Published in final edited form as:
Int Soc Work. 2007 January 1; 50(1): 53–65. doi:10.1177/0020872807071482.

Using principles of community participatory research Groundwork for a collaboration in Brazil

Rogério M. Pinto,
Assistant Professor at the Columbia University School of Social Work, 1255 Amsterdam Ave., New York, NY 10027, USA

Clecy N.T. Schmidt,
Medical Doctor in the Programa de Saúde da Família, Boqueirão, Rio Bonito, Brazil

Paulo S.O. Rodriguez, and
Secretário Municipal de Saúde (Secretary of Health), Rio Bonito, Brazil

Renata Solano
Nurse Coordinator in the Programa de Saúde da Família, Boqueirão, Rio Bonito, Brazil

Keywords

Brazil; community collaboration; participatory international research

The estimated number of people living with HIV/AIDS in 2003 was 40 million worldwide (UNAIDS, 2004). This global pandemic has prompted myriad research projects led by researchers from developed countries, going into developing countries. International research has benefited countries at all levels of development, building scientific knowledge and creating technology exchange (De Cock et al., 1994). Creating a meaningful research agenda in a developing country requires groundwork before research begins. Research requires the endorsement of gate keepers and community acceptance and participation, so preparation for international research must occur before formalized funding is available (Lo and Bayer, 2003).

Solid partnerships between academia and communities are recommended in health-related research, and in HIV research particularly (Centers for Disease Control and Prevention, 1998). These partnerships present opportunities to develop grounded theories and strategies embracing both science and local experience; for ameliorating community health more efficiently than could any research team alone; and for resolving ethical issues (Lo and Bayer, 2003; Mays et al., 1998; Richardson and Allegrante, 2000).

Moreover, international partnerships can ensure both the quality of HIV-related research and the efficacy of outcomes. But few models for participatory research have been developed (Van Rooyen and Gray, 1995), and those available to international researchers provide little insight into the preparatory phase of research (Coughlan and Collins, 2001). Given the rapid spread of HIV in the developing world and the need for international research, knowledge building in this preparatory area is required. The approach discussed in this article will address the initial phases of international research, with emphasis on community inclusion and participation, so that research can be translated into more effective preventive practice.

to whom correspondence should be addressed, [RMP98@columbia.edu].

To illustrate how knowledge of community collaboration can inform the initial phases of international work, this article traces the preparatory work that the authors have done in a small city in the southeast of Brazil. We include five steps, and illustrate how we have addressed them.

Collaborative research framework

Before work begins, researchers working in developing countries should:

1. contextualize the foreign host country;
2. identify collaborators in the host country;
3. seek advice and endorsement from gate keepers;
4. match the expertise, needs and interests of researchers to those of the host-country partners; and
5. establish a solid commitment to future collaboration.

These initial steps for international research reflect the notion of partnerships between university-based researchers and community partners (Altman, 1995; Hatch et al., 1993; Israel et al., 1998; McKay et al., in press). Theoretical models explaining partnerships between researchers and communities suggest that researchers and community partners develop social relationships that can help sustain their research partnerships over time. To maintain such partnerships, various research approaches have been suggested, including participatory research, action research and empowerment evaluation (Brown and Tandon, 1983; deKoning and Martin, 1996; Fetterman et al., 1996).

These approaches recognize the need for involving gate keepers and community members in the preparatory phases of research. This early involvement can help researchers learn the needs of the community from people who live and/or work there. Collectively, these approaches suggest that collaborative research ought to:

1. actively involve researchers and partners;
2. benefit communities through services and/or social action;
3. be culturally relevant to community residents and stakeholders;
4. address social and health disparities;
5. disseminate knowledge through academic and community-based media; and
6. develop programmatic responses (Hall, 1992; Israel et al., 1998; Schensul, 1985).

Step 1: Contextualize the foreign host country

The HIV epidemic and other health disparities in the developing world have prompted complex qualitative and quantitative approaches to data gathering, as well as historically-based, process-oriented social analyses (Friedman, 2002). A minimum standard for international research is necessary for scientific and ethical reasons. It has been suggested that those researching cultures foreign to them must immerse themselves in the culture, must be familiar with the formal and colloquial use of the native language, and must examine the sociocultural factors that influence behavior in that culture (Parker, 2001; Rebhun, 1999).

In contextualizing the host country, it is important not to make generalizations that ignore local differences (Pinto, 2006). For at least two decades, social workers, sociologists and anthropologists have challenged traditional theories that standardize physical and social arrangements and conditions (Gregory, 1994; Kemp et al., 1997). This body of knowledge

suggests that international researchers need to become members, even if from afar, of the communities that host their studies, so that they can be part of the interactions that affect social processes and people's understanding of their behaviors and identities. These interactions may occur at physical, psychosocial and electronic levels, encompassing geographic and virtual spaces and behaviors, social and cultural trends, and psychological constructs and interpretations.

The literature on community participatory research clarifies that what constitutes community is not necessarily geographic proximity, but rather a sense of identity (Israel et al., 1998). This identity can be developed around, for example, sexual practices (i.e. gay communities), disability (i.e. deaf community), or professional interest (i.e. research community). A researcher who wishes to become a member of a community in a foreign country may start by studying the language, history, geography, social structures and politics of that country and of the specific community he or she proposes to study. Colleagues in the host country can arrange for the researcher to visit, and can help him/her identify services (e.g. provide consultations, help write grant proposals, review papers) needed in the community. This will help create a sense of belonging for the visitor, and show that he/she is sincere about becoming a member of that community. These visits must also allow time for community presentations and for informal gatherings and transactions in local restaurants, social clubs and retail stores. This will allow the visitor to make his/her presence felt among the local residents.

Step 2: Identify collaborators in the host country

Community collaboration in the current context means work done by collaborative partnerships between university-based researchers in developed countries, and community leaders, gatekeepers and service providers in host countries. In order to develop partnerships, researchers must first identify appropriate partners/collaborators, and build relationships within the research team (Rapport, 1990). Harper and Salina (2000) propose a model emphasizing the early stages of community collaboration that is useful in guiding researchers in this early stage of international research.

The model calls for the selection of a community institution (a hospital, health center, etc.) as a research partner. The language, culture, customs and day-to-day life in the host country and host community will differ from those of the researcher's culture. In HIV research this concern is perhaps greater because researchers must be comfortable with many sexual and drug-related behaviors that facilitate transmission. Relationships between researchers and community organizations in developing countries often reflect relationships between universities and community-based organizations in developed countries. In both cases, differences involving money, ownership, rigor and time (Fetterman et al., 1996) may create mistrust, and thus must be addressed.

Before approaching a potential partner agency, researchers must study written materials on that agency, and consult with others who have worked with it. Such an assessment may lead researchers to identify a better partner, especially in a community where HIV-specific agencies are not available (e.g. in a rural area). Researchers should assess several areas before approaching a potential collaborator agency, including the population served by the agency, its demographics, types of services delivered, its history of research collaboration and its research-related resources, including personnel.

A researcher has many options as to how to approach a potential collaborator in a foreign country. This can be achieved with an introductory e-mail, followed by a telephone call and/or regular letter. The written message should clearly convey the researcher's interest and his/her openness to new ideas and indigenous knowledge. Knowing the language here is helpful

for oral communications, which have the potential to create a more lasting bond between the researcher and the potential partner (e.g. non-governmental organization representative). After the introduction, the researcher should give the potential partner ample time to respond, because in most cases health workers are overburdened with daily responsibilities. Researchers should not be discouraged by delays. In countries with fewer resources, electronic and postal systems may be overloaded, and communication may require more time than someone from a country with more resources would expect. Once that first contact occurs, however, researchers may proceed to seek advice as outlined below.

Step 3: Seek advice and endorsement from gate keepers

Researchers have called for a more collaborative process with communities, based on a need for research that would account for first, the impact of social and environmental conditions on health; second, the integration of research and practice; and third, greater community involvement and control in partnerships with academicians (Clark and McLeroy, 1995; Dressler, 1993). This approach fosters relationship building in the research team, including peers, community gate keepers (e.g. politicians, social clubs) and research participants.

Ochocka et al. (2002) propose that research relationships resemble personal ones. Researchers should practice trust, honesty and open communication, values that are part of their day-to-day lives. Researchers possess scientific knowledge, the prestige conferred by their degrees and endorsements from their institutions. All these are commonplace in universities, but may be seen by marginalized communities as creating differences that cannot be overcome. Moreover, histories of questionable research practices linked to ethnic prejudice in developed countries may foster mistrust in the international community (Biafora et al., 1993; Thomas and Quinn, 1991). If researchers seeking advice and endorsement from gate keepers disclose their own professional and personal information, they may help themselves and their potential partners to overcome power imbalances.

Lord and Church (1998) suggest that researchers should find common ground where a shared history and values may be developed. This is particularly true in the beginning phase of the research relationship, where flexibility, shared learning and social support can encourage communication. International researchers need to foster informality and intimacy (e.g. using first names, the appropriate use of touch and disclosure of personal information) by weaving their private and public lives into the research space (Lincoln and Guba, 1985). In the process of exchanging information, researchers and community partners may explore the researchers' interests and expertise vis-a-vis the community's expertise, needs and interests.

Step 4: Match the expertise, needs, and interests of the researchers to those of the host-country partners

Lasker et al. (2001: 184) say that synergy, a 'distinguishing feature of collaboration, is the key mechanism through which partnerships gain an advantage over single agents in addressing health and health system issues'. In the initial phases of international collaboration, both the researcher and partners in the host community must address one another's involvement, sufficiency of resources, leadership styles, and management and research needs (Mitchel and Shortell, 2000). Listing assets and research needs from the perspective of the community starts the process of matching resources to those needs, and may foster synergy.

In this stage of partnership formation, researchers must spell out to the potential partner their own assets and needs, indicating their financial and time limitations. Researchers with academic appointments should make clear to community partners:

1. their availability and time constraints;
2. exactly what type of research they can do;
3. their potential funding sources, and their research agendas and restrictions; and
4. the restrictions imposed by their institution on time for field work and consultation.

In addressing these issues, researchers begin to develop the synergy necessary for future work. Synergy here is 'the power to combine the perspectives, resources, and skills of a group of people and organizations' (Lasker et al., 2001: 183). The synergy that researchers achieve with partners in other countries must be more than the pure exchange of resources. To create a whole that is greater than the sum of its parts, researchers must match their values, knowledge, skills, interests, resources and needs to those of their hosts.

Step 5: Establish a solid commitment to future collaboration

Grounded in the community collaboration literature, an international endeavor ought to first, establish research questions driven by community needs and sanctioned by gate keepers; second, conceptualize partner agencies as integral parts of the community and thus as members of the research team; and third, design research methodologies that reflect the missions of the partner agencies (Minkler and Wallerstein, 2003). Researchers and partners can encourage commitment to the project by developing a Memorandum of Understanding (MoU), a working document that includes a mission statement, a statement of the interests of both parties, and an explanation of how each party's needs and resources match the other's agenda. Moreover, the MoU should define the roles and expectations of all involved, and should list each partner's resources and needs.

In this phase, the partners must address ethical issues discussed in domestic and international research literature (Lo and Bayer, 2003), and take steps that can help resolve such issues. Steps should include documenting the structure and functioning of the partnership; forming an advisory board, and providing technical assistance to host partners. As the initial partnership solidifies, researchers can begin to expand the partnership to include government agencies, community leaders and sponsors. Sponsors will invest in a host country's infrastructure, and will propose projects that follow the host country's health priorities and the priorities of the host community.

Applying the model in Brazil

What follows illustrates these steps, and reflects the theoretical underpinnings of the previous section. The first step in this model addresses issues related to understanding a host country and to becoming, in some way, a member of the community where collaboration will occur. In this case, the first author was born in Brazil and lived there until he earned a bachelor's degree in biological sciences. He then moved to the USA. Learning Portuguese was not an issue for him; however, having lived in the USA for nearly two decades, he needed to invest time and resources in learning the social organization and the culture of the Brazilian city in which he proposed to do research.

During the first author's training in biological science in Brazil he met the second author. Later, while earning masters and doctoral degrees in social work in the USA, he developed interests in community health and international research. In 2003, he contacted the second author, now the chief medical provider in a *Posto de Saúte* (or *Posto*), a community-based

institution similar to a clinic, but that provides medical and many other psychosocial services. The *Posto* in the neighborhood of Boqueirão in Rio Bonito, a medium-sized city (463 square km, as per Tribunal de Contas do Estado do Rio de Janeiro (TCE), 2003) on the coast of Rio de Janeiro state in southeastern Brazil. As of 2002, Rio Bonito had a population of 49,691 (TCE, 2003).

The first two authors developed several ideas for research collaboration. These ideas related to specific health needs in Boqueirã o, including individual and family-focused HIV behavioral interventions. The authors communicated electronically and by regular mail for one year, after which time the first author was invited for several visits to Boqueirão. These visits would fulfill objectives in the five steps above, including social interactions and exploring the cultural, geographic and social environments of Boqueirã o. In addition, the visits would allow the first author to spend time with the interdisciplinary team at the *Posto* and learn the operations of the facility. In order to draw other community gate keepers into the partnership, the second author approached the Secretary of Health in Rio Bonito (third author), and also the *Posto*'s nurse coordinator (fourth author).

The *Posto* in Boqueirão is located in a narrow street lined with small houses. The facility is a large converted house with spacious indoor and sheltered outdoor waiting areas. By 8:00am the *Posto* is bustling with workers and patients. The average number of patients served by the medical doctor per day is 50; however, another 150 clients receive myriad services (e.g. social, psychological and dental) at the *Posto* and in their homes. The *Posto* serves 823 families, or approximately 3300 individuals. This *Posto* is one of 11 in Rio Bonito City, all of which belong to the Program for Family Health (Programa de Saúde da Família, PSF). PSF provides families with basic medical treatment and preventive health care.

The interdisciplinary team of providers in PSF Boqueirão include a medical doctor, nurse coordinator, dentist, physical therapist, nutritionist, psychologist and seven community workers supervised by a senior social worker. Following Freire's (1987) pedagogy for identifying oppression and for developing critical consciousness as a means of cultural emancipation, the PSF team strives to educate the community on prevention strategies, in tandem with programs meant to raise consciousness of social, health and environmental issues.

Multiple visits to Boqueirão and its *Posto* have allowed the first author to interact with the doctor, the nurse coordinator and the Secretary of Health, who together represent the community and were sources of advice. During his first visit, the first author made a presentation on his research, as it related to community collaboration. The presentation focused on HIV and collaborative approaches to research, and discussed the theoretical underpinnings of community collaboration. The audience included the teams of all 11 PSFs in Rio Bonito, and provided opportunities for them to address the issues in steps 1, 2 and 3 above.

Subsequent visits allowed the first author to develop social and professional relationships, visit community residents in the company of *agentes comunitárias* (community agents), seek community acceptance, share folk and academic knowledge and provide services. The first author provided consultations and technical assistance on several issues related to attracting and retaining participants in prevention programs (step 4 above). By making home visits with the PSF Boqueirão social service team, he was able to provide ideas for interweaving health and social services, for collecting psychosocial information and for combining front-line experience with scientific knowledge.

Boqueirão and its PSF are resource-lacking entities and require infrastructure for large research projects. However, gate keepers are interested in better understanding the needs of their community and in finding solutions for their social and health problems. A database with information on all PSF Boqueirão client families is available for research. Analysis of these data would not require large sums of money, and could be the first research project for this partnership. In addition, we will apply for small funding to study the relationships between the PSF and its community, and to use this to further assess retention issues and community preparedness for research.

As the partnership solidifies (step 5) we would like to pursue certain research themes. Which factors attract families to PSF? How can we incorporate HIV prevention services into the PSF's routine? What are community members' perceptions about the need for HIV prevention research and services? We developed these themes after much discussion, and also in the process of writing this article. In fact this article initiated the Memorandum of Understanding needed for this research. The PSF has much to offer in the quest for scientific knowledge, and much to add to our understanding of medical practice and public health in a developing country.

We plan to develop a foundation for future research. We would like to develop a community advisory board; expand the partnership to include community residents, university-based researchers in Brazil and local political figures; and analyze available data on the community. These plans take into account areas of research that would benefit all involved. Moreover, our plans reflect the community partners' commitment to developing PSF Boqueirão's capacity to provide HIV services and to advancing scientific knowledge.

International research that upholds principles of community participatory research has been funded not only by the Brazilian and American governments, but by schools of social work in the USA and by other international funding bodies (e.g. the Ford Foundation and the International Association of Schools of Social Work). Our team is in the process of writing a proposal to identify mechanisms through which *agentes comunitárias* for the PSF engage individuals and families to use services provided by local clinics. This pilot study will shed light on the strategies *agentes comunitárias* use in their daily work, and what impact this work makes on the health of community residents. This pilot study, which will be partially funded by the first author's discretionary budget, will serve to gather preliminary data for a larger grant proposal to the National Institutes of Health.

Conclusion

The model presented here comprises five distinct steps for processing meaningful research collaborations with community partners in developing countries. The order of these steps may not reflect the sequential development of all partnerships. They are presented in this order for clarity. The degree to which each element of each step is implemented will depend on the time invested in building the partnership, the agency partner, the type of research and those involved. This article demonstrates that the key tenets of community–university collaboration and participatory research can guide the initial phases of international research, thus providing steps for investigators to follow in order to forge partnerships in developing countries.

In our model, the interaction of both the social (i.e. the researcher and community partners) and the physical environment (i.e. the host country) may affect several levels of human growth and community development in the host country, from the individual to the family and social group to the country (Germain, 1979). This phenomenon, which affects social processes, occurs at many physical and psychosocial levels. The model presented here

embraces both this social work philosophy and the key elements of participatory research. We therefore recommend that researchers use designs that reflect social work's values and preferred methods as well as indigenous knowledge to accomplish the steps in our model.

Acknowledgments

When this paper was completed, Rogério M. Pinto was a postdoctoral fellow at the HIV Center for Clinical and Behavioral Studies, supported by a training grant from NIMH (T32 MH19139, Behavioral Sciences Research in HIV Infection; Principal Investigator, Anke A. Ehrhardt). The authors thank the HIV Center International Core, especially Ida Susser, for providing feedback on an early draft of this article.

References

Altman DG. Sustaining Interventions in Community Systems: On The Relationship between Researchers and Communities. Health Psychology. 1995; 14:526–36. [PubMed: 8565927]

Biafora FA, Warheit GJ, Zimmerman RS, Gil AG, Apaspori E, Taylor D. Racial Mistrust Deviant Behaviors among Ethnically Diverse Black Adolescent Boys. Journal of Applied Social Psychology. 1993; 23:891–910.

Brown LD, Tandon R. Ideology and Political Economy in Inquiry: Action Research and Participatory Research. Journal of Applied Behavioral Science. 1983; 19:277–94.

Centers for Disease Control and Prevention (CDCP). Building Communities' Partnerships in Research: Recommendations and Strategies. Atlanta, GA: CDCP; 1998.

Clark NM, McLeroy KR. Creating Capacity Through Health Education: What We Know and What We Don't. Health Education Quarterly. 1995; 22:273–89. [PubMed: 7591785]

Coughlan JJ, Collins KJ. Participatory Developmental Research: A Working Model. International Social Work. 2001; 44:505–18.

De Cock KM, Ekpini E, Gnaore E, Kadio A, Gayle HD. The Public Health Implications of AIDS Research in Africa. JAMA. 1994; 272:481–6. [PubMed: 8040984]

deKoning, K.; Martin, M. Participatory Research in Health: Issues and Experiences. London: Zed Books; 1996.

Dressler WW. Commentary on "Community Research: Partnership in Black Communities". American Journal of Medicine. 1993; 9(Suppl):32–4.

Fetterman, DM.; Kaftarian, SJ.; Wandersman, R., editors. Empowerment Evaluation: Knowledge and Tools for Self-assessment and Accountability. Thousand Oaks, CA: Sage; 1996.

Freire, P. Education for Critical Consciousness. New York: Continuum; 1987.

Friedman SR. The Need for Dialectical Models as Shown in the Response to the HIV/AIDS Epidemic. International Journal of Sociology and Social Policy. 2002; 22:177–200.

Germain, CB. Social Work Practice: People and Environment. New York: Columbia University Press; 1979.

Gregory, D. Geographical Imaginations. Cambridge, MA: Blackwell; 1994.

Hall BL. From Margins to Center? The Development and Purpose of Participatory Research. American Sociologist. 1992; 23:15–28.

Harper GW, Salina DD. Building Collaborative Partnerships to Improve Community-based HIV Prevention Research: The University–CBO Collaborative (UCCP) Model. HIV/AIDS Prevention: Journal of Prevention & Intervention in the Community. 2000; 19:1–20.

Hatch J, Moss N, Saran A, Presley-Cantrell L, Mallory C. Community Research: Partnership in Black Communities. American Journal of Preventive Medicine. 1993; 9(6 Suppl):27–31. [PubMed: 8123284]

Israel BA, Schulz AJ, Parker EA, Becker AB. Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. Annual Review of Public Health. 1998; 19:173–202.

Kemp, SP.; Whittaker, JK.; Tracy, EM. Person–Environment Practice: The Social Ecology of Interpersonal Helping. New York: Aldine de Gruyter; 1997.

Lasker RD, Weiss ES, Miller R. Partnership Synergy: A Practical Framework for Studying and Strengthening the Collaborative Advantage. The Milbank Quarterly. 2001; 79:179–205. [PubMed: 11439464]

Lincoln, I.; Guba, EG. Naturalistic Inquiry. Newbury Park, CA: Sage; 1985.

Lo B, Bayer R. Establishing Ethical Trials for Treatment and Prevention of AIDS in Developing Countries. British Medical Journal. 2003; 327:337–9. [PubMed: 12907493]

Lord J, Church K. Beyond "Partnership Shock": Getting to "Yes", Living with "No". Canadian Journal of Rehabilitation. 1998; 12:113–21.

McKay MM, Pinto RM, Bannon WM Jr, Guillamo-Ramos V. CHAMP Collaborative Board. Understanding Motivators and Challenges to Involving Urban Parents as Collaborators in HIV Prevention Research Efforts. Health and Social Work. (in press).

Mays GP, Halverson PK, Kaluzny AD. Collaboration to Improve Community Health: Trends and Alternative Models. Journal of Quality Improvement. 1998; 24:518–40.

Minkler, M.; Wallerstein, M., editors. Community-based Participatory Research for Health. San Francisco, CA: Jossey-Bass; 2003.

Mitchel SM, Shortell SM. The Governance and Management of Effective Community Health Partnerships: A Typology for Research and Practice. The Milbank Quarterly. 2000; 78:241–89. [PubMed: 10934994]

Ochocka J, Jansen R, Nelson G. Sharing Power and Knowledge: Professional and Mental Health Consumer/Survivor Researchers Working Together in a Participatory Action Research Project. Psychiatric Rehabilitation Journal. 2002; 25:379–87. [PubMed: 12013266]

Parker R. Sexuality, Culture, and Power in HIV/AIDS Research. Annual Review of Anthropology. 2001; 30:163–79.

Pinto RM. Review of L.A. Rebhun. The Heart is Unknown Country: Love in the Changing Economy of Northeast Brazil, Culture, Health & Sexuality: An International Journal for Research, Intervention & Care. 2006; 17(4):419–21.

Rapport, J. Research Methods and the Empowerment Social Agenda. In: Tolan, P.; Keys, C.; Chertok, F.; Jason, L., editors. Researching Community Psychology: Issues of Theory and Methods. Washington, DC: American Psychological Association; 1990.

Rebhun, LA. The Heart is Unknown Country: Love in the Changing Economy of Northeast Brazil. Stanford, CA: Stanford University Press; 1999.

Richardson, WC.; Allegrante, JP. Shaping the Future of Health Through Global Partnerships. In: Koop, CE.; Pearson, CE.; Schwarz, MR., editors. Critical Issues in Global Health. San Francisco, CA: Jossey-Bass; 2000. p. 375-83.

Schensul SL. Science, Theory and Application in Anthropology. American Behavioral Scientist. 1985; 29:164–85.

Thomas SB, Quinn SC. The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community. American Journal of Public Health. 1991; 81:1498–1505. [PubMed: 1951814]

Tribunal de Contas do Estado do Rio de Janeiro. Estudo socioeconomico 2003, Rio Bonito. Rio de Janeiro: Tribunal de Contas do Estado do Rio de Janeiro; 2003.

UNAIDS. [accessed 30 August 2004] AIDS epidemic update: December 2003. 2004. Available online at: http://www.unaids.org/EN/default.asp

Van Rooyen CAJ, Gray MMA. Participatory Research and Its Compatibility to Social Work. Social Work Practitioner-Researcher. 1995; 8:87–93.