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# Community-Based Research Practices

## Designing Problem-Centered Collaborations



*The candle is not there to illuminate itself.*

—Nowab Jan-Fishan Khan, nineteenth century

**C**ommunity-based research (CBR) involves collaborative partnerships between the research/academic community and community members. CBR is an attempt for researchers to actively involve the communities that they claim to serve through the research process. Researchers will often partner with established community-based organizations (CBOs) (although this is not always the case).

It is important to note from the outset that a great deal of community-based research occurs in order to teach undergraduate students. For example, professors and service learning professionals may develop community-based research projects for their classes. While ideally these projects also serve the needs of the relevant communities, this is not always the case as these projects are typically structured around the academic calendar and the needs of individual professors and their students. This is a complicated subject and one that I am not going to take up in this chapter. As my interest in community-based research is in the context of exploring transdisciplinarity, I focus exclusively on research conducted by researchers (with their community partners) for the sake of their own research and community betterment.

The history of CBR is intertwined with the history of social action research and participatory research (community-based participatory research, CBPR, is considered one approach to CBR; however, given the

relatively brief treatment of CBR in this book I employ the more general term CBR). CBR developed because universities had been viewed by many as detached and unresponsive to the needs of the community (Strand, Marullo, Cutforth, Stoecker & Donohue 2003). In this vein, CBR is a strategy for placing the research community/academy within real-world contexts, and not outside of them. Therefore, there is a natural synergy between CBR and transdisciplinarity.

Community-based research, in its ideal form, is a holistic, synergistic, and highly collaborative approach to research. Whether an individual researcher is embarking on a CBR project with community partners, or whether a team of multi-disciplinary researchers is engaging in a CBR project, CBR is a necessarily collaborative approach to research. CBR requires researchers to share authority over the knowledge-building process. Community-based research projects share a commitment to social action, social change and social justice (Strand 2003).

Community-based research developed in multi- and interdisciplinary research contexts, and is not the methodological property of any one discipline. I suggest that in its best form CBR is necessarily a transdisciplinary modality of research. Although at its best CBR is transdisciplinary, the fact is that for a host of practical and other reasons most CBR projects are not transdisciplinary. CBR is not inherently transdisciplinary, but rather a transdisciplinary approach may be applied to a CBR study. The core principles and design issues reviewed in this chapter and summarized later in table 4.1 represent the criteria for a CBR project to be deemed transdisciplinary. In order to maximize the benefits of CBR, researchers developing projects need to cultivate transdisciplinary perspectives and attend to the challenges that are part and parcel of such an endeavor. One research genre in which this has been occurring is health research.

Over the past few decades transdisciplinary approaches to community-based research have flourished in health studies. There are several factors that likely impact this trend. To begin with, the kind of health problems that have grown in recent decades (cancer, diabetes, HIV/AIDS, obesity) can be prevented or better treated with education, behavioral changes and/or early intervention. Secondly, we have a lot of new information about the benefits of holistic approaches to health. In this regard, in 1984 the World Health Organization defined human health “in terms of combined biological, mental and social well-being with relation to environment” (Pikot & Kopp 2008, 307). Finally, in accord with increases in multi- and inter- and transdisciplinary education, in conjunction with

moves in the health community towards holistic approaches to health, several new, hybrid research fields have emerged and gained popularity.

Biomedical research, which merges medical and biological science, has grown rapidly (Flinterman et al. 2001). As biomedical research has developed, patients have simultaneously advocated for more participation in the research process (Flinterman et al. 2001). Consequently, biomedical research has trended towards transdisciplinary participatory approaches, often turning to CBR. Flinterman and colleagues note that the turn to transdisciplinary approaches to biomedical research “may result in a more structural participation of patients and more deliberate and optimal integration of their knowledge into research processes” (2001, 257).

The biopsychosocial model is another recent development in transdisciplinary approaches to health (Piko & Kopp 2008). This emerging body integrates the natural and social sciences (theories and methods). The guiding assumption in biopsychosocial models is that a patient’s physical body is also deeply impacted by his or her psychosocial processes and research must get at these issues in different ways. Piko and Kopp suggest that “medicine should become an integrated scientific field, at the crossroads of the natural and social sciences, needing a transdisciplinary approach” (2008, 309).

The shift towards transdisciplinarity in health research has coincided with trends towards CBR, resulting in an increase in community-based participatory approaches to health studies. This research advances transdisciplinarity. Let’s look at an in-depth example.

Health disparities across racial, ethnic and social class lines are a persistent problem in the United States, with cancer disparities now receiving considerable attention from the research community. Thinking about these disparities requires going beyond biological/medical perspectives and also paying attention to several social issues that may impact the health profile of a group or community:

- access to healthcare information and screenings
- access to quality medical care
- ways that gender, race, ethnicity, religion, sexual orientation and/or social class influence health screenings
- what makes health education effective or ineffective for different groups and why (in terms of content, form, and distribution)

There are also environmental factors that come into play such as:

- pollution
- exposures to toxic materials
- water and air quality
- food quality (such as the high price and limited availability of organics)

Therefore, this is a transdisciplinary topic by nature. In order to get at the relevant issues, research needs to connect different bodies of knowledge from the natural sciences, environmental sciences and social sciences.

The Tampa Bay Community Cancer Network (TBCCN) is a transdisciplinary organization that was forged in order to study cancer disparities in Florida and create effective health interventions in multiethnic, medically underserved communities. With funding from the National Cancer Institute the TBCCN partnered with local organizations and piloted several studies.

Meade, Menard, Luque, Martinez-Tyson and Gwede (2009) conducted two pilot studies on cancer disparities for TBCCN. Looking at the problem holistically, the team realized that the issue necessitated taking seriously recent transdisciplinary developments in embodiment theory. In this regard Meade and colleagues quote Krieger as follows: “We take it as a basic fact that we all live and act in bodies that literally embody biologically, across the life course—our societal and ecological contexts” (2005, 8, as quoted in Meade et al. 2009, 2). Therefore, the team combined the tenets of different relevant disciplines into a transdisciplinary conceptual structure larger than the sum of its parts. In this regard they applied a “socio-ecological framework” and considered the “embodiment of lifetime exposures” (2009, 2) in order to understand cancer disparities. Given the complexity of the conditions which caused disparities in health the research team needed to develop innovative approaches to the problem. The primary objective was to serve community needs, and thus the principles of community-based participatory research were used.

The research team identified two levels of needs, the first with respect to empirical research initiatives and the second with respect to health promotion programs. Therefore, each pilot study involved the development of a research initiative and an outreach component.

The first study investigated colorectal cancer, which is the third leading cause of cancer deaths among Americans, with US blacks having the

highest colorectal cancer rate and mortality rate of all groups (Meade et al. 2009). Given the dangers in grouping all black people into one homogeneous category, due to possible ethnic differences with respect to food preferences and other differences, the team decided to study three ethnic subgroups of US blacks. The research team recognized that in order to garner support and participation from the community of interest it was vital to employ the principles of community-based participatory research during all phases of the research. Therefore the research team created a cultural advisory group which they used during research design, determining the scope of the project, recruitment and all the way through data interpretation. Meade and colleagues explain the methodological implications and necessity of their participatory approach as follows: “Cultural advisors proved to be a critical asset to understanding and overcoming study design and recruitment barriers. They served as ambassadors and cultural brokers who facilitated linkage to community events and cultural organizations serving the populations of interest” (2009, 4).

Based on what they learned working with their advisory group they developed a mixed methods approach to the research, demonstrating the methodological principle *responsiveness* as a means of staying problem-centered. The sample consisted of twenty men and women in each of the three ethnic subgroups. The mixed-method design included sequential in-depth qualitative interviews followed by quantitative questionnaires administered verbally by a trained interviewer (Meade et al. 2009).

This pilot project led to additional collaborations and concrete outcomes for the community in which the research occurred. For example, the team from TBCCN is working with a geographic information systems (GIS) expert in order to create a map of cancer screening resources in the community (Meade et al. 2009).

The second study also looked at cancer disparities in the African American male population. Specifically, the study addressed early screening for prostate cancer which is the second leading kind of cancer in this population, and again, African-American men have both a higher incidence and mortality rate than any other group (Meade et al. 2009). There is a range of complex issues that converge to create barriers to prostate cancer screening in this population. Preliminary research showed these issues include cultural definitions and performances of masculinity, distrust of the healthcare system, and fatalism regarding cancer (Meade et al. 2009). Clearly, in order to effectively address this topic in light of the

issues just mentioned, bodies of literature that deal with racism, gender, race and healthcare, and the public's perception of cancer, all needed to be a part of any comprehensive approach to this problem. This project required a transdisciplinary approach.

One of the needs identified by the researchers was to create cancer awareness materials that could be easily accessed and understood by the target population. They write: "Cancer awareness materials such as brochures, booklets, and fact sheets are valuable tools used to disseminate information to the community; however, many materials are not always culturally and literacy appropriate nor easily accessible to all population groups" (Meade et al. 2009, 5).

Therefore, the researchers decided to construct a three-part study. In the first phase of the project the researchers aimed to develop customized cancer awareness materials that would be accessible and understandable to the relevant community. In order to do this the research team partnered with local barbers in order to develop the materials and a protocol for distributing them. The researchers elected to carry out the project at barber shops because they are known to attract large numbers of African-American men in the participating communities. This venue was also selected because preliminary research showed it to be deemed a "trustworthy" site within the community, with trust being previously identified as a major hurdle when conducting health research with this population. In the second phase of the research, the team developed a "lay health advisor training curriculum" in order to prepare the barbers to distribute the materials. During this phase of the research the curriculum was put into practice and the participating barbers were trained. The final phase of the research consisted of an assessment regarding the feasibility of using barbers to distribute health information and whether or not that would lead to discussions about cancer screening options with the participants' healthcare providers (Meade et al. 2009).

This pilot project has also propelled additional efforts. For example, the TBCCN is creating a "Barbershop Advisory Council" and taking steps to maintain the availability of the cancer awareness materials and "information stations in the barber shops" (Meade et al. 2009).

Like the colorectal cancer study, this project is an example of taking seriously the promises of both transdisciplinary and community-based participatory research. The research team learned about the population of interest, created a responsive research design that accounted for relevant information about the population, and included the community

partners during every phase of the research. Importantly, the research team also accounted for the community's needs when determining how the research results would be disseminated (to maximize the benefits to the population of interest).

## Core Principles and Research Design Issues

In order to understand the promises and perils of community-based research as a transdisciplinary undertaking it is important to first review the core principles of CBR. Of course, as is always the case, there are naturally deviations in real-world research practice. Every CBR project is unique and faces its own set of challenges. Therefore, not every project is able to fully realize all of the principles that are reviewed (nor should they), and this does not diminish their contributions. My goal is simply to review these principles so that researchers who wish to engage in transdisciplinary approaches to CBR are best able to think through these fundamental conceptualization and design issues, create priorities that best serve their projects, and reflexively consider and report on their efforts. I should also note that there is a huge body of literature on the principles of community-based research which I cannot replicate here. This is merely a brief overview of the core principles of CBR which when taken seriously can facilitate transdisciplinarity.

## Collaboration

Collaboration is vital in any community-based research project. Creswell (2003) suggests CBR centers on the “mutual creation of knowledge” (quoted in Pinto 2009, 933). There is, however, a continuum on which collaboration occurs. The extent of collaboration and the phases in which collaboration occurs can vary greatly from project to project. The higher the level of collaboration throughout a project the greater likelihood that disciplinary borders will be transcended and the project will become transdisciplinary. In other words, a transdisciplinary approach to CBR demands high levels of collaboration. Ideally, the entire process involves deep levels of collaboration between the researcher(s) and community partners. This includes problem identification, conceptualization and planning, data collection and interpretation, and the dissemination of the research results—including (co)authorship. This level of collaboration requires clearly determining, dividing and balancing roles,

responsibilities and resources (Pinto 2009). Pinto provides the following definition of research collaboration: “social processes in which researchers share roles and responsibilities with CBO personnel to accomplish tasks such as recruitment, data collection, interviews, supervising staff, data analysis, and writing and presenting results” (p. 934).

When thinking through issues of collaboration it is important to remember that community identified needs should be at the center of the research. Stoecker advocates developing “community-generated research questions” (2008, 50). Worthington (2007) notes, “CBR is systematic inquiry that incorporates a substantial level of community participation for the purposes of community improvement and social change” (p. 480). When the issues and problems are identified on this basis then the research is likely to transcend any particular disciplinary vision. Stoecker (2008) urges researchers to balance their needs with those of the community they are serving. In this way CBR can bridge the academy and the community. Pinto (2009) suggests that when working with a community-based organization it is also important to integrate the mission of the CBO into the research. In these ways researchers can attempt to achieve “partnership synergy” (Lasker, Weiss & Miller 2001). Again, these kinds of synergistic practices are fundamental to the practice of transdisciplinarity.

In order to better understand the complexity of collaboration let’s take a closer look at Pinto’s (2009) HIV prevention research which explores the relationship between researchers and community-based organizations. Given the range of social stigmas and stereotypes associated with HIV/AIDS, as well as the ability to prevent new infections, this kind of community-based work is particularly important. Pinto collected qualitative interview data from twenty informants working at ten different community-based organizations. Five of the CBOs involved in the study provided primarily medical HIV related services, and the other five CBOs provided primarily social HIV related services (including counseling, prevention workshops, etc.).

The community-based organizations collaborated with academics, physicians, individuals with PhD’s in public health, psychologists, and social workers. It is important to note that the CBOs in this study are transdisciplinary by design, as are many community-based organizations. The composition of many CBO partners, therefore, facilitates the development of transdisciplinary approaches to community-based research if the professional/academic researchers are committed to

transdisciplinary values. Pinto sought to ascertain CBO perspectives on making community-based health research more collaborative in order to aid disease prevention and intervention initiatives. Bear in mind that the major criticism of community-based research centers on an imbalance in power, resources and rewards, *systematically favoring academic/research institutions* who initiate research over their community partners. Pinto's research, which emphasizes *the perspectives of community-based organizations* on the CBR process, is of the utmost importance as we move towards merging CBR principles with transdisciplinary vision in an attempt to best address real-world issues and problems.

Pinto's main findings fall into four broad categories. First, Pinto found that researchers' personal characteristics impact the effectiveness of CBR projects from the point of view of community-based organizations. Ideally, researchers are highly collaborative, experts in the field, have an understanding of the community that is served by the CBO, and are sincere in their efforts. Second, partners working at the community-based organizations were concerned with the characteristics of the researchers' institutions. They favored institutions with positive reputations and scientific resources. Third, the study detailed the major characteristics of collaborative research which include: the research should improve services at the CBO, the research should have a purpose defined by all partners which should be an agreed-upon issue that is relevant to all parties, the research should involve participants and enhance their lives, the research should involve CBO staff at multiple stages of the research and the research should increase the knowledge base of the CBO staff and create avenues for professional development while also decreasing the knowledge gap between the researchers and CBOs (2009, 938–939). Finally, the interview data emphasized the importance of the community partner-researcher relationship. Important aspects of this relationship include: getting to know each other/relationship-building, the researcher getting to know the work of the CBO on a meaningful level, resolving social and professional tensions, dealing with differences instead of brushing them off (for example education, research experience, practical skill sets, etc.), and finding common ground (2009, 939).

The lessons learned in this research can be applied to community-based research collaboration with community-based organizations that deal with a range of topics inside and outside of HIV or health more broadly (for example, homelessness or domestic violence). Additionally, although established CBOs are unique in that they have their own

infrastructure, organization, methodological practices, and budgetary issues, the data in this study are useful in thinking through issues that may arise when any researcher or research team are working with others (whether those others are community members, professionals/practitioners, or researchers from other disciplines)—although they may emerge in different forms, the same issues of collaboration, tension, and respect must be dealt with in any kind of team research.

### **Cultural Sensitivity, Social Action and Social Justice**

It is important to remember that community-based research has a moral imperative. In other words, there is a social justice and social action undercurrent to community-based research projects. In this regard there are a host of ethical issues at play. For example, one must ask:

- Whose interests are being served by the research?
- How have community needs been identified?
- How are issues of power being dealt with throughout the process?
- Is the researcher or research team reflexive about issues of power, authority and ownership?
- Is the research sensitive to the community's cultural definitions and understandings?
- How collaborative is the conceptualization process in which definitions and understandings are agreed upon?
- What issues may arise when working with disenfranchised or marginalized populations?
- How can we work ethically, morally, respectfully and effectively with people who may be different from us?

Summarizing these issues Stoecker writes: “The ideal research project is one that serves community-identified needs, is sensitive to the cultural understandings of the community, and supports action around some community-identified issue” (2008, 50). The more researchers are willing to emphasize community needs for the betterment of the communities they aim to serve, the more researchers will be able to transcend their disciplinary training and bring together all available resources in order to most effectively address the issue or problem at hand. Therefore, attending to the social justice imperative of community-based research also facilitates transdisciplinarity.

## Recruitment and Retention

Recruitment and retention often prove challenging in community-based research. These issues should be built into grant proposals as they may require both time and funds (Loftin, Barnett, Bunn & Sullivan 2005). Multiple recruitment strategies may need to be used (Loftin et al. 2005). In order to be able to effectively recruit research participants and retain them for the duration of the project it is important to make sure there has been in-depth community involvement in the research design process. Community understandings, norms and values should permeate the conceptualization process. This will allow researchers to effectively recruit participants and help to gain their trust so that they will be more likely to continue to participate. Moreover, if culturally sensitive definitions are used then participants are more likely to see their continued participation as valuable to themselves and to their community. Therefore, issues of insider and outsider statuses must be dealt with and not disavowed. Based on their community-based health research with African-Americans, Loftin and colleagues offer the following example:

Culturally competent strategies for recruiting African-Americans might include posters and flyers illustrated with African-Americans posted in doctors' offices, clinics, churches, hairdressers, and barber shops; direct phone calls from African-American outreach workers; health fair screenings; presentations at African-American churches and/or barbershops with demonstrations of the intervention; public service announcements, especially on radio stations with a large black following; advertisements in church bulletins; and quotes from "satisfied customers." (2005, 256)

When thinking through issues of recruitment and retention the value of a transdisciplinary approach is clear. If the goal is to effectively address the issue or problem at hand, and community participation is vital towards reaching that goal, then the needs of the community will supersede the disciplinary perspective of the researcher or research team and ideally foster transdisciplinarity. An issue- or problem-centered approach creates a research context where different forms of scientific, experiential and lay understandings are tapped for their usefulness.

At this point it is important to emphasize that the principles of collaboration, cultural sensitivity and retention are all intimately linked. As alluded to an excellent example comes from Loftin and colleagues' (2005) research on diabetes prevention in rural African-American communities.

These projects were designed, in part, to address underrepresentation in research which the literature indicated was due to “historical mistrust of biomedical research, lack of cultural relevancy and competency, and less access to care” (Loftin et al. 2005, 252). The research team was highly reflexive about dealing with prejudice either as outsiders or, in the case of African-American researchers, as insider-outsiders (Loftin et al. 2005). The main goal of both diabetes studies was to determine effective approaches to recruitment and retention, which meant building “culturally competent approaches” and dealing with ethically charged issues of trust, incentives, and follow-up (Loftin et al. 2005).

The first study was a feasibility study that addressed the issue of culturally competent/sensitive intervention (in this case a dietary self-management intervention that helped people to help themselves). The dietary self-management intervention consisted of three sequenced components: 1) four dietary education classes lasting ninety minutes each, 2) two monthly discussion groups lasting sixty minutes each, and 3) nurse case manager follow-up by weekly telephone calls and one home visit. The retention strategies employed used value-based information and included reminders and incentives. Loftin and colleagues provide a robust explanation of *culturally competent/sensitive approaches* in relation to their research:

Culturally competent characteristics of the intervention reflect the beliefs, values, customs, food patterns, language, and health care practices of Southern, rural African-Americans and seek to integrate these values into healthy dietary strategies. First, the intervention focused on the most meaningful and relevant topic reported by African-Americans in previous research, dietary education. Meals or snacks of typical ethnic food preferences were served at each screening and intervention session to integrate black cultural traditions associated with food. Participation of family members was encouraged to capitalize on the value of family and to provide transportation. Experiential learning approaches, such as participation in a cooking class, were used because they are the primary mode of learning for this population. Peer-professional discussion groups facilitated cultural translation of contents and culturally competent learning methods, such as story-telling. (Loftin et al. 2005, 253)

This project was highly successful because of the in-depth inclusion of community beliefs and values during all phases of the study. Similarly, the second study called “soul food light: preliminary test of the

intervention” also yielded positive results (this study included longitudinal pretest and post-test effects of the intervention).

Loftin and colleagues (2005) note that several factors directly contributed to their success:

- getting the support of key stakeholders (including those in the medical community who were advising their patients to participate);
- gaining the trust of the community and building on existing relationships to do so;
- following the principles of mutuality;
- using respected members of the community in key roles in the research;
- valuing the advice of insiders who are trusted members of the community;
- actively demonstrating caring (the follow-up stage in the research was a critical part of this);
- building follow-up into the research design in order to intervene as problems may emerge (and demonstrate caring).

In terms of providing meaningful incentives for participation, the principles of CBR were again followed successfully. For example, the research team (including both the researchers and community partners) demonstrated the value they were contributing to the community, offered participants formal recognition, and used monetary and other financial prizes (such as gift cards) to encourage continued participation. The researchers also facilitated participation by building solutions to practical barriers into the study. For example, participant transportation was factored into the study (i.e., gas coupons for participants).

## **Building Trust and Rapport**

Building trust and rapport with community members, research participants and CBO personnel is vital in community-based research. In order to retain research participants and yield successful outcomes it is important to continually nurture research relationships. The idea of “research” may be poorly received by members of some communities (Meade, Menard, Luque, Martinez-Tyson & Gwede 2009). This may be especially true when working with disenfranchised or marginalized populations (Meade et al. 2009). Again, the importance of including the community during

research conceptualization and design (as well as during all other phases of the research) is vital. When the community helps shape the potential outcomes and lasting benefits of the research, they will feel more included, valued and empowered. This is an important way to build trust. It is equally important that the relationships researchers build in the community are genuine. Researchers must demonstrate their caring, interest and concern in order to cultivate reciprocal partnerships (Meade et al. 2009).

### **Multiplicity, Different Knowledges, Participation and Empowerment**

Transdisciplinary approaches to community-based research require that a multiplicity of knowledges/ways of knowing are incorporated and valued. Participants in the community, CBO partners, and researchers will all bring different assumptions to bear on the research process. Additionally, all partners will bring different kinds of knowledge—experiential, scientific, and lay—to the project. It is likely that different partners will also bring different skill sets to the project. These different kinds of assumptions, knowledge, and experience must be respected and valued. Strand, Marullo, Cutforth, Stoecker, and Donahue write:

This means that people's daily lives, achievements and struggles are no longer at the margin of research but are placed firmly at the center. CBR requires acknowledging the validity of the local knowledge generated in and through practice in community settings and weighing this alongside institutionalized, scientific, and scholarly professional knowledge familiar to faculty and students. (2003, 11)

Research partners should be willing to learn from one another and willing to teach one another. Pinto (2009) suggests that the most effective projects balance scientific and lay knowledge. When these forms of knowledge are viewed as complementary the research is more likely to be useful to both the community and the researcher(s) (Pinto 2009). Mutually beneficial research is likely to generate higher levels of commitment from all partners. Participatory research designs are often used in transdisciplinary community-based research because they may offer greater community control over the project (Stoecker 2005), and therefore they invite a multiplicity of understandings and renderings to emerge from the research process.

An outstanding example of incorporating different perspectives into a CBR study is the landmark study on community development and

segregation that occurred in Chicago in 1986. Although at the time the research team referred to their efforts as “interdisciplinary,” in retrospect I think it is safe to label this hallmark study “transdisciplinary.” The research objectives were “to document progress made in fair housing work, evaluate ongoing fair housing programs, and identify factors related to the persistence of segregation in some areas. The goal was to further the development of fair housing as an integral part of healthy communities” (Lukehart 1997, 48.). In order to carry out this research a transdisciplinary team was assembled. The team included The Leadership Council for Metropolitan Open Communities (a Chicago-based fair housing organization that began in the 1960s) as well as twelve academic researchers and several members of the Chicago Area Fair Housing Alliance (CAFHA) (Lukehart 1997, 47).

The team of the CBO professionals, activists, academic researchers and community members was actively involved during all phases of the research. Initially the large team participated in a series of meetings to discuss issues and identify research needs (Lukehart 1997). This process led to the development of nine research projects, and due to the impressive and diverse group of people brought into the project the research received considerable funding (Lukehart 1997), illustrating how including a multiplicity of perspectives and knowledges may be viewed as a strength to external groups and can thus be used to garner research support (chapter 6 concludes with a return to this issue). Methodologically, the large group broke down into transdisciplinary subgroups, each comprised of academic and community stakeholders that organized around each of the nine projects (Lukehart 1997). Each team identified its research issue and determined an appropriate methodology; however, the larger group was used as a “sounding board” throughout the process (Lukehart 1997, 48). Research teams relied on a variety of methods, including census data, policy analysis, structured interviews, unstructured interviews, document analysis and participatory evaluation research (1997). In order to continue the process of rich collaboration and multiplicity each research team drafted a report about their findings which was distributed to the entire team for feedback (Lukehart 1997). The group then held a conference at the University of Chicago and invited additional stakeholders—such as members of government, community leaders and activists—to offer feedback (Lukehart 1997). This responsive process of feedback loops led to the writing of the final reports.

This research embodies the best of transdisciplinary cooperation as academic, lay and activist knowledge and experience were brought to bear during all phases—from identifying issues to determining research protocols—and feedback was systematically sought throughout the process. This project serves as an example of how evaluating multiple and diverse knowledge bases, coupled with a participatory approach, can foster highly successful transdisciplinary collaborations.

Community-based research has the potential to empower participants as well. Empowerment can occur in a host of ways, such as through educating participants on areas of interest or concern, providing wanted behavioral intervention strategies, and providing participants an opportunity to have their perspectives and experiences valued and validated in the knowledge-building process. Participatory approaches lend themselves to these forms of empowerment and should be considered when appropriate. The 1986 Chicago-based community development project illustrates how including relevant stakeholders during all phases of the research empowers community members, who, in that case, became agents of social change within their communities, even impacting public policy.

### **Flexibility and Innovation**

Community-based research requires flexibility and innovation, issues which are heightened in a transdisciplinary effort where multiple resources and viewpoints are brought together in a problem-centered capacity. Things do not always go according to plan with these kinds of projects, and researchers must be willing to adapt to circumstances as they emerge. In transdisciplinary research the issue or problem at hand remains at the center of conceptualization processes and methodological decision-making. This means that the research design may need to be evaluated and revised throughout the research process. As noted earlier, it is for this reason that transdisciplinary research typically follows a recursive research design (Pohl et al. 2007). This can be particularly challenging in CBR because there are so many different partners who need to collaborate throughout the research process. All partners need to be open to adapting to new information and circumstances for the success of the project. Moreover, innovative approaches to problem-solving should be cultivated.

The need for flexibility and innovation, however, must be balanced against the need for structure. In this way transdisciplinary approaches

to research create a paradox; they require both openness and structure. While all partners must be open to adaptation, it is vitally important that roles and responsibilities are clearly delineated. Ideally, the division of labor will receive considerable attention from the research partners prior to the commencement of the conceptualization and data collection or intervention process. Partners should all agree on, and understand, their roles and responsibilities within the project. As new situations emerge that may change the division of labor, partners should again convene (ideally in person but at minimum via telephone or email) to come to a new, modified arrangement based on unexpected changes. It is important that the structure of the project is created in a collaborative process and checked throughout the process so that all partners' expectations are met.

## Representation and Dissemination

The representation and dissemination of research results is challenging in community-based research and transdisciplinary research (in any genre), so this issue is greatly heightened in transdisciplinary approaches to CBR. There are multiple issues to consider.

First, it is important that the research results have the potential to positively impact the community that was involved in the project. Typically, traditional academic writing is of little value to anyone outside of academia (an issue in and of itself that points to the need for new approaches to knowledge-building). The public has little to no access to academic journals, the format of academic writing is exclusive and prohibitive (i.e., filled with jargon), and the timeframe for academic publication doesn't allow for the rapid dissemination of research findings to the community that participated in the study. Therefore, it is important to disseminate research results through "alternative" channels which may include:

- brochures/informational pamphlets distributed at local organizations, business, schools, religious centers or CBOs
- radio broadcasts
- Internet postings
- stories in local newspapers
- presentations at public meetings or in community locations
- other venues likely to reach the target audiences

The importance of disseminating research findings in appropriate venues is evident in the example of the Chicago-based community development research noted earlier. As mentioned, the team presented preliminary findings at a local conference that they organized and to which they invited many non-academic stakeholders. Additionally, the team held a press conference during which they presented their findings to the media and public (Lukehart 1997). Given the group's desire to impact public policy regarding fair housing and segregation, and to include the public in their own development process, inviting the media into the process was vital. In this regard, the press conference had the double effect of educating the public and putting pressure on local government in order to promote positive social change.

It is also important to consider new or “alternative” forms of representation. For example, some transdisciplinary researchers turn to arts-based forms of representation which have the potential to reach and resonate with larger audiences, break-down stereotypes and build critical consciousness. Arts-based forms of representation are reviewed in the next chapter but may include:

- theatrical performances
- musical or dance performances
- poetry or spoken word readings
- documentary film screenings
- visual art or photography displays
- online photoblogs
- other forms

Next, it is important to consider issues of authorship. While differing from traditional academic research, in CBR the community (theoretically) may “own” the results, at least from an ethical stance (Strand et al. 2003). Put differently, in a CBR project the relevant community has a major stake in the research process. For example, findings may have the potential to impact the community's development process, healthcare opportunities, or access to educational services. There may be public policy implications as well. Therefore, does the community have the right to determine how results are used? Typically, researchers retain the ability to represent and disseminate research findings at their discretion; however, the expectations of all parties must be fleshed out and negotiated. This is much more complicated in research practice.

- Who gets to represent the research?
- Who gets to disseminate the results?

Group research efforts carry many challenges in this regard. It is very important to come to understandings about these issues prior to beginning the research process. This is another area where all partners' expectations should be stated and discussed, and then a plan should be agreed upon. There are many issues to consider here. First, researchers from different disciplines may have different disciplinary norms for publication and authorship (including the ability to produce co-authored versus single authored works, given tenure, promotion and funding constraints). If more than one researcher is working on the project, the team will have to decide what data/results are “common property” that any team members can write about (and if there are any restrictions on acceptable publication venues, citing the group work, and so forth) and what, if any, data/results “belong” to any individual team member. Questions to consider include:

- What are the expected co-authored outcomes of the project?
- Where will co-authored outcomes be published/disseminated?
- How will the writing and editing process occur in ways that are fair to all partners?

Even if there is only one researcher, he or she will have to work this out with the community partners. For instance, when an individual researcher or team of researchers works with a CBO, all of the same issues of authorship and co-authorship must be addressed. All of this needs to be considered carefully in a collaborative context.

Additional issues to consider include:

- What rights do the research participants have to represent and/or disseminate research results?
- How will issues of “the team” be dealt with/noted?
- What expectations does each partner have?
- How will issues of informed consent, confidentiality and anonymity be dealt with, particularly when researchers from different disciplines and CBO partners may have very different norms regarding these issues?

**Table 4.1 Summary of CBR Principles and Design Issues in Transdisciplinary Research**

Principles	Methodologically Enacting the Principles
Collaboration	Multidisciplinary teams comprised of differently positioned stakeholders with different perspectives and experiences. Deep levels of collaboration during all phases of the research.
Cultural Sensitivity, Social Action, Social Justice	Cultural understandings are valued and community identified needs are determined. Research has a social action agenda and social justice undercurrent.
Recruitment and Retention	Culturally competent approaches to recruiting participants for the duration of the study.
Building Trust and Rapport	Genuine and respectful relationships are built (and valued as vital for retention and successful outcomes).
Multiplicity and Different Knowledges	Different ways of knowing are incorporated and valued during all phases of the research. Participatory designs are used when appropriate.
Flexibility and Innovation	Recursive research designs and problem-centered methodologies are employed reflexively, making time and space for feedback and modifications.
Representation and Dissemination	Research findings reach relevant audiences through creative representational formats and the use of appropriate “alternative” venues for distributing findings.

### *Policy Implications*

The research examples cited throughout this chapter show the possible connections between community-based research and policy-making that positively impact the affected communities. For example, policies regarding public school lunches have received considerable media attention in

recent years as a result of dramatic increases in childhood obesity. Community-based research projects, such as the development and subsequent testing of a culturally competent food intervention in rural African-American communities, can yield important data about how to best create policies that serve local populations.

Of course, impacting the policy making process is difficult at best; however, it is an important extension of many CBR practices. Social/public policies are political and power-laden (Wedel, Shore, Feldman & Lathrop 2005). They are plans of action that may carry widespread consequences for the communities that they impact (Wedel et al. 2005). Unfortunately, as policies are often politically motivated, the publics they most affect are often left out of the process. Community-based research has the potential to uniquely impact policy making, particularly when conducted from a transdisciplinary approach. Due to their social action and social justice imperatives, many community-based research projects are undertaken with the goal of contributing to policies that impact the communities at hand. This is clear in the example of development and fair housing practices in Chicago.

Policies typically deal with how the state relates to local populations/communities (Wedel et al. 2005), making the need for community involvement obvious. In order to participate in policy-making processes the public needs to be engaged in shaping the policy agenda (McTeer 2005). In order for this to occur the public needs to be both informed and engaged (McTeer 2005). CBR is an avenue for creating this kind of engaged populace. Moreover, CBR can generate data that can be used to lobby for changes in current policies. In this regard it is important to bear in mind that “policy makers create and implement policy out of or along with, *already existing* programmes” (Carlsson 2000, 202). Therefore, CBR projects can be designed to examine the impact of current policies on particular communities and how those policies can be improved for the public good.

By adopting transdisciplinary approaches to CBR, the issue or problem remains at the center of the inquiry. Moreover, all available resources will be tapped in order to most effectively serve the research purpose. Finally, by amassing a wider range of intellectual capital, researchers are more likely to develop persuasive research reports that they and their community partners can use to lobby for community-centered change.

### *Cross-Cultural Projects and Transnational Research Collaborations*

Research challenges are compounded and new challenges emerge when multi-disciplinary research teams are conducting studies in multiple countries and settings. In addition to the issues that occur whenever a multi-disciplinary research team is working together in a transdisciplinary effort (such as coming from different research paradigms, building respect and rapport, determining the division of labor and clearly setting up goals and responsibilities, and so forth), transnational research raises additional practical and ethical issues (for example, language barriers).

Treloar and Graham (2003) provide two examples of transdisciplinary health studies projects conducted in transnational settings. The first study, conducted by the International Clinical Epidemiology Network (INCLIN) on the cross-cultural context of obesity occurred in five (mostly developing) countries: Australia, Cameroon, Egypt, India, and Indonesia. The research team employed focus groups in order to “explore the personal, interpersonal, organizational, and societal influences on diet, body image, and physical activity” (2003, 925). The team was made up of researchers primarily from the social sciences but different disciplines who were a part of a long-standing international network. A range of practical issues emerged, such as language training, unreliable e-mail and fax communications systems at the different research sites, developing a theoretical framework for the study (a challenge in transdisciplinary research), and different levels of expertise in qualitative research (Treloar & Graham 2003).

Although there were many successful aspects of this study, it is important to consider some of the challenges the researchers faced in order to learn from their experience. For example, they dealt with discrepancies in ethical standards between the medical scientists and the social scientists (for instance, regarding when informed consent was needed). The researchers also had different levels of experience with interviewing (both data collection and analysis) which made data comparison across the sites problematic (Treloar & Graham 2003). There were also issues with respect to funding and technology (Treloar & Graham 2003). For example not all of the focus group interviews were recorded due to a lack of available recording technology (Treloar & Graham 2003). There were also disparities regarding how to translate the data (given the

different languages the raw data was in), and unfortunately no uniform approach was agreed upon. Therefore, some sites translated the coded data and summaries while other sites just translated summaries (Treloar & Graham 2003). This failure points to the need for additional funding for bilingual staff members in transdisciplinary transnational projects. Otherwise, bilingual staff members may be overburdened with work, and there may be a failure to translate and transcribe the data in a uniform and thus comparable way.

Despite these challenges the researchers did develop a transdisciplinary conceptual framework which allowed for a systematic coding and analysis procedure. Treloar and Graham explain this procedure as follows: “The Australian investigator used the three topic areas (diet, body image, and physical activity) and the four levels of the conceptual framework (personal, interpersonal, organizational, and societal) to explore patterns across the five data sets. The results of this process were distributed to investigators at each site for comment” (2003, 928).

The second study Treloar and Graham (2003) review, conducted by the International Study of Perioperative Transfusion (ISPOT), used a mixed method survey and interview approach in a health technology assessment study in ten developed countries: Australia, Canada, Denmark, France, the Netherlands, Israel, Japan, Scotland, Spain, and the United States. The research team consisted mainly of medical scientists; however, qualitative researchers were located in two sites. Differing from INCLIN, these researchers were not a part of an established research team and came together only for this project and did not spend time developing a truly transdisciplinary theoretical framework, which greatly minimized the positive outcomes from this study. There was also a range of issues regarding different levels of funding and different levels of commitment, determining publishing formats, differential expertise and experience that were not dealt with collaboratively.

Together, these two studies show what is possible in transnational research while also pointing to the challenges. I suggest that the development of a transdisciplinary perspective during initial planning and coming together, and a focus on maintaining a transdisciplinary approach, would have enhanced each of these projects. This was the case in the “Household, Gender and Age Project” reviewed in chapter 3. The research team, spanning eight continents, devoted ample time to project development, particularly building the conceptual structure, and as a result the process yielded many successes.