

DEVELOPING A PARTICIPATORY ABORIGINAL HEALTH RESEARCH PROJECT: "ONLY IF IT'S GOING TO MEAN SOMETHING"

KRISTEN JACKLIN
Northern Ontario School of Medicine

PHYLLIS KINOSHAMEG
*Wikwemikong Unceded Indian Reserve
Community Researcher*

ABSTRACT: COMMUNITY-BASED RESEARCH METHODS were used in a study of health needs with the Wikwemikong Unceded Indian Reserve, Ontario, Canada based on critical theory, Indigenous teachings and participatory action research (PAR). The process of developing the project led to the elucidation of eight key principles deemed necessary for the development of a project that is both culturally and community appropriate: partnership, empowerment, community control, mutual benefit, wholism, action, communication and respect. Adherence to these eight principles appears necessary for an ethical and an effective research process in Aboriginal communities.

KEY WORDS: Participatory Action Research, Community Based Research, Aboriginal, Canada, Research Ethics, Critical Medical Anthropology

Received: October 16, 2007; revised: March 1, 2008

The biggest problem in conducting a science of human behaviour is not selecting the right sample size or making the right measurement. It's doing those things ethically, so you can live with the consequences of your actions. [Bernard, 2006]

RESEARCH HAS BEEN A PART OF LIFE FOR Aboriginal people in Canada since the time of contact with Europeans. For example, missionaries wrote about the cultural practices of Aboriginal people in their journals, and later kept statistics about baptisms, deaths, and marriages in their parish registrars; trading post managers collected statistics on the composition of bands, their subsistence patterns and movements; and early anthropologists

detailed their life-ways (Hallowell, 1955; Jenness, 1935; Landes, 1937; Speck, 1915). Later, government superintendents collected information on bands for their annual reports now found in the Government of Canada Sessional Papers. Today, the Canadian government continues to require the submission of statistics from Aboriginal communities and often requires specific research studies to be carried out in order to qualify for funding; for example, community needs research must be conducted before Health Transfer¹ funding is released to First Nations communities (Health and Welfare Canada, 1992).

It is no wonder, then, that those currently conducting research with Aboriginal communities often hear the words "we've been researched to death." In addition, complaints are often leveled that studies are shelved and "nothing is ever accomplished." Academic researchers have noted that research is often perceived as irrelevant to community needs, a threat to local autonomy and a drain on resources (Elias & O'Neil, 2001). During the community-based research we describe herein, residents cited recent instances when the community was not made aware of the results of studies and did not receive copies of the publications or findings. It is not surprising, then, that there is a great deal of mistrust of both research and researchers. The subtitle of this article "Only if it's going to mean something" are the words spoken by an Aboriginal youth from Wikwemikong when asked if she would be willing to complete a questionnaire on community needs. Aboriginal people no longer tolerate traditional research approaches; instead, they ask to be involved and insist on knowing how the research will aid the community (Berardi, 1998; O'Neil, Reading & Leader, 1998). They feel that for research to be effective the solutions must come from within, merely aided or facilitated by external researchers (Royal Commission on Aboriginal People, [RCAP] 1996). Researchers have a responsibility to Aboriginal people and to their profession to work with communities towards research partnerships that are ethical by local standards and meet the needs and expectations of the community.

The community partner for this research, the Wikwemikong Unceded Indian Reserve, is situated on

Manitoulin Island on the North Shore of Lake Huron, Ontario. It is the largest of the seven reserve communities on Manitoulin Island. The band members from Wikwemikong are Ojibwa, Odawa, and Potawatomi. All three of these dialects of the Algonquian language family, as well as English, are spoken in Wikwemikong. The reserve covers a large geographical area of 105,300 acres, and is approximately 40 km north-south and 16 km east-west (Wikwemikong Community Health Plan, 1989, 1994). Approximately 2,800 band members live on the reserve, with an additional 3,700 Wikwemikong band members living off-reserve (Wikwemikong Unceded Indian Reserve [WUIR], 2001).

We describe the evolution of a research partnership between Jacklin, conducting her dissertation research, and the Wikwemikong Unceded Indian Reserve. The second author, Kinoshameg, was the executive assistant for seven years and researcher for one year at the Wikwemikong Health Centre (WHC) and was primarily responsible for monitoring Jacklin's work. In this paper we document the development of the research process in Wikwemikong, one that was felt to be meaningful and useful for both partners and appropriate for the culture and community. The application of critical theory,² Indigenous teachings and participatory action research (PAR) in the Wikwemikong Unceded Indian Reserve led to the elucidation of eight key principles of research deemed necessary for research processes that are ethical and culturally appropriate: partnership, empowerment, community control, mutual benefit, wholism, action, communication and respect. Beginning in 1999 and the years since this initial research, the authors and others in the community have collaborated on a community needs assessment (1999–2001), a youth needs assessment (2002–2003), health services evaluations (1999 and 2004), culturally appropriate personnel policies and procedures for the WHC (2003), developmental diabetes research (2005–2007) and a diabetes quality of care study (2007–current). The experience described in this article was crucial to the development of the long-term research relationship that has been sustained.

It is not by chance that the eight principles proposed as a result of this research are also inherent to the new *CIHR Guidelines for Health Research Involving Aboriginal Peoples* (CIHR, 2007) and to the locally developed *Guidelines for Ethical Aboriginal Research* (Noojmowin Teg Health Access Centre, 2003). Kinoshameg was a member of the national Aboriginal Ethics Working Group who developed the CIHR guidelines and was a volunteer on the Manitoulin Aboriginal Research

Review Committee who developed the *Guidelines for Ethical Aboriginal Research*. As a result, many of the lessons learned from this research (1999–2001), and in particular the eight principles we outline, have either implicitly or explicitly made their way into both local and national ethical standard documents.

Theoretical Foundations

The research with Wikwemikong drew on two theoretical orientations. The *critical medical anthropology* (CMA) framework situates health in a political-economic context, and views biomedicine as an extension of the capitalist world system which legitimizes and perpetuates social inequalities (Singer & Baer, 1995). It is widely recognized that past policies of the Canadian government concerning Aboriginal people have kept this population at a disadvantage economically and politically—and their communities in a perpetual state of dependence and underdevelopment (Fleras & Elliot, 1992). CMA is congruent with local theories concerning the influence of historical and contemporary politics and policies on the health of the community (Jacklin, 2007). There have been many calls for action-oriented research with Aboriginal people (Ervin, 2000; Ryan & Robinson, 1990; Warry, 1992), which have come directly from criticisms leveled by the communities in response to the abundance of research that has been conducted on them, with little or no noticeable benefit to the community. CMA “aims not simply to understand, but to change culturally inappropriate, oppressive and exploitive patterns in the health arena and beyond” (Singer & Baer, 1995). Its wholistic³ emphasis is compatible with Aboriginal people's approaches to healing (RCAP, 1996; Wikwemikong Community Health Plan, 1989, 1994). CMA considers many factors in its analysis such as history, environment/ecology, politics, economics and culture. It also frames the research question in various levels of analysis such as the macro level (political systems), intermediate level (the clinic), micro (community) and individual level (personal) experience (Singer & Baer, 1995).

The second theory underlying this project was *community centred praxis* (Singer, 1993; Singer, 1994). This model for health research takes critical medical anthropology and adds PAR (Singer, 1993). *Praxis* implies *ethical action* as a central feature in research.⁴ The principles of community-centered praxis include: continuing discussion with community members, research that reflects concerns of the community, transfer of research skills to community members, research that

contributes to the goals of the sponsoring agency (community-based organization), and research that regards empowerment and self-determination as a means of change (Singer, 1993; Singer, 1994). These are principles that have been identified by Aboriginal people in Canada as central to the research process (RCAP, 1996), and have been employed by other researchers working in this area (Elias & O'Neil 2001; O'Neil, Kaufert, Kaufert, & Koolage, 1993; Ryan & Robinson 1990; Schell & Tarbell, 1998).

While critical theory laid the foundation for the research framework and analysis, the research process was guided by PAR and the seven grandfather teachings from the Anishnabe tradition: wisdom, love, honesty, respect, humility, bravery and truth. Participatory researchers have a deep commitment to the betterment of humanity through equality (Smith, 1997a). Researchers are willing to give up, or share power in order to improve the well-being of others. When PAR is used correctly, the community is involved in the conception of the project as stakeholders who define the research question, participate in planning and designing the project, and are involved in implementation and evaluation. Researchers have adopted PAR protocols to make research more democratic; however, Indigenous people have argued that PAR still does not prevent outsiders from adopting colonial attitudes towards research (Cornwall & Jewkes, 1995; Smith, 1999), and that although many researchers working with Aboriginal people use the term *participatory*, there are few instances where truly participatory research has been applied or reported on in Aboriginal communities (see Elias & O'Neil, 2001; Ryan & Robinson, 1990; Schell & Tarbell, 1998).

Research Negotiation and Planning

Jacklin began to discuss the research project with the WHC on August 9, 1999. She had previously worked at the Health Centre earlier that year as a member of a consulting team hired to evaluate the process of Health Transfer which had provided insight into the problems faced in providing health services. Through meetings with the Health Director and Health Board in October 1999, it was decided that Jacklin would be given permission to carry out research at the Health Centre on the condition that it was meaningful and useful to the community. That condition was met by negotiating a dual research role for Jacklin in which she would assist the Health Centre in conducting a community needs assessment as part of their community health plan

(CHP) development⁵ and would at the same time collect data for her dissertation.

This project presented two main challenges: (1) engaging a community that felt past research had been unethical and disempowering caused them to feel that outsider researchers were primarily concerned with advancing their own careers and not with improving life in Wikwemikong, and (2) implementing a participatory research project that would meet community needs while also allowing the Ph.D. candidate to fulfill her academic requirements. Community member's suspicion was heightened by knowing Jacklin would advance her credentials as a result of the project, and because she had to negotiate between the scientific community (her supervisory committee) and those holding Indigenous and local knowledge. The academic research focus for Jacklin centered on community healing through empowerment and engaged a colonial and political discourse to examine factors that facilitate the perpetuation of poor health in Aboriginal communities. Because of this, Jacklin was able to argue to her supervisory committee that the process for this research was as important to the project at its outcomes. Research methods were constructed to reflect community research needs and to ensure the appropriateness of the questions, tools and language. The methods resulted from numerous consultations with people in the community. Methods included literature reviews, two years of participant observation, key informant interviewing and a community needs assessment. Consistent with a participatory approach, the specific methods were largely determined by the community (Ervin, 2000). The community needs assessment design and delivery represented the greatest area of community involvement and control. Participant observation, key informant interviewing, and literature reviews were largely left to Jacklin's discretion.

Gaining permission to enter the community to conduct research was a lengthy and difficult process. Although the Health Director at the time favoured the idea, protocol required that the Health Board make a recommendation to Chief and Council that the research be permitted. The process began with discussions with the Health Director and Executive Assistant on August 9, 1999. Jacklin was then asked to present a short research proposal to the Health Board on October 7, 1999. During the presentation to the Health Board, concerns raised were that Jacklin was not a band member and that a band member should have the first opportunity to conduct the research. Board members also conveyed that they "were researched to death" with little or

no benefit to their community. The research design proposed, however, would ensure the use of local research assistants and “knowledge for use”; that is, the Health Board was assured that the document would be used to meet the requirements for their Health Transfer funding agreement with the federal government and could also be used for other proposals and health centre strategic planning. The proposal highlighted the use of participatory methods and adherence to the seven grandfather teachings. A positive recommendation was made to Chief and Council on November 10, 1999.

Following Health Board approval, Kinoshameg composed a research contract that outlined the expectations of the researcher, and covered ownership of data, dissemination, and confidentiality. It is noteworthy that Jacklin was required to go through the approval process a second time when the Health Board members were replaced by the Standing Committee on Health comprised of five elected members of the band council approximately 6 months after the initial approval. The second approval process resulted in a minor delay in the research, but was worthwhile in that it engaged the new health committee in the research and ensured continued interest in and support for the project.

After the research negotiations were complete, Jacklin began to meet informally with staff and community members, introducing herself and informing them about the CHP research. There was much interest in the needs assessment in the community. She was introduced to most agencies in the community, discussed the project with them and invited their input.

The Management Team⁶ which oversaw the operations of the WHC after the departure of the Health Director was the key community partners for the research. All decisions and information flowed to, through, and from this group, which became a vital and integral part of the research. Kinoshameg was the lead for this Management Team.

Participatory Survey Design

In the first six months of working with Wikwemikong, five other surveys were circulating in the community. Some of these surveys were topical needs assessments that were required for various forms of program or service funding; others were regional or national health status surveys. In talking with staff at the Health Centre, it soon became clear that they felt the community would not be anxious to participate in another survey; however, if it were necessary then staff felt it should be comprehensive and limit the need for other surveys. Consequently, it became one of the goals of the research

to develop a comprehensive survey instrument that included questions that could be used by other departments and agencies in meeting their own needs assessment requirements.

The survey instrument for the needs assessment was to include quantitative and qualitative questions and the topics covered were to include physical, mental, emotional and spiritual health. The needs assessment questions were initially created and selected based on the principal investigator's knowledge of health issues in the community (Jacklin & Warry, 2000) and for Aboriginal people in Canada in general (First Nations and Inuit Regional Health Survey, 1999; Health Canada, 1999, 1999a; RCAP, 1996). This type of data could be used for advocacy and negotiations with the government; for example, it could be used to compare the health status and behaviours of Wikwemikong residents to other First Nations and with national averages, and it could be used to track changes in Wikwemikong over time.

The survey questions were reviewed by staff members with expertise in specific areas (e.g., the Nutritionist, the Research and Evaluation Assistant, the Diabetes Educator, and the HIV/AIDS worker). Next, it was given to Health Centre Program Managers and the Director of Operations at the Wikwemikong Band Office for their comments and revisions. The feedback from these staff members was substantial. The acting Nurse in Charge provided extensive and useful comments in terms of medical details; others, such as the Environmental Health Program Manager, Director of Operations, and the Administrative staff (Executive Assistant and Office Manager) provided valuable comments concerning the wording and appropriateness of questions.

After considering comments from Health Centre Staff and making adjustments in response to them, the survey was taken to the Community Services Members meeting, commonly known as the Inter-Agency Meeting.⁷ Members of the organizations represented at this meeting were given the same instructions as the Health Centre staff and program managers, and were asked for comments, questions, and concerns. Written feedback was received from four organizations. The comments were useful and additions were made to reflect the needs and concerns of those organizations (e.g., some added their own organizations' questions on service use, and suggested rewording of other questions). At the request of the Standing Committee on Health, four local research assistants also participated in the final stages of survey development, and the Committee members reviewed and commented on it. Inclusion of the research assistants in the survey development process

turned out to be a critical step in preparing an instrument that could more accurately measure health in Wikwemikong, and in creating a data collection method that would make participants feel confident in the promise of complete confidentiality. Research assistants helped to refine check box response questions to include choices that were more applicable to the community, and they suggested revision to wording that would be more comfortable and natural for the participants.

The survey questions, format, and methods were also reviewed by Jacklin's committee at McMaster University and by the McMaster University Research Ethics Review Board. After all comments were considered and the survey was revised, the four research assistants pre-tested the survey prior to its implementation. The final draft of the survey was presented and approved by the WHC Standing Committee on Health and the McMaster University Research Ethics Review Board.

Advertising—Communication

The community partners felt that part of the consent process should include the widespread distribution of information on the research to the community well in advance of and during the research. Therefore, prior to commencing community interviews, the research was widely advertised in the community. Information posters were mailed to every resident, flyers were posted on community bulletin boards, an advertisement was run on the local television network, and an advertisement was put in the local newspaper each month the research was under way. Staff and local agencies were informed of the research at meetings, so that they too could respond to community members' questions and direct them through proper channels if concerns or questions were raised.

Local Research Assistants

Four local post-secondary students were hired for three months as research assistants to conduct the interviews (the same research assistants who participated in the survey development). A fifth research assistant was brought in for two months to help with data entry. Jacklin provided each of the four students one week of training on conducting face-to-face interviews and following the sampling plan. It also provided them with knowledge they needed to understand: (a) why certain questions were being asked, (b) how the information could be used by the community, and (c) Jacklin's role and research relationship with the community. It was hoped that the training would prepare them to answer any questions

community members might have about the research as well as to develop research capacity in the community. During the training, research assistants had an opportunity to brainstorm their own definitions of health and culturally appropriate research. Research assistants felt that fears around confidentiality in the community might prevent participants from sharing very personal information during the interviews. Together, the research assistants and Jacklin developed a new approach to the interviews that provided greater comfort for participants when answering these questions, for instance, giving them the choice to write in their answers privately, and keeping identifying information in one envelope and sealing completed surveys in an unmarked envelope in front of participants. Research Assistants all signed an oath of confidentiality.

The research assistants were community members ranging in age from 19 to 40; two were fluent in the local Ojibwe dialect. During the research phase, they were able to speak to many of the issues facing the community. Hiring local research assistants to conduct surveys or interviews, *per se*, does not make research participatory (see Hagey, 1997; Pretty & Scoones, 1995). Involving community members, including their voices in the conception, implementation and analysis of research, does. Thus the expertise and local knowledge of the research assistants was incorporated throughout the research process and assistants became important members of the research team. For example, while the primary role of the research assistants was data collection, they were also involved in analyzing the data. Research assistants and Jacklin met frequently as a group to look at emerging themes. This gave the research assistants the opportunity to conduct the first layer of analysis for the project and enabled more in-depth investigation into those topics as the research progressed. The research assistant hired for data entry was also encouraged to discuss his perceptions that were forming as he entered the data. These preliminary community-based inputs helped to guide data analysis for the final report.

Gathering Voices

In working with the management team and staff at the Health Centre, it was decided that a random sample would be the best method to ensure that the voices in the health plan were representative of all age groups, both sexes, and all satellite villages. This method also ensured that those who did not normally have an opportunity to speak had a chance to be heard in the community health plan. Households were selected from the community's 911 emergency response list using a

random counting method. This list had been updated in 1999 and included all on-reserve households. Some community members who were not part of the sample wanted to complete an interview. In these cases Jacklin conducted the interviews. The information provided in these interviews tended to focus on service issues and was considered for planning and evaluation recommendations, but was not included in the main analysis. Key informant interviews were conducted with specialized informants such as health centre staff and managers working in various program areas, directors of community organizations and community informants holding local knowledge.

Interviewing

The random sample list was divided into four parts, one for each research assistant. They could then exchange participants among themselves if necessitated, for example, by language barriers, interviewing a family member, etc. Surveys were administered verbally to the participants and the research assistants recorded the answers on the surveys. Consent was sought at the level of the community through Health Board/Health Committee approval and subsequently by Chief and Council, and at the individual participant level. Participants were given an information page with project details, including the use of data outside the community e.g., for journal publications; their right not to participate, skip questions, withdraw; information on ethics review; communication of findings; and, on the reverse side, a list of local organizations that could be called if they became distressed. Each research assistant verbally reviewed the information with participants and then asked for verbal consent to participate.⁸ The information page was left with the participant. Research assistants gave a five-dollar gift for participation and a separate information page for those who wished to participate further. The research assistants kept notes on each interview to help Jacklin better understand the data. The notes were manually coded by theme and analyzed in a numeric database (Microsoft Access 2000).

In the end, 350 band members 18 years or older were surveyed. This represents 20% of the on-reserve population within that age range and 45% of households. We sought to interview as many band members as time and money permitted. Some complicating factors included: (1) the length of the interview (ranging from one to three hours depending on the individual), (2) interviewing during the summer when community members are often away or busy with community activities such as the powwow, and (3) the number of other surveys

experienced by the community that year. Despite these difficulties, research assistants' notes showed only six refusals to participate. Reasons given for the refusals included: do not use community services ($n = 3$), do not like surveys ($n = 1$), too many surveys lately ($n = 2$).

From Participant Observer to Advocate

An anthropological approach to participant observation was used during this research. This involved a lengthy fieldwork period, immersion in the fieldwork setting, participation in community life, and removal from the research site daily to reflect on the knowledge gained (Bernard, 1988). Jacklin conducted two years of participant observation during this research. Treated as a staff member at the WHC, she attended staff meetings, was given office space at the Health Centre, attended monthly Community Services Members meetings, conducted informal interviewing with staff, and participated in program observation. She also attended staff training sessions where staff often spoke about particular problems they experienced in service delivery, and was invited to participate in policy discussions between local governance and First Nations and Inuit Health Branch (FNIHB). This traditional anthropological approach of "taking up residence" allowed for continuous communication, trust and relationship development, advocacy, and a flexible and responsive research approach.

Dissemination

A community concern expressed from the onset was the lack of use of past research results in the community; therefore, producing knowledge for use became a key goal for the research. Data entry and data analysis took several months after completion of the final interviews, and report writing more time again. There was, however, a need to get the information back to participants in a timely manner and a need for the data to be available for the Health Centre to use for funding proposals. Therefore, Jacklin conducted a preliminary data analysis, doing simple tabulations to provide an overview of the results. Preliminary results were tabulated at 100 and 200 survey entries. The preliminary results were presented in a newsletter format and distributed by mail to all 350 participants. Research briefs on selected topics were presented to Health Centre management on various topics upon request; for example, a preliminary report on environmental health was prepared so that the data could be used in a proposal for program funding.

We also used community bulletin boards to present posters on various health topics based on the survey,

e.g., one month the results on tobacco use were displayed along with health promotion information on smoking. Every two months the display was changed until all of the topic areas had been covered. In some cases the themes were coordinated with the monthly health promotion activities of the health centre staff; for example, nutrition results were presented during nutrition month. The bulletin boards were displayed in the health centre; however, in one case another agency borrowed the display for their own centre. While getting the information back to the community members was a priority, it was also very important to get the information to the service providers and those in positions of authority. It was hoped that directors of organizations in the community as well as local politicians would use the results for strategic planning, funding proposals, and community development. In order to build awareness of the results as well as the availability of data, Jacklin presented the results in the community. Presentations were made to the Wikwemikong Health Services Committee, the Community Services Members Meeting, and a public Chief and Council meeting. Each presentation was tailored to the audience to maximize the effectiveness of the information dissemination; that is, beyond the overview of the research and results, presentations focused on things that the agency or organization had the authority to work on.

Discussion

Those in the field of Aboriginal health research have a responsibility to respond to ethical and methodological concerns over the research process in Aboriginal communities. The research with the Wikwemikong Unceded Indian Reserve has attempted to meet those concerns by placing the research within the CMA and community-centred praxis (action) frameworks and employing principles of PAR and the Indigenous teachings. What emerged from this approach was a set of eight principles that, upon reflection, stood out as necessary elements for a successful research partnership with the Wikwemikong Unceded Indian Reserve (Table 1). It is recognized that every community will have unique research needs and expectations, and that these needs and expectations will develop and change over time (i.e., they will be culturally and community specific). While this description is intended to aid other researchers who work with Aboriginal communities, it is not proposed as a model to be followed step-by-step. Rather, it advocates that research with Aboriginal people and communities be founded in the eight principles so that an appropriate model will emerge from the process.

Figure 1 illustrates the research model that emerged in Wikwemikong. The eight principles as laid out apply to the entire research process. They can be viewed as both inputs and outcomes; that is, they are brought into the process (invested) at the start and used throughout, and they are strengthened as a result of the research. In this model, as the research process proceeds through planning, implementation, knowledge production, and action, and the participants cycle through engagement, capacity building, empowerment, and self-determination in research, these personal attributes are strengthened each time the process occurs.

The model is displayed in a circle to symbolize that (1) the model is wholistic; all are connected and dependent on each other; and (2) the progression is cyclical; there is continuity.

Participation. Community participation and research partnerships cannot be taken as a given when initiating research with Aboriginal peoples. One must consider that imposition of a PAR project on a community when it is neither wanted nor necessary is just as colonizing a process as is traditional research. Chrisman, Strickland, Powell, Squeochs and Yallup (1999) note that community *participation* is variable and depends on the group one is working with. A community may not want money to be spent on long-term participatory research; they may feel that there are other priorities in the community such as more immediate solutions to health problems. Ornelas (1997) found, in his work on a PAR project concerning hospital-community relations in Honduras, that health was not a priority for the community; the people had difficulty seeing the value in health research when life to them had little value. In another case of PAR that involved forestry management in Nepal, the community did not want to take control over the resources; they wanted collaboration with the state forestry department and nothing more (Gronow, 1995). Singer (1993) refers to an incident during a PAR project where local health workers, who felt they represented the needs of the community, perceived more research on the problem as a delay in solving an already identified social problem. Therefore, the degree of participation that occurs will vary depending on the community, organization, and researcher. A research foundation built on the eight principles highlighted here can determine the level of participation (if any) that a community wants or needs at that time.

The model that evolved in Wikwemikong was an academic-community partnership. In this case, Jacklin became the research coordinator, Kinoshameg the lead contact, and community workers (Health Centre managers, and research assistants) worked with us to form

TABLE 1. Eight Principles of Appropriate Community-Based Participatory Research.

Principles	Research Philosophy	Specifics
PARTNERSHIP	Local involvement and participation in planning and implementation	The project should be conceived by the community. The methodology should include mechanisms for community representatives to participate in the research design, process and outcomes. Communication should be continuous through the process.
EMPOWERMENT	Research as a process that enhances community empowerment and moves towards self-determination	The project incorporates and values local knowledge and experience. The project meets the political/policy needs of the community. Community participation guides the research process. Capacity is developed in the community.
COMMUNITY CONTROL	Community maintains ownerships and control of research process and outcomes	The tools developed, the results, and the planning belong to the community, not the researcher. There is a process for the community to review, comment on, and approve the tools, methods, findings, reports, publications, etc.
MUTUAL BENEFIT	Working in partnership with and for the community for a mutually beneficial outcome	There are tangible benefits for the community. Process allows for skills and knowledge transfer. Academic outcomes (dissertations, publications, presentations) reflect community needs.
WHOLISM	Use and production of wholistic knowledge	Value is placed on all forms of knowing: spiritual, cultural, local, and academic. Knowledge transfer is two-way. Local knowledge is respected.
ACTION	Knowledge produced is used for action	Wholistic knowledge to be used for action is the result. Cycle of knowledge to action is continuous.
COMMUNICATION	Commitment to communication, dissemination and knowledge translation of research and results	Local colleagues, participants, and community members are aware of the study, its progress, and the results. Data is readily available and accessible to community members. Knowledge produced is communicated to participants, community members, policy developers, government officials and academics.
RESPECT	Respect for local research philosophy and culture	A research philosophy that respects and is compatible with local teachings and culture is maintained. Local ethical standards are respected and adhered to.

the research team. The management team was the primary group involved in the research, made many of the decisions and provided advice and guidance. The Health Services Committee also participated in the research, e.g., project negotiation and survey design, and was required for formal approval of the research, the survey questions, and the final report. The Chief and Council had final authority over any decisions made by the Health Services Committee. The Community Services Members group and WHC staff also provided advice and guidance, albeit to a lesser extent. This is the model that emerged and met the needs of the community at the time. While all of these groups were eager to be involved and help with the research, it was not economically feasible for them to completely control or guide the process. The Health Centre underwent both administrative and governance

changes during the life of the research, and staff and especially managers were struggling to ensure that the Health Centre continued to function during these changes. Hence, it was unreasonable for the Health Centre to designate a committee or group to take charge of the research. Jacklin, then, became the research coordinator. Since there was no local mechanism for research approval and monitoring or ethics review, Jacklin had a high degree of involvement and control over the research. This could become a problem in situations where the researcher is not bound by a professional code of ethics or not required to obtain ethics approval from another source.

Communication and Dissemination. Dissemination was an ongoing, integral component of the research as opposed to a culminating stage. It was important to provide continuous updates and preliminary findings as

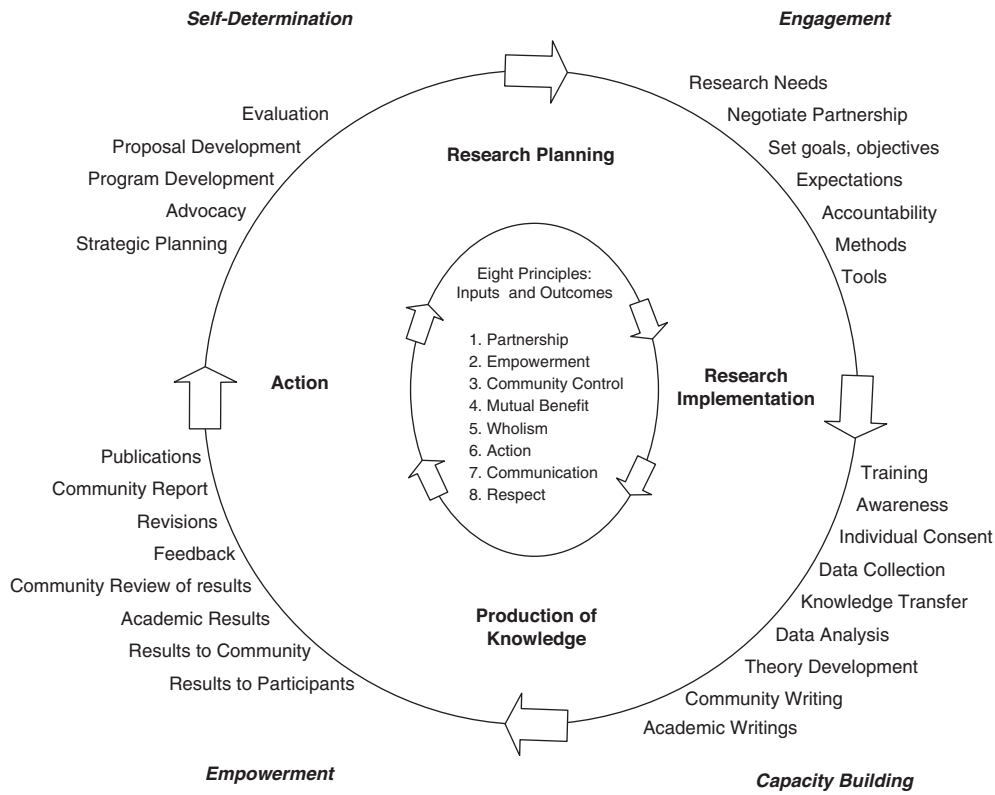


FIG. 1. Wikwemikong Community Needs Assessment Research Model.

they became available. This ongoing communication was greatly aided by the Health Centre’s willingness to accept the investigator as “staff” during the life of the research. Jacklin’s presence in the community allowed her to respond quickly to questions, concerns, and ideas regarding the research, and essentially to make the research more accessible to the community. Investment in the public awareness campaign proved highly successful as research assistants reported that participants would say “I was expecting you,” or “I was wondering when you were coming.” One research assistant later wrote that most participants anticipated their interview: “Most times I was told ‘I knew you were coming around,’ ‘I heard you were coming this way,’ ‘come on in and let’s get this over and done with’” (Mandamin, 2003).

Continual and forthright communication allowed for a high degree of flexibility in the research process. As most community-based researchers would admit (see Chrisman, Strickland, Powell, Squeochs, & Yallup, 1999; Elias & O’Neil, 2001), a great deal of what happens in research is not mapped out in proposals of study, but rather occurs in response to various situations as the study progresses.

Challenges to communication with governance occurred due to the extended time required for the research and a relatively fast turnover in health boards and chiefs and councils. During the research process we worked with three health authorities: the Health Board, replaced by the Standing Committee on Health, replaced by the Health Committee during the final months of community dissemination. This resulted in a committee of new members receiving the results from a study two other groups of community members had approved and managed. The same was true for the Chief and Council, who experienced one turnover during the research. While some band councilors remained on council and saw the project through, there was no continuity in the membership of the three health authorities. Kinoshameg, a strong advocate for the research, was instrumental in ensuring smooth transitions and relations with each of the new stakeholders.

Dissemination of the results to the community and participants in a relevant and acceptable format was noticed and appreciated by community members. It also provided an opportunity for community members to challenge and confirm the results. Although it was not labeled *knowledge translation* at the time, our research

methods had built in a knowledge translation (KT) plan and prioritized dissemination of the results to the community. Knowledge translation, as a concept applied to Aboriginal health research, came about in 2004 when the Canadian Institute of Health Research (CIHR) provided funding for developmental work on the topic. This development has been highly compatible with the PAR philosophy. Academic publications are valued by the community, and this particular publication has been requested; specifically, community members felt it important for other researchers and other Aboriginal communities to be aware of the process used in Wikwemikong.

Building Research Capacity. One of the most challenging aspects of the eight principles was transfer of skills relating to capacity building. The only outsider in this research was the principal investigator. All research assistants were post-secondary students from the band membership. Research assistants were selected based on their interests in the health or social sciences. Extensive training was provided and communication with Jacklin occurred daily. Weekly progress meetings indicated that skills transfer between Jacklin and the research assistants was successful. Research assistants were trained in technical and conceptual research skills. However, most of these band members are not currently employed in positions where their research skills can be put to use in the community, and in fact, some are no longer working or living in the community. This represents a loss of both technical and conceptual skills.

Likewise, the assistant who was trained to run the database program has also become employed elsewhere. This situation has created a dependency on the investigator for data retrieval. Part of the difficulty stems from a lack of community resources to have a formal research position or department within the community or organization to ensure consistency. In hindsight, it would have been desirable to include the program managers, or regular health centre staff, in the training process. This situation could not be rectified without organizational and political commitment to building research capacity in the community, which would include the approval of work plans that incorporate research training, and funding allocated to research positions. As a result of a reorganization at the WHC in 2005 Kinoshameg was moved into a newly created research position. She also became internationally recognized for her knowledge of Aboriginal research ethics. The creation of the research position at the WHC demonstrates the commitment of the organization to research.

Another example of capacity building occurred when the Health Centre management set a goal to conduct a youth needs assessment similar to the community needs assessment research. The Health Centre management took a much higher degree of control over this research process and the Youth Services Program Coordinator worked hard to ensure that a greater degree of skills transfer occurred during this research (Jacklin, 2002). This has been followed by two externally-funded diabetes research projects (2005–2007 and 2007–current) emphasizing even more capacity building.

One of the most significant outcomes of the research was the professional aspirations that developed in one of the research assistants (Mandamin) as a result of working on the project. This research assistant went on to pursue a Master's degree in Social Work. She wrote in her admission plan of study that the impetus for her interest and application was her involvement with the CHP research and specifically the opportunity it provided her with to better understand the needs of Elders. In speaking with Mandamin she has expressed an interest in continuing towards a Ph.D. and coming back to the community with her research skills (personal communication, March 31, 2003).

Community Ownership and Control. Many researchers are wary of sharing or giving up control over "their" research. Participatory work requires researchers to make a leap of faith such as we have often asked communities to have in us. Potvin, Cargo, McComber, Delormier, & MacCaulay (2003) write that "Researchers often fear that equal partnerships with communities are equivalent to abandoning their freedom of defining the object of their enquiries." However, this has not been our experience. When the research process is shared and partnerships become more equal, it opens the way for knowledge and skills exchange. Researchers' work is enriched rather than restricted by sharing or giving up power and control over the research process. By placing value on local knowledge, academic researchers become open to other ways of knowing, other ways of doing, and as a result are involved in the production of knowledge that is unique (see Ornelas, 1997; Ross, 1989).

However, issues of scientific control became salient as the final dissertation was produced and defended (Jacklin, 2007). Concerns were expressed by academic committee members that not submitting the data to statistical testing potentially misleads the reader by presenting associations that would not be valid when tested with statistical models. However, participatory researchers have found that communities may view expert-driven

methods as coming with the risk of loss of control over determining what has legitimacy and validity, and ultimately the danger of "outsiders controlling what constitutes reality for other people" (Christians, 2005). It has been argued by Aboriginal peoples and communities that a method considered to have "scientific excellence" is essentially an academic "self-serving barrier that keeps control and resources where they are" (Schnarch, 2004). As a result, the position ultimately taken is that community control and empowerment are necessary for healing and that in order for empowerment to occur colonization must end. A de-colonized approach to the research, therefore, is an essential part of the process, and a high regard was given to local and Indigenous knowledge and ways of knowing. Methods that placed power with those external to the community were negotiated and used sparingly. We advocate, for example, that the reporting of frequencies and descriptive statistics, rather than advanced statistical analysis, when coupled with qualitative data and participatory methods, provide valid and reliable data and serve an important role in the community-based and academic understandings of health status and conditions. This position allows for the opportunity to present and discuss quantitative findings in a way that can be understood, debated or confirmed by the community without compromising respect for the legitimacy of local and Indigenous knowledge or perpetuating academic hegemony in Aboriginal research (see O'Neil, 1993; Smith, 1999).

Knowledge for Use. Knowledge for use was an expressed goal of the research, but it is also something over which the investigator has little control. As Lee (1999) writes: "action should be in the hands of the people . . . people taking responsibility, or putting their new-found skills and confidence into action." From the outset, it was hoped that the participatory nature of the research would facilitate the transition from knowledge to action. It was always known that, at the very least, the needs assessment report would be used to fulfill the CHP update requirement of Wikwemikong's Health Transfer Agreement. The degree to which it was known about and used beyond this purpose is one measure of the effectiveness of the participatory research process.

We were pleased that use of the data began before the data analysis was even complete. Requests for information from the needs assessment were made from the Recreation Committee, the Environmental Health program manager, the Health Director, the Wellness Program, the Mental Health program, and one external health organization, as soon as the interviewing process was complete. Most of these requests were for data to

support funding proposals, although in some cases the requests were for information regarding program planning decisions. Once the presentations were made in the community, and following the completion of the final report, more requests for the data came in from other community organizations. Significantly, the Health Director requested a strategic planning session be held with the program managers of the Health Centre to address the findings and recommendations from the needs assessment report. This session resulted in the creation of 13 strategic goals, each with several objectives. It was decided by the Health Director and management that every six months they would meet to evaluate their progress on each of the goals. More recently, the Health Centre held a strategic planning retreat with all staff members where the goals were reviewed and evaluated again.

Conclusion

It is important that, as the terms *participatory* and *community-based research* become common key words in research and funding proposals for Aboriginal research, the underlying principles and spirit of these methods are not lost in their application. Equally important is the avoidance of the temptation to view participatory research as a panacea for research with Aboriginal peoples. Each community is unique in its research needs and wants.

Today we require a new approach to Aboriginal research (Hedican, 1997; Warry, 1992). This area of investigation requires a dual production of knowledge for use: academic knowledge and community or local knowledge, as well as recognition that research is *research for action*.

Aboriginal peoples are taking responsibility for the research process in their communities; now researchers must take responsibility for what was done in the past, what is being done today, and what future generations of researchers will do.

Best Practices

Researchers working with Aboriginal communities must have a deep commitment to participatory research. This means that researchers' greatest concern and their motivation for the research are the betterment of community well-being through empowerment. Consequently, the researcher must unlearn the expert role they have been entrenched in throughout their university and professional careers and be prepared to take the time to listen, learn and take direction from the

community. The researcher also must be prepared to vigorously advocate for the legitimacy of knowledge produced from PAR and CBR under the scrutiny of academic colleagues.

First impressions are important. The researcher must begin the process with an understanding of local culture, history, and politics. Understanding history and in particular historical relationships with one's own culture are important preparation for concerns and criticisms the researcher may encounter. A formal introduction to the community leadership and presentations of ideas followed by participatory discussions will be appreciated. Persistence, patience and understanding are qualities that the researcher may need. After eight years of working with the community we still begin each project defensive to criticisms concerning the history of research in the community.

Working with pre-established committees or creating local research advisory boards is an effective mechanism for ensuring the research questions, methods and dissemination are community driven.

Useful strategies include: capacity building, participation of staff, community members, and leadership in the design, delivery, and analysis of the research; advertising the project widely and offering the opportunity for feedback and questions; hiring, training, and valuing local researchers as partners in the process; accepting local knowledge and guidance concerning the research even when it contravenes conventional scientific standards; embracing critical theory and embedding advocacy into the research framework; and implementing a dissemination plan that includes knowledge translation to the community first followed by policy makers, government, and the scientific community.

Research Agenda

Because PAR incorporates a critical theory approach that necessarily challenges mainstream practices and values, it is highly susceptible to criticism. Consequently, we urge researchers to describe and demonstrate the legitimacy of their findings by documenting their methods of validation and by writing about the foundations of their methods. Without explicit reporting on what researchers consider *participatory* in their research, it is often difficult to establish the degree to which published studies adhere to the principles of PAR or the degree to which they engage primarily the methods associated with PAR. This in turn makes it difficult to ascertain whether the degree of PAR expressed in the findings resulted from decisions made by the community versus investigator-driven decisions. It also makes

any critical evaluation of PAR exceedingly difficult. We encourage journal editors and researchers to consider making space for more detailed and descriptive articles focused on theory and method.

Educational Implications

A key challenge in accomplishing political action based on PAR findings from Aboriginal health research has been dealing with societal perceptions of Aboriginal peoples in Canada and specifically a preponderance of mainstream neo-conservative values and beliefs which are expressed by the elected leadership (see Warry, 2007). These mainstream values reflect ignorance of the history of relations between Aboriginal and non-Aboriginal peoples in North America. Basic education in primary and secondary school must address this issue. At the post-secondary level, the values of PAR and community-based research are best taught within an historical framework rather than in a simple methods-based approach. This historical framework ensures that researchers understand *why* PAR is an appropriate method for research on vulnerable populations and helps to avoid the potential mis-application of the methods of PAR to improve basic research outcomes (for example, improving response rates or gaining permission to conduct research) rather than applying PAR as an approach to facilitate community healing.

Acknowledgments

Chi Miigwitch to all the individuals and organizations in Wikwemikong who lent their time and expertise to the Community Health Plan research project. A special thanks to the Wikwemikong Health Centre management and staff, and Health Board and Committee members for their participation and support, and to the research assistants: Agnes Mandamin, Grant Peltier, Lorraine Toulouse, Melissa Peltier, and Robbie Shawana for their high standard of work and dedication.

This research was supported by the Social Sciences and Humanities Research Council of Canada (award #752-99-1273) and by the School of Graduate Studies at McMaster University, and received ethics approval by McMaster University Research Ethics Board and the Wikwemikong Standing Committee on Health.

Author's Note

Address correspondence to: Kristen Jacklin, Human Sciences Division, Northern Ontario School of Medicine, 935 Ramsey Lk. Rd, Sudbury, ON, P3E

2C6. Phone: 705-662-7277; Fax: 705-675-4883, E-MAIL: kristen.jacklin@normed.ca.

Authors' Biographical Sketches

Kristen Jacklin, Ph.D. is a Medical Anthropologist and Assistant Professor at the Northern Ontario School of Medicine. Kristen has been involved in Aboriginal community health research for 10 years and is currently engaged in a variety of community-based participatory projects including research on diabetes, mental health, and HPV vaccination in First Nations. Kristen is the primary author of the paper and was the principal investigator for the research.

Phyllis Kinoshameg, B.A., has more than two decades of experience in applied research. Phyllis worked on various community-based health research projects for the WHC and the Manitoulin Aboriginal Research Review Committee (MARRC). In 2004 Phyllis was appointed to the Aboriginal Ethics Working Group (AEWG), an advisory body to the Canadian Institutes of Health Research (CIHR). Phyllis is a band member of Wikwemikong Unceded Indian Reserve, Ontario, Canada.

Endnotes

¹Health Transfer is a National program funded by the First Nations and Inuit Health Branch of Health Canada that allows the transfer of administrative funding for health services from the government to the local communities. Transfer is a lengthy process with many mechanisms for accountability, reporting, and evaluation built into the process.

²Critical theory originated with the Frankfurt School (Max Horkheimer, Theodor Adorno, Herbert Marcuse, and Jürgen Habermas). It provides a basis for social inquiry aimed at reducing domination and increasing freedom. Contrasted with positivist traditions, critical theory is normative, that is, value-laden. Those applying critical theory seek human emancipation—liberation, political rights, and equity for disenfranchised populations. In practice, critical theory seeks to understand and explain deficits with the current social situation by empowering those affected to analyze, theorize, and act to change it. Its evolution has been such that today any philosophical approach with similar practical aims could be called critical theory—including feminism and post-colonial research (Kincheloe & McLaren, 2005).

The critical medical anthropology framework was developed by Singer and Baer (1995). Drawing on the writings of critical theorists from the Frankfurt School, the CMA approach to the study of health and medicine

operates on "the belief that social inequality and power are the primary determinants of health and health care" (Baer, Singer, & Susser, 1997:3). It advocates a praxis approach that seeks to both study and change "culturally inappropriate, oppressive and exploitive patterns in the health arena and beyond" (Singer & Baer, 1995:60). Its authors point out that ". . . through their theoretical and applied work critical medical anthropologists strive to contribute to the larger effort to create a new health system that will 'serve the people'" (Baer, Singer, & Susser 1997:33). Critical medical anthropology was deemed appropriate for research concerning First Nations people and communities because it is widely accepted that both past and present policies of the federal government of Canada have disadvantaged and marginalized this population (RCAP, 1996). CMA provides a framework to analyze and understand health from a political economic vantage point; four main levels of analysis are provided: (1) the macro-social, described as capitalist world systems and the global hegemony of biomedicine; (2) the intermediate-social, described as "institutions" concerned with health or health policy; (3) the micro-social, defined as doctor-patient interactions; and (4) the individual, who is the patient (Singer & Baer, 1995; Baer, Singer, & Susser 1997).

³Although CMA and other academic references use "holistic" rather than "wholistic" in writing about this concept, we follow the advice of Wikwemikong community members in adopting the "wholistic" spelling. Although literally "holism" comes from the Greek root "holo" for "all," "entire," "total," we found locally that it is the English language differentiation between "whole" and "hole" that leads Aboriginal people to view the use of "hol(e)" as inappropriate when applied to the concept of wholism.

⁴Common use of the word *praxis* is sometimes synonymous with "action" or "practice." Use of the term *praxis* in relation to community-based and participatory research, however, is more complex. *Praxis* implies "ethical action" aimed at empowering people to become liberated from everyday hegemony. *Praxis* can be achieved through a process by which theory (local/community-based and academic) and practice intersect and interact to foster empowerment and action (Warry, 1992).

⁵The community health plan (CHP) is a document required by the First Nations and Inuit Health Branch of Health Canada (FNIHB) for all communities with health transfer agreements to deliver health services (Health and Welfare Canada, 1992).

⁶The Wikwemikong Health Centre Management Team was created following the resignation of the Health Director in 2000. The team was comprised at the time of the Executive Assistant (Phyllis Kinoshameg),

Office Manager, Environmental Health Coordinator, and the Wikwemikong Unceded Indian Reserve Director of Operations. Later in the research process, a new Health Director was hired.

⁷This is a monthly meeting of representatives from all local social and health related agencies and organizations providing services on the reserve.

⁸We found that written consent was not appropriate for residents in Wikwemikong at the time of this project.

Community-based research partners advised that this is related to the culture having an oral tradition based on a moral, or cultural, code known as the Seven Grandfather Teachings; it is also based on the great mistrust surrounding the signature process that has arisen from historical relationship between colonial powers and Aboriginal peoples, especially the Treaty-making process. As a result, we asked participants for verbal consent and recorded the time, date, and location the consent was given.

References

- BAER, H. A., SINGER, M., & SUSSER, I. (1997). *Medical Anthropology and the World System: A Critical Perspective*. Westport: Bergin & Garvey.
- BERARDI, G. (1998). Application of participatory rural appraisal in Alaska. *Human Organization*, 57(4), 438–446.
- BERNARD, H. R. (1998). *Research Methods in Cultural Anthropology*. Newbury Park, CA: Sage Publications.
- BERNARD, H. R. (2006). *Research Methods in Anthropology: Qualitative and Quantitative Approaches, Fourth Edition*. Lanham, Maryland: AltaMira Press.
- Canadian Institute of Health Research [CIHR]. (2007). CIHR Guidelines for Health Research Involving Aboriginal Peoples. Prepared by CIHR Ethics Office. Retrieved March 22, 2007 from <http://www.cihr-irsc.gc.ca/e/29134.html>.
- CHRISMAN, N. J., STRICKLAND, C. J., POWELL, K., SQUEOCHS, M. D., & YALLUP, M. (1999). Community partnerships research with the Yakama Indian Nation. *Human Organization*, 58(2), 134–141.
- CHRISTIANS, C. G. (2005). Ethics and Politics in Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research, Third Edition* (pp. 139–164). Thousand Oaks: Sage Publications Inc.
- ELIAS, B. & O'NEIL, J. (2001). *Building Capacity in Applied Population Health Research*. Manitoba, Canada: Centre for Aboriginal Health Research.
- ERVIN, A. M. (2000). *Applied Anthropology: Tools and Perspectives for Contemporary Practice*. Boston: Allyn and Bacon.
- First Nations and Inuit Regional Health Survey [FNIRHS]. (1999). *First Nations and Inuit Regional Health Survey, National Report*. Published by the First Nations and Inuit Regional Health Survey National Steering Committee.
- FLERAS, A. & ELLIOT, J. L. (1992). *Aboriginal-State Relations in Canada, the United States, and New Zealand*. Toronto: Oxford University Press.
- FREIRE, P. (1970). *Pedagogy of the Oppressed*. New York: Continuum Publishing Co.
- GRONOW, J. (1995). Shifting Power, Sharing Power: Issues from User-Group Forestry in Nepal. In N. Nelson & S. Wright (Eds.), *Power and Participatory Development: Theory and Practice* (pp. 125–132). London: Intermediate Technology Publications.
- HAGEY, R. S. (1997). The use and abuse of participatory action research. *Chronic Diseases in Canada*, 18(1). Retrieved October 12, 2007 from http://www.phac-aspc.gc.ca/publicat/cdic-mcc/18-1/a_e.html.
- HALLOWELL, A. I. (1955). *Culture and Experience*. Philadelphia: University of Pennsylvania Press.
- Health Canada. (1999). *Toward a Healthy Future: Second Report on the Health of Canadians*. The Federal, Provincial and Territorial Advisory Committee on Population Health. Ottawa: Minister of Supply and Services Canada.
- Health Canada. (1999a). *Statistical Report on the Health of Canadians*. The Federal, Provincial and Territorial Advisory Committee on Population Health. Ottawa: Minister of Supply and Services Canada.
- Health and Welfare Canada. (1992). *Transfer* (Health Transfer Handbook). Ottawa: Health and Welfare Canada.
- HEDICAN, E. (1997). *Applied Anthropology in Canada: Understanding Aboriginal Issues*. Toronto: University of Toronto Press.
- JACKLIN, K. (2002). *Wikwemikong Youth Needs Assessment Report*. Prepared for the Waasa Naabin Community Youth Services Centre (Community Report held at the Wikwemikong Health Centre). Wikwemikong, Ontario, Canada.
- JACKLIN, K. (2007). *Strength in Adversity: Community Health and Healing In Wikwemikong*. Doctoral Dissertation. Department of Anthropology, McMaster University, Hamilton, Ontario, Canada.
- JACKLIN, K. & WARRY, W. (2000). *Wikwemikong Unceded First Nation Health Transfer Evaluation Report*. Prepared for the Wikwemikong Health Board (Community Report held at the Wikwemikong Health Centre). Wikwemikong, Ontario, Canada.
- JENNESS, D. (1935). *The Ojibwa Indians of Parry Island, Their Social and Religious Life*. Bulletin No. 78, Anthropological Series No. 17. Ottawa: National Museum of Canada.

- KINCHELOE, J. L. & MCLERAN, P. (2005). Rethinking Critical Theory and Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research, Third Edition* (pp. 303–342). Thousand Oaks: Sage Publications.
- LANDES, R. (1937). *The Ojibwa of Canada*. In M. Mead (Ed.), *Cooperation and Competition Among Primitive Peoples* (pp. 87–127). New York: McGraw-Hill.
- LEE, B. (1999). *Pragmatics of Community Organization*. Mississauga, Ontario: Common Act Press.
- MANDAMIN, A. (2003). *Being a Native Researcher in Your Own Community*. Paper presented at the First Annual Native Social Work Conference: Articulating Aboriginal Paradigms: Implications for Aboriginal Social Work Practice. Sudbury, Ontario, Canada.
- NELSON, N. & WRIGHT, S. (1995). Participation and Power. In N. Nelson & S. Wright (Eds.), *Power and Participatory Development: Theory and Practice* (pp. 1–18). London: Intermediate Technology Publications.
- Noojmwon Teg Health Centre. (2003). Guidelines for Ethical Aboriginal Research (GEAR): A resource manual for the development of ethical and culturally appropriate community-based ethical research within the First Nations communities in the Manitoulin area. Retrieved October 17, 2007 from <http://www.noojmwon-teg.ca/default5.aspx?l=,1,613>.
- O'NEIL, J. D., KAUFERT, J. M., KAUFERT, P. L., & KOOLAGE, W. W. (1993). Political Considerations in Health Related Participatory Research in Northern Canada. In N. Dyck & J. B. Waldram (Eds.), *Anthropology, Public Policy, and Native Peoples in Canada* (pp. 215–232). Montreal and Toronto: McGill-Queen's University Press.
- O'NEIL, J. D., READING, J. R., & LEADER, R. (1998). Changing the relations of surveillance: The development of a discourse of resistance in Aboriginal epidemiology. *Human Organization*, 57(2), 230–237.
- ORNELAS, A. (1997). Pasantias and Social Participation: Participatory Action-Research as a Way of Life. In S. E. Smith, D. G. Willms, & N. A. Johnson (Eds.), *Nurtured by Knowledge: Learning to Do Participatory Action-Research* (pp. 138–172). New York: The Apex Press.
- POTVIN, L., CARGO, M., MCCOMBER, A. M., DELORMIER, T., & MACCAULAY, A. C. (2003). Implementing participatory intervention and research in communities: Lessons from the Kahnawake Schools diabetes prevention program in Canada. *Social Science and Medicine*, 56(2003), 1295–1305.
- PRETTY, J. N. & SCOONES, I. (1995). Institutionalizing Adaptive Planning and Local Level Concerns: Looking to the Future. In N. Nelson & S. Wright (Eds.), *Power and Participatory Development: Theory and Practice* (pp. 157–169). London: Intermediate Technology Publications.
- ROSS, A. (1989). *We Are All Related*. Denver: Wiconi Waste.
- Royal Commission on Aboriginal People. (1996). *Volume 3: Health and Healing*. Ottawa: Supply and Services Canada.
- RYAN, J. & ROBINSON, M.P. (1990). Implementing participatory action research in the Canadian North: A case study of the Gwich'in Language and Cultural Project. *Culture*, 10(2), 57–71.
- SCHELL, L. M. & TARBELL, A. M. (1998). A partnership study of PCBs and the health of Mohawk youth: Lessons from our past and guidelines for our future. *Environmental Health Perspectives*, 106(3), 833–840.
- SCHNARCH, B. (2004). Ownership, Control, Access, and Possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Journal of Aboriginal Health*, January, 80–95.
- SINGER, M. (1993). Knowledge for use: Anthropology and community centered substance abuse research. *Social Science and Medicine*, 37(1), 15–25.
- SINGER, M. (1994). Community-centred praxis: Toward an alternative non-dominant applied anthropology. *Human Organization*, 53(4), 336–344.
- SINGER, M. & BAER, H. (1995). *Critical Medical Anthropology*. Amityville, NY: Baywood Publishing Company, Inc.
- SMITH, L. T. (1999). *Decolonizing Methodologies: Research and Indigenous Peoples*. London and New York: Zed Books Ltd.
- SMITH, S. E. (1997a). Deepening Participatory Action-Research. In S. E. Smith, D. G. Willms, & N. A. Johnson (Eds.) *Nurtured by Knowledge: Learning to Do Participatory Action-Research* (pp. 173–264). New York: The Apex Press.
- SMITH, S. E., WILLMS, D. G., & JOHNSON, N.A. (EDS.) (1997). *Nurtured by Knowledge: Learning to Do Participatory Action-Research*. New York: The Apex Press.
- SPECK, F. G. (1915). The family hunting band as the basis of Algonkian social organization. *American Anthropologist*, 17, 289–305.
- WARRY, W. (1992). The eleventh thesis: Applied anthropology as praxis. *Human Organization*, 51(2), 155–163.
- WARRY, W. (2007). *Ending Denial: Understanding Aboriginal Issues*. Peterborough: Broadview Press.
- Wikwemikong Community Health Plan (1989). (Unpublished community report held at the Wikwemikong Health Centre). Wikwemikong, Ontario, Canada.
- Wikwemikong Community Health Plan (1994). (Unpublished community report held at the Wikwemikong Health Centre). Wikwemikong, Ontario, Canada.
- Wikwemikong Community Health Plan (2001). (Unpublished community report held at the Wikwemikong Health Centre). Wikwemikong, Ontario, Canada.
- Wikwemikong Unceded Indian Reserve (WUIR). (2001). Band Office Indian Registration System. Total Population Statistics by Sex and Residence as of December 31, 2001. Wikwemikong, Ontario, Canada.

