research, and interactions with the group. Recommendations were made from the group for the bylaws to contain specific descriptions of working committees, the frequency of meetings, and the number of allowed absences from meetings.

Subsequent Collaborative meetings focused on discussion of the balance of power between academic, community and health care members of the Collaborative which would be created by structural guidelines established in the bylaws. Throughout the development of the Collaborative, the balance of power between academic and community members was a primary concern. During the discussion of the bylaws, it was determined that the positions of chair and vice-chair should not be held by academics, in order to avoid the power imbalance which would result. Either members of the health care community or members of the general community were recommended to hold the positions of top leadership. Because the Collaborative had been developed in a fluid manner up to that point, and continued evolution was expected, the proposed bylaws were designed to easily incorporate changes over time to reflect the ongoing maintenance of the partnership.

Review of Membership in the Collaborative

After four years, the Collaborative recognized the need for a review of the membership status section of the bylaws. This identified need resulted in a review and revision of both the guidelines and other aspects of the bylaws, such as membership guidelines and leadership structures. Within the Collaborative, there was extensive discussion over the course of several meetings of the way to modify the bylaws to reflect members’ active and inactive status. After extensive conversation, guided through consensus and incorporating input from both academic and community perspectives regarding the definition of membership, the bylaws committee was charged with modifying the membership to include...
two categories reflecting the levels of activity. The issue of membership was resolved when members agreed on the two categories of membership as: Active and Inactive. The Collaborative agreed that all members were required to have completed Undoing Racism training and to have signed the “Full Value Contract” as specified in the original bylaws, and to pay the annual dues. It was decided that Active members would be allowed to vote in all decisions made by the Collaborative; whereas Inactive members would serve as a valuable resource to further the mission and activities associated with the Collaborative, and could choose to continue their involvement as “Friends of the Collaborative.”

As in the previous example of the Consortium, the development of the Collaborative bylaws required a great deal of time for discussion to eventually reach consensus. The development and the final adoption of the bylaws strengthened the unified identity of the Collaborative, stabilizing the group through common expectations and guidelines for ensuring equal partner participation, conflict resolution, and distribution of resources.

**Structure 5: CBPR Conflict Management Procedures**

In CBPR initiatives, it is common and expected that conflict will emerge during the honest and sincere integration of the perspectives, experiences and expectations of diverse partners. As with all relationships, those developed during partnered research are prone to growing pains and friction. As described in the following two examples, our CBPR partnerships have come to develop formal and informal **conflict negotiation** and management procedures (CMPs) in order to help facilitate the successful negotiation of these challenging and necessary experiences within CBPR. (Also see Chapter Three in this volume for a discussion of “Addressing Conflict” in the context of group process and CBPR partnerships.)

In the case of the Collaborative, an informal process for dealing with conflict emerged from the willingness of members to speak openly and honestly about issues, and from the culture of the group which includes a commitment to relationships and sensitivity to group dynamics. Because we believe that all members are important and have gifts and ideas to contribute, the Collaborative values equitable participation in discussion and decision making, which at times resulted in tension within the group. The recognition of tensions or potential conflicts led to the practice of discussing and examining what might be contributing to tensions as they arise, and this practice came to be called “pinch moments” by
the group. An early example of a pinch moment occurred during the writing of the NIH proposal for the Cancer Care and Racial Equity Study (CCARES) project (http://www.greensboronhealth.org), and related to the process of deciding on the project’s budget. Failure to follow procedures, which included having the five community and one academic members of the budget subcommittee meet regularly to review and guide budget decisions for the proposal, led to resentments that threatened the level of trust within the group. By honestly discussing concerns and recommitting to equitable participation in the development of the budget, this pinch moment created a template for how conflict could be addressed in the future.

Later, there was a reemergence of distrust which could have been a threat to the partnership. After receiving a nonfundable score and reviewers’ comments from the NIH Study Section, community partners were upset by their first experience with the academic research review process for funding. Community partners organized a series of meetings, which did not include university partners, to air opinions and feelings of distrust and frustration with the academic process. Meeting without university partners contributed to lack of transparency and inadequate understanding for the full Collaborative on the meaning and relevance of the reviewers’ comments for revising and resubmitting the CCARES application. Resulting confrontations between community and university partners required multiple uses of the pinch moment mechanism to engage the full Collaborative in group processing. Reestablishing transparency and trust was required in order to move forward with equitable contributions to revising and resubmitting the proposal, which was ultimately funded. In sum, the culture of the Collaborative, which stresses the importance of relationships and includes the values codified in the Full Value Contract, allowed the partners to transform conflict situations into pinch moments, which strengthened the Collaborative and contributed to growth.

A second example involving the Consortium illustrates a more formal conflict resolution committee structure created initially to review and address issues associated with the distribution and access to financial resources for partnership activities and research. The conflict resolution committee comprised a chair who was a health agency member with degrees in both law and public health, and two additional members (one academic and one community) from the partnership, appointed by the Consortium president. The initial conflict incident leading to the establishment of the conflict resolution committee arose after subcontracts
were issued by the university to community partners. Initially, invoices for subcontracts were to be submitted by community agencies to the university grants management structure directly, as the federal fiscal agent. Per the grant proposal’s established guidelines, the funding agency indicated that payments could be advanced to all subcontracted parties associated with the research. This was particularly important because the partnering community-based organizations and nonprofits lacked the available financial resources to pay for salaries and operational costs from internal resources, and relied on reimbursement from the university grants management system. Larger institutions and government agencies are more likely to possess such internal financial resources. Despite approval from the federal funding agency, it was not the policy of the university partner fiscal management office to advance subcontract funds.

The Consortium’s steering committee agreed that with the necessary approvals from the funding agency, the community partners should be advanced the necessary payments needed to complete their responsibilities for the project. This issue was referred to the conflict resolution committee, which tasked the chair to negotiate the change in fiscal policy with the University Office of Sponsored Research. After six months, the university modified the fiscal policy to allow the advance release of funds—and it was apparent to the partnership that this change would not have occurred if not for the efforts and dedicated attention provided to the issue by the conflict resolution committee. Without a change in advance payment policy, it is likely that community partner organizations may not have been able to afford to remain active members of the Consortium and the valuable interdisciplinary partnerships developed may have been lost. Commitment of all partners, academic, health department, and community, was essential to the productive resolution which resulted. Keeping all partners informed and involved in the decision-making process was vital and, as illustrated in this example, "necessary conflict" that emerges can be resolved when a formal and transparent process is established.

INFRASTRUCTURE FOR DISSEMINATION PHASE

Structure 6: Publications and Dissemination Guidelines

When teams representing broad CBPR collaborations are engaged in preparing findings and reflections from the research process, shared learning occurs. Academic dissemination guidelines help ensure the research findings are disseminated to the appropriate audiences, facilitating evidence-based practice and policy development.
demics have traditionally monopolized the process of knowledge creation and dissemination, and in turn the process of learning (Hall, 1982). This has been apparent most notably in the conduct of research and the publication of findings in peer-reviewed scholarly journals. There is tremendous power in the act of knowledge creation, and when this process is monopolized, the power becomes concentrated in these same actors. In CBPR, opportunity for equitable participation in knowledge creation and dissemination is intentionally created (Farquhar & Wing, 2003; Parker et al., 2005). (For additional information on and examples of dissemination, see Chapter Fourteen in this volume.) With baseline data collection beginning in 1993 for the Consortium’s four-county coalition’s respective evaluations and the Kellogg Foundation’s overall evaluation (1992), the Consortium’s steering committee anticipated the need for a protocol that would ensure broad participation in identifying, articulating, and disseminating findings and other lessons learned. Furthermore, among the Consortium’s academic members, four were junior faculty being reviewed the following year for tenure and one was a doctoral student intending to focus her dissertation on organizational capacity-building by the Consortium. Hence, the steering committee appointed an ad hoc committee to draft “Authorship Guidelines” for the Consortium (see downloadable supplement for this chapter). The preambles acknowledges formally that members have both an opportunity and responsibility to share their experiences with others. The intent was to make transparent that although several media are available, the most likely medium to be used is the written word, and it was recognized that faculty are likely to be most interested in writing for publication. However, faculty genuinely wanted to share credit and authorship with agency and community counterparts. Thus, the guidelines noted that contributions to publications could include: providing original ideas that were critical to the implementation of a project or development of a paper; making suggestions as to how to write about the Consortium’s experience(s); or reviewing and commenting on a draft of a written paper. Moreover, the criteria for determining coauthorship were adapted from the International Committee of Medical Journal Editors’ Ethical Considerations in the Conduct and Reporting of Research: Authorship and Contributorship (http://www.icmje.org/ethical_1author.html). In sum, the resulting Authorship Guidelines represented the Consortium’s efforts to focus on a broader set of “contributors” to a written document, rather than the narrower definition of “writers” in defining authorship.

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In the case of the Collaborative, these guidelines have been codified in the bylaws, which describe the organization, processes and policies of the Publications and Dissemination Committee, as well as guidelines for the development of manuscripts, presentations, brochures, and Web page content. The composition of this Committee includes at least two persons representing the three main constituencies of the collaborative: academics, health providers, and community members.

For the Collaborative, the process of disseminating research results can take many forms—presentations in informal and professional settings, communicating with the media, preparation of reports and manuscripts and information on our Web site. Members of the Collaborative felt that nonacademic as well as academic publications should be encouraged as an important form of knowledge dissemination. The content of the Collaborative’s Publications and Dissemination Guidelines were developed by modeling those of the Consortium, described briefly above. For the purpose of the Collaborative dissemination document, the term “publication” refers to any and all forms of dissemination of information.

A standing Publications and Dissemination Committee of members of the Collaborative was formed to facilitate the review of proposed publications. The membership of the Collaborative decided that in order to maintain a balance of power and control, this committee would consist of seven representatives from the collaborative, including at least two members with university or college faculty affiliations, at least two members of the health care community, and at least two members of the wider community who do not have either of the previous affiliations. Any proposal for dissemination (for example, conference abstract, public presentation, manuscripts) submitted for review must include evaluation by a member from each Collaborative subgroup in order to be approved. Key example elements of the Collaborative’s Guidelines include a clear description of the lead author’s role, criteria for authorship, guidelines for authorship order, guidelines for publication review procedures, as well as guidelines for expedited or rapid review procedures.

Identification of a lead author, whether community or academic, was based on the individual member’s interest and willingness to do the work and dedicate time necessary to complete and coordinate the Publications and Dissemination Guidelines procedures, including establishing and coordinating the publication working group, forwarding final draft to the Publications and Dissemination Committee for review, and presentation of oral publications to the Collaborative.
as a whole. Criteria for determining coauthorship reflected commonly accepted principles, such as including individuals whose original ideas were critical to the implementation of the related project, those who offered suggestions that contributed to the writing up and publication development of the related project experience, or both. All authors must have made substantial contributions to the following to be included as an author:

- Concept and design or analysis and interpretation,
- Drafting the document or article critically for important content,
- Reviewing the document or article critically for important content; and
- Approval of final version to be published.

Individuals who may have less experience writing for publication or presenting at formal conferences would qualify as coauthors if, either individually with the lead author or with the entire working group, they:

- Were involved with conceptual discussions about the work or interpretation of findings,
- Reviewed and made comments on at least one draft of the presentation or paper; and
- Reviewed the final version and gave approval.

A detailed example and guidelines established for structuring the dissemination of research partnership materials is available in the downloadable supplement for this chapter.

**LESSONS LEARNED AND IMPLICATIONS FOR PRACTICE**

It is essential that each of the structures described in this chapter not be adopted as is by other research partnerships. Rather, we recommend reviewing them to initiate conversations with all members of a partnership about making it transparent to all regarding how decisions are to be made and how accountability for equitable participation would be ensured, and adapting some of these structures,
as appropriate. For example, should a partnership consider the Consortium’s bylaws to be relevant and adaptable to their anticipated needs, then it would not likely require nine months to create and adopt as it did for the Consortium. It will require, nonetheless, dedicated time by the entire partnership or an ad hoc committee to tailor the bylaws and engage all partnership members in deliberating and adopting them.

It is also important to recognize that some of the structures and mechanisms discussed in this chapter may not be relevant for all participatory research partnerships. For example, investigators interested in working to understand and address the health of individuals living within native and tribal nations have a number of unique considerations. Indeed, the concept of tribal sovereignty is paramount to recognize in the research process with American Indian/Alaska Native partners (Brugge & Missaghiian, 2006; National Congress of American Indians Policy Research Center, n.d.; and Schnarch, 2004). Based on the unique historical and treaty-based relationship between U.S. federal and tribal governments, a series of Executive Orders were issued between 1994 and 1998 to elevate the federal-tribal relationship to one of government-to-government. This recognition of tribal sovereignty has led to the emergence of structures that require equitable decision making with regard to investigators and the research process. Examples of such structures include institutional review boards governed by the Cherokee Nation and Navajo Nation and negotiated rates to cover Facilities and Administrative (F&A) costs of federally funded research (Becenti-Pigman et al., 2008; Indian Health Services Institutional Review Boards, 2012). These policies for equitable decision making in research are not in place, however, for community partners outside of federally recognized tribal nations. Nonetheless, recognition is growing that community research partners also warrant some degree of autonomy or sovereignty in decision making. To ensure equitable decision making, new structures may need to be established. Though these structures may take different forms than those found in tribal nations, an infrastructure at the community level can provide sustainability for equitable participation and community control that is necessary for the principles of CBPR to be put into practice. (For more information and key examples of participatory research being conducted with tribal communities, see Chapters Two and Eight in this volume.)

The deliberations and procedures for achieving consensus on developing an infrastructure for equitable decision making will likely reveal and confront difficult truths. For example, conversations about a community’s history and current
experiences with oppression or objectification of professors as being arrogant and out of touch will undoubtedly require courage from some and cause discomfort for all. Nonetheless, such conversations are necessary for research partnerships to foster a climate of diversity and inclusiveness, withstand transitions in leadership and membership, persevere through gaps in funding, and manage political and cultural conflicts. We have found, however, that although these conversations are necessary, they are not sufficient for maintaining the necessary partnership-guided principles needed for a research partnership to achieve its mission and goals. Based on our combined experience of 28 years as two CBPR partnerships in North Carolina, we conclude that an explicit infrastructure for equitable decision making must be in place to move up the rungs of Arsenstein's Ladder of Citizen Participation or the levels of DHHS Continuum of Community Involvement.

Finally, as national recognition grows in the field of public health on the importance of research that is multidisciplinary, translational, and engages communities as partners, so have the inadequacies of current research policies and mechanisms for promoting research partnerships. Community-Campus Partnerships for Health, a nonprofit organization that promotes health through partnerships between communities and academic institutions, has adopted 10 Principles for Good Community-Campus Partnerships (http://depts.washington.edu/ccph/principles.html). The U.S. Department of Health and Human Services is proposing sweeping changes to the regulations that govern research involving human subjects. New infrastructures for equitable decision making are being created by tribal nations, for example through the National Congress of American Indians Policy Research Center to govern the ethical conduct of research with non-native investigators (www.ncaiprc.org). Hence, more work is needed to develop and examine the relevance and effectiveness of emerging innovations in structures for initiating and sustaining equitable decision making within research partnerships.

**SUMMARY**

Although the six structures described may serve to cultivate and sustain research partnerships, they are also central to and consistent with the CBPR principle of equitable participation by all partners. For all partnerships to thrive and endure,
constant attention and hard work are required from each partner—regardless of the vows and good intentions expressed at the outset. And this is even more so for community-academic research partnerships, which are purposely formed to bring together worldviews and skill sets that are multidisciplinary and culturally diverse, on the one hand, with the challenges of managing contradictions and conflict while being inclusive, on the other. Hence, to anticipate these challenges, consideration should be given to the a priori creation of an infrastructure for equitable decision making that is transparent to all partners and accords accountability to the full partnership for each phase of the research enterprise. In this chapter, we offered examples of mechanisms and structures aimed at ensuring equitable decision making during the formative, implementation, and dissemination phases.

DISCUSSION QUESTIONS

1. Based on this chapter’s discussion of creating and implementing an infrastructure for equitable participation in decision making, if you were a member of a newly formed CBPR partnership interested in applying for research grant funding, in what ways might you begin conversations among the partners regarding bylaws and ethical conduct of research?

2. Within a CBPR partnership that has been awarded research funding, what conflicts might you anticipate? If members of this partnership were uncomfortable with addressing conflict, how might you begin to structure conversations among all members to contribute differing insights and expertise on how to anticipate and manage “necessary conflict”?

3. Thinking back to the different dynamics of the Collaborative and Consortium illustrated within this chapter, what are the pros and cons associated with developing formal structures, such as written bylaws?

KEY TERMS

Bylaws development
Conflict negotiation
Structures for equitable decisionmaking
Undoing Racism training

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REFERENCES


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