What Factors Influence The Practice Of Community-Based Participatory Health Research In The Canadian Arctic?

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ABSTRACT

The literature about community-based participatory research for health offers an approach to investigating health issues that involves community members, practitioners and researchers as equal partners and co-investigators, on issues of importance to the community. There are currently few examples of how to develop and implement community-based participatory research (CBPR) projects in the Canadian Arctic. The study investigates the practice of CBPR in a project that took place in the Kitikmeot Region of Canada's central Arctic.

Research was conducted using a case study approach. Extensive documentation from all stages of the project in the Kitikmeot were critically examined through the lens of the principles of community-based participatory research, within a Northern context. The researcher was involved with all stages of the Kitikmeot project, and therefore contributed an insider perspective to the data analysis and interpretation.

Findings about the factors influencing the practice of CBPR in the Arctic are reported relative to some key principles of CBPR, including community consultation, problem definition, cyclical and iterative processes, education, and communications. Various factors, including the formation of a community-based working group, adequate funding, sufficient time, attention to communications and education, and the importance of the issue to the community contributed to the successful completion of the project. The unique environment of the Arctic poses challenges to the practice of CBPR. Implications for capacity development, and policy, and recommendations for further research are identified.

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Chapter One

Introduction and Methodology

Introduction

The term *community-based research* can be used to describe research that takes place in a community rather than in a hospital or research institution (American Academy of Pediatrics Policy Statement, 2004) and it can also be used to refer to research in which the community is involved in all stages of the research process (Minkler & Wallerstein, 2003). The use of the same term referring to a range of community involvement in the research process is confusing and may lead to a situation where the assumptions of the researcher about the extent of community engagement are quite different from those of the community.

Such differences in assumptions can be problematic. Differing assumptions about the level of community involvement in a research project can reduce the likelihood of successful research outcomes for either or both the community and the researcher, leading to mistrust and confusion. In Aboriginal communities, particularly in the North, there is an increasing need to identify and clarify assumptions about roles and responsibilities in a community-based research initiative. The focus on Northern community-based health research as one of two pillars of Canada's contribution to the upcoming International Polar Year (2007-2009) has accelerated the need for this clarification (IPY, 2006).

In less than 10 years, an approach to research that emphasizes "the participation and influence of nonacademic researchers in the process of creating

knowledge" (Israel, Parker & Becker, 1989, p.177), has gained sufficient momentum to be included in an authoritative book on qualitative research. Guba and Lincoln, (2000), added "Participatory" as an inquiry paradigm to Denzin and Lincoln's Handbook of Qualitative Methods that was published in 2000 (p.168), however, it was not included in the description of paradigms in the earlier version of the Handbook that was published in 1994 (noted in 2000, p.164). Participatory research is now an accepted research paradigm and a methodology. At the same time, the literature is sparse about how to operationalize the principles of participatory research into practice, particularly in remote communities.

In the early 1990's, a specific issue in Canada's North provided an opportunity for a community-based health research project to develop which appears to reflect principles of participatory research, and which will be the focus of the present research. The issue was that of environmental contaminants.

The widespread presence of environmental contaminants in the Arctic, which originated outside not only the borders of the Northwest Territories but also of Canada, was a unique situation. The awareness of these contaminants, and the many questions that they invoked, took shape over the course of only a few years in the mid to late 1980's (Shearer & Han, 2003). Environmental contaminants such as polychlorinated biphenyls (PCBs), toxaphene and DDT were identified in several species of traditional foods consumed by indigenous Northerners, including Inuit and Dene/Métis. In particular, marine mammals such as polar bears, seal, beluga, narwhal, walrus and some species of fish had elevated levels of some metal and organochlorine contaminants (Lockhart,

Wagemann, Tracy, Sutherland & Thomas, 1992; Muir et al., 1992). What was at stake with the identification of contaminants in the North was the health and safety of indigenous Northerners as a result of consuming traditional foods that were the mainstay of their diet and culture. Traditional foods were not, and are still not, under the jurisdiction of Health Canada's food safety regulations because they are not commercially bought or sold.

In response, an ad hoc committee was established in 1989 that was chaired by the federal Department of Indian Affairs and Northern Development (DIAND) with membership that included Aboriginal organizations, territorial governments, other federal departments, and two universities. This ad hoc committee developed what would become the conceptual framework for the Northern Contaminants Program, which was subsequently included as one of four programs in the Arctic Environmental Strategy. In 1991, the Arctic Environmental Strategy was funded $100 million over six years (Environment Canada, 1996). The Treasury Board submission was drafted and approved quickly, relative to how long these steps often take, and the amount of funding allocated gave a clear indication that the federal government was committed to environmental issues in the Arctic, including environmental contaminants.

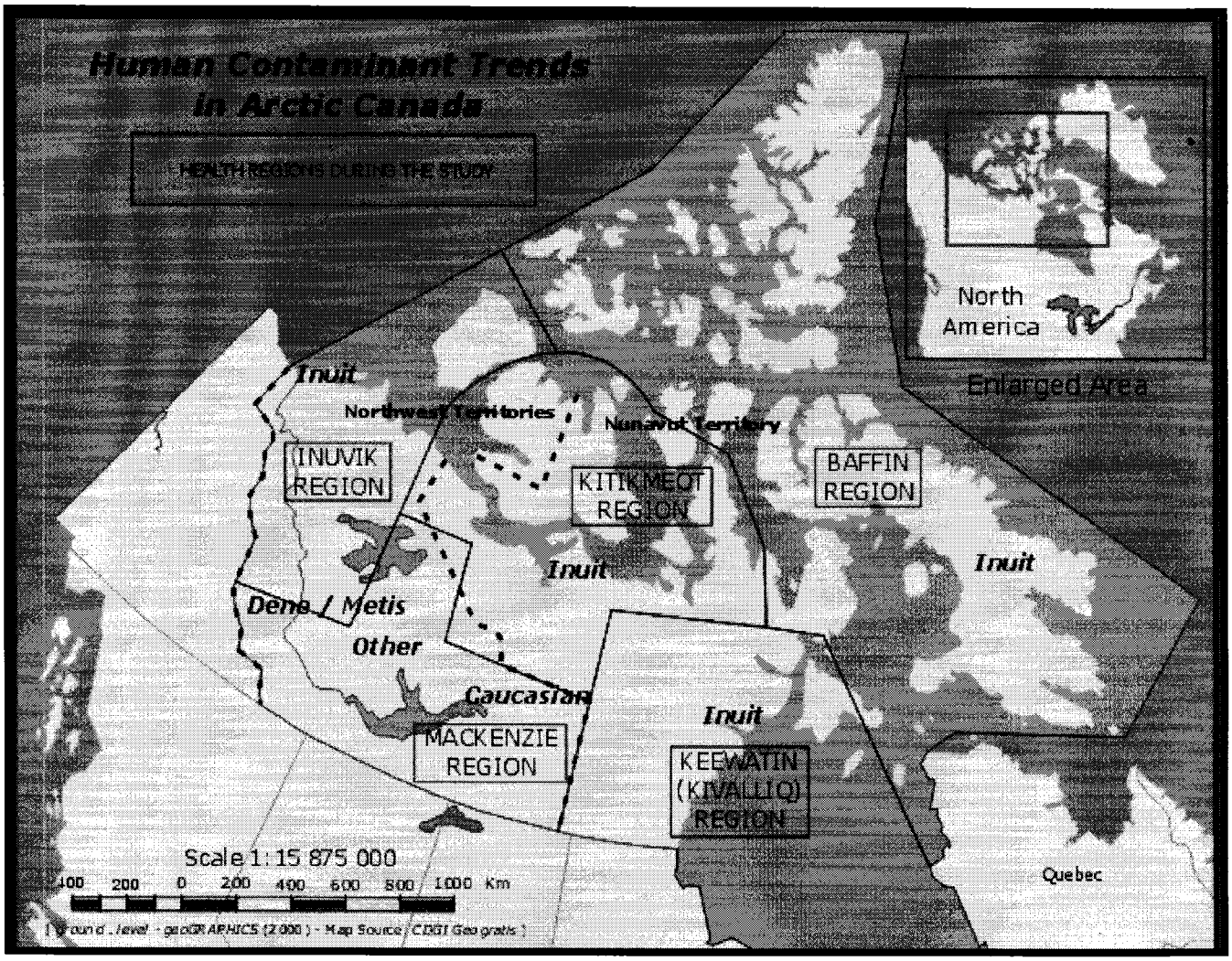
One of the projects that was funded by the Northern Contaminants Program in 1992 was called Human Contaminant Trends in Arctic Canada (HCT). This project was led by the Government of the Northwest Territories, and was intended to produce a baseline of exposures to priority environmental contaminants in maternal and umbilical cord blood in the Northwest Territories

(NWT) and Nunavut (NU). In 1992, there were five health regions in the NWT, which included NU at that time (Fig.1). The first health region to participate in the HCT project was the Kitikmeot region. The work that took place in the Kitikmeot by a community-based working group pioneered and implemented the approach and developed the materials that would be used or adapted by other health regions in the NWT and Nunavut in their participation in the Human Contaminant Trends in Arctic Canada project. As such, examining the processes and products related to the work that took place in the Kitikmeot region provides a unique opportunity to examine mechanisms of community-based health research in the North. The ground-breaking work that would take place over nearly three years in the Kitikmeot region forms the case study of community-based participatory health research that will be examined in the present study.

Canada's central Arctic - the Kitikmeot Region

The Kitikmeot region is located in the western region of Nunavut, with characteristics that clearly define it as both rural and remote. It is the smallest of the three regions in Nunavut, and had a population of 5067 according to the1996 census (Government of the Northwest Territories, 1996). There are eight communities in the Kitikmeot region which were populated by 87% Inuit in 1996. Communities in this region include Holman, Taloyoak (formerly called Spence Bay), Cambridge Bay, Pelly Bay, Kugluktuk, Gjoa Haven, Bay Chimo, and Bathurst Inlet. In 1996, community size ranged from 50 in Bay Chimo to 1350 in Cambridge Bay.

Figure 1. Study Location showing health regions during the study (prior to creation of Nunavut).



The communities of Kugluktuk (formerly Coppermine) and Cambridge Bay constituted 50% of the Kitikmeot population in 1996, with other communities averaging about 500 residents. All communities are coastal, with residents heavily dependant on the ocean for the beluga, ringed seal and other marine mammals, as well as land-locked and sea-run char. Caribou is also a staple of their diet (Jensen, Adare, & Shearer, 1997).

In the 1990's, communications between communities and outside the region was mainly by telephone, with frequent disruptions of service. Short-wave radios were also popular, particularly with people hunting or fishing near their communities. Travel between communities was infrequent because it was very expensive, with all scheduled flights going through Yellowknife. Computers were not widely used, and internet service was inconsistent in the mid-1990s.

At the time of the case study, the Kitikmeot region was part of the Northwest Territories, as it was prior to the division of the NWT with the creation of Nunavut in 1999. This brief overview of the Kitikmeot highlights the region having distinctive qualities of very small communities, occupied predominantly by Inuit, who were geographically remote, experienced challenges with communications, and who maintained traditional cultural practices. These factors provide a unique context, and unique challenges, for the practice of community-based participatory research.

Purpose

The purpose of the study is to improve understanding about the practice of community-based participatory health research in the Canadian Arctic. There is

an increasing need for researchers, practitioners, and communities to develop a common understanding about assumptions inherent in a research paradigm and methodology that has potential to engage those involved in meaningful and lasting improvements in the health of Northerners.

Research Question

The research question in this study is: what factors influence the practice of community-based participatory health research in the Canadian Arctic? Detailed records of the Human Contaminant Trends in Arctic Canada project that was developed and implemented in the Kitikmeot region between 1993 and 1995 provide a unique opportunity to examine a case of participatory health research from beginning to end.

My Perspective

Being a member of the Working Group in the Kitikmeot region that led all stages of the work provided me with an opportunity to contribute first hand to the development of the program as it unfolded, and to witness and participate in what I experienced as a synergistic, empowering and productive experience. At the same time, I experienced considerable frustration and challenge in my role as practitioner and intermediary between community ideas and plans and federal proposal and funding timelines as an employee of the Territorial government.

As Head of the Contaminants Unit in the Territorial Department of Health, I was the leader of the territorial-wide Human Contaminant Trends in Arctic Canada exposure baseline monitoring initiative. (e.g.,Walker, Nuttall, Allen, & Christensen, 1993; Walker et al., 1995). The first-hand involvement I had with

many aspects of the work of the Kitikmeot Working Group, provides me with an understanding of what transpired from a perspective not readily captured in documentation, and places me as an insider in the context of the present research. While being an insider provides a unique opportunity and perspective, it also requires diligence and attention to factors influencing my perspective.

Methodology

Overall Research Design

A naturalistic paradigm refers to a theoretical research perspective that is characterized by research: occurring in a natural setting to include context; using the researcher as the main data gathering instrument; including tacit or intuitive knowledge; using qualitative methods; using purposive or non-random sampling; using inductive data analysis; having the theory emerge from data; choosing an emergent research design; facilitating negotiated outcomes; using a case study reporting approach; using idiographic (ie. specific case particulars) data interpretation; tentative application of findings acknowledging context specificity; defining boundaries relevant to emergent focus of research; and developing criteria for trustworthiness specific to the case. (Lincoln & Guba, 1985, pp. 39-42).

These components of naturalistic inquiry are very different than the components of a quantitative inquiry, which manifest a positivist paradigm.

Case Study

A case study "is the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances" (Stake,

1995). Synthesizing the work of several others, from an education perspective, case studies are described as being "particularistic, descriptive, and heuristic and [relying] heavily on inductive reasoning in handling multiple data sources" (Merriam, 1988, p.16). Acknowledging that a case study is perceived by some as a methodology (Merriam) and others as the object of study (Stake), Cresswell's definition is that "a case study is an exploration of a '333bounded system' or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context" (Cresswell, 1998, p. 61). This definition has similarities with that proposed by Yin, who states "A case study is an empirical inquiry that: investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used" (Yin, 1989). Similar between these definitions are the elements of a case study being bounded, being contextually specific or particularistic, and involving multiple sources of data. Implicit in all are the characteristics of naturalistic inquiry as described above by Guba and Lincoln (1985).

I chose a case study for several reasons. These reasons included the value of what could be learned from the work that transpired in the Kitikmeot region, the abundant documentation related to all phases of the work, the bounding of the work in time and place, and my first-hand involvement as a member of the Kitikmeot Working Group. In addition, the case study provided me with an opportunity to critically appraise what had taken place, with the benefit of

time for reflection and interpretation, and with insights gleaned from the literature review.

Qualitative Description

Qualitative description was the approach used for the examination of the data within the case:

> "Qualitative descriptive studies offer a comprehensive summary of an event in the every day terms of those events...Researchers conducting qualitative descriptive studies stay closer to their data and to the surface of words and events than researchers conducting grounded theory, phenomenologic, ethnographic or narrative studies. In qualitative descriptive studies, language is a vehicle of communication, not itself an interpretive structure that must be read. (Sandelowski, 2000, p. 336).

While there is considerable literature about the main traditions of qualitative research, it has been noted that qualitative description, or interpretive description as it is also termed (Thorne et al, 1996), has received much less attention. This is despite the fact that "it is one of the most frequently employed methodological approaches in the practice disciplines" (Sandelowski, 2000, p. 335).

The theoretical and philosophical orientations of qualitative description are those ascribed to naturalistic inquiry, with the intended outcome of developing an understanding of a phenomenon in its natural state (Sandelowski, 2000). A foundational forestructure is proposed for this type of description, rather than "a formal conceptual framework [required for traditional descriptive research], [which is] an analytic framework constructed on the basis of critical analysis of the existing knowledge [and] represents an appropriate

platform on which to build a qualitative design" (Thorne et al, 1996 p. 173). While this foundational forestructure may change during the process of inductive analysis, it serves to explicate the essential elements of the research design and subsequent analysis, thereby facilitating others to advance the research findings (Thorne et al., 1996, p. 173).

Qualitative description was used in the present study because of the nature of the data set, which consisted of multiple types of documentation over an extended period of time, and the research question, which required the development of an understanding of circumstances made feasible through a descriptive approach.

Sampling

Sampling in qualitative description, as with other naturalistic inquiry approaches, "begins with the assumption that context is critical" (Lincoln & Guba, 1985), rather than focusing on being representative of a population for the purposes of generalizability as in the positivist tradition. In general, six types of qualitative purposeful sampling strategies have been described, including "sampling extreme or deviant cases, sampling typical cases, maximum variation sampling, sampling critical cases, sampling politically important or sensitive cases, and convenience sampling" (Lincoln & Guba, 1985, p. 201). These types of sampling have in common that they constitute an emergent sampling design (e.g., not decided upon in advance of data collection), serial selection (next unit to be sampled is determined by outcome of present unit), focusing of sample (relevant units determined by emerging hypothesis), and sampling to redundancy

(e.g., to no new information) (Lincoln & Guba, 1985, pp. 201-202). Of these, maximum variation sampling may be the most useful to qualitative description (Sandelowski, 2000, p. 338), described as being "to document unique variations that have emerged in adapting to different conditions" (Lincoln & Guba, 1985). More specifically, the collection of data relevant to qualitative description studies is mainly focused on identifying the *who*, *what*, *where* and *how* of the phenomenon under study (Sandelowski, 2000, p. 338).

An important consideration in data collection in qualitative description, and the subsequent analysis, is "what it is you want to be able to say something about at the end of the study" (Patton,1980, as cited in Kuzel, 1992, p. 34). This consideration contributes substantially to how the boundaries are established for the study, and "this initial boundary of the problem may also be thought of as a sampling frame" (Kuzel, 1992, p. 35). Also related to this consideration is the unit of analysis under investigation. In case study research, the focus is on one unit of analysis, although there may be several phases or factors contained in that one unit (Merriam, 1988, p. 46). In this research, the unit of analysis was the document, which will be described in the following section.

Sampling in the present study

In the present study, the sampling frame was bounded by time. There was a clear beginning and end to the case, June 1993 to December 1995, which was well supported by documentation. A maximum variation sampling strategy was used to describe the case, with a focus on circumstances unique to the Canadian Arctic. Prior to sampling, the data were sequenced chronologically, and

catalogued. A timeline was produced that characterized the events between June 1993 and December 1995, and which itemized the various data sources that were available to support the description of these events. Sampling proceeded by asking who was involved, what was taking place, where was it taking place and how did it develop from the beginning to the end of the sampling period. Multiple documents were reviewed for each time period, with notes taken and subsequently summarized. Summary notes were verified by reviewing the data to check for errors or omissions, and seek disconfirming evidence.

Data Sources

Data sources that support the exploration of the research question included documentation, my lived experience, and member checking by key members of the Kitikmeot Working Group.

Documentation sources included Kitikmeot Working Group meeting minutes, draft terms of reference, workshop proceedings, participant recruitment kits, training materials, regional program office monthly activity reports, newsletters, in addition to specific products of the Group's activities, such as posters, fact sheets, and videos. As well, there was a Program Implementation Summary Report and a Final Data Report summarizing maternal and cord blood results for organochlorine and metal contaminants (by ethnicity and by region), as well as program evaluation results from health workers and participants (Rohlmann, Seddon, & Mills, 1996). The data sources of potential use to this study are summarized in Appendix 1, and are categorized as being primarily related to either *process* or *product* specific to the work in the Kitikmeot Region.

Process materials are related to the ongoing development of community consultations in relation to the maternal and cord blood monitoring program. As such, I sampled these materials to describe what took place in terms of people, time, and outcomes according to the research question. Product materials are related to specific end-uses within the context of the maternal and cord blood monitoring program in the Kitikmeot Region and were also sampled in the development of the case.

Ethics

The documents described above have been previously distributed within and outside the Kitikmeot Region, and are not considered to be confidential. According to the Tri-Council Policy Statement:

> Secondary use of data refers to the use in research of data contained in records collected for a purpose other than the research itself.... This issue becomes of concern only when data can be linked to individuals, and becomes critical when the possibility exists that individuals can be identified in the published reports. (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, 2005, p. 46).

This study did not identify individuals who were participants in the maternal and cord blood monitoring program from the Kitikmeot region, or individuals who participated in the work of the case study. Naming the regional coordinator in the Acknowledgements section was done with her permission. Any publications reporting results of this study will not include reference to specific individuals, groups or agencies as negatively influencing the development and/or implementation of the maternal and cord blood program in the Kitikmeot Region.

Rigour

Research integrity has been determined in several ways. Being an insider required that I be vigilant about factors influencing my perspective. I recorded my feelings, thoughts, biases and decision making processes in a memo journal during data collection and analysis. I sought disconfirming evidence from the data. Regular feedback from my supervisor provided opportunities to identify and address assumptions and biases not captured in my own self-reflection. As a member check, I distributed final draft of Chapter Four, the case, and Chapter Five, the analysis of the case, to two key members of the Kitikmeot Working Group and incorporated their feedback. Their feedback affirmed the accuracy of the case description, and the plausibility of the analysis. One member recommended additional details be included to clarify the process of results communication to participants, which have been incorporated into the appropriate section.

Conclusion

The research question is addressed in the study by exploring the literature about community-based participatory health research and the roles of those involved, characterizing the northern context in relation to the case, examining and analysing the case, and reporting the results of that research. Factors that facilitated and hindered the development of the case are identified, and recommendations are proposed to enhance the development and implementation of community-based participatory health research in the Canadian Arctic.

Chapter Two

The Northern Context

Introduction

The purpose of this chapter is to provide the context for the case study and subsequent analysis, with a focus on the issues and circumstances during the time period the work of the case study took place.

The focus of the case study is a community-based monitoring program that was developed and implemented in one health region of the Northwest Territories as part of the territorial-wide program in the NWT to establish a contaminants exposure baseline. I will briefly describe the origin, purpose, goals and early factors that influenced the development of the territorial program to provide details that are necessary to contextualize the case study.

The need for a territorial wide program to determine the types and amounts of contaminants in NWT residents was included as one of 10 priorities in a health research priorities workshop that took place in Yellowknife in 1989, where it was stated:

> There was the view that within the Northwest Territories priority should be given to applied research rather than research which does not have practical applications...An exception to this point relates to environmental contaminants where it was felt that more basic information is needed about contaminants for measuring risks and changes in their distribution and potential impact on health. (GNWT,1989, p. 3)

Government of the Northwest Territories

In response to the priority identified about the contaminants issue, the Government of the Northwest Territories established two territorial contaminants committees in 1989, the NWT Policy Advisory Committee on Arctic Contaminants

and the NWT Technical Committee on Arctic Contaminants, and also created a Contaminants Unit within the Medical Directorate of the GNWT Department of Health. I was the first person in the position of Head of the Contaminants Unit, and joined the Department in June 1990. Within the first month on the job, I was assigned the task of establishing an exposure baseline of priority contaminants in populations at risk in the NWT.

The focus of the NWT wide environmental contaminants program was mothers and their newborns. They were identified as populations at risk in response to emerging evidence of neurodevelopmental effects on infants and young children related to prenatal PCB exposure (Jacobson, Jacobson, & Humphrey, 1990). More specifically, mothers' blood and the blood from the umbilical cord of their newborn were the tissues of interest for the territorial program. Blood provided a means of assessing exposure to both organochlorine and metal contaminants, with maternal blood providing an indication of adult exposure, and umbilical cord blood providing an estimate of prenatal organochlorine and metal exposure. Evidence suggested that prenatal exposure to organochlorines and metals was important to characterize (Jacobson et al., WHO, 1990). A similar monitoring program had previously been developed in Nunavik (Northern Quebec) (Dewailly, Bruneau, Ayotte, Rhiands, Weber, Lebel, & Corriveau, 1994).

A source of funding was not identified when the need for a Territorial-wide human contaminants monitoring program was stated in 1989 at the Health Research Priorities North of 60° Workshop (GNWT, 1989). Funding became

possible, however, in 1991 with the creation of the Northern Contaminants Program (NCP), which was established after a landmark report and a series of collaborative meetings between 1985 and 1991.

The Northern Contaminants Program

A collaborative environmental contaminants research program in the Arctic led by DIAND was catalyzed by a report known as the Wong Report (Wong, 1986). This Report synthesized results from disparate and primarily peer-reviewed literature that described the presence of various contaminants over wide-spread areas of the Canadian Arctic. The report had been commissioned "in 1985, [by] an ad hoc committee of federal and territorial researchers ...as a baseline literature review" (Shearer & Han, 2003) and it highlighted for the first time the widespread presence of environmental contaminants in Arctic regions remote from their production, use and disposal, and beyond the range of Distant Early Warning (DEW) line sites. The presence of contaminants so distant from industrial sources generated many questions, as well as concerns about the implications of these contaminants for the health of the peoples of the Arctic, as well as for Northern fish and wildlife populations.

Soon after the release of the Wong Report (1986), a research project was initiated by Health Canada's Medical Zone Director for the Northwest Territories to get a better understanding of what contaminants people in the Arctic might have been exposed to. The purpose of the project was to study the dietary habits of members from one community to assess exposure levels of some key contaminants, including PCBs, toxaphene and mercury (Kinloch, Kuhnlein, &

Muir, 1992). The target community was one which was known to be a high consumer of traditional foods, particularly marine mammals, as indicated through community-based reports of harvested species. Marine mammals were of concern because levels of many contaminants seemed to be highest in beluga, narwhal, walrus, and ringed and bearded seal. The community that was selected in 1985 was Broughton Island, a very small community on the east coast of Baffin Island that had expressed interest in participating in the study.

Over the course of the next three years in Broughton Island, researchers conducted six dietary surveys during different seasons to estimate an annual intake of various traditional food species. As well, blood samples were taken from just over 200 community members, and four breast milk samples were collected. The abstract from the published paper summarizes the findings from the study and the resulting dilemma:

> Traditional Inuit foods are contaminated with chemical residues from industrial and other activities around the world. The intake of polychlorinated biphenyls (PCBs) and chlorinated camphenes (PCCs) exceeds the "tolerable daily intake" (TDI) for many consumers. The implications of long term contaminant intake, even for single contaminants, are not known and will be difficult or impossible to determine in the foreseeable future. Traditional foods form a substantial part of the Inuit diet and are a major source of energy and essential nutrients. Available alternatives imported foods are nutritionally inferior and substitution may lead to nutritional deficiencies and risks to health and to the social and cultural life of Arctic communities. (Kinloch et al., 1992, p. 247)

At the end of the study in 1989, the Medical Zone Director from the NWT was contacted by the Globe and Mail newspaper about the study's results. The findings indicated elevated levels of PCBs, toxaphene and mercury in many community members, as well as an elevated level of PCBs in one of four breast

milk samples that were analysed. These results were provided to the Globe and Mail reporter prior to their communication, interpretation and translation to the community, and were subsequently sensationalized by the media. The acknowledgement in the scientific paper that published the results from the Broughton Island Study after the release of results to the media stated:

> The authors wish to express their appreciation to the Mayor, the Council and the residents of the Municipality of Broughton Island, Northwest Territories, for their patience and cooperation in a study that has brought them a great deal of unwanted attention and raised concerns that cannot fully be dispelled. (Kinloch et al., 1992, p. 276)

Although this was a very negative situation for the community, in retrospect I believe that the Broughton Island Study would come to benefit Northerners across the Arctic, particularly in relation to highlighting the importance of communication and participatory health research practices.

The Government of Canada's response to the many unanswered questions about contaminants was to establish the Northern Contaminants Program (NCP), which began in 1991 and is still active (Dept. of Indian Affairs and Northern Development, 2006).

The NCP is led by the Northern Affairs Secretariat of the Department of Indian Affairs and Northern Development (DIAND), and was developed conceptually in collaboration with 5 Aboriginal organizations, four federal departments and (then) two territorial governments (NWT and Yukon). Funds from the NCP are allocated by the Technical Committee, and administered by DIAND. Phase 1 of the NCP (1991-1997), was "designed around an integrated ecosystem approach comprising monitoring, research and evaluation...with the

main priority [being] to asses the extent of contamination of traditional/country foods used by northern people" (Shearer & Han, 2003, p.43). The overall goal of the program was "to reduce, and wherever possible eliminate, contaminants in traditional/country foods" (Shearer & Han, p.44).

More specifically, the agencies included in the technical and management committee structures of the NCP included DIAND as chair of both committees, government researchers (Environment Canada: Atmospheric Environment Service, Canadian Wildlife Service; Health Canada, Fisheries and Oceans, and DIAND), territorial governments from Yukon, NWT and Nunavut (Environment and Health & Social Services), and Aboriginal organizations. The five Aboriginal organizations involved with the NCP were the Inuit Tapirisat of Canada (now Inuit Tapiriit Kanatami), the Dene Nation, the Métis Nation-NWT, the Council of Yukon First Nations, and the Inuit Circumpolar Conference. As well, "universities, research institutes, communities and individuals provided research, advice and information" (Shearer & Han, 2003, p.44). There was no direct involvement of NSERC, SSHRC or the Medical Research Council/CIHR in the technical or management committees of the Northern Contaminants Program, however some university researchers affiliated with the NCP may have received Tri-Council funding. NCP funds flowed directly from government to government/university, or government to Aboriginal organizations.

I represented GNWT Health & Social Services as a member of the NCP Technical Committee for nine years, from its inception in 1990 until I moved from Yellowknife to Whitehorse in 1998.

In Yellowknife as Head of the Contaminants Unit, I was responsible for several aspects of health and contaminants activities in the NWT. These activities included coordinating contaminants health research in the NWT (which included Nunavut at that time); establishing an exposure baseline for contaminants in maternal and umbilical cord blood across the North; developing education and communications materials about contaminants; and chairing the NWT Technical Committee on Arctic Contaminants. The NWT Technical Committee was financially unrelated to the Northern Contaminants Program and was funded by the GNWT, however it had the same Aboriginal organizations on it as did the NCP Technical Committee. Also on the NWT Committee were regional representatives from federal and territorial governments who were involved in contaminants research on fish, wildlife or people, as well as Health Canada. Altogether there were about 20 members on this Committee.

Summarizing NCP – Phase 1 key results that have led to calls for action, Shearer and Han (2003) report:

- Contaminants have been detected in all components of the northern food chain.
- Animals high in the food chain and high in fat, such as marine mammals, have the highest levels of POPs [persistent organic pollutants].
- Sources of POPs and some metals are distant, and the contaminants are transported from the industrial and agricultural areas of the world to Canada's North by air and water currents.
- Inuit women have levels of PCBs and other POPs in their milk and blood that are five times higher than those of women in southern Canada and among the highest in the world.
- In parts of the North, levels of PCBs in mothers' blood are at, or exceed, levels that have been associated, in studies in the Great Lakes region, with neurobehavioural effects on children. (p.45)

This last key result, quantifying levels of PCBs and other contaminants in mothers' blood, was the product of the work that began in the Kitikmeot region; the case study investigates the community-based processes that led to the production of the blood data. The blood data from the Kitikmeot region (and other regions) were reported domestically, in the Canadian Arctic Contaminants Assessment Report (Jensen et al., 1997), as well as included in the circumpolar Arctic Monitoring and Assessment Reports (1998, 2003) as part of Canada's contribution. These data have also been published in international, peer-reviewed journals (Butler Walker, J., Seddon, L., McMullen, E., Houseman, J., Tofflemire, K., Corriveau, A., et al., 2003; Butler Walker, J., Houseman, J., Seddon, L., McMullen, E., Tofflemire, K., Mills, C., et al., 2006).

> The results of NCP's Phase 1 were far reaching
>
> The strength of the evidence generated by the NCP has been such that, in only six years, Canada greatly accelerated its domestic response to persistent toxic substances through initiatives such as the Federal Toxic Substances Management Policy. More importantly, Canada took an active leadership role in getting the issue of long-range transport of persistent toxic substances onto the international agenda. So compelling was the evidence generated by the NCP that POPs, which were not being addressed by the global community when the program began, are now the subject of legal controls signed in 1998 for the northern hemisphere (CLRTAP POPs Protocol) and are part of a legally binding global agreement (the Stockholm Convention). (Shearer & Han, 2003, p. 46)

The NCP was renewed into Phase 2, and continues to be led by DIAND.

The beginning of the Territorial Maternal and Umbilical Cord Blood Monitoring Program

To support the beginning of the development of the Territorial-wide human contaminants monitoring program, proposals were developed by the GNWT in

1991 and 1992 that included both Northern communications activities as well as discussions between representatives of the GNWT DHSS and government and university researchers.

More specifically, early communications work in the development of the Territorial-wide monitoring program focused on bringing people together to share information about global contaminants, and to discuss local contaminant concerns. In the early 1990's the global contaminants issue was quite new in the North. There was a need to educate people in communities, health centres, regional health boards, hunters and trappers associations, and various government groups about what was known and not known about long-range contaminants in the North.

Communication activities related to developing the territorial monitoring program consisted of organizing workshops, developing fact sheets, and providing information to and via the NWT Technical Committee. These activities took place over the course of nearly three years. The communication activities provided a basis of common understanding to continue discussions with regional health boards, Aboriginal organizations, and others about the territorial human health monitoring program.

Purpose of the Territorial Monitoring Program

The purpose of the monitoring program was to establish an exposure baseline for populations at risk across the NWT for a suite of 14 chlorinated organic pesticides, PCBs, mercury, cadmium, and lead. The exposure baseline would facilitate a means of evaluating future changes in contaminant levels in

blood that might result from either changes in contaminants levels in traditional food species, changes in consumption of traditional food species, or a combination of these circumstances.

The territorial program was called *Human Contaminant Trends in Arctic Canada,* and the objectives were as follows

1. To establish a Territorial baseline of exposure to specific environmental contaminants by NWT residents, particularly newborns and their mothers;

2. To develop, in collaboration with regional health agencies, an ongoing process for meaningful participation of community representatives and health workers in the development, implementation and results communications of this baseline work;

3. To investigate the relationship between contaminants levels in maternal blood and contaminant levels in umbilical cord blood;

4. To assess the significance of these levels, with participating health regions and others, and collaboratively develop risk management strategies;

5. To contribute to national and international databases the levels of environmental contaminants in Northerners;

6. To assess the need for and feasibility of, additional exposure and/or effects monitoring of NWT Northerners. (Walker, Van Oostdam, & McMullen, 2001)

The proposal was for a collaborative effort between the GNWT and its five health regions to develop and subsequently collect maternal and umbilical cord blood.

After more than two years of discussions with the Aboriginal organizations and others to ensure an approach that was acceptable, particularly to the Aboriginal organizations, the proposal was funded by the NCP in 1993. The NCP Aboriginal organizations recommended that the proposal must include mechanisms for seeking full, informed consent from participants, ensuring

participant confidentiality, and communicating results to participants and communities before others. They also recommended the formation of regional contaminants consultation working groups to ensure meaningful community participation during all stages of the development and implementation of the monitoring program.

Conclusion

The issue of environmental contaminants in the Canadian Arctic was identified by the Government of the Northwest Territories, the federal government, regional, national and circumpolar Aboriginal organizations and academics as one that required immediate action in the mid-late 1980s. The Northern Contaminants Program was established in 1991 and funded by the federal government as a multi-year, multi-agency coordinated response. The GNWT initiated a project to determine the exposures of mothers and their newborns to priority organochlorine and metal contaminants by taking blood samples, with full, informed consent, and with meaningful community participation during all stages of the project. Meaningful community participation would become the focus of all aspects of the Human Contaminant Trends in Arctic Canada project. The literature review in Chapter 3 describes several approaches to active and ongoing community participation, and a conceptual framework that links some of these approaches.

Chapter Three

Literature Review

This literature review informs a critical analysis of various approaches which communities can use to meaningfully participate in health research initiatives. Collectively these approaches can be described as a community-based participatory health research.

In order to inform a critical analysis, it is useful to investigate the meaning of community-based participatory research (CBPR) and to examine the roles of community, practitioners and researchers in the context of community-based participatory research for health. An exploration of the key components of community-based participatory research allows it to be situated among other knowledge production practices. Key components of participatory action research, participatory research, adult or popular education, and community development will be described to characterize similarities and differences within a community-based participatory research approach.

Conceptual Basis of Community-Based Participatory Research

This study is conceptually informed primarily by the work of Paulo Freire. Freire was a Brazilian educator who developed an approach to facilitating the transformation of oppressed or marginalized people into people empowered to speak forth and act on their own behalf through their active engagement in identifying and proposing solutions to their oppression. While the focus of Freire's work was primarily educational in nature, key elements of his approach also constitute the theoretical underpinning of some forms of participatory action

research. As such, the following brief overview of key aspects of Freire's work will inform a critical review of participatory research in relation to conventional research practices.

Through a process Freire called *conscientização* (conscientization), oppressed or marginalized people become critical thinkers by entering into dialogue through problem-posing education as subjects of their own experience with others who are also subjects, through action and reflection (praxis) on the world in order to change it (Freire, 1970). Critical thinking is described by Freire as being essential to true dialogue, and characterized as being

> thinking which discerns an indivisible solidarity between the work and the people and admits of no dichotomy between them – thinking which perceives reality as process, as transformation, rather than as a static entity – thinking which does not separate itself from action, but constantly immerses itself in temporality without fear of the risks involved. Critical thinking contrasts with naïve thinking, which sees "historical time as a weight, a stratification of the acquisitions and experiences of the past," from which the present should emerge normalized and "well-behaved." For the naïve thinker, the important thing is accommodation to this normalized "today." For the critic, the important thing is the continuing transformation of reality, in behalf of the continuing humanization of men. (Freire, 1970, p.92)

Critical thinking skills are developed through participation in dialogue, where dialogue takes place between the oppressed and the oppressors. Oppressors engaged with this type of dialogue have acknowledged their role in current oppressive circumstances and genuinely wish to change the situation. As well, "[they] must realize that their own conviction of the necessity for struggle (an indispensable dimension of revolutionary wisdom) was not given to them by anyone else...it is reached by means of a totality of reflection and action" (Freire, 1970, p. 67). The oppressed also must commit themselves to the struggle, and

"[they] must reach this conviction as subjects, not as objects" (Freire, p. 67). Subjects "denotes those who know and act, in contrast to objects, which are known and acted upon" (Freire, p. 36). The distinction between objects and subjects, and the transformation of people from objects to subjects participating in the making of their own experience, are essential to Freire's work. The transformation from the culture of silence of oppressed persons as objects to be known and acted upon, to participants dialoguing as subjects is mediated through a process of problem-posing education that includes both action and reflection.

Problem-posing education draws on the reality and lived experience of everyday life. With problem-posing education, people "develop their power to perceive critically *the way they exist* in the world *with which* and *in which* they find themselves; they come to see the world not as a static reality, but as a reality in process, in transformation " (original emphasis, Freire, p. 83). As well, problem-posing education "bases itself on creativity and stimulates true reflection and action upon reality" (Freire, p. 84). Where the situation may arise that a topic for discussion does not spontaneously arise from a group of people, Freire (1982) clarifies that "if, however, the people are silent, then we have to provoke them, because we are not neutral (p. 34). In this way, topics for discussion can be proposed by facilitators which, when discussed by groups of people, begin to move from an abstract concept (Friere's example is the word, education; 1982) and "starts to become something quite concrete, because people are talking about it...from their perception of education and not from my perception (Freire, 1982, p. 34).

According to Freire, reflection and action are intimately and necessarily linked to each other in the process of transformation. Action is a process of the oppressed "confront[ing] reality critically, simultaneously objectifying and acting upon that reality" (Freire,1970, p. 52). Reflection is a process of "dialoguing with people about their actions" so that they become "their own example in the struggle for their redemption" (Freire, p. 54). Praxis, or the understanding that comes from reflection and action, is authentic when the consequences of actions become the objects of critical reflection. This praxis can only be achieved when there is "trust in the oppressed and in their ability to reason" (Freire, p. 66).

Freire distinguishes between the banking approach to education and educational projects in relation to those who are either objects of or subjects in learning. With the banking approach, learners are viewed as objects, empty vessels to be filled with the knowledge of others, where students are never challenged to think critically about their reality. Educational projects, on the other hand, are those that "should be carried out *with* the oppressed in the process of organizing them" (Freire,1970, p. 78). Ultimately, "liberating education consists in acts of cognition, not transferals of information" (Freire, p. 79).

Critical to the ability to develop liberating or problem-posing education is the need to reconcile the roles of teachers and students. This does not specifically refer to the roles of teachers and learners as we think of them in relation to traditional school/education systems, it can and does refer to facilitators/informers and those within community.

According to Freire, through dialogue, the

> teacher-of-the-students and the students-of-the-teacher cease to exist and a new term emerges: teacher-student with students-teacher. The teacher is no longer merely the one-who-teaches, but one who is himself taught in dialogue with the students, who in turn while being taught also teach. (Freire,1970, p. 80)

In this process, the opportunity exists for students to be critical co-investigators in dialogue with the teacher. The teacher presents the material to the students for their consideration, and re-considers her earlier considerations as the students express their own. "The role of the problem-posing education is to create; together with the students, the conditions ... for the *emergence* of consciousness and *critical intervention* in reality" (Freire,1970, p.81). The banking concept of education, on the other hand, "attempts to maintain the submersion of consciousness...and anesthetizes and inhibits creative power" (Freire, p. 81).

To synthesize these Freirian elements, the emancipation of people disempowered by oppressive or marginalizing forces takes place via cycles of action and reflection, where, through critical thinking and engaging with others as equals, they become empowered as subjects or agents in their transformation as they understand and act on their world with critical consciousness. Knowledge is power, and with power, social change become a new reality. In research or inquiry paradigms, these Freirian elements manifest a participatory paradigm.

Meanings of community-based participatory research

In conventional research practices, knowledge is produced for the purpose of understanding, by academic researchers who control all stages of the research process, for dissemination to other academics and/or funding agencies, generally

within a positivist paradigm and with a focus on specific outcomes (Cornwall & Jewkes, 1995, p.1669). Conventional research practices that take place in a community rather than in a hospital or in a laboratory are also sometimes referred to community-based research, however they are more appropriately termed community-*placed* rather than community-*based* (original emphasis, Minkler & Wallerstein, 2003, p. 3). At the other end of the spectrum, within a participatory paradigm, community-based research practices include the community as co-producers and end-users of knowledge which is produced for action, with results that address issues of relevance to the participating community, and with a focus on process (Cornwall & Jewkes, p.1669; Guba & Lincoln, 2000, p.166).

Community-based participatory research (CBPR), participatory research (PR), participatory action research (PAR), and action research (AR) share participatory and action-focused research approaches. They differ in their traditions of origin, and fall along a continuum on several domains. Historically, action research was at one end of the participatory paradigm continuum, with CBPR, PR and PAR at the other end. I will provide a brief overview of some of the major differences between these research traditions, and then more fully explore domains within the CBPR end of the continuum.

Action Research

The origin of action research is often attributed to Kurt Lewin, who more than 60 years ago proposed an approach to solving systems problems through "cycles of analysis, fact finding, conceptualization, planning, implementation, and

evaluation to simultaneously solve problems and generate new knowledge" (Brown & Tandon, 1983, p. 278). This approach includes the perspectives of both researchers and clients in the research process, and a focus on producing practical knowledge or solutions, often in industrial or organizational contexts (Stringer, 1999). Historically, action research has been characterized as valuing the creation of useful knowledge to address everyday issues and being ideologically aligned with consensus-based social theories and individual or group analysis, all of which have implications for the definition of action research problems, data collection and analysis and the use of research results (Brown & Tandon, pp. 284-286).

Action research problems tend to be identified by senior management in an organization, or by clients who are supported by or in agreement with management, with a focus on developing a solution to a specific issue. Under these circumstances, consensus about the research focus between the dominant group, management, and the subordinate group, the workers, is common, and facilitates the researcher aligning their research focus with others involved. (Brown & Tandon,1983, p.285). With consensus about the research focus among workers, management and researchers, the data collection and analysis and use of research results engender mutual trust and the sharing of research results. Power differences between groups tends not to figure prominently in action research, and resources and authority to access information are likely to be readily available (Brown & Tandon, 1983, p. 285). More recently, Reason and Bradley (2003) have expanded the term action research to include the application

of acquired practical knowledge to the enhanced well being of communities and individuals in economic, political, psychological and spiritual realms of a global ecology; the involvement of all stakeholders in the research process; and the production of new practical knowledge leading to increased capacity to create knowledge, which they describe as emancipatory (pp. 202-203). The addition of a social realm and emancipatory knowledge production to the construct of action research moves action research closer to the PAR end of the continuum, and blurs some previous distinctions.

At the other end of the continuum, the participatory research tradition emerged from work with marginalized, oppressed people in the developing world, particularly Africa (Swantz, 1982), Latin America (Freire, 1970), Indonesia (Colletta, 1982) and Colombia (Fals Borda, 1979-1986, as cited in Fals Borda, 2001, p. 27). Common to approaches in these parts of the world were dissatisfaction with the dominant research methods, including lack of community involvement in the research process, research activities with little or no benefit to the community, pressing social issues, and the academic researcher as exclusive knowledge producer (Hall, 1982). Hall (1982) used the term "participatory research" to capture the essence of the combination of social inquiry and community participation in decision making that research approaches in these parts of the world had in common (p. 21).

Participatory Research and PAR

In their comparative analysis of action research and participatory research, Brown and Tandon (1983) characterize participatory research as valuing the

creation of useful knowledge relevant to social change, and being ideologically aligned with conflict social theories and analysis at a societal level (p. 283). These characteristics lead to the definition of the research problem or focus as originating from the community itself rather than from dominant groups outside the community, which can lead to conflict if the dominant groups want to control the research process (Hall, 1982). As well, the collection and analysis of data and the interpretation of results are controlled completely by the community, who are considered researchers in the co-creation of knowledge (Hall, 1981, as cited in Tandon & Brown, 1983). According to Freire (1982)

> This method of investigation which involved study – and criticism of the study – by the people is at the same time a learning process. Through this process of investigation, examination, criticism and reinvestigation, the levels of critical thinking is raised among all those involved. (p. 30)

Participatory action research is often described as a process that integrates education, research and action (Hall, 1993, p. xiv; Selener, 1997, p.12). More specifically, Hall (2001) "define(s) participatory research as an integrated three-pronged approach of social investigation, education and action designed to support those with less power in their organizational or community settings" (p.171). Hall (2005) credits Orlando Fals Borda with the first use of the term "participatory action research", which he used at a conference in Cartegena in 1977.

As described by Park (1993)

> The explicit aim of participatory research is to bring about a more just society in which no groups or classes of people suffer from the deprivation of life's essentials, such as food clothing, shelter and health, and in which all enjoy basic human freedoms and dignity....Since much of the social

> injustice characteristic of modern society is structural in origin, participatory research acts as a catalytic intervention in social transformative processes. (p. 2)

According to Selener (1997), "participatory research is a process through which members of an oppressed group or community identify a problem, collect and analyze information, and act upon the problem in order to find solutions and to promote social and political transformation" (p. 17). As well, Selener (1997) contends that as a research approach, Freire (1970) proposed thematic investigation through which people identify and analyze their own problems in order to solve them.

> This process implies a change in the traditional role of the researcher, from that of "objective" external researcher to "committed" co-investigator, as well as a change in the role usually assigned to the target population, that is from objects to be studied to active participants in the research process. (Selener, p. 14)

In essence, key elements of participatory action research include multiple roles of the community in all aspects of the research process, including the definition of the research problem, the involvement and control of all stages of the research process, which are mediated through ongoing dialogue in cycles of action and reflection, and the practical application of research findings. Research findings may also have theoretical applications. Through the process of PAR, community members who were previously objects become subjects actively engaged in co-creation of knowledge to improve their circumstance, which is empowering.

Community Development

Community development is a term that includes various approaches to community empowerment within such sectors as health, economic development, housing, agriculture, international development, literacy, and social services (Labonte, 1997). There are multiple definitions of community development, reflecting assumptions from, by, and about community members, community groups, community developers, practitioners, bureaucrats, and others. The definition of community development in relation to health proposed by the City of Toronto's Department of Public Health in 1994, is "the process of supporting community groups in identifying their health issues, planning and acting upon their strategies for social action/social change, and gaining increased self-reliance and decision-making power as a result of their activities" (Labonte, p. 94). Another definition proposed that community development, or community organizing as it's called in the United States, is the "process by which community groups are helped to identify common problems or goals, mobilize resources, and in other ways develop and implement strategies for reaching the goals they collectively have set" (Minkler & Wallerstein, 1997, p. 30).

Community development encompasses multiple conceptualizations, processes and approaches. Common to many of these are four key elements as described by Minkler (1990) including facilitating community and individual empowerment, enhancing community competence, starting where the people are in terms of issue identification, and creating critical consciousness.

Adult education

Adult education is one of the disciplines within community development. Adult education is committed to equality and social justice, and is guided by principles that include

> (a) Programmes should be based on adult needs;
> (b) Adults are more able to articulate their learning needs than children;
> (c) Although adults' ways of learning change with age, the phrase 'too old to learn' is a fallacy;
> (d) Adults often work out quite complex learning strategies to achieve desired goals on their own. (Hall, 1982, p.19)

The focus of adult education is to increase the participation of individuals and communities in issues of concern to oppressed or marginalized groups, and to provide a level of basic education to all people (Hall, p.19). While the word, research, is not included in the term, adult education, the concept of research by and for the people leading to increased participation or other action is part of the goal of adult education (Hall, 1982, p. 19).

Adult education, community development and PAR may but do not always have social justice, emancipatory education leading to social change, and giving voice to the oppressed in common. They differ in their engagement with academia, which is invoked by the word, research. The involvement of academic researchers in the PAR process, and the elitism that so often accompanies expert status, introduces a theoretical/academic vs. practical/community tension in PAR that distinguishes it from forms of adult education. Interestingly though, according to Brown and Tandon (1983) "participatory researchers are often adult educators and community organizers and they tend to analyse problems in terms

of *community and social structures"* (original emphasis, p. 282). In other words, while academia may ascribe specific characteristics to those deemed researchers, within a participatory paradigm these distinctions are less clear.

Community-based Participatory Research

The term, community-based participatory research (CBPR) is increasingly being used to describe a range of community-based knowledge production practices. While there are some variations between them, increasingly they are sharing core principles and values, including "participatory action research, participatory research, action research, mutual inquiry and feminist participatory research" (Minkler & Wallerstein, 2003, p. 5).

In an extensive review of the literature related to community-based research for public health, Israel et al., (1998) describe CBPR as "a partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process" (p. 176). The authors also note that a "fundamental characteristic of community-based research is the emphasis on the participation and influence of nonacademic researchers in the process of creating knowledge [and] with the active engagement and influence of community members in all aspects of the research process". (p.177). Altogether these authors propose eight key principles of community-based research, all of which are located on a continuum and all of which are in play more or less simultaneously

1. Recognizes community as a unit of identity;
2. Builds on strength and resources within the community;
3. Facilitates collaborative partnerships in all phases of the research;
4. Integrates knowledge and action for mutual benefit of all partners...and includes integrating that knowledge with community and social change efforts that address the concerns of the communities involved;
5. Promotes a co-learning and empowering process that attends to social inequalities....[It is a] process that facilitates the reciprocal transfer of knowledge, skills, capacity and power;
6. Involves a cyclical and iterative process....that includes partnership development and maintenance, community assessment, problem definition, development of research methodology, data collection and analysis, interpretation of data, determination of action and policy implications, dissemination of results, action taking (as appropriate), specification of learning, and establishment of mechanisms for sustainability;
7. Addresses health from both positive and ecological perspectives....that emphasizes physical, mental, and social well-being ...and that encompasses biomedical, social, economic, cultural, historical, and political factors as determinants of health and disease;
8. disseminates findings and knowledge gained to all partners. ...The ongoing feedback of data and use of results to inform action are integral to this approach. (Israel et al., 1998, pp. 178-180)

In Hatch, Moss, Saran, Presley-Cantrell and Mallory's (1993) experiences with CBPR in African American communities (as cited in Israel et al., 1998), they describe that "the opportunity arises for communities and science to work in tandem to ensure a more balanced set of political, social, economic, and cultural priorities, which satisfy the demands of both scientific research and communities at higher risk" (p. 181). This perspective of CBPR reflects a somewhat different focus than the fundamental principles of Freire as will be developed in the next section.

Comparative Analysis of CD, PAR and CBPR

The terms participatory research, participatory action research, action research and community-based participatory research are moving towards shared core values and principles, although they differ in their goals and change theories (Wallerstein, 1999, p. 41). These core values and principles include

1. Research participants should actively set the agenda;
2. The research should benefit the community by providing tools to analyze conditions and make informed decisions on collective actions;
3. The relationship between researchers and community members should be collaborative and based on dialogical learning (Freire, 1970);
4. The process should develop capacity of community people to appropriate and use knowledge from which they would normally be excluded;
5. The process should be democratic, enabling the participation of a wide diversity of people; and there should be a balance between research and community goals. (Wallerstein,1999, p. 41)

The aspects of community participation, collaboration, empowerment and action are consistent between community development and participatory action research approaches. As Lindsey, Sheilds, and Stajduhar (1999) contend, "Both [CD and PAR] are developmental processes, PAR for the development of knowledge, and CD for the development of the community...the ultimate goal of both methods is to generate social action to create necessary change" (p.1239). Additionally, these authors assert that "CD is an essential process in PAR, whereas PAR is not an essential component of CD" (p.1242). This conceptualization of CD as an integral component of PAR highlights opportunities for collaborative roles between practitioners and researchers. For example,

practicing nurses and nurse researchers in PAR could collaborate, with practicing nurses contributing the CD aspects of their practice to the research aspects of the PAR nurse researcher (Lindsey et al., p.1242). If practicing nurses are employing CD in their work, then it is reasonable to extrapolate the potentially meaningful role of practicing nurses in PAR to other front-line practitioners, such as health educators, health promotion officers and nutritionists, for example. Wallerstein, Sanchex-Merki, & Dow,1997, p.195) offer insights into the long-term commitment and complexity of integrating Freirian-based community development principles in a PAR health education project with youth, where challenges at individual and community levels informed action/reflection praxis, and power dynamics between "Freirian facilitators" and youth called for ongoing development of critical consciousness.

In the quote from Hatch et al. (1993) above (as cited in Israel et al., 1998), the perspective of "the opportunity [arising] for communities and science to work in tandem...[to] satisfy the demands of both scientific research and communities at higher risk" (p.31) is a departure from Freire's perspective. Hatch et al. (1993) and also to some extent Israel et al. (1998) insert researchers and the research agenda into the Freirian perspective that focuses on the needs and questions of communities as the primary driving force for inquiry. As well, the structure of the sentence in the above quote could imply that the demands of scientific research are more important than those of the communities, given that they are identified first. Comparisons between other principles of community-based participatory research as synthesized by Israel et al. (1998) and Freirian principles also

indicates some reframing of Freire's intent to accommodate the development of research agendas and processes that serve researchers' interests. For example, Israel et al.'s principle number 2 "builds on strength and resources within the community...community-based research explicitly recognizes and seeks to support or expand social structures and social processes that contribute to the ability of community members to work together to improve health" (1998, p. 178) could just as easily be interpreted from a researcher's perspective as a community's perspective. The space that this ambiguity creates could as readily be used to facilitate a researcher-oriented focus as it could a community-oriented focus, only under the guise of community-based participatory research.

Key principles and an understanding of the conceptual underpinnings of community-based participatory research for health are important to distinguish this approach and methodology from conventional research practices, and to highlight where ambiguous spaces occur. To provide insight into how CBPR can manifest in a specific situation, a more detailed examination of the definitions and roles of communities, practitioners and researchers is required.

Roles of Community in Community-Based Participatory Research

The obviousness of the word, community, in CBPR warrants attention to explore more fully what it encompasses.

Definitions of Community

Community can be defined from several perspectives. These definitions can include a particular geographic location, a set of relationships such as those between families, neighbors, friends and organizations, and a political aggregate

of individuals (Eng & Parker, 1994, p.199). Within a specific domain, a community includes membership, common language and practices, mutual influence, shared needs and shared emotional connection (Israel, Checkoway, Schultz, & Zimmerman, 1994, p.151). Another definition for community was proposed as "a group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings" (MacQueen, McLellan, Metzger, Kageles, Strauss, Scotti, et al., 2001, p.1929).

Other descriptions of community include a population group that shares similar traits, a group of individuals that have an issue, concern or belief in common, and a "unit of solution in society" (Checkoway, 1995, p.3). As a unit of solution, community

> is a process through which people take initiative and act collectively. It varies from one area to another, but generally is based on the belief that problems in communities have solutions in communities, and that people should participate in matters that affect them at the community level. (Checkoway, 1995, p.4)

In a detailed look at definitions of community, Jewkes and Murcott (1996) note that historically there have been many attempts to define community, with one study revealing that all that 94 definitions of community had in common was that they involved people (Hillery, 1955, in Jewkes & Murcott, p. 557). In another study, communities were viewed as either aggregational (a group of people with something in common that sets them apart from other groups) or relational (one community in relation to another community), with a sense of sharing that is

heightened when members become aware of boundaries (Cohen, 1975 in Jewkes & Murcott, p. 557).

An important aspect of the definition of community is the central role of the community in developing the definition. The concept and assumptions about sharing emerged as key in a study of 50 community informants in a borough in England involved in a WHO Health For All project. The informants were either involved in the health sector, were community workers or were hired by local government, and were interviewed about their understanding and meaning of communities. Those who identified themselves as being non-members of the community assumed that sharing was part of the construction of the community, whereas those who defined themselves as members of a community identified

> Their own sense of sharing with like others as a central and indivisible part of the meaning. Thus a central feature of any discussion of meanings of community is seen to be the question of who constructs it as well as when and in what situation. (Jewkes & Murcott, 1996, p. 561)

Roles of communities in CBPR

The idealized roles of communities participating in a CBPR project are in part characterized implicitly within the key principles of CBPR described in the review by Israel et al. (1998). Reviewing these eight key principles with a focus on what are implied and necessary roles by a community engaged with CBPR results in a list of qualities that is both interesting and unlikely to exist in reality. This list indicates that ideally communities: (a) are to be identifiable as a unit of identity, and be willing and able to articulate what that identity is; (b) are able to identify their health research needs are; (c) be willing to engage in processes to identify and build on their strengths, resources and relationships; (d) be willing to

engage with researchers and practitioners as equal partners in all phases of the research process; (e) be involved with translating new knowledge into the appropriate actions leading to social change; and (f) be available over an extended period of time for the many stages within research development, implementation and evaluation.

In sum, the community is required to both see itself as a unit of identity called a community and engage with others as that community, either a community of interest or other construct of community. As noted by Jewkes and Murcott (1996) it is essential that when community is being defined, questions about who is constructing it, when and for what purpose, are brought to bear on the construct, given differences between members' definitions from an *in-situ* perspective and perceptions relative to non-members' assumptions. The issue of who defines community, however, is only one of the challenges posed by such a large set of assumptions or expectations as appear to be contained in the key principles of CBPR. Another challenge is that people who are included in the conceptualization of community need to have access to multiple resources over an extended period of time for the intended community participation and community consultation activities to take place. These resources include funds, as well as community members with time, expertise, motivation, community support and an interest in participating as community partners.

How the roles of communities actually take shape within a community-based participatory research project is not particularly well documented (Schultz et al., 2003, p. 295), although they do exist. One such example comes from work

by the Haida Gwaii, a First Nations community in the Queen Charlotte Islands of British Columbia, who undertook a community-based participatory research approach with a diabetes project (Herbert, 1996). In this project, community members consisted of Haida Gwaii elders, community leaders, individuals with diabetes and their family members, community-based health workers who were Community Health Representatives (CHR's – Haida members of the community who had received specific health training), and university-based researchers from the University of British Columbia. Community members contributed to the development of the project's working principles, which included equality between different groups, ownership of the data by research participants, manuscripts to be reviewed by community representatives following their input to data interpretation and with veto power over publication, and that the research team was responsible for any health or social issues that resulted from the research activities, rather than falling to the CHRs to resolve (Herbert, 1996, p. 110). The community members were kept informed of activities during all stages of the research process, so those not directly participating were still involved with the project. Ongoing consultation activities with community members contributed to the focus group format and questions, as well as the interpretation of findings, the development of the conceptual framework, and the development and implementation of diabetes interventions (Herbert, p. 111). The author did not identify specific challenges that emerged during the research process, however she did identify opportunities for empowerment that were manifest during the research activities. Empowerment was evident by the sustained engagement of

the community in the research process, by the increasing responsibilities various community members took on, and by the application of skills they developed in the diabetes research program to other community activities, such as using focus groups to develop another research proposal (Herbercommunity-t, p. 111).

Roles of Practitioners in Community-Based Participatory Research

Some literature includes practitioners as being involved in CBPR or PAR activities (Schultz et al., 2003) whereas others do not (Kuhnlein & Fediuk, 1998). Whether practitioners are described as being included as members of the CBPR research team or not, community and researchers are invariably stated as constituting the research team. Whether or if practitioners roles in CBPR may be assumed on the part of researchers, communities or both, as part of their regular duties, it is important to understanding how the principles of CBPR are enacted to examine what the contributions of practitioners might be.

Definition of practitioners

The term, practitioners, in the context of CBPR includes nurses, health promotion professionals, health educators (Huff & Kline, 1999), nutritionists, community health representatives, health service providers (Schultz et al., 2003, p. 297), and others.

Roles of practitioners in CBPR

The guiding principles of CBPR developed by Israel et al. (1998) and described on page 40 contain implied roles for practitioners just as they do for communities. Some of these roles are the same as they are for communities if practitioners are viewed as a community of interest within a geographical

community. If they were a community of interest, practitioners involved with CBPR would recognize themselves as a unit of identity, would understand their strengths and resources and articulate them, would be able to participate as equal members of a research team, would be able to advance social change efforts through cycles of action and reflection, would take a determinants of health approach in their research participation, and would participate in translating knowledge to all those involved. These roles manifest somewhat differently in actual CBPR projects.

Practitioners in a large scale CBPR project to address social determinants of health on Detroit's East Side played important roles in the project during all stages, and the evaluation of their involvement provides insight into where challenges and opportunities can surface (Schulz et al., 2003). The East Side Village Health Worker Partnership (ESVHWP) consisted of Village Health Workers (VHW) whose work was guided by a steering committee that consisted of VHWs, community organization representatives, health service providers and researchers from academic institutions. The VHWs were community residents who expressed an interest in being involved in the CBPR project, and were willing to take an 8 week training course. The training course was designed to equip them to function as lay health advisors, and included information about health issues and resources in their communities to extend their community development skills, as well as provided opportunities for relationship and trust building between participants in the course.

Altogether 56 community residents joined the CBPR partnership as Village Health Workers, and of those, 51 were women. An evaluation was conducted to understand the motivations, challenges and benefits experienced by the VHWs in their involvement in the research which identified several factors. Factors that contributed to their motivation "[were] centered around the desire to be actively engaged in creating solutions to challenges within their communities...[and] to develop new skills and expand their base of knowledge" (Schulz et al., 2003, p. 299). As well, VHWs valued contributing to the partnership because it brought together others from the community who were committed to their neighborhoods, provided opportunities for collaborative problem solving and developed mutual support, which required time and trust to establish. Challenges of participating in the partnership as Village Health Workers included (a) their time constraints and multiple other commitments; (b) health concerns of themselves and their families; (c) limited resources and inability to influence change in underlying social circumstances that impacted health in their community; (d) mistrust of research and academics; and (e) having community-based agendas and priorities that differed from academics (Schulz et al., p. 299).

Other researchers have contributed perspectives about the contribution of practitioners based in communities. Community health workers have a role in health research activities, which includes functioning as a liaison between community and a research team as well as participating in research activities as a member of a research team (Hill, Bone & Butz, 1996, p. 222). As a team member, community health workers "can translate cultural norms, values,

practices, and goals in two directions: from the community to the investigators and from the investigators to the community" (Hill et al., p. 222). In this capacity, community health workers can identify areas of concern and facilitate their resolution, including issues arising from either or both the researchers perspective or the community perspective. As a member of the research team, community health workers can take on multiple roles, including research assistant, recruitment coordinator, data collector, interventionist and/or project coordinator (Hill et al., p.223).

An important consideration in CBPR in the roles of practitioners and researchers is that they change and evolve over time (Hill et al., 1996; Kelly & Vlaenderen, 1996; Schulz et al, 2003). In an evaluation of the relational and communication processes of a participatory health research project that did not meet its objectives, communication lapses and failure to incorporate enhanced capacity were critical factors (Kelly & Vlaenderen, 1996). These factors identified unstated assumptions and expectations on the part of research team members and the importance of acknowledging and accommodating increasing practitioner capacity over time as essential to facilitate building on learning that had already taken place (Kelly & Vlaenderen). Failure to acknowledge increasing practitioner capacity by the researchers led to breakdowns in communication and resistance by practitioners to engage with the project.

Roles of the Researcher in Community-Based Participatory Research

As with communities and practitioners, understanding the definitions and roles of researchers is important in developing an understanding of how the principles of CBPR can be enacted.

Definitions of Researcher

In traditional academic research, the researcher is defined as having attained an advanced level of academic training, usually at the doctorate level. An assumption that accompanies the attainment of a doctorate degree is that the holder of the degree is an expert in undertaking research. The currency of academia is formal knowledge production, which is quantified in terms of academic or peer-reviewed publications and is valued in terms of tenure, funding, career advancement, and relative position of power within an academic institution. Traditionally researchers or research scientists initiate curiosity-driven research in response to their area of interest, proceed to develop research questions and proposals that are consistent with this area of interest, seek funding, and subsequently implement their research, interpret the findings, and report them in academic journals and at conferences.

The Canadian Institutes of Health Research (CIHR), the predominant funding agency of health research in Canada and the successor to the Medical Research Council, defines in grant guides that "a Principal Applicant is an independent researcher and who has completed formal training in research in a discipline relevant to health research, usually a PhD or equivalent, or health professional degree with research training... is employed by an eligible

institution, and has responsibility for the intellectual direction of the proposed research" (Canadian Institutes of Health Research, 2006). Interestingly, CIHR defines a Collaborator in the 2006-2007 Grant Guide as "an individual whose role in the proposed research is to provide a special service (such as access to equipment, provision of specific reagents, training in a specialized technique, statistical analysis, access to a patient population, etc.) but who is not involved in the overall intellectual direction of the research" (Canadian Institutes of Health Research). At the same time, draft CIHR Guidelines for Health Research Involving Aboriginal Peoples state that "Communities should be given the option of a participatory research approach" (CIHR, 2006). This Article is further elaborated as follows

> Genuine research collaboration is developed between researchers and Aboriginal communities when it promotes a partnership within a framework of mutual trust and cooperation. Participatory research enables a range of levels and types of community participation while ensuring shared power and decision-making. Such partnerships will help to ensure that a research process will proceed in manner that is culturally sensitive, relevant, respectful, responsive, equitable and reciprocal in terms of the understandings and benefits shared between the research partner(s) and Aboriginal community/communities. (p.2)

The attribution by CIHR of only the Principal Applicant in the intellectual direction of proposed research is inconsistent with both a guideline from the same institution as well as the principles of CBPR.

Roles of Researchers in CBPR

In the CBPR perspective, the role of the researcher is only one of several roles that are required, with other roles being that of "leader or "animator", community organizer, popular educator, and participatory researcher. (Stoecker,

2003, p. 102). Research in participatory research refers to the production of knowledge that is co-created by disenfranchised and deprived people that clarifies

> the link between what is needed for a better life and what has to be done to attain it...knowledge becomes a crucial element in enabling people once more to have a say in how they would like to see their world put together and run (Park, 1993, p. 1).

According to Stoecker (2003), CBPR is not a research project *per se,* but rather

> It is a social change project of which research is only one piece. As such, it has three goals:
>
> - Learning knowledge and skills relevant to the task at hand
> - Developing relationships of solidarity
> - Engaging in action that wins victories and builds self-sufficiency
>
> Doing research is not, in itself, a goal. Research is only a method to achieve these broader goals. (p. 102)

The roles of academic researchers in CBPR are inherently tension-filled. As researchers engaged with CBPR, their role is to contribute to the co-production of knowledge that is community-based, community controlled and leading to social change. At the same time, researchers involved with CBPR must still acknowledge and function within the academic setting in which traditional research practices predominate, and in which they are ascribed responsibility for the intellectual direction of the proposed research (Canadian Institutes of Health Research, 2006). Stoecker (2003) describes three roles that academics tend to adopt in relation to CBPR; the Initiator, the Consultant, and the Collaborator (p.100). The role of Initiator of a research project in CBPR by an academic researcher is challenging in that it contravenes one of the basic tenets of participatory research, which is that the questions should come from the

community itself. At the same time, where conditions in the community are not conducive to voicing or identifying research interests or questions as occurs when mere survival is a priority, the initiative of an outside researcher can facilitate movement towards a participatory approach to addressing an issue of importance to the community. The challenge in this situation is to move control of the idea or question from the initiating researcher to the community, which then becomes empowered to continue what has already been initiated (Selener, 1997, p.29; Stoecker, 2003, p. 100). The role of Initiator is consistent with Freire's (1982) perspective that "if, however, the people are silent, then we have to provoke them, because we are not neutral" (p. 34). When the issue that is used to provoke the people is of importance to the community, then ownership of the issue through discussion and engagement will occur, and the Initiator's role will need to change.

Another role that researchers can adopt according to Stoecker (2003) is that of the Consultant (p. 101). In this capacity, the researcher is commissioned by the community to conduct the research, and is accountable to the community. The community can be involved during all phases of the research process, or at milestones agreed to by all involved. An advantage of this approach is the researcher can devote times, skills and expertise to the project that may be outside the community's capacity to engage with continuously, and the resulting report will have the credibility of academia to authenticate its recommendations, which may be more influential than to have a community authored report. A disadvantage of this approach is that if/when the researcher departs or is no

longer engaged with the community, knowledge that was co-produced may not be available to be built on (Stoecker, p.101).

The Collaborator, a third type of role that researchers can take on in CBPR projects, involves establishing an equal relationship with community members and community leaders, where all actors contribute their skills, knowledge and capacity (Stoecker, 2003, p. 101). While this approach may seem appealing, it is influenced by the time community members and leaders have to contribute to the project, which is likely to be less than the researcher, and poses challenges due to the nature of developing truly collaborative relationships.

Researchers in CBPR can engage with the research process in a variety of capacities that tend to be quite different than traditional research processes. Implicit in the role of Initiator, Consultant or Collaborator is the assumption that the researcher understands the implications of their role as an agent of social change, and is willing to accept that role. In acknowledging the challenge of being a researcher based in an academic institution and involved with CBPR initiatives, Hall (2001) noted that "many of us [researchers in academic institutions] operate in situations of contradiction and self-doubt. Doubt may be one of the most identifiable common denominators. Doubt and humility may be the strongest contribution that our work collectively has to offer" (p. 176). Thus, the academic researcher in CBPR has a demanding role.

Roles of Decision Makers

The roles of decision makers, which include government agencies and funding agencies, are also tension-filled when they seek a CBPR approach.

Workers in government agencies who are responsible for program development, implementation, and evaluation, may be aware of specific community issues that are relevant to their work, and have community representatives to collaborate with, however are constrained by managers and directors. Managers and directors who seek a CBPR approach to inform program or service development may not have the resources, knowledge or time to proceed collaboratively with end users or researchers, or have the support of their senior management. Funding agencies seeking a CBPR approach generally must operate according to previously established funding timelines, and with priorities established through strategic planning which likely did not include community input. In addition, funding agencies who do not recognize the critical role of community consultations during all phases of a CBPR initiative may fail to support budgets and timelines that are necessary for successful CBPR outcomes.

Conclusion

Community-based participatory research for health has at its core, key roles for communities during all stages of the research process. These key roles include the definition of the research problem, the collection and analysis of data, the interpretation and dissemination of results, and the application of research findings to improved health. Community members and practitioners participate as nonacademic researchers in the co-creation of knowledge intended to contribute directly to improved community and individual health.

The process of CBPR takes place over a period of time that can be longer than traditional research because of the need to build trust and partnerships

between community members, practitioners and researchers, who are co-learners in the project. Education that addresses community-identified needs, draws on community strengths and is initiated by community members contributes to the ongoing participatory process. Community members, practitioners and researchers contribute as equal members, with learning and teaching occurring among and between them during the life of the project and beyond. Researchers take on different roles in CBPR than in traditional academic research.

This approach reflects the essential elements of Freire's work. Communities have traditionally been marginalized from contributing to the creation of formal knowledge. The practice of CBPR provides a means for communities to become subjects in their own transformation as they critically examine factors contributing to their health. What Freire (1970) described as cycles of action and reflection, Israel et al. (1998) described as a cyclical and iterative process. Through these iterative cycles of action and reflection, dialogue between co-learners informs the project's development and implementation. The cyclical and iterative process will be a focus of the case examined in the next chapter.

Chapter Four

The Kitikmeot Working Group: A case of CBPR?

Introduction

The purpose of this chapter is to examine the details of a research project that took place in the central Canadian Arctic through the lens of two key aspects of community-based participatory research (CBPR), the definition of the problem, and the cyclical and iterative process. Through this examination, these aspects will be explicated from a case which, at this stage, seems to have some characteristics of CBPR. The eight key principles of CBPR were described in Chapter Three on page 40. Although these principles are described separately, they occur on a continuum and are in play more or less simultaneously.

Of these eight principles, I will focus primarily on principle number six. Within principle number six, I will focus on two aspects in the context of a cyclical and iterative process: the problem definition, and the involvement of partners in all phases of the research endeavor.

> 6. Involves a cyclical and iterative process....that includes partnership development and maintenance, community assessment, problem definition, development of research methodology, data collection and analysis, interpretation of data, determination of action and policy implications, dissemination of results, action taking (as appropriate), specification of learning, and establishment of mechanisms for sustainability (Israel et al., 1998, p.178)

The events surrounding the study at Broughton Island described in Chapter Two gave cause for concern to senior Territorial officials about the use of the word, research, in the context of the Human Contaminant Trends project. The concern was that the negative perception of the communication outcomes of the

research project at Broughton Island would have been associated with the Human Contaminant Trends project if the HCT project were to have been referred to as research. For this reason, the word research was not used in association with the HCT project. In its place, the work of the Human Contaminant Trends project was referred to as a monitoring program.

Community Consultation: Development of a community-based perspective

Recommendations that resulted from a workshop that was held in 1992 in the North highlighted processes related to organizing and conducting community consultations in the context of the contaminants issue. The recommendations that arose from the workshop served to inform community consultation and community participation activities that subsequently took place in the Kitikmeot Region as the monitoring program was developed and implemented. They therefore provide a context for the community-based activities that followed in the Kitikmeot.

The Hay River Workshop

A two day contaminants workshop, held in Hay River in March 1992 to exchange information and ideas about contaminants, brought together for the first time Aboriginal organizations, health and government representatives from across the North with Aboriginal organizations, research scientists and government representatives from the South (Christensen, 1992, pp.1-4). The workshop was funded by the Northern Contaminants Program, and included 39 participants. An important topic of discussion at this workshop was community consultation. More specifically, plenary and small group discussions took place to

provide multiple perspectives about why community consultation should take place and what were desirable qualities and processes in conducting community consultations.

Each of the five small discussion groups included individuals from communities, regional and territorial health and government representatives, a research scientist, and a representative from an Aboriginal organization. Discussion leading to recommendations took place about who specifically in communities should be included in subsequent consultation activities about contaminants.

The following response to the question "Why should community consultation take place?" was summarized from the results of five small group discussions

> The community has an ethical, legal, moral right to know, and consultation acknowledges people's basic right to make decisions concerning themselves. Consultation helps with the identification of community concerns and the possible responses. The community is given the opportunity of seeing the benefits of the work, and outside agencies have the opportunity to maintain an effective relationship with the community. Participants feel they are part of a team, and rapport is assured. The issue of impact on a community if the project does not go ahead, can be discussed. The consultation process ensures programs are relevant, successful, accurate, useful and meaningful to everyone. Better information is gathered and the best and most responsible results possible are achieved. Involvement in the decision making process ensures community support. (Christensen, 1992, p. 13)

In response to the question "How do you get people involved, generate interest, and do a community consultation?" there were 21 recommendations put forward by the five groups (Christensen, 1992, p.13). Recommendations included: (a) the importance of community ownership ("let the community take

the lead in organizing the meeting and take full charge of the process", "make the community part of the team" and "hire a community coordinator"); (b) the importance of appropriate verbal communications ("use examples the community can identify with", "use language that is understood and not laden with difficult scientific terminology", "use interpreters from the community"); (c) the importance of continuing communications over time ("spend time in the community. Don't fly in and out. These 'one nighters' are noticed by the residents"); and (d) the importance of evaluation ("evaluate the consultation process being used and ensure that the community understands what is being said"). The small groups also highlighted the importance of "recogniz[ing] that consultation meetings are a two-way process". In discussion results from later the same day, it was noted that consultations (and reporting of results) also had a time element to them, where it may be necessary to "...reinforce results as needed. Consultation and presentation of results is not necessarily a one time effort" (Christensen, 1992, p.14).

Topics related to communications and education were included in the results of small group discussions about common community consultation issues, and were paraphrased as follows

> There is increasing public awareness about contaminants. People are more observant about changes in their environment (fish appearance) and are, therefore, asking more questions – Are the fish safe to eat? Is the water safe to drink? The answers or at least more information about these public concerns must be in usable form.
>
> Effective education is needed. Contaminant information should be available and useful. There is much 'baseline' and traditional knowledge to be tapped, for example the identification of changes in wildlife. Researchers need to utilize these and other local resources, and research

> data must be accurate. Communities need guidelines so they can identify their contaminants-related problems. Then networking, cooperation between all parties and community involvement will take over. (Christensen, 1992, p. 10)

The group from the Baffin Health Region used the circumstances experienced by Broughton Island residents to highlight the essence of their discussions about communications as follows

> Broughton Island was used as an example of concerns about the communication process. The concerns included local perceptions of the problem, media distortion, lack of translation and interpretation therefore no real basis for personal choice, and no action plan. Workshop participants suggested more northern involvement in all aspects of the studies and a communication plan. Further recommendations included; expressing and translating the scientific results and related information as required at a maximum of a grade 9 level, for the community and the media, in both a local and global context. Then the residents could grasp whether just their community was being singled out. An explanation of benefits and risk, with examples, such as PCB's in breast milk versus smoking, was also recommended so that residents could make their own decisions, and take action. (Christensen, 1992, p. 11).

There were other qualities of community consultations that emerged from the small group discussions over the two days

> Community consultation should be an ongoing process at every stage of the project. Residents should be consulted on identifying needs and involved in the planning of a project (Christensen,1992, p. 14); and
>
> ...the need for community consultation to be evaluated (for example by asking the residents to convey back their understanding of the exchange), and involvement of the community in the process, which conveys partnership and ownership. In addition, the communication of findings to the community must include enough information so residents can balance risks and benefits (Christensen,1992, p.12).

As well, in terms of contaminants research specifically, recommendations from the workshop included

> Funding for community education and training, gathering baseline data, conducting similar studies in other regions for comparison (ie., Inuvik

> region with another Canadian Arctic region), and having studies and further needs initiated by the community. ..The community needs to be the driving force (Christensen, 1992, p. 12).

Importantly, workshop participants recommended who should be involved in community consultation activities

> Involve both formal and informal leaders of the community...[also] involve the local, regional and head offices of the Aboriginal governments, hunters, trappers, fishermen, advisors to Chiefs, Renewable Resource Officers, Community Health Representatives, Environmental Health Officers, health centre staff, Hamlet Council and local government officials, Community Health Committees and key Elders who are role models. (Christensen, 1992, p.15)

Taken together, these recommendations highlighted specific qualities in relation to community-based communication and education activities that were important to successful community consultations. How these recommendations for community consultation influenced the work that took place in the Kitikmeot Region will become evident as the case unfolds.

Problem Definition

A contaminants workshop for community representatives and health workers in the Kitikmeot region in June 1993 generated considerable interest in the contaminants issue. The workshop subsequently led to the definition of the problem.

The Taloyoak Workshop

The contaminants workshop was held in the community of Taloyoak (formerly Spence Bay) in the Kitikmeot region on 8-9 June 1993. The workshop was organized by the Kitikmeot Health Board, who invited community and health

representatives from each of the eight communities in the region, as well as three Territorial government staff who were invited to present information on specific topics that were of interest to the communities. The purposes of the two day workshop were to introduce environmental contaminants issues and initiatives, to exchange information and concerns about contaminants, and to form a community-based working group to address regional human baseline monitoring activities (Phillips, 1993). Funding for the workshop came from the Northern Contaminants Program. Workshop participants included "nurses, community health representatives, health board members and mayors...As the target group for the workshop were the local people of the Kitikmeot region, the number of government officials was purposely kept to a minimum" (Phillips, 1993, p. 8). There were no researchers invited, nor were there any references to researchers recorded in the Final Workshop Report. During the course of the workshop, the 15 participants alternated between presentations and small group discussions to provide opportunities to receive new information as well as to discuss what they had learned. Participants recommended that educational materials about contaminants be developed by Northern groups to meet Northern needs and identified the need for fact sheets and other information packages to be produced in plain language for use in communities and with potential participants in the monitoring program.

The presentation that was made by the Kitikmeot Health Board's Medical Health Officer (MHO) was a significant aspect of the workshop. It contained key elements that set the direction for the community-based territorial and regional

development and implementation of the human health monitoring program, and is reported in full

> Human health baseline monitoring (HHBM) is an approach used to determine the degree to which contaminants have accumulated in humans and their possible effects on human health. Research results may provide evidence to other countries for the need of international cooperation. This is important as many of the contaminants reach Canada through long range transportation.
>
> The activity proposed for the NWT is to determine the level of some organochlorines, heavy metals and radionuclides in northern newborns and develop a baseline to evaluate trends over time and regions. Tentatively, cord blood will be monitored for one year at the Stanton Hospital in Yellowknife which will capture the majority of births from the two regions: Kitikmeot and Mackenzie. The monitoring will contribute to national and Arctic Monitoring and Assessment Program databases and provide northerners with information for informed decision making.
>
> An important component of the project is the focused consultation process including: the establishment of Consultation Working Groups in each region with representation from Aboriginal organizations, health boards and communities; workshops for health workers; and information sessions in the communities.
>
> The Consultation Working Groups will develop and modify protocol to direct monitoring activities. It will also serve as a link between communities and coordinators.
>
> Early work done in the NWT and Arctic Quebec has demonstrated that because of traditional dietary habits, northern people may be exposed to some contaminants in traditional foods, which include certain heavy metals, organochlorines and radionuclides. There is presently little information on the kinds and levels of contaminants in NWT northerners. This will provide an opportunity to obtain more information. Initial monitoring and exposure assessments will involve the Kitikmeot and Mackenzie regions. Stanton Hospital provides services to both regions.
>
> Once consultation and information sessions have occurred, and the protocol has been finalized, sampling will begin. A target date of September has been established. The [territorial] proposal was approved by the Arctic Environmental Strategy Science Managers Committee on Contaminants following discussions and recommendations from the Technical Committee on Contaminants in Northern Ecosystems and Native Diets. This Technical Committee has representatives from

> Aboriginal organizations, federal departments, GNWT and the Yukon Government. (Phillips, 1993, p. 17)

Of note is the use of the words *research* and *protocol*. The MHO's lack of reference to university-based researchers in the context of research and protocol implies a more publicly-owned perspective of what is included in these concepts relative to the perspective of health research funding agencies. As well, the MHO's presentation includes references to both circumpolar and national contaminants programs, research findings from Arctic Quebec and the NWT and the rationale for undertaking monitoring activities in the Kitikmeot region. The presentation also specified the purpose, roles and membership of a Consultation Working Group. "This workshop goal was introduced, discussed and received a great deal of enthusiasm from those present" (Phillips, 1993, p. 9).

The nature of the problem that had been identified by the end of the Taloyoak workshop was summarized as follows

> Representatives showed a keen interest in the topics [discussed at the workshop], and felt that their communities would be receptive to the human health baseline monitoring. Many good ideas evolved on ways of communicating the information to members of the communities in a manner that would be understandable and interesting but not alarming. (Phillips, 1993, p. 9)

Hence the problem that resulted in the formation of the Kitikmeot Contaminants Consultation Working Group was twofold: how to communicate about the topic of contaminants in traditional foods without alarming community members; and how to develop and implement a process of establishing a human health baseline for contaminants in maternal and umbilical cord blood without causing undue alarm about the safety of traditional foods.

Overview of the Kitikmeot Region's Monitoring Program

An overview of what transpired over the next two and a half years in the Kitikmeot region will provide a useful framework for the analysis that follows. Briefly, the Kitikmeot region's monitoring program involved collecting samples of maternal and umbilical cord blood from participants who had previously provided written informed consent, usually at least 2 months prior to the delivery of their baby. The consent process and materials, and the program education and communication materials were developed by the community and regional representatives on the KWG. Blood samples were collected at the time of birth at Stanton Yellowknife Hospital, processed and shipped to an analytical chemistry laboratory at Laval University in Quebec. At the lab in Quebec, blood samples were analysed for polychlorinated biphenyls (PCBs), 14 chlorinated organic pesticides, lipids, the heavy metals mercury, cadmium and lead, and the trace elements copper, selenium and zinc. Through a results communication strategy developed by the KWG, participants subsequently received individual results for themselves and the results from their newborn for contaminants with known blood guidelines (PCBs, mercury, cadmium and lead). Communities also received aggregated results soon after individual participants' results had been made available to them. Aggregated results were also reported and interpreted using a video that was produced specifically for that purpose, which was aired on TV and was followed by an opportunity for viewers to phone in with any questions they had. After the program had been completed, evaluations were conducted with community health workers, participants, Working Group members and

various agencies involved with the program. And finally, all materials that were associated with the program's development, implementation and communications were collated into a Final Program Report, including 13 detailed appendices (Rohlmann, Seddon & Mills, 1996).

Between May 1994 and May 1995, there were a total of 80 participants, with a recruitment rate of 50% of the eligible births during the year long recruitment period. Of these participants, 58 contributed both a maternal and a cord blood sample, 8 contributed only a maternal blood sample, 3 contributed only a cord blood sample, and 11 participants had no blood tested.

The majority of the activities related to the regional monitoring program took place between January 1993 and December 1995. Funding for the monitoring program in the Kitikmeot region as well as the Mackenzie region for the three fiscal years was $592,000. Of these funds, 33% were for salaries, 18% for consultation activities, 17% for education and information resources, 26% for analyses of blood samples, and 6% for program operations (Seddon, Walker & Corriveau, 1998). These funds were provided by the federal Northern Contaminants Program. In addition, there were "in-kind" contributions from the regional health board (staff participation and logistics), community health workers, GNWT, and laboratory and maternity staff at the hospital in Yellowknife.

These activities began to take shape in June, 1993, during the contaminants workshop in Taloyoak.

Formation of the Kitikmeot Contaminants Consultation Working Group

Several people volunteered to form the Consultation Working Group, and developed the following objectives at the end of the Taloyoak workshop

- Produce a video on contaminants;
- Review and expand the cord blood protocol outline;
- Develop a consent form;
- Develop an information package on monitoring activities for the community, for health workers, and individual participants; and
- Coordinate information sessions in each community. (Phillips, 1993, p. 9)

The founding membership of the Kitikmeot Contaminants Consultation Working Group (hereafter referred to as the Kitikmeot Working Group) in June 1993 was health workers including nurses, and Community Health Representatives (CHRs), and Kitikmeot Health Board representatives.

The group met several times over the summer, and decided to expand their membership. As the Territorial lead on the overall project, I was invited to join in the fall 1993. An invitation for membership was also extended to the Kitikmeot Inuit Association. In addition that fall, a Regional Contaminants Coordinator, funded by the Northern Contaminants Program, was hired by the health boards to facilitate the development of the monitoring programs in the Kitikmeot and Mackenzie health regions. The Kitikmeot Working Group was chaired by the Regional Contaminants Coordinator from that time until the completion of the project in December 1995.

Cyclical and Iterative Process

One of the key aspects of CBPR is that the work being undertaken unfolds as a cyclic and iterative process, as follows

> [CBPR] Involves a cyclical and iterative process...that includes partnership development and maintenance, community assessment, problem definition, development of research methodology, data collection and analysis, interpretation of data, determination of action and policy implications, dissemination of results, action taking (as appropriate), specification of learning, and establishment of mechanisms for sustainability. (Israel et al., 1998, p. 178).

In the process of developing and implementing the maternal and umbilical cord blood monitoring program that the MHO referred to in his presentation at the Taloyoak workshop, there were three distinct phases. The case will now be examined according to three phases, the initial phase, the middle phase and the final phase.

Initial Phase

The initial phase, which took place between June 1993 and April 1994, began immediately after the Taloyoak workshop.

The Kitikmeot Working Group met for the first time nine days after the June 1993 contaminants workshop in Taloyoak. They met twice a month for the next two months and a total of nine times during this period (Appendix 2). Eight meetings were via conference call, and one was an in-person two day meeting which took place in September 1993 in Cambridge Bay. Common to all meetings was the process of Working Group members coming together to review and discuss issues and materials they were working on, then taking the results of the meeting back to others in their communities or offices for feedback and ideas, which they would then bring to the next meeting. Each meeting presented opportunities for Working Group members to build on their work in the

development of education materials and the monitoring program protocols, including attention to communications processes.

Early topics of discussion included various aspects of communications with different target groups and different topics and the protocols for the monitoring program, particularly the communications protocol and the content of the information packages for various audiences. Another topic of discussion was the content and process for producing the video that had been agreed upon after the formation of the Kitikmeot Working Group at the Taloyoak workshop.

Development of protocol components

A main focus of activity of the Working Group during this phase was development of the components of the protocol for the monitoring program. These components included the objectives of the monitoring program; consultation activities (regional health boards, KWG, Stanton Hospital Ethics Committee and Science Institute license); and methodology. Methodology protocol components included: (a) participant recruitment; (b) maternal and cord blood data collection; (c) sample storage and transportation to Laval; (d) program communications (for communities, health workers, participants); (e) informed consent (process and forms); (f) translations of materials into Inuktitut and Innuinaqtun; (g) lifestyle questionnaire; (h) biological sampling and analysis; (i) data handling and analysis; (j) risk analysis and communication; and (k) dissemination of results (Rohlmann et al., 1996).

The Working Group identified three priority target audiences to receive initial communication packages: 1) potential participants in the monitoring

program, 2) health workers, and 3) communities. Potential participants in the monitoring program were women whose pregnancy had been confirmed, and who therefore could choose to participate in the monitoring program following a process of informed consent. Their participation could include donating either a sample of their blood and/or the blood from the umbilical cord of their newborn.

The term, health workers, described practitioners involved with the monitoring program. They included front line delivery workers, as well as regional and territorial staff and managers

- Health Centre: Nurses and Community Health Representatives;
- Regional Health Board office: Regional and Senior Nursing Officers, Health Promotion Officers, Regional Nutritionists and Environmental Health Officers;
- Monitoring Program: Program Coordinator, Medical Health Officer and the GNWT Contaminants Unit. (Rohlmann et al., 1996, p. 12).

The communities included various groups with each of the communities, including the hamlet council, health committee, elders, schools, and Hunters and Trappers Association (Seddon et al., 1998).

Information packages for the three audiences were developed through an iterative process. The Kitikmeot Working Group came together by conference calls to discuss what types of information were required and how it could be communicated. After the meeting, the regional coordinator worked up Kitikmeot Working Group members' ideas into draft documents. These documents were then returned to the Working Group, usually by fax because computer access was either limited or non-existent in most communities at that time. The attempt was made to have sufficient time between the distribution of documents and the next meeting to provide time for Working Group members to review the drafts

with others in their communities or offices. Without exception, Working Group members contributed to the KWG's work in addition to their full time regular duties.

Other components of the protocol that were topics of discussions at Kitikmeot Working Group meetings in the initial phase included developing flowcharts for participant recruitment procedures, and creating promotional materials to inform and engage communities in the monitoring program. Blood sampling and analytical protocols were also being produced at this time, led by the regional coordinator in collaboration with the GNWT Contaminants Unit head, and others. Those contributing to the technical protocol components included the Chief Chemist and staff at Laval University's Toxicology Lab, researchers from Laval University and Health Canada, and the maternity and laboratory staff at Stanton Yellowknife Hospital (Seddon et al., 1998). The decisions made by the Working Group guided all components of protocol development and completion. Technical protocol elements were sought from the appropriate researchers and incorporated into the protocol document.

An example of the integration of cyclical and iterative processes through which the KWG created the products during the initial phase was the engagement of the Nurses-in-Charge in the monitoring program. Using materials developed by the Kitikmeot Working Group, the Regional Coordinator made a presentation to the health workers in the Kitikmeot region, specifically to the Nurses-in-Charge (NICs), on 1 November 1993. The presentation was made in-person in Cambridge Bay as part of a NIC conference. It included a general

overview of the issue of contaminants, the rationale for the maternal and cord blood monitoring program, an orientation to the draft Health Workers Information Package, and the role of health workers in the development and implementation of the monitoring program.

Health Workers Information Packages included the monitoring program delivery plan, the draft pamphlet on Human Health Monitoring, a fact sheet about Environmental Contaminants, an up to date activity summary for the monitoring program, an outline of the cord blood sampling protocol, a sample consent form, a sample questionnaire, sample results communications flow charts and information about the Kitikmeot Working Group's work. The anticipated responsibilities of community health workers in the monitoring program were also presented. These responsibilities were to introduce the monitoring program to potential participants in the Health Centre after confirmation of pregnancy; provide the Participant Information Package to potential participants during their first prenatal visit; having the consent form signed at the second prenatal visit; completing the first two parts of the lifestyle and traditional food use questionnaire at the third prenatal visit; forwarding the questionnaire and signed consent form with the participant when they traveled to Yellowknife to deliver; and providing information about how and when results would be made available to participants and communities (Rohlmann et al.,1996).

The NICs were invited to contribute their comments to the draft documents that had been presented. Their comments were subsequently incorporated into the protocols by the Regional Coordinator. There was considerable involvement

required by community health workers in the implementation of the monitoring program, and the meeting was an important opportunity for nurses-in-charge to contribute their perspectives and insight to the program.

Education

During the initial phase, there were two aspects of learning for the KWG: learning how to develop education materials; and learning how to prepare a funding proposal. At the Kitikmeot Working Group's conference call in December, 1993, members reviewed their progress on educational materials, including the draft request for proposals for a promotional poster to provide awareness about the monitoring program. They also defined the main elements for the production of a video. The target audiences for the video were potential participants in the monitoring program and communities in the Kitikmeot region. For potential participants, the video would provide the first component of the informed consent process, by generally introducing the issue of contaminants, explaining human health monitoring and the rationale behind it, and then describing more specifically the maternal and cord blood monitoring program that was being undertaken in the region.

In addition to learning how to develop education materials, the members of the Kitikmeot Working Group were learning about the development of funding proposals. In February 1994, the Working Group met via conference call to develop their 1994-95 funding proposal in collaboration with the Kitikmeot Health Board and others, which was subsequently incorporated into the Territorial-wide proposal. The proposal included maternal and cord blood monitoring activities in

the Kitikmeot region as well as the other two health regions that were participating at that time, was submitted to the Northern Contaminants Program for funding consideration, and subsequently funded.

Completion of the Initial Phase

The focus of the Kitikmeot Working Group's work during the months of March and April, 1994, was the completion of the components of the draft protocol. The Working Group was involved with all components, either authoring or reviewing them. Others were also involved in the review process. Prior to the implementation of maternal and cord blood sampling, the Regional Coordinator circulated the draft protocol document for review by Regional Health Board staff, the Kitikmeot Contaminants Consultation Working Group, the GNWT Dept. of Health and Social Services, maternity and laboratory staff at Stanton Hospital in Yellowknife, and laboratory staff at Laval University and Health Canada. The Regional Coordinator made revisions according to the comments received, and forwarded the document to the Stanton Hospital Ethical Review Committee, and subsequently to the Science Institute of the NWT for issuance of a Research License. While university researchers provided technical components of the protocol that included biological sampling and analysis, there were no university ethics reviews conducted, no involvement of health research funding institutions, and no direct involvement of researchers other than as previously described. The Research License was subsequently issued by the Science Institute of the NWT.

Middle Phase

The middle phase took place between May 1994 and May 1995. It consisted of the implementation of the monitoring program according to the protocols that were developed, reviewed and approved during the initial phase, as well as ongoing education and communication activities. The middle phase included "data collection and analysis, [and] interpretation of data" as described in Israel et al. 1998 (p.178) in the context of principle six.

Data collection and analysis

Data collection began in May 1994 and continued to May 1995. Maternal and/or umbilical cord blood samples were collected at the time of birth at Stanton Yellowknife Hospital, processed and shipped to an analytical chemistry laboratory at Laval University in Quebec in batches (Seddon et al., 1998). An example of the participant recruitment package is included in Appendix 3.

A face-to-face meeting was held in Yellowknife in October 1994, to review the data collection progress to date and to plan for future activities. The workshop took place immediately after a territorial workshop with participants from across the NWT and Southern researchers called *Mercury – a health concern in the NWT?* (Rohlmann, 1994). Most Kitikmeot Working Group members were able to attend the two day Mercury Workshop prior to the Working Group meeting. Participation at the mercury workshop was a good opportunity for Working Group members to meet research scientists from various disciplines whose research involved some aspect of mercury (sediments, fish, marine mammals and human

health), and for researchers to meet community representatives and practitioners.

The Kitikmeot Working Group met mainly by conference calls during this phase, with the exception of two face-to-face meetings – one in the fall and one in the spring. There were six conference call meetings, in addition to the two in-person meetings.

Over the summer, meetings were primarily focused on keeping each other updated about implementation activities, including reviews and feedback about the pilot recruitment materials. The Group held preliminary discussion about communication strategies for results, and discussed translation of the video voice track into Inuktitut (Rohlmann, 1996). This iterative process of reviews and discussions about materials or processes, where community and regional input were sought and subsequently incorporated, took place eight times during this phase as reflected in the minutes of eight meetings over the 12 month implementation period (Appendix 2).

Education

Activities related to education and communications continued during the middle phase of the monitoring program. Communications were prioritized, within and between communities, as well as with others involved with the monitoring program. For example, there were 8 monthly newsletters for participating health agencies that the Regional Coordinator produced and distributed. Newsletters included sampling updates and health centre updates, as well as a section for frequently asked questions. The newsletters served communications and

educational purposes, and also help to create and sustain a team approach under the conditions of considerable geographic distances and several institutions. The team consisted of health centres and regional agencies in the North, as well as Aboriginal organizations, Laval University's Toxicology Lab, the Northern Contaminants Program office in the Department of Indian Affairs and Northern Development, and Health Canada in the South. The newsletters were a vehicle for keeping people current about the status of the maternal and cord blood monitoring program in the Kitikmeot region that would have been difficult to do any other way.

Recommendations arising from the October 1994 face-to-face working group meeting were two fold. One set of recommendations was to develop nutritional fact sheets for traditional foods. The second was to proceed with the development of NWT blood guidelines for contaminants in order that materials to assist with data interpretation would be ready when results were available. (Seddon, 1998). The Group decided to prepare nutritional fact sheets for various traditional food species for various traditional food species in order to balance communications about contaminants in these same traditional foods species. An example of the nutritional fact sheets that resulted from this recommendation is included in Appendix 4.

In addition to nutritional fact sheets, there was also discussion about identifying ways to communicate information about contaminants with monitoring program participants and their communities, both educational materials as well as regional/community communications strategies.

Planning for the Final Phase: Creating a Communication Strategy

In anticipation of the dissemination of contaminants results, a face-to-face meeting took place in April 1995, specifically designed to develop strategies for the communication of blood results to program participants and communities. This set of strategies was referred to as the results communication protocol or strategy (Seddon, 1995).

The rationale for creating the results communication protocol arose from the informed consent process. During the consent process, participants who were recruited into the program were informed that they would receive their individual results once sampling and the analysis of all the blood samples had been completed. Importantly, participants were advised that they would receive information on contaminants with known guidelines. The blood results that were discussed included the levels of PCBs, mercury, cadmium and lead in participants' own blood and the umbilical cord blood from their newborns. With the end of recruitment into the monitoring program occurring in May 1995, the April 1995 meeting was timed to enable results communications materials to be created before all the results would be received by the Regional Coordinator from the analytical lab.

The challenge before the Working Groups at the meeting in April 1995 was of a highly sensitive nature – communicating results back to participants and communities about the levels of contaminants in their blood and the blood of their baby. The goal of the meeting was to determine a process that was sensitive and

respectful, and to determine what materials would be required and how they would be developed.

What was highly sensitive was that the sources of most contaminants were the traditional foods that many participants and community members relied on, and that also provided abundant nutritional, cultural and economic benefits. As well, it was a challenge how to report numerical values in a useful and understandable way, despite unfamiliar units such as µg/l (micrograms per litre) or parts per billion, for contaminants that were essentially invisible, and for which there were no Inuktitut words to include in the translation.

At the end of two days, after considerable discussion, a results communications strategy had been developed (Seddon, 1995). The essence of the strategy was that program participants' results would be forwarded to the Health Centres, and the Nurse-in-Charge would be responsible for communicating the results to participants once results for all participants were available from the full year of sampling. Participants had the choice of knowing or not knowing their individual results. Results were put on the participants' medical files regardless to enable future discussions between the individual and their health practitioner. The information placed on the medical file needed to be presented so it could stand on its own in years to come, and as such this was an anticipatory communications consideration. .Seddon (1995) described the three major sets of recommendations that arose from the meeting: those related to the processes of reporting and recording the data; those related to the reporting of

individual results to individuals; and those related to the reporting of results to communities.

For the processes of results reporting, it was recommended that a summary of all participants' results, with all names removed, be produced and distributed to Health Centres once all the results were available, so that individual results could be reported in the context of others. Once individual results had been made available to participants, Health Centres were to communicate summarized results to community groups, which would be prepared by the Regional Coordinator. Visits to communities from Regional Health Board staff and/or territorial staff were to take place at the invitation of the community.

For the processes and materials for reporting of individual results to individual participants, the individual blood results were to be presented using a pictorial form, accompanied by a summary, using easy to understand units, accompanied by information about the guidelines and results of other studies, and were to include the effects of lifestyle choices such as smoking, diet and physical exercise. Results were also to be presented in a balanced way, including the positive effects of a diet that included various traditional food species, as well as the contaminants that may come from these species. Participants were to have take-home information that included questions and answers, overall program results and information about what would be done with the results. As with all program materials that were developed for this program, the literacy level used was about the Grade 9 level, using a plain language style.

For the process of reporting results to communities, Working Group members recommended that a video be produced communicating overall program results, and which were positive, holistic and included specific actions for personal and community lifestyle changes. In addition, for reporting of results to communities, there were recommendations that resources be developed to assist health workers in their role as community contacts for the program. Resources were required both for interpreting and communicating results. As well, there needed to be opportunities to promote team building among community health workers. Beyond the life of the monitoring program, there was a recommendation that information and results needed to become integrated into ongoing community health programs and activities. The recommendations arising from the April 1995 meeting became the template that directed the Working Group's activities for the next seven months, during the final phase of the monitoring program.

Final Phase

This phase occurred from June 1995 to December 1995, with major activities directed by the recommendations of the April 1995 meeting.

Dissemination of results

To prepare for the dissemination of results, the Regional Program Coordinator developed a data management and analysis system that would facilitate the production of statistical information about the data once all samples had been analyzed and the data returned to the program office (Seddon, 1995). In the same iterative way that other monitoring program materials had been developed

by the Working Group, the regional coordinator developed and revised drafts with guidance and feedback from the Working Groups and others. There was only one meeting during this phase, in September 1995, however the extensive recommendations from the April meeting provided sufficient direction to the Regional Coordinator and Working Group members during the final phase.

What unfolded as a result of the recommendations arising from this workshop was the development of several communication tools. These communication tools are summarized in Appendix 5 to illustrate results communications packages developed and implemented for program participants, health workers and communities respectively. Of note is that each of these communication tools reflects the ideas and recommendations of the Working Group members, who were also involved in their production, distribution and use.

In addition to these materials, a second video was scripted and produced that provided program results in a way that complimented the first video that had been produced to introduce the issue of contaminants. The results communication video was aired on a live phone-in TV show, which included a panel of Working Group members to respond to questions that were phoned in by community members.

In addition to the phone-in TV show, results communication packages were distributed to 17 agencies in the Kitikmeot region, including hamlet offices, hunters and trappers organizations, the Kitikmeot Inuit Association, Kitikmeot Regional Council, and Pauktuutit, the national Inuit women's association. The substantial efforts to ensure results were communicated clearly and widely were

intended to address concerns expressed by Working Group members and others about the importance of returning information to those who had provided it (Seddon, 1995).

The timing of results communications was sequenced according to the recommendations of the Working Groups. The intention behind the recommended sequence was to ensure program participants knew their individual results before others knew about the regional results, while at the same time minimizing the time between when other community members might have questions but not have a way to get answers to them. As implemented, participants results were available at their Health Centre for the first 2 weeks of November, followed by community results communicated for the next two weeks, culminating with the phone-in TV show on 29 November 1995.

The Regional Coordinator extended an invitation to all participating communities that she would be pleased to meet with them at their invitation in their community to further discuss the results, however no communities followed up with such an invitation.

Establishment of mechanisms for sustainability

The sixth key principle of Israel et al. (1998) incorporates mechanisms for sustainability in community-based participatory research. While evaluations were not undertaken with a focus on sustainability, the evaluations were conducted to seek feedback and insight about the development and implementation of the monitoring program from several groups, and provided useful information.

Evaluation questionnaires were mailed to community health workers, hospital staff (maternity and lab) and Working Groups two months after recruitment had been completed (August 1995). The evaluation results were reported as being from both regions. Evaluation results are described for both regions unless specified otherwise. In addition, participants were requested to submit written evaluations in January/February 1996.

Despite their perspective that many aspects of the program (e.g., newsletters, videos, posters) were well done, community health workers felt burdened by their roles in the monitoring program. Their monitoring program responsibilities were very time consuming, particularly given their already pressing workloads. Stanton Hospital personnel in maternity and the lab acknowledged the excellence of the program materials, and at the same time cited the monitoring program as adding extra work when staff were already overworked.

The evaluation of the program by the Working Group members helped to illuminate the multiple roles these members identified as part of their contribution to the program, and to the development of capacity within their communities. Working Group members selected all options that were itemized in the evaluation as reflecting the roles of the Working Groups, as follows

- identifying issues about environmental contaminants that are specific to community/cultural groups;
- assisting in designing and planning a program that addresses the needs of community/cultural groups;
- reviewing various forms of communications to ensure issues are addressed and communications are easy to read;
- providing information about the program and monitoring results to community/regional organizations;

- being key resource people to communities on the topic of environmental contaminants;
- providing recommendations for future monitoring activities on environmental contaminants; and
- sharing experiences and issues relating to environmental contaminants. (Seddon et al., 1998, p. 22, Appendix 1).

There was the perception by Working Group members that in these roles, they had facilitated community participation

> All Kitikmeot members agreed that their Working Group provided a useful way of gaining community participation in the planning and implementation of the monitoring program....Some respondents, particularly Kitikmeot members, indicated their personal interest in continuing to work as resource people on contaminants issues, once the monitoring program in their region had been completed. (Seddon et al., 1998, p. 22, Appendix 1).

In terms of program materials, the first video was perceived as being a good introduction to the issues of environmental contaminants, and was viewed not only in health centres, but also in schools, at community meetings and workshops, and in homes. Program newsletters were identified as a useful means of keeping people who were involved with various aspects of the program and who were geographically distant from each other informed and motivated. Participant newsletters were deemed to be a useful way of keeping participants informed about the program during the time between when they had donated a blood sample and when they received their individual results. The posters were described as being a good way of raising awareness about the program, and participants were pleased to receive them as a token of appreciation for their participation (Seddon et al., 1998). Nearly all participants reported reading the newsletters and the nutrition fact sheets about traditional food species, and most

participants reported having enough information to understand their results charts.

The regional maternal and cord blood monitoring program office closed in March, 1996. Before her departure, the regional coordinator produced a final summary report that collated all program materials (Rohlmann et al., 1996). While there had been discussions amongst Working Group members about continuing to meet as a group after the monitoring program was completed, no further meetings took place, and there were no additional funds sought.

Conclusion

In the Kitikmeot region of Canada's central Arctic, a complex health monitoring program was developed and implemented using a community-based approach. A working group was established that consisted of community representatives and practitioners, with researchers acting in an advisory capacity. The Kitikmeot Contaminants Consultation Working Group participated in all stages of the monitoring program, which took place over two and a half years, between June 1993 and December 1995.

The Working Group incorporated recommendations about mechanisms and processes for community consultations that had been proposed in 1992 at a workshop held in Hay River, NWT. These recommendations included the importance of ongoing consultations in helping with the identification of community concerns and possible community-based responses, in developing partnerships with communities, and in the development and communication of

education materials that address community questions and issues over time, using plain language.

The Working Group used an iterative process to develop, review and complete education materials, the monitoring program protocols, the implementation of the monitoring program and the interpretation and communication of results to individuals and communities. The cyclical and iterative process consisted of the Working Group coming together to develop, review or finalize what they were working on, then returning to community members and others to consult with them, and then communicating the community comments at the next Working Group meeting. This process, which was repeated many times, provided opportunities for meaningful community participation during all phases of the monitoring program.

Chapter Five

The Case Explored Through the Lens of CBPR in the North

Introduction

The purpose of this chapter is to critically analyze the work that took place in the Kitikmeot region in light of key concepts of community-based participatory research and the Northern context. The key concepts include problem definition and the involvement of partners in all phases of the research process in ongoing cycles of action and reflection. Factors that either facilitated or hindered the roles of communities, practitioners and researchers will be explored, and tensions identified. This analysis will contribute to an improved understanding of community-based participatory research in the North. It is informed by the textual analysis of documentation about the work of the Kitikmeot Working Group, selected literature, and the knowledge I bring to the analysis from an insider's perspective as a Kitikmeot Contaminants Consultation Working Group member.

It is important to note prior to the detailed analysis an aspect of what may not immediately apparent. In addition to the processes of community-based participatory research that are the focus of this research, there were data that were produced as a result of these processes and actions. The data resulted from the collection of blood samples from mothers and/or the umbilical cord blood of their newborn, with full, informed consent. The blood samples were sent to a laboratory for analysis at Laval University, and the results sent back to the regional program office. The data from the Kitikmeot monitoring program were included in national (Jensen et al., 1997, Van Oostdam, Donaldson, Feeley &

Tremblay, 2003) and circumpolar (AMAP 1998, AMAP 2003) publications as well as two international, peer-reviewed publications reporting levels of organochlorine and metal contaminants (Butler Walker et al., 2003, Butler Walker et al., 2006).

Problem Definition

One of the principles of CBPR is that the topic and focus of the research initiative is driven by needs identified by the community (Israel et al., 1998, p.177). The identification of a community-based problem may be facilitated by community consultation, which is what happened in the Kitikmeot Region.

Community Consultation

The expression "community consultation" is often overused, particularly in the North. It contains assumptions that are important to clarify for the consultation process to achieve the desired results. The Hay River workshop that took place in March, 1992, was designed to identify how Northern communities wanted community consultation to take place about environmental contaminants. The results from the Hay River workshop subsequently informed the community consultation process that took place in Taloyoak a year later. It was at the workshop in Taloyoak in June 1993, that the research problem was conceptualized and which precipitated the formation of the Kitikmeot Contaminants Consultation Working Group.

The results from discussions and recommendations at the Hay River workshop highlighted that a community has the ethical, legal and moral right to know about issues that may affect them, and the action of consultation

acknowledges people's basic right to make decisions concerning themselves. Consultation helps with the identification of community concerns and the possible responses. The community is given the opportunity of seeing the benefits of the work, and outside agencies have the opportunity to develop and maintain effective relationships with the community. For consultations to be most effective, they need to use non-technical written and verbal communications, continue over time, and be a two-way process.

Conceptualization of the problem

At the workshop in Taloyoak, the Medical Health Officer presented the issue of environmental contaminants in the North, and posed why it was important to know more about what levels were in Northerners. What he presented were facts, not a problem. In a Freirian context (1982), it could be said the MHO provoked the people (p. 34). The facts, however, generated concern by those present at the workshop, who identified that what was problematic about the facts was their potential to cause alarm to community members, and the need for action. At that moment, the issue became one of importance to the community representatives.

The Community Health Representatives who were at the workshop were Inuit, who had directly experienced the cultural, nutritional and economic benefits of consuming traditional foods all their lives. Their knowledge about the importance of traditional foods to Inuit, and the possible consequences to the health of their community members of eating contaminated traditional food or worse, not eating traditional foods because of fear about contaminants, did not

need to be presented by anyone. They already knew. This was indicated in the Summary Report

> Representatives showed a keen interest in the topics [discussed at the workshop], and felt that their communities would be receptive to the human health baseline monitoring. Many good ideas evolved on ways of communicating the information to members of the communities in a manner that would be understandable and interesting but not alarming. (Phillips, 1993, p. 9).

Hence the problem that resulted in the formation of the KCCWG was twofold: how to communicate about the topic of contaminants in traditional foods without alarming community members; and how to develop a process of establishing a human health baseline for contaminants in maternal and umbilical cord blood that would be acceptable to communities.

Was the process of problem definition that took place in the Kitikmeot region consistent with key principles of community-based participatory research? According to Cornwall & Jewkes (1995) "the most important distinctions [between participatory and conventional research] centre on how and by whom is the research question formulated and by and for whom are research findings used" (p.1668). In participatory research, these authors attest to the key role of the community in the formulation of the research question or problem. Israel et al. (1998) are less categorical about how and by whom the research question is formulated. These authors include problem definition as one component of a cyclical and iterative process, but do not specify the essential role of community as clearly as Cornwall and Jewkes (Israel et al., 1998, p.180).

Freire's work constitutes an essential underpinning to the conceptualization of community-based participatory research, and it is in

examining his work that the rationale for the critical role of community in the problem definition becomes clear. As described in Chapter Three, the distinction between objects and subjects, and the transformation of people from objects to be acted on by others to subjects participating in the making of their own experience, are integral to Freire's work. The transformation from the culture of silence of oppressed persons as objects to be known and acted upon, to participants dialoguing as subjects is mediated through a process of problem-posing education that includes both action and reflection. Problem-posing education draws on the reality and experience of everyday life.

In the Kitikmeot region, community representatives gave voice to the problem of communicating about contaminants without causing alarm, and the need for action, after learning about the presence of contaminants in the North. This constitutes problem-posing education as I understand it. At the beginning of the Taloyoak workshop, community representatives were essentially objects to be filled by the knowledge of others on the issue of contaminants. Through the presentation of information, and opportunities to reflect on it and discuss it with others in small groups, these community representatives became subjects. As subjects, they organized themselves as the Kitikmeot Working Group and entered into meaningful dialogue with others in their communities and other Working Group members to work on the problem over an extended period of time. The process of problem definition in the Kitikmeot region was consistent with both the theoretical underpinning and a key principle of participatory research practice.

Qualities of Communications and Education

The identification of desirable qualities of communications and education were notably absent in much of the literature I reviewed about the community-based participatory approach. Freire (1970), however, clarifies some aspects of desirable communications and education in the process of students and teacher becoming student teachers and teacher students. For this process to unfold, the communications between students and teacher must be in plain language, ongoing, and two-way to be able to meet the needs of both groups. In addition, the cultural and social context that the students contribute by virtue of being from the [marginalized] community contributes a perspective that becomes incorporated into the dialogue, thereby adding a relevancy that would otherwise be missing.

Without benefit of formal knowledge about participatory research principles, the newly constituted Kitikmeot Contaminants Consultation Working Group's initial focus was on the information needs of members of their communities. There was recognition that there were specific qualities that were required in relation to communities' information needs and how they were communicated, namely that they would be "in a manner that would be understandable and interesting but not alarming" (Phillips, 1993, p. 9). Specific communication and information qualities that were described at the Hay River workshop as being desirable components of community consultations included the use of non-technical written and verbal communications that continued over time and were a two-way process. Specific communication and education

qualities related to key principles of community-based participatory research were not described by Israel et al. (1998), although the products of these qualities, such as trust, cooperation, mutual commitment, building on strengths, resources and partnerships, were identified as inherent in these principles.

Kitikmeot Contaminants Consultation Working Group

The membership of the Kitikmeot Working Group contributed importantly to the qualities of communications and education activities, to the processes that were developed as their work unfolded, and to the cultural perspectives they contributed and incorporated, throughout the life of the project.

Kitikmeot Working Group community representatives were Community Health Representatives (CHRs), who were members of the communities they represented, however they were not volunteer representatives as is sometimes implied in the literature (cf. Israel et al., 1998, p.178). Rather they were trained as CHRs (a two year training program) and employed by the Kitikmeot Health Board to work in the Health Centre in their community. As such, these Working Group members were both community representatives and practitioners.

In their capacity as community representatives, CHRs provided ongoing communications with various sectors of the community about the issue of contaminants in the North as well as the maternal and cord blood monitoring program. The CHRs communicated with the Hamlet Council, the Health Committee, the school, the Hunters and Trappers Association, elders and prenatal women. The content of the communications with others in the community included seeking feedback on draft educational materials about

contaminants as well as several aspects of the monitoring program protocol, particularly participant recruitment materials and the consent form. The consent form, for example, underwent many drafts before community members were satisfied that it was acceptable to their communities and that Working Group members could proceed to the next step. By developing and maintaining communications about contaminants and the monitoring program in their communities, the CHRs facilitated an expanded level of community involvement and participation in the development and implementation of the monitoring program than otherwise would have been feasible.

In their capacity as practitioners, CHRs provided ongoing communication links between various sectors of the community and other practitioners, particularly those who were also members of the Working Group. Other practitioners included CHRs from other communities, Health Centre nursing staff, Kitikmeot Regional Health Board staff and Territorial government staff. Through these communication links, the development of education and monitoring program materials progressed for two and a half years with the involvement of multiple community members and several practitioners.

In addition to the CHRs, other Working Group members were practitioners from the Kitikmeot Health Board, including the Nutritionist, the Medical Health Officer (MHO), Environmental Health Officer (EHO) and Health Promotion Officer (HPO) as well as the GNWT Contaminants Unit head. Each of these Working Group members contributed a perspective that was important to the contaminants issue and the maternal and cord blood monitoring program. For

example, in communities, the Nutritionist and HPO promoted the consumption of traditional foods, the EHO addressed community concerns about bacterial infections in traditional foods, and the GNWT member communicated about specific contaminant levels in specific traditional food species that were consumed, and which often were the same species as those that were being promoted by the nutritionist and HPO. The Working Group meetings provided opportunities for all members to share their perspectives, and for CHRs to subsequently be able to share integrated perspectives with community members.

A key member of the Working Group was the Regional Contaminants Coordinator. As the chair of the Working Group and the only person working full time on the maternal and cord blood monitoring program, the Regional Contaminants Coordinator performed a wide range of duties without which the program could not have taken place. The Coordinator was paid through the Kitikmeot Health Board, however for the three years the funds for this position came from the Northern Contaminants Program. These funds were requested as part of the proposals that were developed annually by the Working Group. Clearly, given the volume of work accomplished by the Regional Coordinator, the work of the Kitikmeot Working Group could not have been conducted without this dedicated position, and also without the skills and commitment the Coordinator brought to the job.

While there were no Southern-based researchers as members of the KWG, the Group had access to researchers through their connection to the Northern Contaminants Program. As a member of the NCP Technical Committee

on Contaminants in Northern Ecosystems and Native Diets, I was familiar with those who were conducting research that was relevant to our work in the NWT and facilitated an ongoing linkage between researchers and the Working Group. Researchers at Laval University, particularly Dr. Éric Dewailly, had previously conducted a cord blood monitoring in Nunavik (Northern Quebec), and provided the Working Group with the sampling and analytical protocols he and his team had developed. Additionally, the toxicology laboratory at Laval University analyzed the blood samples that were collected in the Kitikmeot region, and the head chemist worked closely with the Regional Coordinator in the development of blood storage and shipping procedures from the Kitikmeot region to ensure their preservation and safety during transit. Health Canada researchers and epidemiologists also contributed expertise when requested. In the development and implementation of the Kitikmeot monitoring program, researchers took on the role of collaborators, as described by Stoecker (2003, p.101).

Working Group members had in common an interest in and perspective about the presence of global contaminants in the North and in traditional food species, from a cultural/community perspective or a professional perspective or both, and all lived in the North. The fact that all Working Group members were Northerners was important to the collegiality and cohesion of Working Group members over an extended period of time. Working Group members were able to draw on a shared lived experience to contextualize Group activities, and were able to build trust through ongoing contact and the accomplishment of specific tasks together. More than half the Working Group members were involved with

the project from beginning to the end. Those who changed tended to be nurses in the community health centres, where high turnover of staff can be particularly problematic.

In sum, as a construct, the Kitikmeot Contaminants Consultation Working Group "facilitate[d] collaborative partnerships in all phases of the research...buil[t] on strengths and resources within the community...[and] recognize[d] community as a unit of identity" (Israel et al., 1998, p.178). As such, the Working Group exemplified Israel et al.'s first three key principles of CBPR. Additionally, the Working Group played an essential role in the cyclical and iterative process that invoked the development and implementation of educational materials and the maternal and cord blood monitoring program, as will be subsequently analyzed.

Cyclical and iterative process

The processes of action followed by reflection and consultation that developed in the Kitikmeot Region immediately following the formation of the Working Group were cyclical and iterative in nature. In the context of CBPR, a cyclical process means a cycle of action and reflection, while an iterative process means these cycles occur over time. According to Freire (1970), cycles of action and reflection lead to an understanding or praxis that would not otherwise be possible, and are integral to the empowerment of marginalized people in their transformation from objects to subjects.

The first Working Group meeting took place nine days after the Taloyoak workshop, and was followed by 16 more meetings, or cycles of action and reflection over the next 2.5 years. Each cycle of reflection consisted of Working

Group members coming together with an agenda that had been drafted by the regional coordinator, with opportunities for Working Group members to add to the agenda either before or at the beginning of the meeting. In this way, all Working Group members contributed to the topics of reflection and the focus of the discussions during the meeting. The agenda items that Working Group members contributed were in turn informed by their communication activities with members of their communities or other practitioners/researchers since the previous meeting. In this way, communities participated in the ongoing development of education materials and the maternal and cord blood protocol development and implementation, through and with their community representative, the CHR. These actions exemplify what is intended in the concept of meaningful community participation.

Within the work of the Working Group, the process of multiple cycles of action and reflection provided a mechanism for community-based questions and concerns about contaminants to be identified and addressed. These questions and concerns were brought from communities by Working Group members to the Working Group during meetings, and subsequently formed the basis for the development of fact sheets, video content and monitoring program materials. Community members experienced the genuine interest of others in their questions and concerns, with prompt action by the Working Group, including the opportunity to offer feedback on draft materials to ensure the products that were developed met the community's needs. Such a community-based approach is quite different than one where education and information materials are developed

with minimal or no involvement of the intended audience, and which include assumptions about questions and concerns, as well as responses to them, on the part of a researcher or program developer working outside the community.

The magnitude and duration of community participation over such an extended period of time is substantively and qualitatively different than what is more often described as examples of community participation, such as training someone in the community to translate the interview questions, or hiring and training community members to deliver surveys (Furgal, Kalhok, Loring, & Smith, 2003). The latter can be viewed as a form of community participation that serves the interests of the researcher more that the interests of the community, in that the researcher acquires data as a result of the work of community participation, and the community receives short term engagement in a project that may have limited transferable skills to other research-related or community-related activities. Community participation over an extended period of time develops opportunities for collaboration, which contributes towards empowerment of those engaged in the process. Collaboration and empowerment were also evident in the work of the Kitikmeot Working Group.

Collaboration

There was considerable evidence of collaboration during all stages of the work that was done in the Kitikmeot region, which was particularly apparent through the Working Group. The initial leadership and support provided by the Executive Director and the Medical Health Officer of the Kitikmeot Health Board (KHB) at the Taloyoak workshop in June 1993 demonstrated to community

representatives and practitioners that environmental contaminants were an important issue and one the KHB would embrace with others in communities and elsewhere. In particular, the support of the project that was confirmed at the Taloyoak workshop by the Executive Director enabled other Kitikmeot Health Board practitioners, as well as the Nursing staff in community health centres, to contribute to, and collaborate on, the project as part of their recognized duties. Had this not been the case, recommendations, ideas and perspectives offered by community members and others would likely have met with limited opportunities for advancement, because they required time to develop that could realistically only take place during work hours.

The Working Group demonstrated collaboration immediately after they organized themselves into a Group. They developed a plan of action together that required all of them to make it happen. While representatives of the Northern Contaminants Program, including Aboriginal organizations, were not at the Taloyoak workshop, evidence of their implied collaboration was present in the funding that was approved and required for the workshop, as well as for the subsequent 2.5 years of work in the Kitikmeot region. There was evidence of commitment to both collaboration and the importance of the contaminants issue to communities by the number of meetings that took place, the full attendance at meetings despite telecommunication challenges, and by the long-term membership of several community representatives on the Working Group.

In addition to collaboration between Working Group members, there was collaboration between Working Group members within a specific community and

other members of that community, where advice and input was sought during the development of program materials as well as sharing ongoing program updates. Collaboration was a key aspect of the work that took place in the Kitikmeot region.

Empowerment

In addition to collaboration, there was evidence of empowerment in the work that took place in the Kitikmeot region. A definition of empowerment proposed by Wallerstein (1992, p. 198) is "a social-action process that promotes participation of people, organizations, and communities towards the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice". There was evidence of empowerment during all stages of the work in the Kitikmeot region.

The importance of the issue of global contaminants in traditional food species that have sustained Inuit for generations in the Kitikmeot region is perhaps impossible for non-Inuit to fathom. The opportunity for individuals and communities to contribute to an improved understanding of such an important issue in the Kitikmeot region was empowering. The chance to contribute to national and international efforts to reduce global contaminants entering the North was indicated by several participants who donated a blood sample as being their reason for participating in the program (C. Mills, KWG, personal communication).

Working Group members experienced empowerment during the course of their work together by developing skills and abilities they were able to apply to

expanding their contribution to sustaining the work that was underway. In particular, the collaborative development of funding proposals for submission to the NCP two years in a row provided opportunities to develop a plan of action, formalize it in a proposal, have the proposal approved, and subsequently act on their intentions with sufficient funds.

The role of researchers as consultants for particular information reinforced the Group's ability to both identify and solve problems or issues that needed resolving, and seek outside help when required. This is in contrast to the traditional approach, where researchers control all or most aspects of research activities. As noted by Cornwall & Jewkes, "complete reversals of control [relative to conventional research] may lead to local people contracting in expert outsiders to conduct or facilitate qualitative or quantitative research" (1995, p.1669). In a review of community-based participatory research projects, Viswanathan et al. (2004) identified only one CBPR project of the 60 they reviewed where "the community approached the researchers to initiate the proposal on the basis of the community's priorities and desired research" (p. 3), indicating the unusual nature of such a situation, and conversely, the predominance of traditional research practices despite being identified as CBPR.

In sum, the work in the Kitikmeot region exemplified several key principles of community-based participatory research. The identification of the problem and cycles of action and reflection provided multiple opportunities for meaningful community participation during all stages of the development and implementation of the monitoring program. Communities identified questions and areas of

concern or interest about contaminants, and were engaged in the development of educational materials to respond to those questions. Practitioners collaborated with other practitioners and community representatives in several communities, and others, over an extended period of time, in a remote area of the Arctic and successfully produced data that was subsequently instrumental in providing evidence for the multi-national Stockholm Convention.

Less obvious were the challenges that occurred during the course of the work. The primary challenges were related to capacity. The regional program coordinator was required to manage a large number of complex tasks with little if any technical support, on very tight timelines. Other Working Group members participated in the extensive work of the Group in addition to their full time regular duties. Community Health Representatives frequently undertook consultations with others in their community during evenings and on weekends, and the GNWT member routinely worked on weekends, as did many Group members from the Kitikmeot Health Board.

Factors that Facilitated CBPR in the Kitikmeot Region

There were several factors that contributed to facilitating the work that took place in the Kitikmeot region, including the funding, the relevance of the contaminants issue, and the attention to education and communications.

Funding

Once the concept of regional consultation working groups for engaging community participation in the Human Contaminant Trends in Arctic Canada proposal had been approved by the Aboriginal organizations, funding for the

project was forthcoming. The Northern Contaminants Program was a five year initiative when it began in 1991, and the Human Contaminant Trends project, which was pioneered in the Kitikmeot region, was a multi-year project that included the entire Northwest Territories and Nunavut.

The cost of conducting work in the Arctic, and particularly in Nunavut, is high, given that there are no roads connecting communities, and flying is the only way to get people together. Meals and accommodation were also very expensive, often more than double than what would be required in the South. A regional workshop typically cost $40,000-$50,000, depending on the number of people participating. The cost of developing and implementing the monitoring program in the Kitikmeot and Mackenzie regions was $592,000 over three years. The availability of that amount of money is anomalous for many research projects, particularly one that is not affiliated with either a university or the Tri-Council. What was unique to this situation was both the relevance of the Arctic contaminants issue to the fiduciary responsibility of the federal government, as well as the historical context and challenges that had previously occurred in the community of Broughton Island and the federal government's commitment to improve them.

At the same time as the funding facilitated a community-based approach in the Kitikmeot, aspects of circumstances related to the funding also posed challenges. In particular, who ultimately had authority to implement the work, and who controlled the funding were problematic.

The territorial government was accountable to the federal government (DIAND's Northern Contaminants Program) to: produce blood data in a way that was acceptable to the National Technical Committee and notably the Aboriginal organizations in terms of community involvement and participation; and to be financial accountable to the NCP. The territorial government, however, did not have the authority to undertake the necessary work regionally without the Regional Health Board taking the lead. The work that was done by the Kitikmeot Working Group and in the Mackenzie region was inherently expensive and could not have been undertaken without outside funding. Funds from the NCP also made possible the consultation work preparatory to the formation of the Kitikmeot Working Group and the other regional working groups, and enabled the development of education and communication materials and the monitoring program protocols.

The control over resources for education and communication needs identified by communities for communities, however, rested outside their influence. I often experienced the tension of federal government-driven funding and proposal timelines that were out of sync with what was going on regionally and in the communities. I explained this tension to others as often feeling like I was standing on two horses at a circus, one foot on one and the other foot on the other like, with the horses going different speeds.

While not a focus of the present research, the issue of power relations in CBPR is nonetheless important to acknowledge. One of the tenets of CBPR is that it "involves a collaborative partnership in which all parties participate as

equal members and share control over all phases of the research process" (Israel et al., 1998, p.179). This is the ideal situation, however, the reality may be quite different, given unequal access to resources, skills, time and power (Wallerstein, 1999). Labonte (1994) advocates for an approach to recognizing power differences in the practice of health promotion that includes "[making explicit] the linkages among personal services, small group supports, community organizing, coalition advocacy, and political action" (p. 253). From a researcher's perspective, Wallerstein (1999) described power dynamics that influenced her work leading a participatory evaluation project, in relation to her affiliation with a university, her perceived affiliation with a government agency, and being Caucasian. She acknowledges that "unfortunately at the time, I didn't recognize that I had an opportunity to make visible the power dynamics, by unmasking my own position of privilege and hoping thereby to generate open dialogue of their resistance and concerns" (Wallerstein, p. 42). Hayes and Way (1997), highlight that

> If we hope to link critical qualitative research to practice, we believe it is particularly important to identify and challenge "power-obscuring" practices. In fact, we contend that to fail to do so will actually serve to perpetuate the division between research and practice....We must acknowledge that power relations permeate every aspect of our work, and use this recognition to develop more effective ways of challenging and negotiating them. (¶ 9)

In sum, power relations are not equal between researchers and communities as they begin a CBPR project. Through ongoing open dialogue between researchers, practitioners, and communities, that acknowledges and names disparities in power, opportunities will be created for moving towards a more equitable distribution of power.

Relevance of the contaminants issue

The widespread presence of environmental contaminants in the Arctic, which originated outside not only the borders of the Northwest Territories and Nunavut but also of Canada, was a unique situation. The awareness of these contaminants, and the many questions that they invoked, took shape over the course of only a few years. What was potentially at stake were the health and safety of indigenous Northerners as a result of consuming traditional foods that were the mainstay of their diet and culture. Traditional foods were not, and are still not, under the jurisdiction of Health Canada's food safety regulations because they are not commercially bought or sold. The fiduciary responsibility of the federal government required prompt and effective action. The Arctic Environmental Strategy was established in 1991, with the Northern Contaminants Program as one of four programs and was funded initially for five years.

The contaminants issue was relevant to individuals, communities, health workers, regional health boards, the territorial government and regional, national and circumpolar Aboriginal organizations, for related but different reasons. Common to all was the importance of traditional foods to the health and well-being of Inuit and First Nations peoples of the Arctic.

The relevance of the contaminants issue to the sustainability and viability of traditional Inuit culture, and the importance of traditional culture to individuals and communities, contributed to commitment and motivation of community members, Working Group members, health workers, Regional Health Board staff and government employees and Aboriginal organizations involved with the work

in the Kitikmeot region. Only the Regional Program Coordinator and a part time administrative assistant were paid specifically to work on the contaminants issue in the Kitikmeot region. All others that were involved participated and contributed to the work in addition to their regular duties, often considerably increasing their workload by doing so. Had the monitoring program been less relevant to so many aspects of the health of Inuit, there may well have been less buy-in and subsequently less community and regional and territorial participation.

Adequate Time

Adequate time was an important facilitator of the work that took place in the Kitikmeot region. This was possible because of the multi-year nature of Northern Contaminants Program funding, and the commitment by the NCP to include funding for ongoing communications within a project budget as part of the project funding. Over the course of 2.5 years, the Working Group was able to identify the work that they determined needed to be done, request funding, and once funding was approved, proceed in an agreed upon way, with adequate time for ongoing community consultations. If the Working Group had been forced to conform to a timeline that included stating specific dates for predetermined deliverables a year in advance, then bureaucratic influences would have interfered with the organic nature of the processes of action and reflection invoking the development and completion of products that took place.

Attention to Communications and Education

There was evidence of communications and education from the very beginning to the very end of the monitoring program by the Kitikmeot Working Group.

From the outset, the importance of answering questions that were being asked by community members was of prime concern to the Working Group. The importance of the questions that originated from the community was emphasized during the 1992 workshop in Hay River, and was manifest time and time again in the Kitikmeot work. The educational materials developed by the Kitikmeot Working Group were grounded in questions posed by communities. The process of developing and communicating educational materials was a key function of the Kitikmeot Working Group.

When information needs of various perspectives/agencies were identified and attended to, a common understanding of the issue being discussed was developed and dialogue between these perspectives became possible. Important considerations in addressing information needs included the frequency and purpose of various communications activities and materials, context (local in context of global; community-specific in context of wider region) and collaborative development.

Factors that Hindered CBPR in the Kitikmeot Region

There were relatively few factors that hindered the work that took place in the Kitikmeot region. Those that existed included the lack of existing resources about contaminants in the North particularly in relation to human health, the

multifaceted protocol needed for the maternal and cord blood monitoring program, and the lack of institutional support.

Existing Resources

When the Kitikmeot Working Group began its work in June, 1992, there were very few information or education resources about environmental contaminants in the Arctic. Materials that were available tended to be of a technical nature (eg. Murray & Shearer, 1992; Murray & Shearer, 1993) and not suited for plain language use in communities. The lack of available plain language resources was largely due to the relative newness of the issue. As well, the information needs of communities had not been identified at that early stage of the NCP. The lack of existing resources that the Working Group could use or adapt in consultations with their communities meant the Working Group had to develop these resources themselves, which was both time-consuming and expensive. The Working Group members, however, also benefited from their involvement in this work. Members were required to learn about the technical aspects of the contaminants issue before they could develop the plain language materials, thereby increasing their capacity to function as technical resources to their communities. As well, the materials that were developed had the ownership of the communities, Working Group and region.

Multifaceted protocol

The protocol for the development and implementation of the maternal and cord blood monitoring program was complex, and consisted of many components. At the time the Kitikmeot Working Group was established, there

was not even a complete list of the elements that were required in such a protocol. While this hindered the work in the sense that there was a lot of effort (and time and funds) required to develop all that was required, it also helped the work in that what was produced had to be completely developed from the ground up. Specific technical expertise was sought when it was needed, and that was helpful and appreciated. In fact, it may have hindered the nature of the work if the protocol had been already available, because it would not have reflected communities' input and perspectives to the extent it did.

Institutional support

There was considerable and sustained lack of institutional support, particularly during the early stages of working on the Human Contaminants Trends project, and particularly at the Territorial level. The Territorial government was not set up to support the nature of the work we were undertaking. The library had very limited capabilities in terms of literature searching, interlibrary connections, and journal subscriptions. Interlibrary loans often needed to be returned the day after they arrived so they would be received at the lending institution within the three week timeline. I rarely, if ever, was able to make use of these materials, or share them with others. The corporate culture of the Health Department at the time made it very difficult to establish a team approach. The Department heads were not aware of the large amount of work required to develop and implement a program such as the Human Contaminant Trends project. At the Regional Health Board level in the Kitikmeot, there was institutional support through the participation of Kitikmeot Health Board staff in

the Kitikmeot Working Group. However, they participated in addition to their regular duties, thereby considerably increasing their work load. Access to libraries and journals was even more limited at the Regional Health Board level than they were at the Territorial level.

Distance

The distance between communities limited opportunities for members of the Kitikmeot Working Group to work together in person to all but two of their 17 meetings during the course of the project. Conference calls often provide fewer opportunities for spontaneous/creative problem solving, and offer more challenges drawing input and comments from those who are shy or lack confidence in offering their perspective, particularly newer members.

The distance between Kitikmeot communities, Yellowknife and an academic institution with relevant expertise limited the support and collegiality that may have been possible and helpful in a number of ways during all stages of the project.

Policy

Regional Health Boards had autonomy to develop and implement programs in their region. However, it is less clear if this would also be the case if it were called research. As there are no longer health boards in the NWT, it is difficult to investigate this aspect further at this time. This difference in acceptable or allowable or mandated activities may be an important difference between government and academic policies in relation to program development and implementation and research development and implementation respectively. If

program development is seen to be inherently more acceptable, applicable and relevant to community health practice, regional health agencies may undertake activities they describe as program development rather than as similar work which might be considered research if conducted by university researchers. Similar work referred to as program development by practitioners and as research by academics perpetuates the separation between practice and research, which may limit opportunities for mutually beneficial collaboration.

Conclusion

A critical analysis of the development and implementation of the monitoring program in the Kitikmeot region led by the Kitikmeot Working Group exemplified the work as a case of community-based participatory research. The analysis facilitated the identification of several key principles of CBPR in operation simultaneously. These principles included the problem definition originating from communities, cyclical and iterative processes over two and a half years that created multiple opportunities for community members and practitioners to develop collaborative and empowering responses, and meaningful community participation during all phases of the research process.

While the qualities of education and communication materials and processes associated with CBPR are rarely described in the literature, the attention to these qualities during all phases of the work that took place in the Kitikmeot highlight their importance in the practice of CBPR, particularly in cross-cultural settings. The role of practitioners in CBPR is inconsistently reported in the literature as being integral to the practice of CBPR. In the case of the

Kitikmeot Working Group, practitioners played key roles during all phases, suggesting that practitioners are essential to the practice of CBPR in remote, cross-cultural settings.

Chapter Six

Taking a Step Back: Where To From Here?

Summary

The work that took place in the Kitikmeot region that was facilitated by the Kitikmeot Working Group began organically, as a group of community and regional representatives who offered to participate in the development and implementation of a complex health project. Their interest in participating resulted from their concerns about the problem of communicating about contaminants with community members without causing alarm, and their belief in the need for more information about contaminants in Inuit at risk. There were no presentations about the principles of CBPR or the theoretical work of Freire or others during the course of the first workshop, or at any other meeting, either by phone or face-to-face, throughout the two and a half years of their work. There was also no academic intervention in relation to CBPR, either during the formation of the Working Group, the development of their planned activities, or the development and implementation of the work the Group did over an extended period of time unless specifically requested. In isolation and in the absence of being informed about the concepts, processes and expectations of CBPR, the Kitikmeot Working Group's work exemplifies the tenets of participatory research.

Of particular relevance in the present research was insight into the development of understanding how to operationalize community-based problem definition through the identification of community concerns as an outcome of community consultation. Concerns identified with a community developed into a

problem originating from the community. This approach is in sharp contrast to a more common community consultation approach in the North, where researchers bring their already developed research problem, and often their plan for addressing it, to the community to seek support or approval from the community, with minimal or no prior involvement of the community.

Community Consultation

As well, the present research provides details about qualities of communications that are related to CBPR as exemplified by community and regional activities, including the often-used expression "community consultation". What is intended to take place within community consultation was discussed and developed by community and regional representatives, along with others, at the workshop that was held in Hay River in March 1992. The elements described as being important to community consultation that were identified at this workshop were subsequently incorporated into the development of workshops held throughout the NWT and Nunavut, into the work in the Kitikmeot region, as well as into the work of the Territorial health-related contaminants program. In itself, the development and implementation of recommendations from a workshop into the practice of what they were intended to inform is noteworthy, and a component of community consultation that may be easily overlooked.

Community consultation is an important aspect of CBPR, although perhaps assumed but rarely stated in the literature. It is a process in which communities contribute an integral component to the work by bringing to the table their expert perspectives about a multitude of factors influencing their health from

their everyday lived experiences. Community members have a right to be informed about health-related issues that may affect them, and are key partners in the identification of research issues, the development of research questions, and the development, implementation and evaluation of research efforts to address these issues.

Synthesizing the processes and actions described above, community-based communications are most successful when they include opportunities for various perspectives (ie. community and regional representatives and researchers) to both speak and to listen, and to learn from each other. Through this type of dialogue, opportunities unfold for those who are participating to both teach and learn with each other. Dialogue can ensue when the topic is important to the community, and include relevant background information which is presented in plain language, in the context of both benefits and risks as well as local and global circumstances. Evidence of successful community-based communications in relation to a health research project would be: the collaborative development of a research question that answers a question of importance to the community; the collaborative development, implementation and evaluation of the research; and the focus on communications that were co-constructed and co-delivered. In the process, opportunities for trust, collaboration, mutual respect and a sense of empowerment develop and grow.

The Role of Northern Leadership

In Chapter 1, I characterized my role as straddling two horses at the circus, with the horses going different speeds. One speed was that of communities and

the region, where attention to consultations and education was a top priority, which appeared slower in terms of decisions and sampling to others who were not involved with such activities. The second speed was that of the federal government, where timelines for proposals, deliverables and financial reporting were driven by fiscal year requirements, which were invariably different than community and regional timelines. In addition to managing different timelines, the leadership role of the Northern CBPR practitioner/researcher was to facilitate the development of a shared vision between Northerners involved, or potentially involved, with a project, and others from the South who were also interested in the project. Once a shared vision was developed, the leadership role sustained the vision through facilitating ongoing dialogue, and creating opportunities for collaboration and capacity building. In larger projects, such as this one, Northern leadership is required at more than one level. For example, in the Kitikmeot Region, there were community leaders (KWG members), the regional leader (regional coordinator), and the territorial leader (myself). At each level, the leader functioned to bridge between the other levels, as well as with others such as funders. A common vision between leaders is important to sustaining the overall vision of the project. Inherent in all leadership roles is the importance of structural supports from the workplace, including institutional support, supervisor's support, policies that are consistent with CBPR practice, and opportunities for training and networking. At some times during the work in the Kitikmeot region these supports were present and at other times they were not. At the community level, changes in staffing of the CHR or community nurse resulted in a change in the Kitikmeot

Working Group membership. This led to a lapse in community-level leadership continuity, which was eventually restored by attention to providing background information and to team building. At the territorial level, I was consistently involved in all phases of the KWG work, and so can not speculate on what or how the Kitikmeot work might have gone differently had that not been the case. Roles of leadership, whether at the community, regional or territorial level, develop and mature through ongoing communications and collaborative efforts with others involved in the project. The success in the role of a territorial leader who comes either during or after a project such as the work in the Kitikmeot region would likely initially be more related to that individual's respect for and trust in the work and workers that have contributed to date. Sustaining that leadership role would be related to the leader sharing similar perspectives with others already working on the project about the overall direction and focus of the work, and to the approaches being used to conduct the work.

From my perspective as territorial leader in the context of the Kitikmeot Working Group, while the horses that were going different speeds in my metaphor never did reach the same speed, they did approximate it more closely as the project evolved and deliverables were produced. It became clearer how to link community-based perspectives with actions leading to products that corresponded with fiscal timelines, which reduced that tension.

The Northern Context

There are no universities North of 60^0, and no research centres in the North with a focus on human health. With the exception of regional centres such

as Yellowknife, Iqaluit and Whitehorse, communities are small and often difficult to access. The communities in the Kitikmeot region, for example, can only be reached by air, and travel between communities usually requires passing through Yellowknife, which adds considerably to the cost. Within communities, there are invariably multiple issues requiring immediate attention, with too few people to do the work. Rarely if ever are there community members who have research training. Perhaps most important is the reality that community members cannot contribute their ideas, perspectives, insight and work to the development and implementation of CBPR projects as volunteers. Researchers and practitioners are paid for their ideas, perspectives, insight and work, and it is both unrealistic and insulting to expect community members not to be paid. Token payment, or honoraria, do not acknowledge the invaluable and essential role that community members play in CBPR. This is particularly true in the North, where the cost of living is high, jobs are often scarce, and their perspective is essential to the context of the research.

Practitioners employed at the community, regional or territorial level are also busy people, whose job descriptions rarely if ever include contributing to research initiatives. There is often a high turnover rate of nurses in communities, which contributes a lack of continuity to projects that extend beyond 1-2 years. Practitioners who are able to participate in research activities require support and approval from their supervisors. Supervisors may not identify direct benefits of their staff participating in research for their areas of responsibility, and likely lack resources to back-fill the position to continue the provision of regular services.

The support and leadership provided by the Executive Director of the Kitikmeot Health Board for staff to participate in the monitoring program, which was long term and included most communities, is rare. As noted in their evaluations, many practitioners felt burdened by their participation in the monitoring program, despite the quality of the work. On the rare occasions that practitioners do participate in a community-based health research project, the likelihood of them subsequently finding the time to write about their experiences is slim indeed, and will continue to perpetuate the dearth of practical insight into the practice of CBPR.

For researchers, the cost of traveling to remote Northern communities is high and it is often difficult to know who in the community to consult with, in addition to the political leadership, to discuss and develop possible research ideas. The lack of available information about the community-based health research needs and priorities that may have been identified by some Northern communities presents a serious obstacle to connecting those with compatible research interests. Academic institutions and research funding agencies are currently limited in their capacity to accommodate research initiatives that may require $100,000 or more for initial consultation activities leading to the development of a proposal which, by the very nature of CBPR, is unable to provide specific deliverables or timelines without considerable consultation.

In addition, there has been a notable increase in research activities in the North over the past couple of years, which will only continue to increase as the International Polar Year (2007-2009) draws near. Canada has two main

components to the IPY – climate change, and Northern community health research (IPY, 2006). We in the North are currently unprepared to participate in such an intensive Northern health research focus, which includes not only researchers from Canada but also researchers from several other countries as well. Communities in the North are particularly not well prepared to participate.

Implications

Although not intended to be comprehensive, attention to the following considerations would contribute to enhanced opportunities for community-based participatory research projects to be developed in the Arctic.

Capacity Development

Capacity development includes training for community members and practitioners who are interested in participating in health research activities, funding to support initial and ongoing training activities, and funding to staff positions that include participating in health research in their regular duties. Such a reallocation of funds from within community, regional, and territorial governments would require political will and a belief in the relevancy of health research activities that will identify and propose solutions to real life issues in real time. This political will is currently lacking.

Policy Changes

Policy changes at multiple levels of government to encourage, facilitate and support community members and practitioners participating in CBPR activities would be an important step. Structures for leadership that support bridging between practice and research, and that support enactment of CBPR in

a sustainable way would also be very important. These changes also need to include training and time to write about their experiences to inform next steps. Without these changes, there will continue to be insufficient contributions to Northern research by practitioners. The lack of literature about the implementation and practice of CBPR will continue to limit its development.

Unique Role of Northern Practitioner

A practitioner who is contributing to a CBPR initiative as a coordinator or in a leadership capacity in the North is in a unique role. The individual is functioning between the world of the community and the world of the academic institution, although is not a member of either world. Whether the practitioner is working for a local, regional or territorial government, or a non-governmental organization, there are currently few mechanisms for support. Support could include: establishing and maintaining contact with practitioners in similar roles in other rural or remote jurisdictions; training opportunities that were amenable to distance education that included realistic expectations and the development of meaningful knowledge and skills; and invitations to meetings and conferences by researchers and others that invited practitioners' unique contributions to ongoing discussions.

Study Limitations

There are limitations to the present research. The factor of time is perhaps the most notable, with 11 years elapsing between the end of the monitoring program in the Kitikmeot region and the completion of this research. During that time, the Nunavut land claim was implemented in 1999, dividing what was one territory into

two. With the creation of Nunavut, another complete territorial government structure was established in Nunavut, the regional health boards in both Nunavut and the NWT were disbanded in favor of decentralized health authorities, and many community, regional and territorial practitioners have moved on.

Another limitation to this research is that only my perspective is reflected in the analysis and interpretation of the case. The nature of the Kitikmeot Working Group was collegial, respectful, diligent and committed to high standards. Problems or concerns that were brought to the Working Group during meetings were discussed and worked on together. Yet I have produced this thesis with only my perspective about work that others have contributed so much to. My plan to address this limitation is to involve past Working Group members as co-authors in the production of a peer-reviewed paper, which will be submitted within the next year and present the case from multiple perspectives.

Further Research

Research about the practice of CBPR in remote areas would contribute to capacity development, policy changes, and improve understanding about the roles of communities, practitioners, researchers, and decision makers. Research that examined current beliefs, concerns and lack of trust by some Northern communities about health research would provide insight into topics that needed to be included in community consultations. Research that focused on identifying mechanisms for facilitating collaboration between Northern practitioners and researchers would contribute to developing linkages between practice and

theory, North and South, and could lead to more timely, and more relevant research for, by and with Northerners.

My experience

As a Northern practitioner, member of the Kitikmeot Working Group, and the person responsible for the territorial Human Contaminant Trends project of which the Kitikmeot region played such a key role, the opportunity for retrospective critical analysis and reflection during the production of this thesis has been enlightening.

Circumstances for practitioners in remote regions present challenges which, once identified, can be considered differently. Professional isolation, limitations to establishing outside contacts with little time to maintain them, and limited access to additional training, provide tangible opportunities to identify capacity development possibilities with other practitioners and researchers. Of particular relevance is acknowledgement and respect by Southern researchers, bureaucrats and practitioners of the important role played by Northern practitioners in the practice of CBPR in the North.

After working on the Human Contaminant Trends project for the past 16 years, half as a paid practitioner and half as a volunteer, I am grateful for the opportunity to have contributed to this work, and am glad it is now finished.

Conclusion

With increasing focus on Canada's North, such as the International Polar Year will bring, the impacts of global climate change which are already being experienced in the North, and the pressing health issues facing many Northern

residents, an approach that acknowledges the essential role of the experiences and contributions of Northerners in finding solutions is imperative. The present study indicates that the practice of community-based participatory research in the North, with adequate resources, is a viable approach to meaningful investigation for Northern communities, practitioners and researchers.

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Appendix 1

Data Sources

The following summarizes the documentation that was available for the text based analysis of the work of the KWG between the periods 1993 to 1995. These documents describe different aspects of the Working Group's activities and as such shed light from different perspectives. I have divided them according to whether they were primarily relevant to process or product issues:

PROCESS

1. Program Implementation Summary
    - Included overview of the development and implementation of the Maternal and Cord Blood Monitoring Program from perspective of regional office. Issue identification, identifying target population characteristics, training, communications products.
    - Included details of timing in training and communications implementation.

2. Kitikmeot Region Summary Report – Environmental Contaminants Workshop, Taloyoak. 8-9 June 1993.

3. Kitikmeot Consultation Working Group
    - Conference calls/meeting schedule
    - Membership

4. Press Releases
    - Contaminants in People video (June 1 94)
        - Press release
        - Distribution list
        - Backgrounder
    - Contaminants and Your Health video (Nov. 22, 95)
        - Press release
        - Distribution list
        - Backgrounder

5. Video Distribution list documents
    - Environmental Contaminants in the North
    - Contaminants and your health

6. Tracking Forms
    - Health Centres' Tracking System
        - defined roles and responsibilities of health worker/nurse involved with recruitment, informed consent and sampling preparation
        - Includes a flowchart
    - Yellowknife Medical Clinics Tracking System
        - defined roles and responsibilities of health worker/nurse involved with recruitment, informed consent and sampling preparation
        - Includes a flowchart
    - Participant Tracking/Information forms
    - Results communications tracking sheet
    - Community Issues/Concerns Tracking Form

7. Program Evaluation Forms (E.F.)
    - Health Workers E. F.
    - Hospital Staff E.F.
    - Working Group E.F.
    - Participants E. F.

PRODUCTS

8. Fact Sheets
    - Traditional food and nutrient fact sheets produced by Dene Nation
    - DHSS fact sheets
    - DRR fact sheets
    - Fact sheet binder distribution list

9. Health Worker Training – Information documents
    - Delivery plan – for Kitikmeot and Mackenzie Health Nurses
    - Delivery plan – for Yellowknife Health Clinics
    - Briefing for Potential Participants
    - Contaminants Program Intervention Protocol – A Guide for Health Workers.

10. Health Worker Training
    - Dates of meetings
    - Presentation outline for health worker overview to Contaminants
    - NIC (Nurse in Charge) presentation to Kitikmeot NIC's re: roles & responsibilities of health workers in cord blood study.
    - Maternal OB briefing – Stanton

11. Presentation Sessions
    - Audience and dates of presentations, including overheads

12. Results Communications – Results Communications Steering Committee
    - ~ packages
    - participant results communications package
    - community results communications package
    - Inuktitut Results Communications Package
    - Innuanaqtun Results Communications Pkg
    - Results Communications – Community distribution list
    - Participant File Reports

13. Activity Reports
    - Monthly activity reports from July 1994 to December 1995

14. Newsletters
    - Newsletters for Participating Health Agencies (June 94 – July 95)
    - Newsletters for Participants Nov 94, June, Oct Nov 95)
    - Newsletters for Communities (August 95; Nov. 95)

15. Sampling and Analytical Protocol
    - Blood collection procedures
    - Biological sampling protocol
    - Protocols for biological sampling, processing, storage and shipping
    - Lab Analysis – statement of work
    - Limits of detection and normal values for metals

16. Data Management

    - Description of MRHS/KHB Contaminants Databases and programs

Appendix 2

Summary of Kitikmeot Working Group meetings

The Kitikmeot Consultation Working Group was formed during a Contaminants Workshop help in Taloyoak June 8-9, 1993.

Conference Calls and Meetings:

June 8-9, 1993	A 2-day environmental contaminants workshop in Taloyoak
June 18, 1993	Discussion of working drafts of the maternal and cord blood monitoring protocol.
July 7, 1993	Ongoing discussions about the protocol and possible production of a video
July 30, 1993	Review of video production possibilities. Discussion of information packages to be developed for community, health workers, potential participants.
August 13, 1993	Discussion of protocol document
August 20, 1993	Refine program protocol, outline information packages and flowcharts. Program promotion activities (e.g., poster)
Sept 13-14, 1993	A 2-day meeting by the Kitikmeot Working Group in Cambridge Bay to discuss program protocols, and promotional activities for the program.
November 1, 1993	Presentation to a Nurse-in-Charge Conference and Working Group meeting in Cambridge Bay. Reviewed participant questionnaire and consent form.
December 22, 1993	Review of education materials, including poster and video.
February 9, 1994	Overview of funding proposals, review status of poster/video
May 3, 1994	Protocol update, pretesting of questionnaires, video/poster development.
July 26, 1994	Update on implementation activities of the monitoring program, preliminary discussions about results communications strategies.
August 15, 1994	Review of recruitment information. Options for video translation.
October 7, 1994	First joint working group meeting held in Yellowknife. Discussions took place regarding a number of items including: development of educational/communications materials, regional/community communications strategies, possible development of a glossary of terminology relating to contaminants.
January 31, 1995	Review and ranking of proposed activities for 1995/96; discussion of program promotional activities (e.g. newspaper insert).
February 14, 1995	Review/discussion of fact sheets, glossary development, possible joint working group meeting.
March 20, 1995	Review of fact sheets/resource binders
April 10-13, 1995	Second joint Working Group meeting held in Yellowknife. Focus of discussions was results communications.
Sept. 18, 1995	Review of results communications packages. Mackenzie Consultation Working Group membership and purpose reviewed. No further meetings to be scheduled by the Chair.

From: Rohlmann et al., 1996, Appendix 1

Appendix 3

Sample materials from Participant Recruitment package

Maternal/Cord Blood Monitoring Program
Participant Consent Form

An opportunity exists for you and your baby to contribute to information on the health of our northern environment. The Kitikmeot Health Board and Mackenzie Regional Health Service, with the support of the Stanton Yellowknife Hospital's Board of Directors and the GNWT Department of Health, is delivering a program in Kitikmeot and Mackenzie communities in order to measure contaminants (pollutants) in women and babies.

At birth, all newborns have blood taken to help find out about their general health: this blood is taken from the part of the umbilical cord that is attached to the afterbirth, or placenta. All mothers also have blood taken for similar reasons. For women who wish to participate in this program, additional blood will be collected from the mother and the umbilical cord in order to find out if there are contaminants present.

I give my informed consent to be a participant in the Maternal/Cord Blood Monitoring Program.

By giving my consent, I understand that . . .

√ I have been provided the opportunity to discuss this program with my nurse, doctor or Program Coordinator so that I can provide my informed consent to participate in this program.

√ I have the opportunity to ask further questions about this program and my participation from my nurse, doctor or the Program Coordinator at any time.

√ my participation is voluntary.

/ I can withdraw from this program at any time, and for any reason, by letting my nurse, doctor or the Program Coordinator know of this decision in a manner that is convenient and acceptable to me.

√ my name, date of birth and address will remain confidential and will be used for follow-up by regional health authorities only if levels of contaminants (with known guidelines) are found to be outside of an acceptable range.

√ participating in this program includes signing this consent form, completing a brief survey and permitting blood samples to be collected in the manner described above.

√ the additional blood samples will only be used to check for environmental contaminants.

√ I will be provided the option of knowing my own results for those contaminants which have known guidelines.

√ after my results have been made available to me, the general results of the program will be provided to community and regional agencies, and will be used by governments of the Northwest Territories and Canada, in partnership with other northern countries, to help stop pollution.

Participant's Name (please print)	Witness' Name (please print)
Participant's Signature	Witness' Signature
Participant's THIS number	Date

Fax this form to Program Coordinator as soon as it is signed, then mail: 920-6523 (phone) 920-4015 (fax).

NWT 4323/1094

PROGRAM COORDINATOR

MATERNAL AND CORD BLOOD MONITORING PROGRAM

Mackenzie Regional Health Service and Kitikmeot Health Board

Funded by the Arctic Environmental Strategy (Northern Contaminants Program) and in partnership with NWT Aboriginal groups and GNWT Health and Social Services.

The Mackenzie Regional Health Service and Kitikmeot Health Board are delivering a program in the Mackenzie and Kitikmeot regions which looks at environmental contaminants in mothers and babies. This program began in May 1994 after extensive consultation with communities, Aboriginal organizations, health professionals and GNWT Departments, and will continue until March 1995.

Purpose of the Program

Early work done in the NWT and arctic Quebec have demonstrated that traditional foods of fish and wildlife have many important benefits to people. However, it has also been found that Northern people can be exposed to some environmental contaminants in traditional foods. Currently there is little information regarding contaminants in NWT residents. The monitoring program is a first step to seeing if contaminants are in people and if contaminant levels are increasing or decreasing. Other northern countries are also monitoring their people: together, these countries are working to stop the production and use of these contaminants worldwide.

Types of Contaminants Being Monitored

Two kinds of contaminants will be looked at in this program: organochlorines, which are manufactured chemicals often found in pesticides, fertilizers and industrial activities; and heavy metals, which occur naturally but are found in higher levels due to industrial activities. Organochlorines to be measured include PCB's while heavy metals include mercury, lead and cadmium.

Monitoring Contaminants in People

Contaminants in people can be monitored by examining the foods that people eat and by analyzing body tissues or fluids. This program is measuring for the presence of contaminants in blood. Tests on blood provide good information on levels of organochlorines and heavy metals in people.

Who Can Participate?

The monitoring program is available to women living in the Mackenzie and Kitikmeot regions who deliver their babies at Stanton Yellowknife Hospital. Women are introduced to the program during their pre-natal visits at their community health centre or clinic. Information kits about the program are given to women by nurses: these kits have information about environmental contaminants and how to become involved in the program. Women and their families can discuss the program with health centre nurses or the Program Coordinator.

Participant Activities

Participation in this program is *voluntary*. Women who want to participate can sign a consent form. Once the consent form is signed, a short survey is completed: questions asked help to identify lifestyle choices that may influence the types and levels of contaminants found in people. When a woman delivers her baby at the hospital, blood samples for this program are taken *at the same time that the hospital collects blood for its own health tests*: one sample is taken from the mother and another sample is taken from the umbilical cord after the baby has been delivered.

What Will be Done With the Results?

Participants can be informed of their own results for contaminants which have known guidelines. Results will be accompanied by information which will help participants understand their results and, if appropriate, to make informed lifestyle choices in order to reduce exposure to certain contaminants. *Individual results will be confidential between participants and their regional health authority*. Summarized results will be provided to each participating community and region.

Support for the Program

Consultation Working Groups have been established for both regions to provide a link between participating communities, Aboriginal groups and regional health agencies. These Working Groups collaborate with the health agencies in issue identification, program design and implementation, and reporting of results.

Would You Like More Information?

For information about the program or how to become a participant, contact your community nurse or Laura Seddon, Program Coordinator. For information about contaminants in general, contact Jody Walker, Contaminants Unit (GNWT Health & Social Services) at (403)920-6973 (ph) or (403)873-5072 (fx).

Laura Seddon, Program Coordinator, Box 520, Yellowknife, NT X1A 2N4. (403)920-6523(ph) (403)920-4015(fx)

MATERNAL/CORD BLOOD MONITORING PROGRAM

CONTAMINANTS IN THE NORTH

FACT SHEET

WHAT ARE CONTAMINANTS?

Contaminants are substances that may be harmful to plants, animals and people. Contaminants may be manufactured, like pesticides, or may occur naturally, like mercury. Some contaminants can be easily seen, such as an oil spill or a leaking battery. Others can be smelled, like contaminants in cigarettes. Some contaminants, however, may be too small to be seen or smelled.

There are three groups of chemical contaminants:

- **organochlorines**, such as PCB's, dioxins and furans, are manufactured and can be found in pesticides and fertilizers, and waste from pulp and paper mills or other industries;
- **heavy metals**, such as mercury, cadmium and lead, can come from cigarettes, car/truck exhaust fumes, mining and other industries and also occur naturally in low amounts; and
- **radionuclides**, such as strontium, cesium and uranium, are used in nuclear power plants and military weapons and also occur naturally in low amounts.

HOW DO THESE CONTAMINANTS GET TO THE NORTH?

Some contaminants are produced here in the NWT through activities such as community and industrial waste disposal. The majority, however, come from other parts of the world and arrive in the Canadian north and other northern countries through four major paths:

- **air currents** carry some contaminants north and fall to the ground with rain , snow or dust;
- **water currents** move some contaminants into northern waters;
- **people** bring products containing contaminants to the north for industrial or personal use;
- **migrating animals**, such as caribou and geese, may carry contaminants picked up from other areas.

HOW DO CONTAMINANTS GET INTO OUR FOOD?

Contaminants that enter our water, air and land can get into plants and animals that we eat. While some traditional foods may have some contaminants in them, they are also very nutritious and beneficial to people! It is important that people understand the health value of traditional foods while also being aware of contaminants: this information will help people make healthy lifestyle choices.

CAN CONTAMINANTS AFFECT ANIMALS AND PEOPLE?

Work done on wildlife shows that contaminants can affect the way these animals grow and reproduce. However, very little is known about the kinds of effects different types and amounts of contaminants may have on wildlife and people. At this time, the Arctic Environmental Strategy is providing northerners with the opportunity to increase their knowledge about contaminants in order to make informed choices which will help to promote a healthy lifestyle and environment.

WOULD YOU LIKE MORE INFORMATION?

There are agencies which are looking at environmental contaminants in the NWT: GNWT Renewable Resources, GNWT Health, Regional Health Boards/Services, Department of Fisheries and Oceans, Department of Indian Affairs and Northern Development, the Canadian Wildlife Service, and the Dene and Métis Nations. Contact these agencies to determine what programs may be happening in your area.

Contact GNWT Health (Contaminants Unit) for more information on NWT contaminants:
403-920-6973 (phone) or 403-873-5072(fax).

Contact Environmental Health Officers to discuss issues relating to contaminants for your region:

for the Kitikmeot region:	403-983-7333 (phone)	403-983-2253(fax)
for the Mackenzie region:	403-920-6592 (phone)	403-920-4015(fax).

Contact the Program Coordinator for more information about the Maternal Cord Blood Monitoring Program:
403-920-6523 (phone) or 403-920-4015 (fax).

Find out how you can help protect our environment!

August 1994

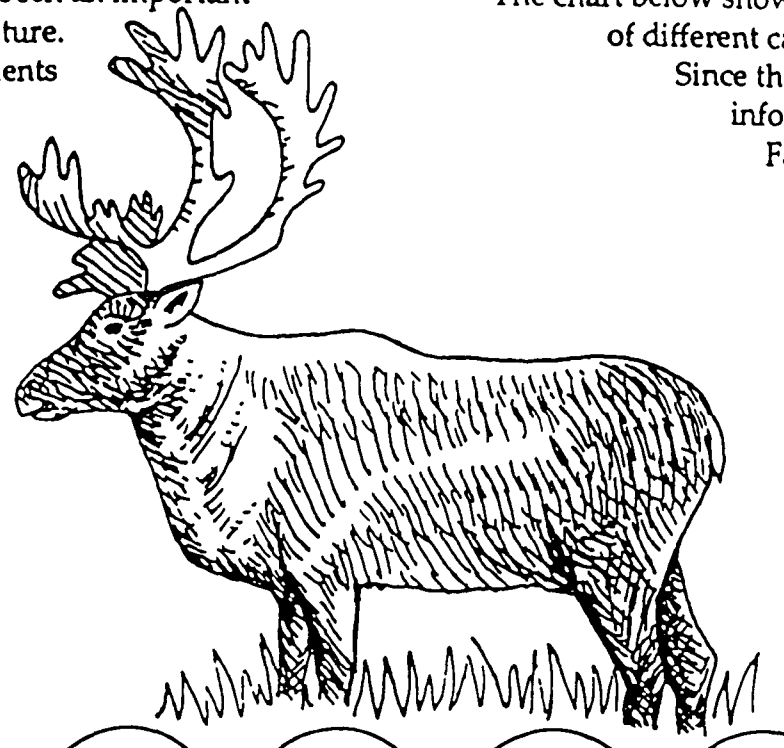
Appendix 4

Example of Nutrition Fact Sheet for Traditional Food Species

CARIBOU

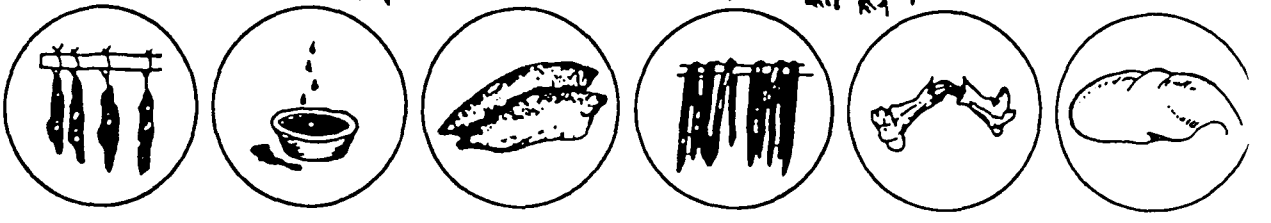
CARIBOU IS GOOD FOR US !

For generations caribou has been an important part of the Dene diet and culture. Caribou gives us many nutrients that help build and repair body tissues. It also provides us with energy and helps to keep us healthy. As well, many parts of the caribou are used for clothing and crafts. There is no waste of the caribou.



WHAT DO WE KNOW ABOUT CARIBOU

The chart below shows the nutrient rating of different caribou body parts. Since there is little nutrient information on Caribou Fat, it is not listed as a body part. As well no research has been done on caribou kidneys Our elders tell us that caribou liver and kidney are healthy for us. We think they have similar nutrient values.



Nutrient Rating / Body Part	Meat	Blood	Liver	Intestine	Bone Marrow	Stomach Contents
Excellent Source	Protein	Iron	Protein * Iron Vitamin A	Fat		
Good Source	Iron B Vitamin	Protein		Protein Iron	Iron Fat	Iron Vitamin A
Poor Source	Fat Calcium	B Vitamin	Fat Calcium	B Vitamin Calcium	Protein B Vitamin Vitamin A	Protein Fat B Vitamin Calcium

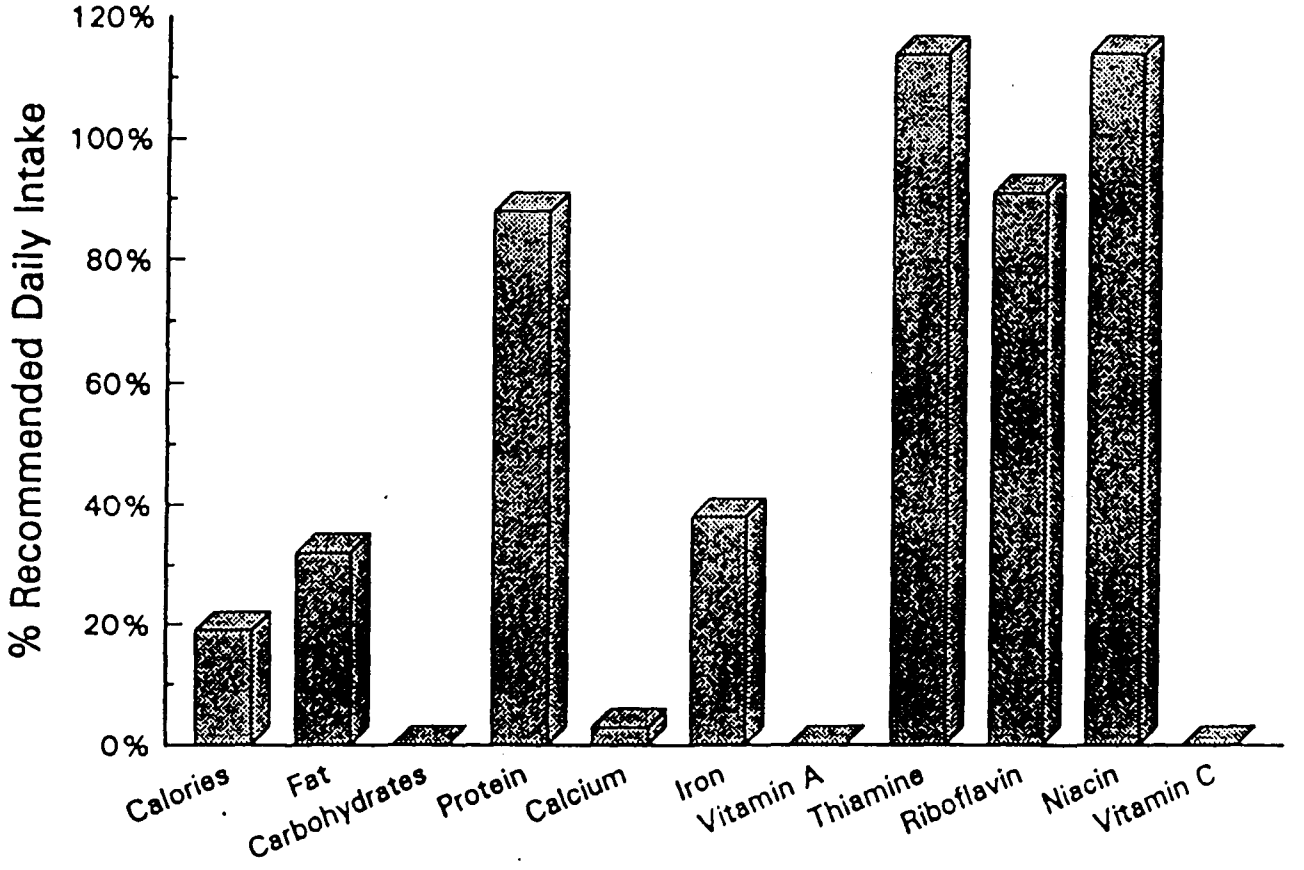
* **AN EXAMPLE OF HOW TO READ THE CHART:** Caribou liver is an excellent source of Protein, Iron and Vitamin A.

DID YOU KNOW ?

- It is best to choose traditional foods because they are rich in nutrients.
- Smoking or drying helps preserve the meat and may increase the amount of some nutrients. This is due to moisture loss during the drying process. Smoked or dried meat is great for travelling and snacks.
- The fat content of caribou meat is very low (1%) compared to 12-45% for beef, pork and poultry.

TO FIND OUT WHAT OTHER FOODS PROVIDE THESE NUTRIENTS AND WHY THEY ARE IMPORTANT TO OUR HEALTH, REFER TO THE **NUTRITION FACT SHEET SERIES ON NUTRIENTS**

Nutrient Bar Graph for 90 grams of Dried Caribou



This graph shows the percent of nutrients that 90 grams of dried caribou meat contributes to the Recommended Nutrient Intake (RNI) of a 13 - 15 year old female.

FOR MORE INFORMATION CONTACT:

- Your Local Health Centre
- Your Band Office
- Your Regional Nutritionist
- The Dene Nation (403) 873-4081

The following resources will provide you with more information about *Caribou:*

Native Foods and Nutrition - An Illustrated Reference Resource (1994). Health and Welfare Canada.

Northern Food, Tradition and Health Kit (1992). Nutrition Section, Department of Health, GNWT.

Nutrient Bar Graphs. A Teaching Aid to Learn the Value of Native Foods (1984). Health and Welfare Canada.

Nutrient Value of Some Common Foods (1988). Health and Welfare Canada.

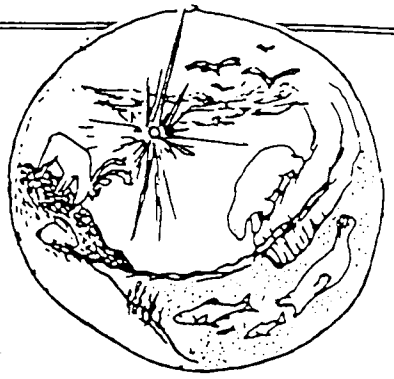
Use and Nutrient Composition of Traditional Sahtu (Hareskin) Dene/ Metis Foods (1994). Kuhnlein et al. CINE.

Produced by Mackenzie Regional Health Service and the Dene Nation. Funded by the Arctic Environmental Strategy. March 1995

Appendix 5

Examples of Results Communication Materials

Maternal/ Cord Blood Monitoring for Environmental Contaminants
Kitikmeot Participant Newsletter # 4 (November, 1995)



What was the monitoring program all about?

As a partner with other northern countries, the NWT is involved in monitoring programs for environmental contaminants. As part of this effort, the Kitikmeot Health Board and Mackenzie Regional Health Service are looking at what types of contaminants may be found in mothers and babies in the Mackenzie and Kitikmeot regions. Women who delivered their babies at Stanton Yellowknife Hospital volunteered to participate in the program. Most of the funding for this work came from the Arctic Environmental Strategy.

Contaminants in people can be measured by checking for contaminants in, for example, hair, blood and urine. In this program, blood was checked for contaminants because blood provides good information on some contaminants.

What will this program be able to tell you?

The monitoring program was set up to provide some basic information about what kinds of environmental contaminants may be present in people who live in the Kitikmeot and Mackenzie regions. This is the first monitoring program in the NWT to look at various types of contaminants at the same time. This means that there may be some questions you have that can be answered. However, there is still a lot that isn't known by anyone about these contaminants and their impact on the environment, wildlife or people. There is still a lot to learn!

What this program can tell you.

- ✔ What kinds of environmental contaminants you may have been exposed to over your lifetime, especially the last few years.
- ✔ How much contaminants are present in your blood and in the umbilical cord blood of your baby.
- ✔ How your results compare to other participants' results.
- ✔ What you can do about contaminants.

What this program cannot tell you.

- ✘ What your results mean for the health of you and your baby. The health effects of many of these contaminants are not known, especially when these contaminants are at low levels.
- ✘ What you can do to remove contaminants from your body. There is no pill that you can take to remove contaminants from your body. However, your body can remove many of these contaminants over time - some contaminants can be removed from your body faster than others.

What were the results of the monitoring program?

- The charts show results for several contaminants.
- Most program participants showed some levels of contaminants in their blood. This was expected since there is pollution all over the world. Most of this pollution comes to the NWT from far away.
- For a contaminant such as cadmium, it was possible to show how smoking cigarettes can increase a person's cadmium level. This is because tobacco contains cadmium and many other contaminants.
- The program also found that the foods people eat can be a source of contaminants. Other monitoring programs will help provide information on this area.
- Other contaminants were measured, however, there is little information available to understand what these results may mean.

Should people continue to eat traditional foods?

Yes! Traditional foods have many, many health benefits. Caribou, bear, fish, birds and other wildlife provide the same or better nutrition than store bought foods.

Contaminants are low in most traditional foods, but tend to build up in the fat and organ meats in older animals, and animals which eat other animals. At the present time, contaminants are at low levels in most traditional foods. For example, people can eat unlimited quantities of caribou meat.

Will contaminants affect people's health?

Contaminants in the north have been found at low levels. It's not known what types of health effects may come from these low levels. We only know that low contaminant levels don't appear to be causing obvious health problems.

What can people do about contaminants?

Consider the kinds of lifestyle choices we make:

- reduce or stop smoking;
- continue to eat a wide variety of traditional foods;
- be careful when disposing of household wastes like old paints or cleaners;
- get involved in your community ... remember...what ends up in the dump doesn't just disappear;
- be aware of your environment and report any changes you notice in the water, land and wildlife around your community.

DO YOU HAVE ANY QUESTIONS?

Please contact your local health centre (H.C.) or your Kitikmeot Working Group representative.:

Maternal and Cord Blood Monitoring for Environmental Contaminants
Participant Results Summary

Over the past year women in the Mackenzie and Kitikmeot have volunteered to participate in the monitoring program. About 280 women gave blood samples while they were at Stanton Hospital delivering their baby. These blood samples were then looked at for contaminants.

How to read your chart :

- Your results are shown by the star symbol on each chart. There are two charts: one shows the maternal (mother) levels and the other shows the umbilical cord levels. No star symbol on the chart means your results were not available.
- The green bar charts show the range of results for all participants, going from the lowest amount measured to the highest amount measured.
- All contaminants are measured in ppb which means parts per billion. One ppb is about as much as one cranberry in 20,000 pails of cranberries.
- The average contaminant level for all women participating in the program is marked. "Average" means most women were close to this level.
- The low levels of contaminants found for all women, including yourself, do not appear to be causing health problems.
- Your charts also shows the levels of contaminants where some people could begin to have health problems. This information, shown in blue, is included to help you better understand your results.
- Community health workers (nurses, doctors, CHRs) can discuss your results with you.

Who else will see your results?

- Your results are confidential. They are available only to you and your health worker.
- General program results will be available to participating communities and agencies. Results will also be shared with other northern communities in Canada and the circumpolar north. This information will assist northern countries in working to stop pollution.

What happens next?

- Other regions in the NWT are starting monitoring programs of their own. Information from these monitoring programs will give a picture about contaminants in people all across the NWT. This information will assist northerners in deciding what the next steps should be.

Concerned about your results?

- Have a close look at your chart. Remember, everyone has small amounts of contaminants in their body.
- Your health centre has more information about contaminants. There is a video and a fact sheet binder to help answer your questions.
- If you are still concerned about your results then talk to your health worker.

Letter to participants who had maternal results but no cord results.

November 1, 1995

Maternal/Cord Blood Monitoring Program: Mackenzie & Kitikmeot Participants

Dear Participant,

As you know, when participants delivered their babies at Stanton Yellowknife Hospital, a small amount of blood was collected from the mother as well as from your baby's umbilical cord. This blood was then looked at for environmental contaminants (or pollutants).

I am contacting you at this time to let you know that your blood results are now available. Please note that we are unable to provide you with your baby's umbilical cord blood results. For some participants, including yourself, cord blood samples were not available for testing for one of two reasons: (1) there was not enough blood sample available for contaminants testing after other routine blood tests had been completed by the hospital; or (2) the containers holding the blood samples were damaged during shipment to the laboratory which performs the tests.

Enclosed is information for your review:

1. Participant newsletter #4;
2. A one-page summary to help you understand your results;
3. Two charts: your blood results and a chart which shows general results for cord blood levels. Both charts give results for those contaminants which have known guidelines.
4. Fact sheets about the nutritional benefits of some traditional foods;
5. A booklet about environmental contaminants activities in the N.W.T.

Would you like to know more about environmental contaminants? The Mackenzie Regional Health Service and the Kitikmeot Health Board are holding a phone-in TV show November 29, 1995 from 7:00 p.m.- 8:00 p.m on TVNC. A panel of northerners, who have a variety of working experiences in the environmental contaminants area, will answer your questions. A new video, about environmental contaminants and people's health, will also be shown. We hope you will participate in this "first time ever" phone-in show about environmental contaminants in the N.W.T. Call in with your questions.

Thank you again for your participation in the program. If you would like more information about environmental contaminants, please contact your health worker.

Yours Truly,

Program Coordinator

Letter to participants who did not want to know their results.

November 1, 1995

Maternal/Cord Blood Monitoring Program: Mackenzie & Kitikmeot Participants

Dear Participant,

As you know, when you delivered your baby at Stanton Yellowknife Hospital, a small amount of blood was collected from yourself as well as from your baby's umbilical cord. This blood was then looked at for environmental contaminants (or pollutants).

When you volunteered for this program, your health care worker let you know that, if you wished, you could learn of your own test results. At that time, you indicated that you did not wish to receive these results. For your information, program results are now available and have been forwarded to your medical file. Should you wish to see your results please request them from your health worker (nurse or doctor). Your own results will remain private between your health care worker and yourself.

Given your interest in this topic we are enclosing some information:

1. Fact sheets about the nutritional benefits of some traditional foods;
2. A booklet about environmental contaminants activities in the NWT.

Would you like to know more about environmental contaminants? The Mackenzie Regional Health Service and the Kitikmeot Health Board are holding a phone-in TV show November 29, 1995 from 7:00 p.m.- 8:00 p.m on TVNC. A panel of northerners, who have a variety of working experiences in the environmental contaminants area, will answer your questions. A new video, about environmental contaminants and people's health, will also be shown. We hope you will participate in this "first time ever" phone-in show about environmental contaminants in the N.W.T. Call in with your questions.

Thank you again for your participation in the program. If you would like more information about environmental contaminants, please contact your health worker.

Yours Truly,

Program Coordinator

Maternal & Cord Blood Monitoring Program

A few notes about the four contaminants and their possible health effects as relevant to the participants of this monitoring program

CADMIUM

Sources?

- ➜ occurs naturally in low amounts: volcanos and wind-blown dust are the main natural sources.
- ➜ used in batteries, fertilizers, mining activities, and the manufacture of paints and plastics.
- ➜ generated from burning fossil fuels and wastes.
- ➜ main sources in people is from cigarette smoke.

Why is it found in the NWT environment?

- ➜ carried to the NWT by global air and water currents.
- ➜ found in cigarette smoke.

Possible health effects?

- ➜ there are no known health effects for those levels which were found in this monitoring program.

LEAD

Sources?

- ➜ occurs naturally in low amounts: found in rocks.
- ➜ generated by industrial activities (smelting and soldering) and the burning of wastes and fossil fuels which contain lead.

Why is it found in the NWT environment?

- ➜ carried to the NWT by global air currents.
- ➜ commonly found in rocks of the Canadian Shield (a large area of western/central NWT).

Possible health effects?

- ➜ there are no known health effects for those levels which were found in this monitoring program.

Some information on contaminants excerpted from the Department of Health and Social Services fact sheets in Contaminants and Your Health: NWT Fact Sheets. This summary page was compiled as part of an information package in the Maternal and Cord Blood Monitoring Program (Mackenzie Regional Health Service and Kitikmeot Health Board), November, 1995.

Maternal & Cord Blood Monitoring Program

A few notes about the four contaminants and their possible health effects as relevant to the participants of this monitoring program

MERCURY

Sources?

- ➜ occurs naturally in low amounts: released from the weathering of rocks, volcanoes and forest fires.
- ➜ used in electrical products, paints and mining activities.

Why is it found in the NWT environment?

- ➜ commonly found in rocks of the Canadian Shield (a large area of western/central NWT). These rocks may release more mercury into the environment than rock types in other parts of Canada.
- ➜ carried to the NWT by global air currents and river/ocean currents.
- ➜ discharged as a by-product of mining.

Possible health effects?

- ➜ there are no known health effects for those levels which were found in this monitoring program.

POLYCHLORINATED BIPHENYLS (PCBs)

Sources?

- ➜ first manufactured for commercial use in 1929: used in many industrial fluids because they are very stable and heat resistant.
- ➜ used in heavy electronic and heat-exchange equipment as well as in inks, oils, sealants and caulking compounds.
- ➜ North American ban (1977) on the manufacture, importation and non-electrical uses of PCBs.
- ➜ electrical uses are being phased out, with strict regulations on handling and disposal of PCBs.
- ➜ improper disposal and accidental spills during 1930-1970s resulted in the release of PCBs into the environment worldwide.

Why is it found in the NWT environment?

- ➜ trace levels of PCBs have been found everywhere in the environment around the world.
- ➜ carried to the NWT by global air and water currents.
- ➜ older industrial equipment brought into the NWT may contain PCBs

Possible health effects?

- ➜ there are no known health effects for those levels which were found in this monitoring program.