

TRUST THE PROCESS: COMMUNITY-BASED RESEARCHER PARTNERSHIPS

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INTRODUCTION

In recent years, Aboriginal communities across Canada have begun to seek ways to increase their participation and control of research that affects them. Similarly, academics are seeking new methods to include parallel and complementary knowledge in their research, including traditional knowledge and community experience and expertise. New approaches, theories, and methods related to, or derived from, Indigenous ways of knowing are appearing. Among the approaches that have emerged are community-based participatory research (CBPR), and, closely related, the role of the community-based researcher (CBR). This paper reviews some of the literature that traces the emergence of the role of CBRs as a strategy for community engagement in research. We discuss ethical issues that CBRs encounter in their practice, and some of the lessons we have learned together as a CBPR team.

LITERATURE REVIEW

There has been a surge of interest and activity around the process and practice of community-based research in the last few years (Israel et al., 2005; Macaulay et al., 1999; Minkler and Wallerstein, 2003). Current approaches move away from a postcolonial stance of expert-subject, the rigor vs. relevance dilemma (Friedman, 2001), and problem-based focus, to what is sometimes called collaborative inquiry (Kelly, Mock, and Tandon, 2001),

co-operative research (Heron and Reason, 2001) or appreciative inquiry (Ludema, Cooperider, and Barrett, 2001; Pynch and Castillo, 2001). These approaches all fit under the umbrella of Community-based Participatory Research (CBPR), engaging community members and their research partners in a collaborative and participatory process where each partner contributes, learns, and builds capacity of the other in a balance between action and research (Minkler and Wallerstein, 2003). This literature review provides the foundation of community-based participatory research and specifically explores the role of community-based researchers in the research process. Databases such as Academic Search Premier, Web of Science, TOC Premier, Medline, PsycINFO, ERIC, and Google Scholar were used to search for terms (CBPR, community researcher, community-based researcher, community, research partnership, and community engagement) that characterize the topic.

Useful web-based discussions are also taking place on web sites sponsored by organizations such as *Community-Campus Partnerships for Health*, that facilitate sharing of resources and information on community-based participatory research and debate about CBPR practices (<http://depts.washington.edu/ccph/index.html>). They support a series of member interest groups some of which focus on Aboriginal and Indigenous people's health. Networks such as the Centre for Participatory Research at McGill University (PRAM) are emerging to focus on training of health care professionals in participatory research approaches (<http://pram.mcgill.ca/>). Other networks and institutes are appearing as well, formalizing collaborative research partnerships with community organizations beyond academia.

The CBPR approach, with its focus on collaborative teams, incorporation of community, academic-based knowledge (Edwards and Gibson, 2008), and research outcomes that can precipitate change, is a departure from the more traditional objective perspective (Boser, 2006; White, 2006) and has been welcomed by communities. In the past decade, communities have developed strong research leadership skills, becoming active partners in research where they had previously been the passive subjects of scientific studies. This is clearly demonstrated through the successes of communities such as Kahnawake Diabetes Prevention Program (www.ksdpp.org/), D line Uranium Team (www.deline.ca/contacts/contactUranium.html), the Tłıch  Community Services Agency, and broader health research programs such as the Network Environments for Aboriginal Health Research (NEAHR)

program (www.cihr-irsc.gc.ca/e/27071.html#centres) supported by Canadian Institutes for Health Research (CIHR). Even though over the past decade these models have demonstrated successful community/academic research relationships and outcomes there remain challenges and opportunities for improvement.

The fundamental dichotomies that exist between academic and community partners range from their agendas for research, the power differentials in partnerships, to ownership of and identity with the research project (Cottrell and Parpart, 2006; Stoecker, 1999). In a review of CBPR projects in Canada (including both Indigenous and non-Indigenous projects), Flicker and Savan (2006, p. 26) suggest

that academics dominate most areas of the research process (including designing the research question, developing the methodological approaches and analyzing the data) ... community members were reported as the "least involved" partners.

CBPR is, by definition, intended to promote change and empower the communities involved; thus much CBPR is inherently political. Every research partner, external or community, brings a range of agendas to any research discussion (Baker et al., 1999; Gibson, Gibson, and Macaulay, 2001), some explicit, some not. As the framework for a research project develops, a partner's unanticipated political or professional motives may come to light. Establishing equality among the research partners early in project design through open discussion of differences, full disclosure, and participation in all planning stages enables teams to enhance communication and collaboration, and positions the community as a full research partner, rather than an advisor or consultant (Macaulay et al., 1999; Austin, 2004; Cottrell and Parpart, 2006). "Only through engaging in open dialogue about the inequities and hidden nature of power, can the relationship become reciprocal and ultimately transformed" (Wallerstein, 1999, p. 49).

Community-based research partnerships are complex, and fresh ethical challenges arise (Fadem et al., 2003). Lincoln (2001, p. 27) observes,

Formalistic protocols do not go nearly far enough in the intimate, face-to-face, democratic work of action research. Consequently, research teams are revising the codes daily, working through intricate interlocking relationships built on trust and caring ... with little formal guidance.

The primacy of the community context in the research process is now an accepted component of research theory and models (Winkler, 1993). Considerable work also has been done by Aboriginal groups regarding ethical issues from a cultural perspective (Patterson, Jackson, and Edwards, 2006; Glass and Kaufert, 2007; Government of Canada, 2005; Macaulay et al., 1998). Whether partnerships are formalized by verbal discussions or official written agreements (Macaulay et al., 1998; World Health Organization, www.who.int/en; Israel et al., 2005) the agreed upon principles must be brought practically into the research realm.

When community members are engaged as meaningful partners in the research process (whether in project design, data collection, analysis, or dissemination) then the team is able to negotiate the appropriate level of community leadership and involvement (Inuit Tapiriit Kanatami [ITK] and Nunavut Research Institute [NRI], 2007), thus mitigating potential power imbalances. The depth of community involvement can be affected by the relevance of the research topic, the research experience of the community, and/or their capacity (i.e., time, financial, human resource) to take on the addition demands of research (Schensul, 1999; Stoecker, 1999). Projects that have CBRs who are also members of the target population can help strengthen trust of participants, aid in accessing hard-to-reach study populations, and ease communication with participants (Schensul, 1999; Marais, 2006).

Although the literature acknowledges the importance of community involvement and the type of roles CBRs can play in the research process, there is a distinct lack of discussion from the perspective of the community-based researchers, the challenges they may face in conducting research in their own communities, and the strengths that their involvement brings to research methods. From a researcher's perspective, Goldberg-Freeman et al. (2007) outline the need to *understand* community when establishing collaborative relationships, and the results from their community data collection emphasized the importance of enhancing continuity for community development and ongoing feedback with the communities to increase trust. They found that "residents with personal, direct research experience had more positive attitudes about research than individuals who merely had heard about research in the community" (p. 237). Engaging community members as CBRs in the research can provide avenues to address such issues directly versus in retrospect. Choosing the right community members as CBRs can be a delicate process, yet training trusted people, using formal

consent processes for data collection, reviewing appropriate data collection techniques, and signing confidentiality agreements with local researchers, are processes that can contribute to participant trust and confidence in local CBRs (see Edwards et al., pp. 111–128).

TRAINING AS PART OF THE RESEARCH PROCESS: STRATEGIES AND LESSONS LEARNED FROM CIET'S WORK WITH ABORIGINAL COMMUNITIES IN CANADA

Much of the work we undertake with Aboriginal communities in Canada focuses on individual and community resilience in the face of challenges such as HIV/AIDS, suicide, substance abuse, and violence. For many communities, while there is the knowledge that these problems exist, less is known about how exactly to improve things. Community-based surveys can provide important data around the extent of the problems, and what strengths can be built upon in order to reduce the number of individuals at risk. To ensure high levels of trust and participation, the research should be conducted by a CBR, who is a member of the community.

A CBR is more than just a fieldworker. The CBR is the strength of the CBPR model, providing the community perspective to the research on a day to day basis. CBRs increase community capacity to contribute to and provide leadership in research projects, as they learn to advise on ethics, methods, and communication of results, enhancing their skills in these areas. Through their work, they collect higher quality data that reflects the reality of the community. While a regular fieldworker would be trained to perform a particular task such as data collection (and usually not in their own community), CBRs are involved, on behalf of their community, in a cycle of learning and feedback with the community leaders, the research team, and other CBRs. Selection of CBRs who are mature, sensitive, and trusted by their community is part of the research process. In many of our previous studies, CBRs were predominantly female, with little male participation. Some projects would benefit from an increase of males, and of youth CBRs, who would have better access to their peers. Through repeated cycles of research and training, CBRs take on increasing responsibilities and new skills and will play an ever stronger and more determining role in research in their own communities. In turn, it's not just the CBRs who receive train-

ing: external partners are also trained through this process, learning and understanding about community strengths and processes.

UNDERSTANDING OUR ROLES

An important aspect of facilitating strong community research partnerships from the outset of a project is for all members of the team to understand their roles within the broader project. Typical roles can be challenged as outside researchers understand the value of and place for their knowledge and expertise and realize that they may not be the primary leader or final decision maker of the research process in the community. CBRs will apply their expertise and experience and even learn new skills that enable them to assume larger leadership roles. For example, providing training throughout the life of the project allows for participation in a reiterative process inclusive of methodology, questionnaire design, data collection, data entry, and analysis. Depending on interest level, CBRs may start off with a few specific tasks at the outset of the research process, and become more and more involved through training with each successive research cycle they participate in.

One key challenge is to not overstate research roles within the team. Academics and other external researchers will not be experts in community research based on the experience with one project. Every community is unique and may require a different approach or form of relationship. Projects that place limitations around skill training and community involvement risk impeding community interest and underutilize CBRs as a resource. In turn, a CBR will not become an epidemiologist or an expert in community-based research through involvement in one project. Collecting survey data about sensitive issues in their community is not easy. CBRs who have a holistic understanding of their role and how they will contribute to and benefit from the research tend to stay motivated and are more likely to stay engaged and participate in other community-based research projects. Community members who take on research roles may find they are justifying their involvement when they begin to conduct the project in their community (Tuhawai Smith, 1999). A clear understanding of roles allows all members to better communicate the process to outsiders be they community research participants, academic partners, or others (government, health professionals, etc.).

An illustrative example is the understanding and review of the data collection instruments. All of CIET's questionnaires are standards based and

pilot tested. Existing questionnaires on similar topics are reviewed to generate the first draft of the questionnaire. However, all data collection instruments and protocols need to be attuned to the local setting to ensure they will work properly — a questionnaire designed for a resilience to suicide study among First Nations youth in Nova Scotia may not be completely transferable to a Métis community in Alberta. This customization can include changes in language, use of terms that are culturally appropriate, and the inclusion of particular resilience concepts or strategies that might be community specific. All CBRs, and other community members are directly engaged in the task of representing the community voice. Typically, CBRs provide leadership in the initial review of the survey questionnaires. Their initial concerns usually relate to the length of the questionnaire, inclusion of questions they fail to see as relevant to the process, or questions they feel are too sensitive to include. Upon further discussion and sharing of experience and expertise among the entire team, an official questionnaire is negotiated. The team adapts the questions to reflect the context of the research which may include alternative wording for existing questions. The time invested at this stage of project design creates logical links between the questionnaire and the *analysis plan* thus producing a culturally appropriate survey instrument. Also, if translation of the questionnaire is needed new issues can arise in ensuring that the terms translate well from English to the new language and that the intent of the questions is maintained. This requires extensive work from certified CBR or community translators to ensure back translation (when the questions are translated back to the original language) maintains meaning.

PRACTICE AND ROLE-PLAYING BEFORE DATA COLLECTION

There is no better way for CBRs to learn the task of data collection than to practise and repeat it. Even when CBRs feel they know exactly how they are going to approach a potential respondent to introduce the study, they are often surprised at how difficult this is when asked to do it for the first time in a role-playing session, even when they are provided with a script. They also underestimate how much their body language, tone of voice, eye contact, and explanation of the project matters to a potential respondent. Only through role-playing and practice do these skills develop.

During role playing, certain difficult situations can be introduced hypothetically and potential responses to challenging questions can be rehearsed.

These may include role playing a parent who wants to read the responses that their child has given. Or it could cover ways of responding to respondents' queries without introducing any researcher bias into the results. At this stage of the role-playing process, the research team can learn a lot about challenges that may be unique to the community at hand, and strategies to overcome these challenges can be discussed.

Another situation that requires practice relates to ethical issues. As communities develop their own research expertise, new challenges of consent and confidentiality arise. For example, the age when parental consent is required and the method of obtaining it varies among communities. It is important to honour the way communities typically do this. The process may involve local authorities, as well as government and university reviews, depending on the research project and partners. In some projects, different processes and modified questionnaires are designed for youth below a certain age. Once the age of consent is determined, then strategies for explaining the consent process to the participants must be developed. These require practice and rehearsal by the CBRs; ensuring knowledgeable and informed consent is a central part of the CBR training for the research process.

Maintaining confidentiality is important, as is realizing the effect that the survey and/or interview findings can have on the CBR when the research is done in their own community. All members of the research team must consider and discuss ways of addressing these challenges prior to the research. CBRs also learn to ensure support for participants who are disturbed by memories or flashbacks of difficult situations, triggered by the question in the research process. The research team must be ready with support contacts for such situations, particularly when the research is around sensitive issues like suicide or domestic violence. Establishing confidentiality and sharing of the research findings protocols is also important and can be addressed in a data-sharing agreement that is signed by the elected leadership or their designate and the external research team leader prior to conducting the research. Role playing is a strategy for reinforcing the professional role of researcher within the CBR's own circle of neighbours and friends. Practice builds confidence in this role, which may be new for some.

UNDERSTANDING AND INTERPRETING DATA

An important step in training CBRs to understand and interpret data is to involve them in the data entry process. It is true that the manual task of

data entry can be taught in a relatively short period of time, and having a CBR enter hundreds of records does not add much value once they have developed the skill (other than the practical advantage of getting it done). However, through the process of manual data entry, CBRs learn more than just the skill. They become very familiar with the types of responses that arise. In many cases, the actual responses are not what were expected. The CBR also begins to understand how a dataset is built, and how coding of responses works. After entering many records, CBRs gain a better understanding of how long the data entry process takes, what potential errors can be introduced at this step, and why double data entry and validation (to reduce errors in digitization) are necessary. These are important concepts for CBRs to understand for future projects.

During data entry, while being exposed to real data, CBRs will also inevitably begin to think about the responses and to spot trends. It is, of course, important to remind the CBRs that nothing should be concluded at this point: the data still have to undergo strict epidemiological analysis. It is advantageous to have their minds open to the evidence they see unfold before them, rather than just relying on their own opinions. This skill becomes crucial when CBRs are exposed to analysis techniques as well as the interpretation and sharing of them. With an increased understanding of what can and cannot be concluded from the data, CBRs can lead the discussion around the findings, how they might be interpreted, and what action can be taken based on the results.

Decision-making processes are complicated, varying among communities and sometimes involving many community leaders, Elders, service providers, community members, and other experts. The more understanding of the process and results the CBRs have, however, the more they can help in mobilizing the right people to enact change.

CHALLENGES AND SUGGESTIONS FOR THE FUTURE

Ideally, once trained in the research process, CBRs will continue to apply their knowledge in their own work, and in subsequent research projects. In turn, external researcher partners can build upon the things they've learned from the community and apply them to other projects as well. However, project work at the community level is intermittent and not usually a full-time position. Thus, most CBRs are employed in other work and cannot always take the time off as research initiatives arise. Nonetheless, there is

an obligation to ensure that there are continuing opportunities for CBRs to practise their skills, and to pursue research as a career, if they are interested. This should include all aspects of research including access to further training, funding, project design, analysis, and knowledge translation.

The CBR movement will benefit from networks — CBRs from different regions and projects could get together and share their experiences, both with and without participation from external researchers. This could take shape in the form of Internet groups, with occasional face-to-face meetings. These networks will help CBRs feel less isolated in their communities, and widen the funnel for development of a cohort of Aboriginal researchers. In turn, community-based and external researchers can continue to grow their partnerships and build trust. Related to this, we can improve the emotional support provided for the CBRs themselves during and after data collection. As many of the topics we study are sensitive, during implementation of these projects we make efforts to ensure support for the respondents should taking part in the survey trigger a negative memory. The same support should be offered for the CBRs themselves, when researching sensitive subjects. Being a researcher does not preclude us from being vulnerable to unexplained personal reactions and/or outcomes.

CONCLUSION

CBPR is a dynamic and exciting process. The skills that both the CBRs and external researchers gain are generally an addition to their existing expertise and enhance their ability to work within their communities and on other research projects. The input of the CBRs also enriches the findings and allows for interpretations of the research that might be impossible for external researchers alone. Training also contributes to the capacity of the community to review, participate in, and initiate research projects that can provide the necessary evidence for policy and program development.

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