

Community Research for Change e-Workbook



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Introduction

Community Research for Change talks about ways that research can help create positive changes in your community's health and wellbeing. Research is a deliberate, planned and organized way of gathering information. The knowledge that is created from research can help change a situation by increasing awareness and understanding of the issues. Certain types of research can also promote change by the way they are done, by bringing people together, empowering and building capacity, for example, community participatory research and Indigenous methods.

The history of traditional indigenous knowledge refers to the historical existence of traditional indigenous values and practices of an indigenous social group. The practices are tied to maintaining balance in life and living in harmony with all that surrounds us. Historically, traditional indigenous knowledge is not documented or recorded as it employs oral transmission of that knowledge to allow for its perpetuation. Traditional knowledge derives from numerous sources, the knowledge contained by these social groups does indeed stem from traditional, spiritual and empirical sources. No single nation/tribe possesses identical practices and or beliefs; however, the holistic paradigm itself recognizes the contributions of emotional, spiritual, mental and physical well-being, aspects that work in conjunction with language to create the direct link to traditional knowledge. Since the beginning of our history we have held traditions that are meant to be life teachings that encourage balance in life as well as respect for the earth in which we inhabit. This of course has been disrupted by the intrusion of Western paradigms that employ hierarchical and linear approaches, which have had immense negative impacts on the perpetuation of indigenous knowledge (Martin-Hill & Soucy, nd).

Purpose

The aim of this workbook is to help guide you in learning more about research for change, with questions and workspace for you to reflect on the information and relate it to your own community health and research needs. This workbook is intended for all First Nation communities, including urban and rural communities, on and off reserve communities, Friendship Centres, Aboriginal Health Centres and schools.

Community Change

'Community change' in this workbook is about change that improves health and the broad determinants of health such as poverty, maternal and early childhood care, self-determination, education and training, socio-economic status, language and culture, identity, personal and community wellness, residential schools, mental health,

Traditional Knowledge, housing, food security, chronic disease, infectious disease, addictions, and others.

There are many types of change that a community may want to initiate or support and a key ingredient in any change process is community **empowerment** which enables people to identify issues and take action to create change. Solutions must come from the people themselves. Laverack (2001) identifies several aspects of community empowerment:

- Participation
- Leadership
- Organizational structures
- Problem assessment
- Resource mobilization
- Asking 'why'
- Links with other people and organizations

Participation is a requirement of community empowerment. Participation is linked to leadership, as leaders need participants to support the work and participants need strong leaders to give vision and structure. Ladner (2009) writes that in order to enable community wellbeing the community leadership needs the capacity to respond to the "needs, priorities and aspirations of community" (p. 94). They need to empower the community and be champions for change. It is important to all meaningful input from grassroots people.

Laverack notes that it is important to include informal leaders as well as formally elected or appointed leaders. Informal leaders can include anyone who has a positive reputation in the community for example, elders, youth role models, working mothers, etc. Organizational structures (like committees, Elder groups, spiritual or youth groups) can enable empowerment by providing a sense of cohesion or connection to the community members; demonstrating concern for community issues, and providing community members with a sense of belonging. Assessing a problem together empowers people when community members are given all the information and resources they need to participate in an equal way and there is a culture created that supports people to critically assess or ask 'why' things are done the way they are. Creating partnerships with others in the community creates more hands or minds for the work and can provide further support and resources. Including different target groups gives a good cross-section of the community to represent various perspectives.

In considering research for change, communities may wish to:

- Raise awareness of health issues and notify leadership.
- Set priorities, make plans and allocate resources for the health sector according to the following:
 - Who is most affected?
 - What are the effects?
 - What are the needs?
 - How can we address this?
- Lobby for government funding or strengthen funding proposals.
- Design new health programs or interventions.
- Evaluate the performance of a health program or intervention.
- Change or modify existing health or community programs. If community resources are being put into a program that is not effective, research can provide evidence of this and support the community in taking a new direction. Asking what people want can provide evidence-based input to new directions or ways of doing existing programs, such as the need to:
 - Expand, downsize or cancel a program.
 - Increase or decrease the number of people attending a program.
 - Introduce a new healing or health approach to the community.
 - Increase community participation in planning how programs are run.
 - Learn or teach new skills.
 - Change policies.
 - Better understand the needs and preferences of program participants.
- Consider how the research might directly and indirectly impact the community in the short and long term. For example, does the community research address poverty reduction and institution-building? A community might also look at a particular group in the community that has a particular health concern to address health disparities, for example, among youth, elders or people who are HIV positive.
- Study communication processes to see how change happens or how conflicts are resolved.
- Research psychosocial programs designed to reduce health disparities and to support healthy development (Fisher & Ball, 2003).
- Ask community members about what changes and solutions are most needed.

Communities Taking Control

When key members of the community (for example, health planners, healers or any specific group affected by research) are involved in all stages of research, more people understand why a study is being done and it promotes community engagement. There is greater community ownership and more meaningful research conducted. People feel that they are a part of the solution and they are more likely to believe that the research will address their real issues. When all members of the community are included the whole community gains knowledge and understanding and takes responsibility for using that knowledge to create change and new solutions. Community members must feel 'ownership' of the research.

Historically, research in First Nation communities has been done by outside non-Aboriginal researchers, who held control of the process; did not necessarily study what was important to the community; interpreted the results without the appropriate cultural awareness, respect and sensitivity, and did not necessarily give back to the community (Castellano, 2004). Ownership, Control, Access and Possession (OCAP) are principles to ensure First Nations' full participation in appropriate and relevant research that is done in an ethical way, to develop community capacity and foster self-determination (NAHO, OCAP, 2007). These principles are particularly valuable when responding to external researchers to ensure that the research benefits the community and does not cause any undue harm.



The Kahnawá:ke Schools Diabetes Prevention Project developed a code of research ethics for community research with external researchers that are aligned with OCAP (Macaulay, Delormier, McComber, Cross, Potvin, Paradis, Kirby, Saad-Haddad, & Desrosiers, 1998). The First Nations Regional Longitudinal Health Survey (RHS) is an example of First Nations led regional and community partnerships in a national research project. This process was guided by the First Nations Information Governance Committee of the RHS and their own code of research ethics (Assembly of First Nations, 2007).

Some of the national Canadian organizations that fund research have developed ethical guidelines that require researchers to partner and collaborate with communities as part of their funding allocations. These guidelines for conducting research involving Aboriginal people require all funded researchers to consult with the community, give community members the opportunity to be involved in all stages of the research, ensure ongoing communication with the community, and support education and training to build research capacity in the community. Details can be found in the recently revised *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Interagency Advisory Panel on Research Ethics, December 2009), which applies to the

three federal research agencies in Canada: the Canadian Institutes of Health Research (CIHR), the Social Sciences and Humanities Research Council (SSHRC) and the Natural Sciences and Engineering Research Council (NSERC). Chapter 9 of this document is specifically devoted to Research Involving Aboriginal Peoples.

For more information on community control and ethics please see the following resources from the First Nations Centre:

[OCAP: Ownership, Control, Access and Possession](#) (2007).

[Considerations and Templates for Ethical Research Practices](#) (2007).

Types of Research

Research can be divided into two general types – quantitative or qualitative. Both types of research are important and valuable for different reasons and together they can provide a holistic approach. Quantitative provides the frame or skeleton, while qualitative provides the substance or details. In past, mainly quantitative research was used, but qualitative is becoming more common and it answers the questions ‘why’ and ‘how.’ For example, quantitative research can tell you how many people in your community have diabetes while qualitative research can tell you how diabetes has affected their life or what helps them manage.

Quantitative research tends to report information (results) in percentages which are based on large numbers of people, for example, the percentage of people who have certain behaviours, health conditions or beliefs. Information may be gathered from surveys or health administrative data which is routinely collected at a health centre. Surveys are often administered by phone or mailed out and usually every person is asked exactly the same questions with a set number and type of brief responses that the person selects from a questionnaire form. Quantitative information is valuable in planning programs and services, and monitoring trends or changes over time. For example, knowing the number of people in a particular age group can help plan services and a survey of needs can help inform decisions about the types of programs and strategies that are needed (Kenny, 2004).



Qualitative research opens the door to meaningful community participation. Qualitative research is more compatible with our traditional ways of resolving issues. Qualitative researchers ask general open questions and do a lot of listening. Study participants are invited to talk in depth about their experiences, thoughts or feelings. Research questions ask why something is happening or how an issue can be addressed. Information can be gathered through telephone or face-to-face meetings, either one-on-one with a researcher or in a group, for example, in focus groups (Patton, 2002) or

talking circles (Kenny, 2004). The information may be recorded and transcribed or detailed notes are taken about what was said, so it can be well understood. Depending on the interpretation (also called analysis) method, these notes are reviewed to identify similar and different themes. For example, in a study at the Battleford Tribal Council in Saskatchewan, researchers identified themes related to First Nations women’s perspectives of a healthy body – these themes highlighted the importance of Elder knowledge, family history and the role of women, and practical aspects of healthy food preparation (Poudrier & Kennedy, 2008).

Narrative research is a qualitative research method that uses stories to learn about and understand an issue or problem. Stories are very powerful ways that people share experiences and information and they can be told from one person to another or in a group setting. Being able to share a story can also be empowering and healing. If the story is told in a group then everyone in the group is a listener. Analysis or interpretation involves looking at themes that emerge from the content and the emotion of the story teller and as reflected upon by the listener(s). It creates interaction among participants which stimulates more thought and expression of ideas (Williams, Labonte & O’Brien, 2003).

What are some of the research projects that have been done in your community?

1. _____
2. _____
3. _____
4. _____
5. _____

For more information on types of research please see these resources from the First Nations Centre:

[Health Information, Research and Planning](#) (2009).

[Research Tool Kit](#) (2003).

Community Based Participatory Research (PR)

Participatory research (PR) is designed to be collaborative, to include community members in all stages of designing, developing and implementing the research as well as writing and disseminating the results. Participatory research is intended to support change because of the philosophy of empowerment and inclusion that it is based upon. Whether research is conducted solely by the community or with external researchers, a participatory model provides guidelines for including a broad range of community members, from youth to Elders, to be involved in the research process (NAHO, April 15, 2003). Participatory research is very compatible with the principles of Ownership,

Control, Access and Possession of data (NAHO, OCAP, 2007). There are many different types of research that communities can do in a collaborative way.

Community-based participatory research:

- Recognizes the community identity and traditions.
 - Includes the strengths and resources of the community.
 - Facilitates collaborative partnerships in all phases of the research.
 - Integrates knowledge and action for mutual benefit of all partners.
 - Promotes a co-learning and empowering process that attends to social inequalities.
 - Involves a cyclical and iterative process.
 - Addresses health from positive and ecological perspectives.
 - Disseminates findings and knowledge gained to all partners.
- (LaVeaux & Christopher, 2009).

Participation is more than just involvement. It is more active. Community participation means the community has the control or power to make decisions about how the research project is done. A community can participate in some or all aspects of the community research process. It is a choice. Generally the respective researcher and community roles depend on time and resource availability or constraints, and personal expertise and preferences.

Balance of power and shared learning are key aspects of Participatory Research. Traditionally, mainstream research assumed that the researcher was the expert. But PR views external researchers, community researchers and community members as each having expertise, which is shared in mutual respect and learning for the good of the community. Researchers share their expertise in research methods with the community. Community expertise in the issues and needs of the community, community culture and traditions, and personal experiences, is shared with the researchers (LaVeaux & Christopher, 2009; McHugh & Kowalski, 2009). Sometimes a problem will not be fully understood by a researcher. For example, an external researcher may think that an evaluation of health services is needed to address a health problem, but members of the community may want to study how the poor housing conditions are impacting health and what can be done about it. In the Aboriginal perspective, wholistic thinking is prominent – ‘if one part of our community is not working, it affects the whole.’

Creating a Participatory Research Team in Rural Saskatchewan

A study of healthy body weight and body image was initiated by Miwayawin Health Services (MHS) due to concerns about high rates and risk of diabetes in the community. The Director, Janice Kennedy, contacted the Indigenous Peoples’ Health Research Centre (IPHRC) (a partnership between First Nations University of Canada, the University of Regina and the University of Saskatchewan) to assist with the study. A community research facilitator of IPHRC then contacted Dr. Jennifer Poudrier, a Métis researcher from the University of Saskatchewan who worked with MHS. Together they built a research team that included community members from the Battleford Tribal Council regions, health centre staff and a Cree-speaking community-based research assistant. A sharing circle was used to collect data (Poudrier & Kennedy, 2008).

Participatory Action Research (PAR)

Participatory Action Research (PAR) is similar to Participatory Research (PR) but there are some important differences. In both approaches researchers work collaboratively with the people who are the focus of the research and the research is intended to create change to improve an issue but Participatory Action Research is different in that:

- There is an expectation that the people affected by the research will have more control.
- The research is done in order to take specific action. It involves both research and action.
- It tends to look at the structures and systems that impact people rather than specific behaviours and actions of the people themselves (Evans et. al., 2009).
- PAR recognizes the role of dominant structures, oppression and culture on health and wellbeing.
- It aims to challenge those dominant structures and the ways they may be inequitable or favour certain groups over others. There is a commitment to action and social justice, and to exposing and changing power relations (McTaggart, 1991).

PAR takes what is called a 'critical theory' approach which means it directly addresses political and social structures that can empower and oppress certain groups. Critical theory "accepts the facts of historical oppression from the onset, without the need to justify the historical context" (Kenny, 2004, p. 17). For example, rather than asking 'did the system fail them?' a critical theory or PAR study might ask 'how did the system fail them?' The assumption or common understanding is that it did fail in some way and this has already been established and does not need to be proven or discussed. As another example, if youth were having difficulty in school, the school might want to study the behaviour of students, while the students or a researcher using critical theory might want to study school policies and practices that discourage student participation or discriminate against certain students. This is one reason why collaboration with those who are being studied is so important, so the right questions get asked before the study is designed. The specific ideas or views about oppressive structures that are included in a research study will depend on the community.

In summary, Participatory Action Research:

- a) Takes place in the community and addresses real-life problems as identified by the community.
- b) Involves full collaboration between participants (as co-researchers) and researchers.
- c) Incorporates local knowledge and traditions.
- d) Honours that diverse experiences within a community provide an opportunity to enrich the research process.
- e) Involves a circular process. It involves thinking about and reflecting on the action that is needed, taking the action and then reflecting on the impacts of the action.
- f) Addresses systems or structures (organizations, processes) that impact people.
- g) Aims to change those structures or to create social transformation.

Participatory Action Research at an Urban High School in Saskatchewan

This study took place at Nutana Collegiate, Saskatoon, an urban high school with students from “dozens of Aboriginal communities.” Due to questions about how to define the community, researchers from the University of Alberta and the University of Saskatchewan first met with an Elder and then, on his advice, with a core group of students who would have a key role in defining the community. The core research group included young Aboriginal students who were interested in creating programs that addressed body image, such as a writing group and body talk. The primary researcher spent time at the school with the students – all day, five days a week for a full school year (McHugh & Kowalski, 2009).

Participatory action research is about change. Questions to ask the community include:
Does something need to change a little or a lot? Why?

Does it need to be altered or discarded and then created as new? How?

These two questions address what Tuck (2009) describes as the reform versus revolution paradox – the tension between two approaches to the theory of change. Revolutionary changes are usually quicker but may be unstable. Reform advocates for a more incremental change that is slower but more sustainable. The type of approach used depends on the type of problem being solved, the urgency and severity or impact. It is important to understand the change that is needed, wanted or envisioned by the community and to be aware of differences. When members of a community have different ideas about how things need to change there can be a lot of discomfort or conflict. Bringing this into the open is helpful.

Indigenous Frameworks and Methods

Indigenous methods include “research by and for Indigenous peoples, using techniques and methods drawn from the traditions of those peoples” (Evans, Hole, Berg, Hutchinson and Sookraj, 2009, p. 894). Participatory Action Research is compatible with Indigenous methods of research. Where PAR identifies structures and systems that oppress and aims to empower those who are oppressed by them, Indigenous methods identify the historical legacy of colonization (Martin-Hill & Soucy, nd) and the specific systems that require attention as dominant settler or Western systems (Evans et. al., 2009). Whereas in the past non-Aboriginal researchers have studied First Nations, in an Indigenous framework, First Nations may study the dominant colonizing Western structures, for example, to understand how they are impacted by them and how to obtain more equitable access to services or programs.



Fisher and Ball (2003) stress that it is important for participatory researchers to include community-specific cultural factors, acknowledge historical trauma and engage the community while protecting tribal interests. Research that acknowledges the historical framework has the greatest likelihood of producing lasting community change. These authors note that the practice of inclusion (collaboration) may be challenging in communities that are “subjected to oppression and discrimination”, and therefore, flexible approaches need to be used.

Tuck (2009) describes an Indigenous framework that can guide communities in their approach to resolving conflicts or tensions related to change. The framework presents four different perspectives – sovereignty, contention, balance and relationship.

Sovereignty is “a call for recognition and full realization of rights to social, cultural, and spiritual (tribal) identities and to our own envisioned political development” (2009, p. 56).

Contention is a process of “individual and collective self-education” and “openly and creatively [challenging] dominant assumptions” (p. 57) in an ethical way. It basically asks, how do you contend with the challenges, tensions or inequities?

Balance is appreciating that the community as a whole has the right balance of knowledge, responsibilities, vision or power, rather than focusing on homogeneity or an exact sameness for everyone. Another way to look at balance is listening to the voices from within as well as the voices from the community.

Relationship includes relationships between people, between ideas and with the earth. Tribal relationships between people begin with the idea of a

collective and then expand to “include, celebrate and support the diversity of its [individual] members” (p. 62). The Tribal Participatory Model (Fisher & Ball, 2003) includes:

Principles	Mechanisms
Tribal sovereignty	Tribal oversight
Tribal self-governance	Use of a facilitator
Tribal self-determination	Training and employing of community members as project staff
Tribal consultations	Use of culturally specific assessment and intervention methods

LaVeaux and Christopher (2009) made the following recommendations specific to Native American communities but they can guide both external and community researchers in successfully implementing participatory research with First Nations communities.

Have these been used in your community?

- Acknowledge historical experience with research and with health issues and work to overcome the negative image of research
- Recognize tribal sovereignty
- Differentiate between tribal and community membership
- Understand tribal diversity and its implications
- Plan for extended timelines
- Recognize key gatekeepers
- Prepare for leadership turnover
- Interpret data within the cultural context
- Utilize indigenous ways of knowing

Participatory Action Research with Indigenous Methods in British Columbia

‘Barriers and Opportunities for Health and Social Service Delivery to the Urban Aboriginal Communities for the Okanogan Valley’ is a PAR project that aims to understand the challenges of urban Aboriginal people “trying to use mainstream institutions” (Evans et. al., 2009, p. 901) and how and why the Friendship Centres in the area mediate service delivery. The research collective wanted to know the elements of mainstream social and health service delivery that “drive Aboriginal people to the margins” (p. 902). When the researchers met they used talking circles to facilitate equal opportunities for sharing and speaking among all members of the group. When the researchers met with the study participants, they used a traditional community research process that was locally developed and is specific to the traditional territory, called En’owkinwixw, as a way to facilitate “action-oriented” consensus.

How Does Research Create Change?

Participatory Action Research and Indigenous Methods of research create change by building community capacity, making the research more meaningful, promoting empowerment, and generally supporting self determination.

Building community capacity: Communities gain skills, new knowledge and experience from participating in and working together on a research study. Community capacity should increase with each research project in which the community is involved. Researchers can contribute directly to the community in ways that extend beyond the research in appreciation of their partnership. For example, McHugh & Kowalski (2009) offered free yoga classes, grant writing expertise, and support to obtain funding. These authors note that strong relationships are key factors in the success of PAR projects. See the table below called 'What Kinds of Training Does the Community Need?' for more details.

Creating credible, meaningful valid research: When community members are involved in the research process it improves the research because the focus is aligned with the real community issues, the questions are more relevant, there is greater comfort with and participation in the study itself and the interpretation of the research is appropriate (Macaulay et. al., 1999). For example, if a community member is being asked to evaluate a government funded program and the person interviewing him or her is a representative of the government program, the community member may not feel as comfortable talking about problems due to fear of impacting the funding that goes to the community. If a member of the community, as a co-researcher, is interviewing the same community member, this power dynamic is not present and this makes it easier to speak freely in the interview. By involving people in the planning, implementation and reporting stages they are empowered and informed. The message to them is that they have something valuable to offer and their thoughts and voices should be heard (NAHO, April 2003, p. 10). Even the study topic that is selected sends a message that this is an important issue to address. The more people participate, the stronger the research.

Empowering: Participatory research empowers because it honors the strengths and traditions of communities and involves learning new knowledge, all of which are tools for empowerment. Participation means taking control and enabling communities to make change (McHugh & Kowalski, 2009). Participatory research involves providing training and support in research methods with the goal of empowering community members to conduct their own community based research (Fisher & Ball, 2003; Macaulay et. al., 1999). Researcher expertise is part of the empowerment process. Researchers have a responsibility to know about various research methods, the best methods to use in a given situation (Kenny, 2004) and how they can be used in different ways or

modified to fit with the needs and desires of the community, both in terms of the type of research that is done and the way it is done.

Self determination: Communities build capacity towards self-determination as they govern and manage, solve problems, respond to new situations, make informed evidence-based decisions, strategically plan, identify and set priorities, evaluate programs, and effectively and efficiently manage health and health related resources (First Nations Centre, 2009). In the words of Marlene Brant Castellano (2004) “the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable” is “fundamental to the exercise of self-determination” (p. 102). In a United Nations report on the State of the World’s Indigenous Peoples, self-determination is directly linked to the right of indigenous peoples to “manage their own heritage, knowledge and biodiversity” (United Nations, 2009, p. 65).

Researchers and participants in the Kahnawake Schools Diabetes Prevention Project reported “self empowerment” and an “increase of physical and social capacity” (Macaulay, Comanda, Freeman, Gibson, McCabe, Robbins & Twohig, 1999, p. 776). During the project the community implemented a school healthy nutrition policy, built a recreation path and added a dozen new yearly events. The community was able to fund the project on its own for a year after funding ceased and used the knowledge, skills and experiences gained from this project to continue the health program. Also working in an educational setting, Flores-Kastanis (2009) notes that change occurs through the cultural features of an organization – the ways that people challenge institutionalized practices that are meant to maintain and strengthen “existing... power positions” (pp. 399-400). Change occurs when there is tension between the way things are done and new ways to do things or questions about the way things are done. In action research, changes are introduced and the people who are participants in the study are involved in those changes.

Urban Elders Becoming Empowered through PAR

Elders, called the “grandmothers,” reported a number of positive empowering changes from their participation in a study in their urban community. By learning more about their health conditions they gained a better understanding of the ways of their Western medical doctor. Acquiring information and skills helped them to be more assertive with each other, with their families and in public. They organized a meeting with the provincial social services minister to express their concerns about the services and before this many of the grandmothers had never spoken publicly or attended a formal meeting. They learned about services that were available in their urban community and how to access them. By working together on the project, they grew as a community and supported each other, where before, some of them kept to themselves. The grandmothers made more connections in their community and became more active, involved and respected in their community. They critically analyzed issues, engaged in decision making and spoke out (Dickson, 2000).

Independent versus Participatory Research with External Researchers

It can be difficult for communities to have full ownership of research that is funded by outside researchers when research proposals are submitted prior to the community's involvement and decisions have to be made at the proposal stage (Dickson & Green, 2001) and funding is allocated only to people in academic institutions (Martin-Hill & Soucy, nd). Community capacity is strengthened by resources that are provided to ensure full participation of community members. Resources need to be provided to community members for their time and contributions, information sharing and training, and knowledge transfer between Elders and youth. It is important that the community makes its concerns known at the very beginning of these studies as there is a better chance of making change early before active research begins.

The following checklist sets out some key indicators for determining whether or not independent researchers have conducted or will conduct research in First Nation communities that is ethical, effective, collaborative, and empowering:

Checklist for Community Capacity Building Processes

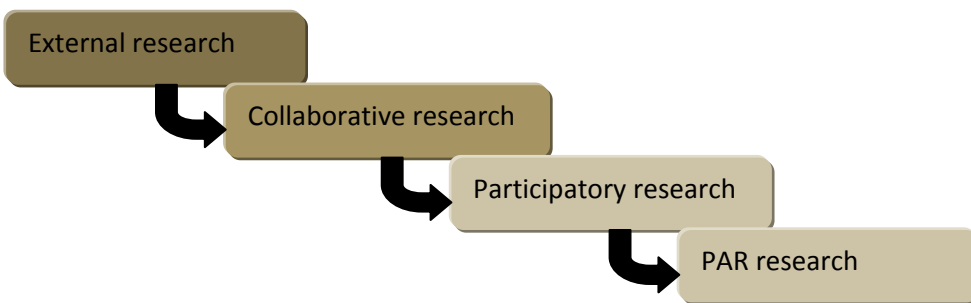
How did researchers do in your community?	Yes	Somewhat	No
Researcher:			
• Listens			
• Involves the community			
• Involves FN expertise			
• Facilitates			
• Enables			
• Guides and is guided			
• Makes changes			
Financial resources are available or provided for community participation in the study			
The community is involved in the ways it wants to be involved			
The community is involved to the extent it wants to be involved			
Training is provided in all areas needed in order for the community to participate fully			
FN researchers are hired whenever possible			
Participants feel free to express themselves			
Researchers provided information on the results of the research back to the community in a way that was useful.			

Depending on the type of research, participation and empowerment can vary from minimal or moderate to full participation in some or all of the research activities. Thinking about a research project that was done in your community, you may wish to consider how the community participated in the various stages of the study:

Project name: _____

Project Stages:	Minimal participation	Moderate participation	Full participation
Planning			
Data collection			
Interpretation			
Dissemination			
Action			

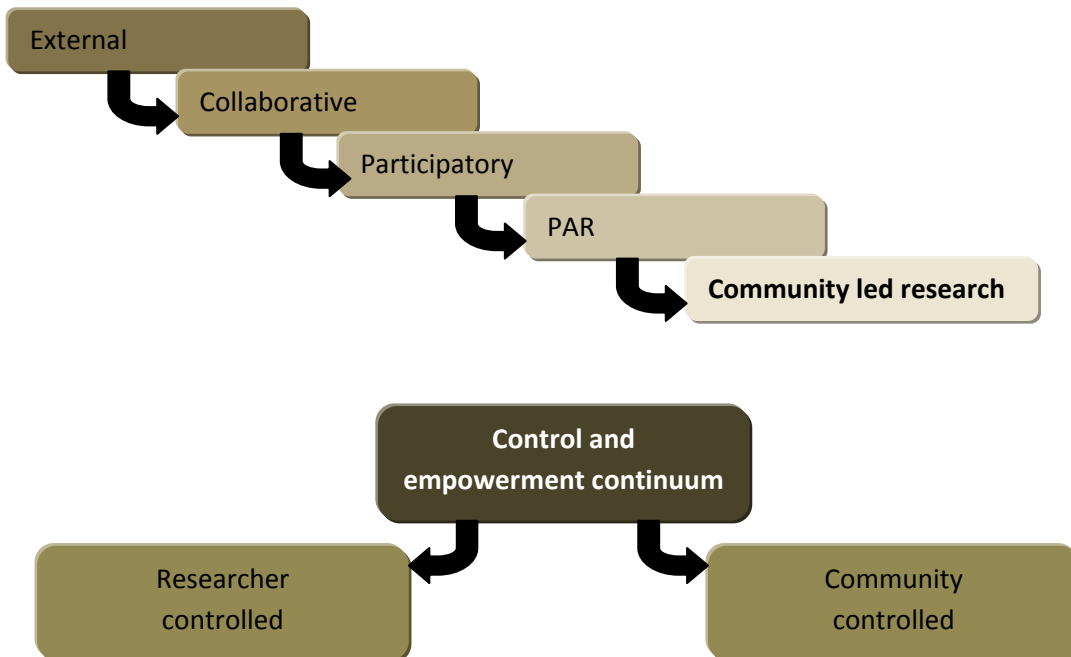
Participation can be thought of as a continuum, from low to high and according to different types of research. Greenwood, Whyte and Harkavy (1993) place PAR at the 'high participation' end of the continuum where "authority over and execution of the research is highly collaborative" (p. 176). In this model, participation and control increases as you go from external research to PAR research.



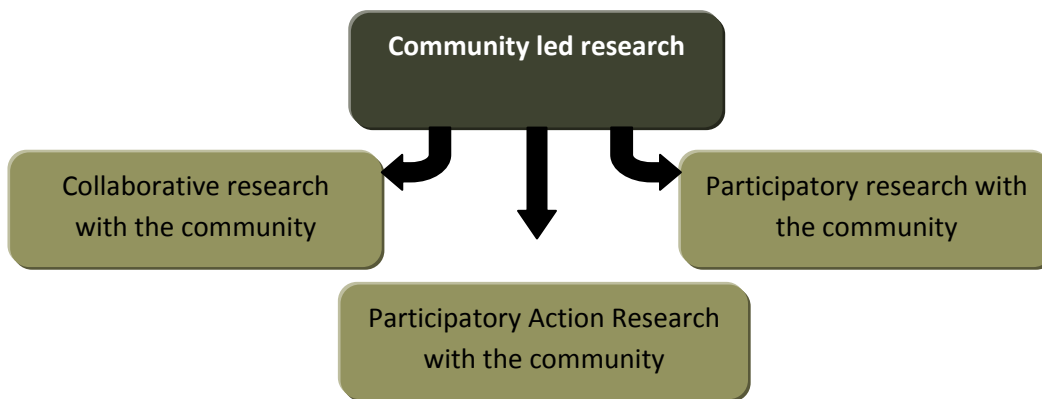
Looking back at those research projects that have been done in your community, how involved would you say your community was? This exercise works well in a group so everyone can share ideas. You may want to list some of the different projects below:

Research Projects	A little bit of involvement – Mostly done by external researcher	Somewhat involved in some stages	Very involved in some stages	Involved in planning, conducting & disseminating the results	Fully involved in all stages of the research
1.					
2.					
3.					
4.					
5.					

While community Participatory Action Research is considered by many to be the most empowering and engaging model, community participants in this type of study design do not have the same power as the researchers who decide to do PAR. The participatory model still assumes the researcher has control because they are in a position to ‘give’ it to the community. For greater and more equal sharing, the community might have researchers who are collaborators with the external researchers and therefore would have an equal say in the methods and process. Or, a community may have the capacity to do research without external researchers. If research is initiated and led by the community, then the community has full control and can then choose to collaborate with outside researchers. Then the model looks like this:



With community led research, a participatory research model would impact community members directly and indirectly affected by the issue that is being studied. The degree of community participation in research that is led by the community can vary and the same principles apply when doing community research for change – that is, the more members of the community (experts, formal and informal leaders, elders, youth, people experiencing the issue) involved in the research process, the greater the opportunity for change. The degree of participation, the ways of participating and the community members involved, will likely depend on the type of research, the issue being addressed, whether it is quantitative or qualitative, whether it involves sensitive issues and how connected the community members are within the community. Martin-Hill and Soucy (nd) caution that “political organizations should not be sole partners in research” due to the potential for bias (p. 41).



Since communities are responsible for all types of information collection for administering programs as well as conducting research, there will be quantitative as well as qualitative research methods used. Two examples of how participatory research can be used with different types of research:

Type of Research	Using a Participatory Approach
Community health data surveillance and collection of health administrative data	Since this information is likely to include all members of the community a participatory approach would include members of the community in identifying the types of information that should be collected, monitored and reported on, in the community depending on the issues.
Program evaluation	The evaluation could include the staff who deliver the program and the participants in the program. Other members of the community may also be involved like others who plan or run programs. Ask what information should be included in the evaluation. For example, some program evaluations measure attendance, but the participants may not be as concerned about numbers as how the program has helped them.

Participation cannot be forced. Participatory research starts with the intent to participate with the people affected by the issue and then the intent is shared, considered, nurtured, and developed together within the limits set by participants based on preferences, resources and conditions (Greenwood, Whyte and Harkavy, 1993). Researchers are responsible for facilitating community participation by providing information, education, and training, and practical and financial support as they are able. Community members decide on the way they want to participate and how much they want to participate. At a minimum, the community should have control over decisions about the research project.

Fletcher (2003) has a number of suggestions which can apply to both internal community researchers and external academic researchers. Check the ones that apply to research done in your community.

- Make the community the meeting place for discussing the research.
- Recognize informal authority within the community.
- Be open about all the objectives of the study.
- Listen closely.
- Maintain strict confidentiality.
- Establish mechanisms to deal with misunderstandings.
- Give people opportunities to voice concerns throughout the research process.
- Report regularly to the community.
- Respect the social dynamics of the community.

For information on types of research and the research process please see the following First Nations Centre resource documents:

[Health Information, Research and Planning](#) (2009)

[OCAP: Ownership, Control, Access and Possession](#) (2007). Appendix A in *OCAP* includes a list of questions to ask when considering involvement in outside research.

Sharing Some Ideas on Empowerment

Community empowerment is complex and there are times when gains in community empowerment could result in some loss of individual empowerment. Similarly, it could mean that some individuals could be empowered while other individuals could be less empowered in the process. Including stakeholders in the research process who are affiliated with the power structures, could bring tension in meeting community goals but the community can be empowered to speak effectively with these people. A risk of excluding them could be that the community is more empowered to speak with each other, but not as empowered to speak with external representatives. Including these external

The Research Process

Conducting research involves various activities which correspond with Cancian & Armstead's (1990) four broad stages in the research process – negotiation and dialogue, orientation, joint research and joint action (as cited in Dickson & Green, 2001).



In the negotiation and dialogue phase, it is important to create communication and governance structures to be in place throughout the research process.

There are many tasks that community members can be involved in:

- Recruitment of co-researchers
- Establishing communication processes
- Facilitating focus groups
- Clarifying issues
- Designing questions
- Interviewing
- Reviewing transcripts or notes from interview or talking circle
- Making corrections or clarifications
- Selecting quotes from transcripts that can be used in the report
- Selecting themes or headings
- Reviewing final product(s) by co-researchers or other community representatives
- Creating resources or products to disseminate to the community
- Selecting ways to disseminate them
- Identifying who to disseminate to
- Delivering the results

People to Include in Research Partnerships

There are four general segments of the community to consider when identifying and inviting people to participate and when disseminating findings – the whole community, formal and informal leadership, special groups (Elders, women, youth) and the individuals who participate in the research and provide information by answering questions (Kenny, 2004).

Consider your community and how they should be involved.

Kahnawake Schools Diabetes Prevention Project

This project used a participatory research model and had three partners in the research project: 1) the Community Advisory Board (CAB) consisting of 40 volunteers from community organizations and the private sector, 2) the community based researchers (including diabetes caregivers and educators) and 3) the academic researchers. Funding originated from the academic researchers but it was the community that decided to focus on diabetes prevention among elementary school children. All three partners developed a Code of Research Ethics to guide their work together. The CAB developed policies for the research project and provided guidance throughout. All community partners were involved in interpretation of the results and if there was disagreement between academic researchers and the community then both or all views would be included in publications or reports. The academic researchers were “guardians of the data” while the research was being conducted and once complete, it was turned over to the community (Macaulay, AC, Delormier, McComber, AM et. al, 1998, p. 106).

An Urban Canadian PAR Project with Elders

In a midsized western Canadian city, 12 Aboriginal women (referred to as the grandmothers) worked as co-researchers in an urban participatory health assessment involving about 40 grandmothers to assess the effects of a weekly gathering of health promotion activities (Dickson & Green, 2001). In this PAR study the research team included about 12 grandmothers, a project advisory committee, project staff, research associates, and the external researcher. The grandmothers verified the data and its interpretation in the report. They also reviewed and endorsed the work of the other members of the research team in their design of the interview questions, consent forms, work plan and contracts. In addition to the grandmothers, the research team included a project advisory committee of seven Aboriginal women, three project staff from the community health clinic, two research associates who were Aboriginal women hired and trained by the grandmothers and staff to assist with the interviews, and the external researcher.

Role/experiences	Names of people to include.	What can they offer?	How can they be involved?
Traditional leaders, informal leaders			
Elected leaders, Band council			
Local experts of traditional knowledge			
Local experts with academic knowledge			
People with organizational skills			
People with office and computer skills			
People with interviewing skills			
People with practical skills			
Youth			
Women			
Children			
Elders			

What kinds of training does the community need?

Type of Training	Who needs it?	Who can provide it?
<input type="checkbox"/> Understanding the research		
<input type="checkbox"/> Understanding confidentiality		
<input type="checkbox"/> Understanding consent		
<input type="checkbox"/> Understanding bias		
<input type="checkbox"/> Interviewing skills		
<input type="checkbox"/> Facilitating a group		
<input type="checkbox"/> Developing questionnaires		
<input type="checkbox"/> Managing data		
<input type="checkbox"/> Transcribing		
<input type="checkbox"/> Reviewing interview transcripts		
<input type="checkbox"/> Project management		
<input type="checkbox"/> Computer skills		
<input type="checkbox"/> Interpreting Results		
<input type="checkbox"/> Presentation skills		
<input type="checkbox"/> Others?		

Establishing Communication Processes

“If researchers are truly ‘collaborating’ with the participants and the community, they stay in constant communication at every stage of the research process.” (Kenny, 2004, p. 13) The following questions apply to all members of the research team as well as the community. Talking about these questions with everyone will help create communication pathways and understandings.

- What will you communicate? What do you want to know?

- Whom will you communicate with? Who needs/wants to know, be consulted, or give information?

- How will you communicate? How do you want to give and receive information?
 - Face to face
 - Individual
 - Small groups
 - Community gatherings
 - Telephone
 - Email
 - Newsletter
 - Reports
 - Internet
- How often will you communicate? How often do you want to be informed or consulted?

Other First Nations Centre resources:

[Surveillance Tool Kit](#) (nd)

[Understanding Health Indicators](#) (2007)

[Privacy Tool Kit](#) (2005)

PLEASE PROVIDE US WITH YOUR FEEDBACK ON THIS DOCUMENT.

[Click here.](#)

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