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The Challenges of Collaboration for Academic and Community Partners in a Research Partnership: Points to Consider[1]

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ABSTRACT: THE PHILOSOPHICAL UNDERPINNING OF Community-Engaged Research (CEnR) entails a collaborative partnership between academic researchers and the community. The Community-Based Participatory Research (CBPR) model is the partnership model most widely discussed in the CEnR literature and is the primary model we draw upon in this discussion of the collaboration between academic researchers and the community. In CPBR, the goal is for community partners to have equal authority and responsibility with the academic research team, and that the partners engage in respectful negotiation both before the research begins and throughout the research process to ensure that the concerns, interests, and needs of each party are addressed. The negotiation of a fair, successful, and enduring partnership requires transparency and understanding of the different assets, skills and expertise that each party brings to the project. Delineating the expectations of both parties and documenting the terms of agreement in a memorandum of understanding or similar document may be very useful. This document is structured to provide a "points- to-consider" roadmap for academic and community research partners to establish and maintain a research partnership at each stage of the research process.

KEY WORDS: community-engaged research; community-based participatory research; community-academic partnerships; community; community-based organizations; memorandum of understanding; data dissemination

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THE PHILOSOPHICAL UNDERPINNING OF Community-Engaged Research (CEnR) entails a collaborative partnership between academic researchers and the community. While the relative roles of community research partners and academic researchers differ across the continuum of CEnR research, all CEnR models contrast with the traditional model in which academic investigators define and control all aspects of the research project and only seek interaction with the community for recruitment and enrollment, disappearing when data collection is complete.

The Community-Based Participatory Research (CBPR) model is the partnership model most widely discussed in the literature. In CPBR, the goal is for community partners to have equal authority and responsibility with the academic research team. This is not to say that each partner has an equal role at each stage of the process. Rather, CBPR partners negotiate roles and responsibilities depending on the different expertise brought by members of the community and of the academic research team as well as the different goals and motivation of each party. Because one goal of an academic-community partnership is the bidirectional flow of knowledge, training and skills, expertise by one party

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in one domain does not mean that this party excludes the participation of the other party or takes full control of that component of the research. What can be accomplished will be constrained by the interests of each party, the time that they can afford to allocate, the amount of trust that underlies the relationship, and the resources available to them.

The implicit promise of research collaboration between academic and community research partners is that each group has the opportunity and authority to exercise agency—each group has a right to provide input regarding the course of the project and a right that this input be weighed and considered by the partner group. Although the partners' primary interests may not be completely congruent, they are compatible in that they both have the goal of improving health. For example, the academic researcher may be interested in determining lead levels in preschool children to determine feasibility for a therapeutic trial whereas community research partners may want this information to advocate for greater public health resources.

Shared authority in CBPR requires mutual and respectful trust between the partners. Trust is established by relationship-building, spending time together listening to each other's concerns, interests, and needs, and incorporating them into the research agenda (Minkler & Wallerstein, 2008). Negotiation and discussion are vital to this process. As trust grows between the partners, each partner may be more willing to make temporary concessions to promote a long-term collaborative relationship. For example, a funding opportunity may be specified for a particular project. While this may be a project that fits the expertise and interest of the academic researcher, a community's goals may be broader or only tangential to that particular project. The community partner may decide to participate, however, if it believes that the data generated will be useful to improving access to health care in the long-term, or to obtaining adequate pilot data to interest researchers and funders in a project that is more relevant to the community's needs.

A crosscutting theme in CBPR is the need for respectful negotiation both before the research begins and throughout the research process and beyond to ensure that the concerns, interests, and needs of each party are addressed. Further, the process usually entails open discussion of research results with stakeholders from the group or community to achieve concrete improvements in the community. But as will be discussed, the dissemination of results entails risks and complexities that must be anticipated in the collaborative development of the project. The degree of trust that exists prior to the initiation of a research protocol may influence the extent to which roles and responsibilities need to be formally delineated and strictly followed, versus the degree to which accommodations and modifications can occur as the project ensues. Delineating the expectations of both parties and documenting the terms of agreement in a memorandum of understanding (MOU) or similar document may be very useful.

In an accompanying article, we provide an analytical framework for exploring the risks that arise when academic researchers and communities partner in CEnR. In this document we enumerate points to consider by academic and community research partners at each stage of the research process in order to establish and maintain a research partnership. We consider what steps are needed starting with the development of a relationship between academic researchers and the community even before a specific project is conceived; to the development of a research agenda, a plan for the procurement of funding, project implementation and data collection; through data analysis, data dissemination and a consideration of post-projects steps necessary to sustain the relationship and maintain or promote the benefits that the community has attained. Our main focus is CBPR that involves a translational healthcare agenda. While many of these same considerations are relevant to other forms of CEnR, we focus on CBPR because of its commitment to shared community authority, responsibility, and resources. Moreover, while many of these same considerations are relevant to other research agendas (e.g., environmental projects, housing projects), we lacked adequate expertise to be able to claim that this point-to-consider document is either necessary or sufficient for such projects. This document is meant to enumerate the factors that need to be considered for a community-academic partnership to successfully undertake translational healthcare research. Given the breadth and diversity of communities and translational healthcare research agendas, we do not claim that the questions we pose are comprehensive or sufficient in all circumstances. Rather, we believe that a robust engagement by the partners, using this document as a starting point, will allow for the successful negotiation of most community-engaged translational healthcare research, while acknowledging that a particular translational research problem or a particular community-academic relationship may need to identify and address additional issues.

Method

A seven-member writing team convened to develop a framework for providing HSP in CEnR. The team consisted of one academic CBPR researcher and one community

research partner; four with specialization in human subjects protections with three who self-identify as ethicists and one in research subject advocacy; and one research associate with interest in HSP. Through iterative collaboration, the writing group developed a taxonomy and framework for the risks presented by CEnR. Implications were explored, and appropriate safeguards discussed. Two stakeholder meetings were held with numerous academic researchers, community research partners, community activists and other HSP program personnel. At the first meeting, 6 additional academic researchers involved in CEnR were invited, as were 10 community research partners/community activists, and 8 persons engaged in HSP. The stakeholders were asked to give presentations about the process of CEnR from the perspectives of the academic research partner and the community research partner, respectively. Some were asked to describe the benefits, burdens, incentives and obstacles faced by those involved in CEnR, while others were asked to discuss specific ethical challenges that arise when doing research with communities that are both partners and participants. There were both large group and small group break-out sessions to give all attendees a chance to express themselves. Following this meeting, the writing team developed a taxonomy of risk, with a particular focus of exploring the breadth of risks faced by disparate groups. At the second stakeholder meeting, the writing group (minus the research subject advocate) met with 5 additional academic researchers involved in CEnR, 7 community research partners/community activists and 7 HSP experts to seek feedback on the ethical framework and supplemental documents developed to serve community-academic partners and HSP program personnel respectively. While there was much overlap in the participants who attended the first and second meetings, we intentionally made some changes to increase the diversity of viewpoints. All stakeholders at the second meeting were asked to comment on written drafts and most were asked to give oral presentations regarding strengths and weaknesses of the three documents.

Before the Project

(This section is adapted and reprinted from Ross et al., "Human Subjects Protections in Community-Engaged Research: A Research Ethics Framework," this issue.)

Finding or Forming the Community Research Partner

Although it is common to hear people talk about the "African American Community," the "South Side of Chicago community," or the "HIV community," these entities are not established communities with internal structure, but groups of individuals with a shared characteristic (race/ethnicity, geography or disease, respectively). Individuals belong to many such groups, some of which they belong to voluntarily, and others involuntarily, some of which they embrace, and others which are imposed upon them. A community, by contrast, is a structured group—a group with its own social structure often with identifiable leaders. Communities may be formed because of a shared characteristic, trait, experience, belief, attitude, interest, or historical event; but merit their status because they have an internal structure, identifiable leadership, and sustain themselves over time. Sometimes, academic researchers want to work with members of an unstructured group, and these groups can be empowered to have structure for the purpose of the research. The structure may come from external sources (e.g., a community-based-organization or CBO) or internally (e.g., the researcher helps the group organize and establish leadership). For the purpose of this project, we define a community to include both structured groups that exist irrespective of the research (established communities) and groups that are structured for the purpose of the research either by external or internal sources.

For some academic researcher-community partnerships, the community is easily defined and approached. For example, an academic researcher may seek to partner with a church (established community) to evaluate pilot questions about the impact of spirituality on health beliefs and health outcomes. The academic researcher may seek permission from the minister who may help identify interested parishioners or may delegate this responsibility to an extant church committee that is focused on community healthcare needs. To the extent that the project involves an established community, the legitimacy of certain spokespersons (e.g. church leaders) is clear and they are the portals to relationship building. Although the legitimacy of the leader's agency to make decisions is established, the decision to permit a researcher to enter the church community may not be viewed positively by all congregational members. Some congregants may question why the minister's authority as spiritual leader gives him or her authority to promote or reject a voluntary activity in healthcare research, creating tensions between the group and its individual members. A community's decision (or the decision by the community's leadership) may threaten the cohesiveness of the community whose sense of identify is not centered around the particular health concern. Collaboration with academic researchers, then, may cause a structured group

to be vulnerable to disassociation of individuals or even splintering of the community itself.

Some groups are unstructured and it may be more difficult to identify its members or to determine who legitimately speaks for the group. For example, imagine an academic researcher interested in doing research on the healthcare needs of abused women. Often these women are isolated and do not know each other. Even if they were to be connected, they may not view themselves as a community. In fact, for many of them, a primary goal may be to escape this situation, and as such they may not want to develop relationships with women similarly situated. However, some of these women may affiliate with a few CBOs that provide needed mental health services and can direct them to safe shelters. To partner with these women, the academic researcher may partner with one or more CBOs that serve these women to give them a voice in defining the research priorities and the methodology to be used. This does not imply that the sample is representative of all abused women: different CBOs may give voice to different women to different degrees and may make priorities with greater or lesser input from a diverse sample of clientele. This is one reason why academic researchers may want to partner with multiple CBOs or to seek multiple community partners.

Members of community groups that are formed for the research engagement itself, or that are defined by their relationship to a service CBO, are more vulnerable than members of established communities because of greater agency concerns regarding who speaks for the community. To the extent that the ideal representation within a community is determined by its members, this is not achieved when members are not adequately organized to self-determine leadership, and it often is the responsibility of a third party (e.g., a CBO) or the researchers themselves to ensure that there is a leadership structure to provide agency. In such circumstances, the idea of group agency is opaque and concerns of the legitimacy of the representatives who speak for the group magnifies agency risks. Agency risks occur both when individual members experience some degree of pressure because the group's internal or external leadership partners with the academic researcher about projects that they may not support; and when individual members experience a sense of frustration when they know that opportunities exist but that their leadership did not pursue those opportunities. It is also more likely that academic researchers impose their own agenda on unstructured groups that have not identified for themselves their own research agenda priorities.

POINTS TO CONSIDER

- Are the prospective research participants members of an identifiable group with whom the academic researchers can partner?
- Is the group structured (an established community) or is it unstructured?
- Does the group have designated leadership (structured group) or can leadership be created, either externally (via a CBO) or internally (by group self-organization)?
- Is/are the community leader(s) responsive and inclusive to the needs of the group that he/she/they represent(s)?
- Do/does the leader(s) understand the requirements of the research project and the risks and benefits for his or her specific community?
- Are the community leaders respected by the community and the academic researchers?
- Is there a CBO that provides services to the group for whom the research agenda is consistent with its mission?
- Is/are the leaders/CBO willing to learn/acquire knowledge that will be beneficial to the group that it/they represent(s)?

Finding an Academic Researcher Partner

Usually an academic researcher approaches a community with a research proposal, although sometimes communities have research ideas and need to find appropriate academic partners. Before agreeing to partner with a particular academic researcher, the community must be satisfied along three dimensions: (1) that the researcher is capable of performing the research; (2) that the research is expected to benefit the community or that it is useful to the community in ways that justify its participation; and (3) that the community can trust the researcher to pursue the particular research project in a manner respectful of the community. In addition, the community needs to assess the researcher's willingness to use the research findings to effect change, aware of the constraints that academic responsibilities may place on the researcher and his or her ability to pursue advocacy or long-term involvement. Assessing, and when possible, seeking assurances from the researcher's institution about its commitment to the community, may help the community decide whether a longitudinal partnership is likely to be successful.

POINTS TO CONSIDER

- Does the academic researcher have the skills, experience, and resources necessary for the specific research project?

- Does the academic researcher seem willing to collaborate and respect the agency of the community?
- Is the researcher committed to long-term relationships with community partners?
- Is the researcher willing to pursue the advocacy and policy issues that emanate from the research? If not, can others help in these roles?
- Does the academic researcher have some degree of institutional commitment for promoting successful academic-community partnerships?

Agenda Setting and Developing a Joint Work Plan

Practitioners of CBPR emphasize that CBPR is not a methodology but an orientation to research. Traditionally, this orientation has been focused on social justice, and CBPR is often described as a more participatory and action-oriented approach (Minkler & Wallerstein, 2008). Whereas traditional clinical research focuses on distributive justice concerns regarding the distribution of risks and benefits, CBPR focuses on both distributive and non-distributive concerns of justice. Non-distributive concerns of justice (often referred to as social justice concerns) focus on health care disparities, the needs of vulnerable populations, and the need to address such issues as stigma, lack of respect, and lack of institutions and social practices that support capacities for self-determination—for both individuals and groups (Powers & Faden, 2006). The first step in addressing social justice concerns is choosing a research agenda that addresses a significant health issue for the community that is both a partner and participant in the proposed research. By collectively engaging in agenda setting, the community's priorities are incorporated into the research strategy. A community advisory board (CAB), if properly constituted to be inclusive and responsive to the community (Montanaro, 2009), can be helpful at this stage. Data show that despite demographic differences between members of a CAB and members of the community, CABs can effectively represent the community's needs (Conway, Hu, & Harrington, 1997).

POINTS TO CONSIDER

- Has there been adequate dialog to ensure that the health priorities of the partnership reflect the community's needs?
- Does the academic researcher have the skills and interest to address the research needs of the community?
- Is funding available for this type of research?
- If funding is not available for a particular research priority, are the academic researcher and community willing to pursue other projects and attempt to procure funds for addressing this top priority at a later stage?

Research Design and Implementation

In the design of CBPR research, both the community and academic research partners are expected to have input into research design and implementation. The academic researchers often bring expertise in research methodology and data analysis, key components for scientific integrity. The community partners often bring additional expertise: knowledge of community needs, beliefs and interests, and practical knowledge regarding the community's social structure.

When approached by an academic researcher about a particular funding opportunity, community partners may reject particular projects because they are not congruent with community priorities, or because they fear that the data that may be obtained may be unflattering and expose vulnerabilities of the community or threaten the social structures or agency of the community. In such a case, the researcher and community may simply part ways. However, when the academic researchers have a relationship with the community, both parties may seek to negotiate and modify the proposal or pursue variation(s) of the original project that may be more acceptable to the community (Minkler & Wallerstein, 2008).

Input from both the academic and community research partners is appropriate at all stages and about all components of the research project. Questions asked by either partner may offer insights not previously considered or anticipated. Within each stage of research the expertise of each party can complement that of the other, e.g., in decisions about sampling, the academic researcher might provide expertise in determining appropriate sample size for scientific soundness and power while the community partner might provide expertise regarding how the appropriate sample size might be obtained. There may be situations where one party requests training in the areas of research in which they lack expertise in order to be a more effective research partner for the current project as well as for future projects.

An effective partnership requires transparency about the research goals and methods. This requires a delineation of the research hypotheses; the foreseeable risks and benefits of participation from both the individual and community perspectives; the potential impact on the community from participation as well as from the findings that may emerge; how data will be analyzed and disseminated; and what will happen to the data and to the partnership once this particular research project has concluded. Conflicts of interest or perceived conflicts of interest should be disclosed and discussions undertaken about how they should be managed.

The partners should be clear about what is and what is not negotiable. Some decisions may be out of the hands of both parties (e.g., a legal requirement for reporting suspected abuse; or a funder's requirement to publish all data, even if unflattering). However, when flexibility is feasible, negotiation should occur and must be respectful of both parties.

Two issues that should be negotiated prior to data collection are who will control the data during and after the study and how intellectual property (IP) rights will be determined. The academic researchers or the community may want to maintain primary control of data for future use. To the extent that future use is anticipated, consent for such usage from the individual participants should be sought during the consent process. Decisions regarding who has the authority to permit access to the data, what types of future uses are permissible, and what type of oversight such secondary data analyses require should be delineated in an MOU and should be shared with individual participants during the consent process. In some cases, the funders (e.g., the National Institutes of Health [NIH]) require broad accessibility of third-parties to the data, but in other cases, access can be restricted. In both circumstances, who will have the authority to participate in decisions about access and future uses should be clarified before the data are collected.

IP rights include both questions of authorship and ownership of discovery; they should be addressed prospectively. With respect to authorship, many journals limit the number of authors on a manuscript, and some journals have specific requirements about the type and degree of input required to justify authorship. The order of authorship may be very important for the academic researchers and this should be clarified upfront although roles may change as work progresses, necessitating a re-evaluation of the agreement. Patentability of discovery has economic implications and may be even more contentious. Decisions must be made about whether to apply for a patent, who will have access to tests or treatments that are developed, and who will share in the proceeds that IP may generate. Two case studies are informative: In *Greenberg vs. Miami Children's Hospital et al.* (Merz et al., 2002), parents of children afflicted with Canavan disease gave samples and resources to Dr. Reuben Matalon to develop prenatal and carrier testing for Canavan disease on the assumption that such tests would be made accessible and affordable to the public. Unbeknownst to the Canavan families and organizations, Matalon and his employer, Miami Children's Hospital, obtained a patent for the Canavan disease gene, and began to charge royalties and to limit the availability of testing. Although most of the judicial charges against Matalon and Miami Children's Hospital were dismissed (except the claim of unjust enrichment) (Merz et al., 2002), Sharon Terry has endeavored to prevent such an outcome for individuals with Pseudoxanthomatous Elasticum (PXE) (Terry et al., 2007). Terry helped found the PXE international advocacy group, and she has taken a proactive role in defining and funding the research. She is even named in the patent issued for the discovery of the PXE-related gene (U.S. Patent No. 7,364,904, 2008) and therefore can ensure that the patent is not used against the community that provided the samples and money for the research.

POINTS TO CONSIDER

- Have the possible results of the research been anticipated and discussed?
- Do conflicts of interest (COI) exist? Is there a COI management plan that is acceptable to all?
- What components of the research are modifiable, and have the interests of both parties been explored?
- What components of the research are non-negotiable and are these constraints acceptable to both parties?
- Will the data be usable for future research projects? Has an agreement been reached about who has access to, and control of, data after the research is completed?
- Has an agreement been reached about authorship?
- Has an agreement been reached about intellectual property?

Applying for Funding

Funding is critical for the success of research. In CBPR, funding may be necessary to support both the academic researcher and the community members as they seek to develop a potential collaborative research relationship prior to the design of the study. Funders may need to be educated about the need for resources prior to developing a research protocol in CBPR.

How funds and resources are distributed and managed between the academic partner and the community requires negotiation. NIH policy now permits more than one principal investigator, which can facilitate resource sharing by collaborative research partners. Other funders should be encouraged to permit this practice as well. However, academic centers often have personnel who are specifically trained at grant award accounting which involves very specific reporting requirements. To the extent that community partners want to have monies and resources distributed directly to them, they need to

ensure that they have the expertise to manage grant funds, lest they put the project and the academic research partner at risk. One solution is to include funding for a community-based grant manager into the grant proposal. However, the additional costs may make the grant less competitively viable, and concerns that the community grant management position is not sustainable may make it difficult to hire a person with the necessary expertise.

POINTS TO CONSIDER

- Who is eligible to apply for funding as principal investigator(s)?
- Who will apply for funding as principal investigator(s)?
- Does the funder have an appreciation for the degree of collaboration intended by the research partners?
- If each partner will manage part of the funds, does each partner possess adequate expertise in managing grant funds and the resources and expertise necessary to fulfill reporting requirements?

During the Project

The Consent Process for Individuals and Groups

Since the drafting of the Nuremberg Code as the first international code of research ethics, the consent of the individual research participant has been the cornerstone of research ethics (Nuremberg Code, 1949). The consent process must address the risks and benefits that the research poses to the individual as an individual. With the engagement of communities, the consent process should also address the risks and benefits that the research poses to the group and to the individual as a member of a group. The potential participant needs to understand that his or her individual participation is voluntary, even if endorsed by community leaders. The potential participant also needs to understand that his or her decision not to participate will not affect other services; and that the individual who does agree to participate can withdraw at any time.

There is some discussion in the research ethics literature about requiring group consent in CBPR in addition to individual consent (Wallerstein & Duran, 2006) although questions about how to determine the legitimacy of group consent and whether unanimity or majority rule suffices have not been resolved. Group consent may be required for access into certain established communities (e.g., group consent to enter an Indian reservation to do research), but the idea of group consent may not be morally justifiable or necessary for access into other communities (e.g., access into unstructured groups that are given structure externally for the purpose of doing research). Even when formal group consent is not necessary or justifiable, the benefit of engaging with a community and procuring its endorsement is a cornerstone of all CEnR. While labor-intensive, the rewards are great in that it affirms for individual community members the support of community leaders which may reduce inherent distrust that individuals, particularly members of vulnerable communities, may have towards researchers in general. This may reduce some of the barriers to recruitment and consent and improve retention. However, group endorsement may also pose risks to individuals, particularly vulnerable individuals, because an individual could substitute the community's endorsement for a personal assessment of the risks and benefits. Even in established communities in which group consent may be legitimate, the individual participant must have the power to decide whether or not to participate. Questions of how to ensure that individuals can choose not to participate despite the group's endorsement and whether individuals can choose to participate despite the group's refusal to engage are complex issues.

Community consent or endorsement can be expressed by an MOU that is developed and affirmed by both the academic researcher and the community research partner. An MOU is useful to delineate rights and responsibilities as well as agreements as to what the research will entail and to address prospectively how disputes or other potential sources of controversy will be handled.

POINTS TO CONSIDER

- What are the risks of participating in the research project for the individual and the community?
- What are the risks to non-participating community members?
- What are the possible risks to agency to individuals from the group's involvement?
- What are the possible benefits of participating in the research for the individual and the community?
- Is formal community consent appropriate, considering the history, established structure, and cohesiveness of the group?
- If formal community consent is not needed, how has the group or community expressed its endorsement of the research project?
- If formal community consent or informal endorsement is given, have adequate measures been taken to ensure that individual members understand that their participation is voluntary?
- Have the research partners developed an MOU that signifies agreement by both parties to proceed?

RECRUITMENT AND RETENTION

The recruitment and retention of research participants is critical to a project's success. The collaborative relationship between the academic researchers and the community may aid in recruitment efficiency and retention. In recruitment and other outreach components, academic and community partners may employ community members in order to increase recruitment effectiveness and to provide training, skills and opportunities. Community research partners need to be trained in research ethics and HSP to ensure adequate safeguards. Partnerships may decide to employ individuals who live in the neighborhood but are not actual members of the community under study for recruitment and data collection to safeguard the privacy of the potential participants (e.g., employing childless individuals to collect data about single mothers).

In longitudinal studies, the ability to retain participants is difficult and labor-intensive, but failure to do so may compromise the data. Community partnership can help with retention, given that individuals may feel a greater sense of ownership of, or trust in, the project, and therefore a greater desire to see the project succeed. Retention can also be improved by continued dialogue and public engagement with the community and its leadership. The key is the trust that is at the core of the partnership which is reinforced by continual engagement. For some groups, particularly those that have difficulty in assembling because of geography, physical limitations, or other social barriers, online social networking tools may help promote longitudinal relationships and reinforce the trust already established.

However well-meaning, recruiters and data collectors may create some degree of undue influence on community members. While there are data to show that recruitment by individuals with whom potential participants can identify or trust can increase recruitment, some participants may feel greater pressure to participate than they normally would if they were approached by unknown researchers (Epstein, 2008). One way to reduce the risk that community members are not voluntarily consenting is to provide training in research ethics and HSP for all community members engaged in the research, particularly for those involved in recruitment. Refusals need to be respected and there must be external personnel (e.g., members of the institutional review board [IRB] or the CAB) that individuals can contact if they feel any undue influence to continue participation.

POINTS TO CONSIDER

- What are the risks and benefits of involving community members in the recruitment of participants?
- Have the potential conflicts of interest in recruitment been adequately addressed?
- Are there mechanisms for feedback from the community to the group leadership and research team regarding recruitment efforts?
- Are there mechanisms to mitigate the community's undue influence on an individual to participate?

DATA COLLECTION

The research data collected may be in the form of answers written on a paper survey; video or voice recordings of a focus group, or clinical and behavioral outcomes following a diagnostic, therapeutic, or clinical intervention. In each case, the data need to be collected and managed for later analysis. The process of collecting and managing the data, like the process of recruitment, may provide an opportunity for partnering groups to share responsibilities and resources. Data collection may also be a source of economic empowerment in the community. However, when community members are employed as data collectors, concerns about maintaining ethical standards arise. Specifically, confidentiality of data may be more difficult to ensure when socially proximate individuals collect data from each other. Data collection processes can be implemented that circumvent the data collector from having actual knowledge of the participants' responses (e.g., having the research participants type their answers onto a laptop computer rather than having the data collector input the data). Hiring data collectors from the neighborhood who are not actual members of the community under study can also help safeguard the privacy of the potential participants yet still provide needed employment opportunity to the neighborhood.

Data collection occurs over a period of time. Prior to the start of a project, the research team develops a data safety monitoring plan (DSMP) that must be submitted and approved by an IRB. A DSMP should specify what activities it will monitor. This may include consent monitoring, verification of the fidelity of data collection and processing, and/or reviewing adverse events, violations of protocol, mishandling of data, or other HSP violations. In clinical trials where the endpoints are morbidity and mortality, the DSMP often entails constituting a formal data safety monitoring committee (DSMC). While such clinical trials are uncommon in CEnR, and even less so in CBPR, a research partnership may decide that a community advisory board (CAB) will function as a DSMC. Alternatively, it may choose to constitute a DSMC with academic and community members for help with decisions about how to handle and monitor adverse events, about stopping the study

early, and about revising consent forms to be more explicit about emerging risks. The DSMC membership should be negotiated before the research starts. Before accepting its charge, the DSMC should come to agreement about whether it will have access to all data; whether the data will be blinded; what would be reasons to unblind the data; and what authority it will have to halt or stop the research. The research partnership must be willing to develop guidelines with the DSMC about when there should be communication with other sources of HSP (see "Nine Key Functions for a Human Subjects Protection Program for Community-Engaged Research: Points to Consider," this issue).

POINTS TO CONSIDER

- Have academic and community research partners received culturally sensitive HSP training?
- Are ongoing processes in place to audit whether HSP are adequate?
- Can community members be empowered to oversee protections in their community's own research-related work?

Data Analysis, Interpretation, and Dissemination

After data are collected, they are analyzed, interpreted, and prepared for dissemination both to the community itself and to the larger scientific and sociopolitical bodies that may be interested in the data. The academic research and community partners need to think creatively about how to ensure that the results are shared with the community in a way that is comprehensible, useful and empowering. In general, research data are returned in aggregate and only rarely are individual results reported back. To the extent that requests for individual results can be anticipated, the research partnership should decide prospectively whether this will be provided. In either case, the plans for reporting back of aggregate and individual results should be considered proactively and delineated in a MOU and in the consent form that individual participants must sign. The results should be reported back in a way that is meaningful for the community using outreach communication strategies like newsletters, web pages, and public presentations.

In the analysis and interpretation of data, the competing agenda of the academic researcher and the community research partners may come into tension. While the academic researcher may intend to make claims that are as generalizable as possible, the community group may only focus on local relevance. Conversely, the community partner may not understand issues of external validity and may make claims that are not warranted by the research methods and data. Although both academic and community partners are guided by a goal of bettering health, the academic researcher may see the research as part of a larger process of scientific discovery whereas the community may see it as the first step toward productive on-the-ground action. Not only does this tension mean that research partners will sometimes want to focus on different parts or aspects of the data, but also that research partners will sometimes have very different interpretations of the same data. In some cases, the same data can be used to support or detract from the ability to procure wanted services; in other cases, the data can be interpreted as promoting or detracting from social stereotypes and prejudices. When understanding and interests diverge, conflicts may arise regarding how the data are presented, the forum in which the data are presented, and decisions about what data to publish.

Some issues of data dissemination can be anticipated prospectively. For example, academic researchers may plan to publish their data in scientific journals. If so, negotiating rules of authorship should be addressed as some community partners may want, and have the expertise to take on, a significant role. Alternatively, community partners may prefer publishing in media that emphasize wider access to the reports (e.g., online mass-media journals) for leverage in getting services, and may want the researchers to help them in these activities. Tension can develop because many academic journals will not publish findings already reported elsewhere. Therefore, who will have authority to disseminate the data, to decide the manner of data dissemination, and to decide what responsibilities each party has to data dissemination should be addressed prospectively (Yale Center for Clinical Investigation CARE: Community Alliance for Research and Engagement, undated). Practical issues concerning data storage and future access should be agreed upon prospectively because participants will need to consent to data storage and future use. In some cases, the funder may require sharing of raw data, and participants should know this as well, particularly as it may impact their decision to participate.

The community needs to consider prospectively the concerns that the findings may illuminate, and whether they are truly willing to let these data be collected and disseminated. Research findings are not always predictable: some findings will be unanticipated, and the consequences of reporting data cannot always be known prospectively. When data analysis reveals unflattering findings about a community, the academic researcher

may experience pushback from her community partners regarding her plans to disseminate the findings. How the data are framed may have social implications for the group (Nicholson et al., 2008; Sanders, 1997; Smith, 2007) and for public policymakers and the public-at-large (Fox, 2005; Judd et al., 2005). Both the academic researcher and the community may make claims to "ownership" of the data and rights to its use. Both have legitimate claims as both partners will have been integral to data collection and have a stake in data analysis. For this reason, speaking of ownership is likely to be a dead end. The academic researcher and community partners need to work together to ensure that the data are disseminated in a respectful manner that minimizes harms to the community. Neither the academic researchers nor the community research partners should claim absolute veto power because there are obligations to other stakeholders (e.g., the granting organization, the service communities that may need the data). To minimize conflict, interpretation and dissemination concerns should be addressed prospectively. Provisions for conflict resolution in MOUs are useful to avoid breaches of partnership and to ensure respectful negotiations regarding how to disseminate data.

POINTS TO CONSIDER

- Does the community seek any restrictions on data reporting and dissemination?
- Has an agreement been reached as to how culturally sensitive results, or results with potential negative implications for a community, will be framed and disseminated?
- Will the data be usable for future research projects? And who will control this access?
- Will the academic researchers provide some training on data analysis and journal publication?
- How should the community partners be listed in publications?

After the Project

Community Benefits and Sustaining Relationships

In almost all situations, it is to the benefit of both the academic community and the communities with which they partner to maintain the relationship that has been forged. Because community groups often have goals focused on local relevance, community capacity-building, and group empowerment, the research may function more to promote social justice goals rather than scientific discovery and generalizability. Given these goals, there may not be any clear completion to CEnR projects. This creates a tension for the traditional academic career, which involves a string of separate but related projects that may investigate hypotheses that require different communities for study participation. However, to the extent that academic researchers are often members of teams, it behooves team members or the broader University community itself, to identify individuals who are willing to maintain and sustain the relationship given the time, energy and investment that CEnR entails.

On both sides of the relationship, funding and time barriers exist. Academic investigators should consider what obligations they might have to their community partner after the collection, analysis, and dissemination of data. A minimum requirement is for the academic investigator not to leave the community worse off than it was prior to participating in the research. However, in most cases, given the usual inequities in power, resources, and authority, the investigator, with the help of his or her University community, should assume a higher degree of responsibility. Academic researchers or their institution should try to help the community partners secure continued funding and resources to sustain the health benefits achieved during the intervention, the lack of which may lead to frustrations and harms to the participants and the community. Good-faith efforts are particularly important when implied during negotiations prior to the project's implementation.

POINTS TO CONSIDER

- What are the short-term benefits and long-term benefits that the community receives from research collaboration?
- What short-term benefits and long-term benefits do the academic researchers receive from research collaboration?
- Is the research project part of larger programmatic research within the academic institution that requires sustained involvement with the community, or is it a self-limited project of defined duration?
- Have the academic researcher and the community/group/leadership discussed the implications of the projects' completion—both positive and negative?
- Have any plans or promises been made to preserve the relationships, infrastructure and benefits developed in the community after the life of the project?

Concluding Thoughts

Academic-community partnerships provide a means to perform translational research in a way that is useful for, and respectful of, the communities that are both partners and participants in the study. A fair and effective

partnership is founded on trust and requires sharing of authority and resources throughout the research. The negotiation of a fair partnership requires transparency and understanding of the different assets, skills and expertise that each party brings to the project. Prospective negotiation of the issues raised in this document can help promote a successful and enduring partnership.

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