ALIGNING EXPECTATIONS FOR FUNDERS AND COMMUNITY RESEARCHERS

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ABSTRACT

Over the past two decades the various Canadian sources of research funding have moved from an academic, science-based focus to a more inclusive model, encouraging applications that support research partnerships with community organizations. This transition in definitions and expectations is creating challenges for some funders, as well as academic and community applicants. With the advent of community-based participatory research new perspectives on respectful, ethical research partnerships are appearing. The paper reviews some of the challenges and strategies for community partners, academics, and funders in terms of research approach and practice.

Key words: community-based participatory research; ethics; respectful research; ethical partnerships

INTRODUCTION

Over the past two decades the various Canadian sources of research funding have moved from an academic, science-based focus to a more inclusive model, encouraging applications that support research partnerships with community organizations. This transition in definitions and expectations is creating challenges for some funders, as well as academic and community applicants. For example, some funding organizations are struggling to promote rigour while adapting to this emergent approach; some academics are struggling with the implications of shared ownership and reduced power in their research; and some communities are struggling with responsibilities for which they were not prepared. The shift from academic ownership to shared ownership, or community/organizational ownership creates a complex web of expectations, and just beneath the surface are the ethical implications for such research (Durham Community Research Team, 2011). With the advent of community-based participatory research (CBPR), under its many names (Action Research, Participatory Research, and others), a number of models have emerged (Minkler and Wallerstein, 2008) with new perspectives on respectful, ethical research. In these modes of research, community representatives, with profound local knowledge and experience, identify a research priority and contribute to achieving the research goals relevant to their community (Israel et al., 2008).

This paper draws on experience with thirty-five community partners over twenty years, with funding from Canadian federal sources, provincial and territorial governments, and several foundations.

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ACADEMIC PERSPECTIVE

The early models of CBPR were based on the assumption of academic leadership and accountability. Until very recently an academic appointment was required to receive a research grant from the major Canadian research funders, Tricouncil granting agencies, and Health Canada. Grants were always managed through the academic home institution of the principal investigator. Academic researchers are still evaluated in part by the number of grants they hold and the number of papers they have published in peer reviewed journals. The competition for grants influences the need for academics to be credited for their leadership role, and to be first author, if not sole author, on research papers. This expectation is increasingly challenging in participatory research projects. Where previously academics automatically owned the data they collected, this is no longer true. Ownership is often negotiated with community organizations through data sharing agreements, and some Aboriginal communities and funders are now requiring application of the principles of ownership, control, access, and possession (OCAP) (Schnarch, 2004), or similar ethical agreements; thus the structure and organization of the research field is changing to reflect the conditions of such partnerships. The academic expert is becoming a facilitator, an equal partner on a team of researchers with complementary expertise (Edwards and Gibson, 2008a), and the term “researcher” now can include community partners.

COMMUNITY PERSPECTIVE

Until recently communities were not considered likely research partners. They were more often research sites, where researchers “targeted” populations. Some places became centres for many kinds of research, with little or no coordination among the researchers, from various disciplines and institutions. Research fatigue occurs when a community weary of researchers taking up time and resources to answer externally defined research questions, with no apparent benefit to the community. This has been a common complaint in some Aboriginal communities. As Willie Ermine (2004) observed, very often, this misunderstanding has resulted in violence and the urge to dominate or change the others’ existence to a more discernable form, more easily predictable, or fitted into modes of thought more familiar, more palatable... The cultural tensions looming over the Indigenous/West relations, in their historical dimension, are particularly magnified on the contested ground of knowledge production and in particular its flagship enterprise of research.

Some communities experience damaging effects from the negative labeling of research topics such as sexually transmitted infections, suicide prevention, addictions, and family violence. The research, while meant to help to prevent these issues, may inadvertently stigmatize the communities involved. The media also pick up on such labels (VanderKlippe, 2006). No longer willing to be the objects of research projects, many communities are insisting on a voice in framing the research question, determining the approach, conducting the research, and implementing the results.

UNPAID LABOUR IN COMMUNITY-BASED PARTICIPATORY RESEARCH

With the emerging CBPR framework, models range from token involvement of community partners to projects led by community organizations. Some funding proposals are asking for the potential benefits of the research outcomes to the community partner (Gibson and Gibson, 1999) with protocols for funding community partners directly. At first glance this seems like a positive move, and indeed it can be if several major challenges are addressed. A major challenge is to ensure that the administration capacity of the community organization can accommodate the reporting and accounting requirements of the funders. At least one community organization has returned a federal research grant after realizing how much time and effort were involved; the benefits were simply not worth the administrative cost. At present, although universities receive separate funding from major granting agencies to manage administration, this is not true for community organizations.

Another challenge for communities in research partnerships is the in-kind contribution expected...
from the community, such as time spent in preparing parts of the grant application, and if funded, time spent on research training, interviews, data gathering, evaluation, and related tasks. Academic researchers are paid by their institutions to apply for research grants and to conduct research; usually community partners take on research responsibilities in addition to their paid positions, or as volunteers. Negotiating in advance how much real time a research project will take, and how this will be covered, whether acknowledged as an in-kind contribution or paid activity, can reduce research fatigue. Anticipating the community commitment accurately can mean the difference between success and failure of a research project. It is especially important to build in time and appropriate personnel for knowledge translation and communication activities at the end of the research, as well as for planning evidence-based interventions, and next steps in an ongoing, sustainable process. Some funding agencies such as the Canadian Institutes for Health Research have established grants for proposal development and funding for knowledge translation. This can partially address problems of unpaid work in proposal development and research design.

Raising expectations is another risk in partnering with communities for major research grants. In most competitions, only a small percentage of applicants will be successful. For example, in a recent major application for $2.5 million only four out of twenty-eight proposals were funded. Each application requires weeks of work in literature reviews, preparing and approving drafts, building the partnerships, and writing letters of support. Unless the applicant is on salary, this is unpaid time, or for other partners, an unexpected addition to their workload. The community engagement necessary for such applications raises hopes and expectations which are likely to be dashed, given the current funding averages. This is another cause of research fatigue and disillusion for potential community partners.

**COMMUNITY COMPLEXITY**

The current model of CBPR implies a dichotomy with two central partners, the academics and the community; however, the community partnership is often multifaceted, and requires further definition. For example, is the partner one organization, or several organizations, and are they in one or several communities? Are there partners from companies or government? What role will each play? What levels of approval of the research partnership will be required by each partner? How long is that likely to take? (Gibson et al., 2001). A case example is a team of urban immigrant and Aboriginal CBRs who were seeking a common approach to prevention of tuberculosis. Four Aboriginal communities and three immigrant agencies were represented at the table. Negotiating the common research agenda required many meetings and workshops, and shared meals, which we have found promote partnerships and trust (Gibson et al., 2004).

Most projects require leadership approval from participating communities and organizations. An early question for the emerging research team is, who is the leadership, and what approvals are required. This may be simply a letter from the Chief, or from the health director, or the education coordinator. Appropriate leadership buy-in is extremely important. In one situation, academic researchers were invited by a group of community middle managers to address the issue of suicide prevention through CBPR. When leadership support was requested for the application, it became clear that the leaders would not support the project. They were concerned about the sensitivity of the topic and how the research might reflect negatively upon their community. The project was stopped, as continuing could have created further conflict in this already fragile community.

If the community has not participated in a CBPR project before, the decision-making process regarding who has what authority, who will be trained and to what extent, can take time. In some projects, this process has required several attempts as the community organization learned about this new process, and local leadership changed. In the past there was an underlying sense that academics were doing the community a favour by conducting research with them. Designated community partners, however, are usually busy people who are committing to another layer of responsibility and time. As
the complexity of partnership emerges, techniques to assess the full range of responsibility are becoming part of a respectful research process (Edwards and Gibson, 2008b), particularly in communities with a history of successful research partnerships. The project team will include people in the community/organization whose knowledge is relevant, who are committed to the research outcomes, and who understand the benefits that might accrue from the project. Although political appointees are common and often useful, there must also be representatives with relevant organizational and community knowledge. In sum, as Marie Battiste (2008, p. 503) points out, “These [research] projects should be managed jointly with indigenous peoples, and the communities being studied should benefit from the training and employment opportunities generated by the research.”

**LANGUAGE**

The system of proposal writing and reporting for research grants has led to a conceptual and technical language that includes key words, such as capacity-building, knowledge transfer, ethics review, sustainability, and intervention. This language changes often as new concepts emerge, and technical definitions help to define research objectives and methods. Technical words can be drawn from other contexts, and meanings may vary. The language can differ from one field or discipline to another as well. Until recently a characteristic of academic writing was a depersonalized style that reinforced the commitment to the scientific goal of “objectivity.” However, technical jargon can be interpreted differently by researchers and community members. For example, the confusion that can occur in doctor-patient discussions when technical terms are not explained has been addressed in the literature (Rotor and Hall, 2006). Even when the definition of a scientific term is understood in one setting, its meaning may vary in other settings (Boroditsky, 2011). As with any language, it is not enough to know the vocabulary without learning the idioms and expressions. As we move towards more active community participation, funders and academics are continually reviewing academic practices in relation to community interpretations and expectations. Proposals are usually written by academics, creating a gap between proposals and outcomes unless the meaning of such academic language and the related expectations are clarified and negotiated with community partners. This gap may be invisible to the researcher as academics speak their disciplinary dialect fluently without conscious focus, while other partners may make assumptions about meaning based on their own experience and context. Open and respectful interpretation is often required.

A related issue is the use of acronyms. Many funders ask community reviewers to be part of the reviewing team, and too many acronyms can be very confusing, even if definitions are provided. Scientific journals, including *Pimatisiwin*, are now accepting and sometimes seeking papers written in a more accessible style. Some funding agencies have added a plain language summary of the project as part of the application requirements, and have also created a more appropriate format for the resumes of non-academic applicants and partners. In time, with a serious commitment to community collaboration, a common language of mutually understood terms may emerge.

**SUGGESTED STRATEGIES**

**IDENTIFYING THE RESEARCH QUESTION(S)**

Although funding sources are specific to a fairly narrow range of research topics, identifying and refining the research question may take some time. Even if the community partner(s) have agreed to the research focus, and initiated the project, determining the actual question and selecting the appropriate methods can take some time. Success in this early stage is often based on a pre-existing trusting relationship among the partners. Where the term researcher once implied an academic or professional person, usually from outside a community, it can now include community researchers, and other partners, with varying interpretations of words and phrases. Once again, the actual research question(s) and methodology require a negotiated terminology that is clearly understood by all partners. Where
funders tend to label research topics negatively, research questions can be framed positively. Current research questions often begin with “What are the factors that influence resilience to...” (insert the issue such as additions, suicide, etc.).

Translating research tools such as surveys and interview guides into Indigenous languages can also take time and local expertise. In two projects an Indigenous language advisory committee was convened to identify/create appropriate words and phrases to discuss new concepts such as a) sexuality — to modify the local terminology which had mostly negative connotations (Edwards et al., 2008), and b) nutrition — where there were no words in the local language for newer food products being introduced.

PLANNING THE TRAINING
Community-based researchers have varying levels of relevant experience and training, and the research preparation requires knowledge of research methods and communication skills to bring their research abilities to a consistent level. The research team must determine who is to be trained, to what level, and with what goals. We have learned that there are two concurrent models for community-based training: the horizontal and the vertical. The horizontal axis includes the people who take part for a while, come and go, and are not really part of the core team of community-based researchers. They may already have full-time jobs, they may be political appointees, or other factors may prevent them from a full commitment. Vertical trainees are those who attend most sessions, fully engage in the research process, and are most likely to produce reliable data. They understand confidentiality and consistency, as well as the mechanics of the survey or interview tools. Participants who fall into the horizontal category are valuable; although they may not play a central role in the research, they do spread the word around the community about the research, and often increase participation in an informal way. When we speak of research sustainability, we refer more to those along the vertical training axis, whose skill level is higher, and who may well apply their knowledge to future projects as part of a long-term research partnership. They will also be valuable in knowledge translation and communication of the results at the end of the data analysis process, particularly for contextualizing quantitative data and interpreting qualitative data. In our experience, consistent participation of CBRS is directly related to the strong and active commitment of the leaders to whom CBRS are accountable in their community positions.

EXTENDING THE LENGTH OF GRANTS
Funding agencies are reflecting the need for longer research periods in community-based projects. A three-to-five-year grant is still considered a long period, but in a community, addressing important research issues takes considerable time, and sequential grants are not guaranteed. The current availability of grants for knowledge translation/dissemination of results with the communities, and for evidence-based interventions, is promising.

DISCUSSION: RIGOUR AND REALITY
CBPR opens up a new discussion of data reliability. The goal is to strike a realistic balance between the varying levels of training and research ability among the CBRS with their insider knowledge of the research environment. With surveys, the issue of rigour arises as each survey tool is examined and modified by a community group. If there are sequentially related surveys, the comparability can be difficult if the cultural content is inserted by different groups of advisors over time. We have found that while data collected by CBRS is sometimes thought to be less rigorous by traditional scientific standards, this data is often richer and more informative, based on culturally sensitive and appropriate wording. This is often a sort of trade-off, and yet we have learned that the insider knowledge is in many cases just as valuable as the absolute comparability of data; the results are more likely to be applied to programs and policies if insider interest and engagement are sustained. The measures of successful data collection, then, are quality and reliability of data collection as well as community interpretation and application. The goal is to achieve a realistic balance between rigour and authenticity, which can only be achieved through discussions of the process and findings with community partners.
EVALUATION
Measuring research outcomes has also become an important issue in CBPR, in deciding what is to be evaluated, by whom, and how. Traditional evaluation assesses the validity of the data and the strength of the outcomes within a scientific paradigm. More recently, additional or alternative evaluation methods include measuring breadth and up-take of interventions and knowledge translation over time. In-depth interviews with CBRS and participants can reveal the effectiveness of a research project from the community and/or CBR personal perspective (see Hopkins, 2012, pp. 231–248). Such interviews can take place both during and after the active research phase. Finally, community engagement, usually a qualitative and hard to measure component of research (Cargo et al., 2011), may be reflected in ongoing community discussions, the media, local radio, the press, and internet.

ETHICAL ISSUES
Methods will change throughout most CBR projects. There is an emerging language to describe this likelihood in grant applications: the research questions are posed, pending community approval; the survey tools or questionnaires drafted, pending community approval; and the outcomes are listed as anticipated. This is a difficult call for funders who must judge a proposal on the likelihood that objectives will be defined and achieved, based on a somewhat vague proposal. One solution is a phased ethical approval process; appropriate strategies are still emerging. The down side is the potential for increasing the administrative burden for the researchers.

Conducting research within one’s own community or organization involves a number of overlapping personal and professional roles, especially in small communities. A CBR may also be a mother, wife, community health researcher, and political leader. Boundary crossings are defined by Malone (2012, p. 4) as “benign overlapping relationships whereby [a researcher] lives in close proximity to clients and may move in the same social circles.” Realistic levels of confidentiality must be negotiated, and effectiveness is often based on trust and professionalism. Boundary management is a set of skills that should be included in CBR training for research in small communities.

Each project works from the standards that have been set out by the funding source, the academic institution, and the appropriate leadership representing the community organization. Again, from Malone (2012, p. 5), “Distinctions need to be made between confidentiality, anonymity, and privacy ... as only confidentiality could be justifiably offered.” Flexibility may be formally negotiated, or informally practised in modifying procedures to achieve two central goals: to protect the identity of the participants to the level deemed appropriate for the project, and to ensure cultural safety (Cameron et al., 2010), including physical, mental, emotional, and spiritual well-being of the community-based researchers as they cross their personal and professional boundaries.

CONCLUSION
Funding reservoirs for health research seem to be diminishing, making the in-kind participation of communities, perhaps by providing some resources, such as staff time, even more important. The danger is overloading staff, but as communities become aware of the benefits of conducting their own research, such funding allocations are emerging. Respectful procedures that are developed with community partners at the outset can forestall misunderstandings and delays in the research process.

New partnership models are emerging, offering common principles about respectful research relationships (GNWT...). Although guidelines exist, we have found that each community project is a new adventure, and that in contrast to the academic principle of transferability of research models, there is benefit to adapting and re-shaping each project to fit the community context (Gibson, G. et al., 2008). As community members gain research skills, the ability to conduct their own research becomes a valuable legacy.

REFERENCES


Dr. Nancy Gibson, a medical anthropologist, is currently collaborating on community-based health research with the Tłı̨chǫ Government in northern Canada on prevention of sexually transmitted infections as well as strengthening Aboriginal community capacity to address self-identified issues and health priorities. Nancy is a Senior Researcher with CIET, an NGO based at the University of Ottawa that provides research training and facilitation to communities for program and policy development. She is professor emeritus at the University of Alberta, where she served as Chair of the Department of Human Ecology and Science Director for the Canadian Circumpolar Institute. She also chaired the National Human Health and Well-being Science Review Panel for the Canadian International Polar Year program.

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