FIRST NATIONS
ARTHRITIS SELF-MANAGEMENT PROGRAM

REPORT TO

THE BRITISH COLUMBIA HEALTH RESEARCH FOUNDATION

IHPR
Institute of Health Promotion Research
University of British Columbia
Vancouver, BC Canada

THE ARTHRITIS SOCIETY
BC and Yukon Division

> ***"We have more questions to ask and we're not just going to say "thank-you very much for your help" and that's it, you know. We want to know why, and what, and how… This kind of program needs to be offered to elderly people, to middle aged people, to teenagers, to little people… because it's an education and education is learning… A lot of our First Nation people… never asked any questions, … and now we're asking questions."***
>
> Excerpt from interview with First Nations Program Leader

Funding for this project was made available through a grant from the British Columbia Health Research Foundation.

FIRST NATIONS ARTHRITIS SELF-MANAGEMENT PROGRAM

REPORT ON PROJECT

EXECUTIVE SUMARY

This project was initiated when four native communities in B.C. requested The Arthritis Society to work with them on the problem of arthritis. The native communities themselves had identified arthritis as a priority. The purpose of the proposed project was to determine whether the Arthritis Self-Help Management Program, which has been used extensively throughout Canada, could be used in native communities.

This report describes the results of a series of four inter-related research projects conducted jointly by The Arthritis Society of a First Nations Arthritis Self-Management Program and to identify areas where the program can be strengthened for use with native communities throughout Canada.

The overall results indicate that the First Nation Arthritis Self-Management Program has had significant positive results on health (arthritis control) and quality of life in sixteen First Nation communities in British Columbia. Results suggest that the program could be implemented with similar successes in other First Nations communities in Canada.

To negotiate appropriate methods that included the native communities as full partners. The Arthritis Society and native representatives employed participatory research processes. A health promotion planning model guided the process and both quantitative and qualitative research methods were used. Health promotion seeks not only immediate impact on reductions in behavioural risks, symptoms, or voluntary changes in environmental conditions, but also, and equally importantly, empowers participants to engage effectively in the community's affairs. Grant funds from the British Columbia Health Research Foundation supported the collaboration.

In the first study, leaders from the native communities defined their experience with the problems of arthritis, thus specifying the desired outcomes and the research questions. A health promotion planning framework was used by the partners to address the problem of determining desired outcomes. This framework starts with the aspects of the problem or with the goal considered most important to the community. This goal

was defined in relation to “quality of life”. A tested and validated health promotion planning model called PRECEDE guided development of interview questions. Impact questionnaires were used to elicit information from 18 in-person interviews with leaders from eight rural communities. The questions focussed on three main areas: on quality-of-life, on beliefs about arthritis, the program, and the kinds of benefits the program could facilitate, and on suggestions how the community could help interpret the results. The purpose of the interviews was to determine what benefits and/or changes the leaders wanted to bring about. The information was analysed in two ways: by a group process involving the First Nations Advisory Committee and by the research project investigator using standard methodology.

The results of the first study were considered highly positive. First Nations leaders identified the outcome goals for the project and ways the Arthritis Self-Management Program could meet these goals within the communities. Strong working relationships were formed.

The native communities and The Arthritis Society then worked as partners in planning and adapting the Arthritis Self-Management Program for use in the First of local groups, and in evaluation of the program using the native communities’ own standards as identified in the first study. Because the original Arthritis Self-Management Program is based on interactions within the group, cultural beliefs and practices of the First Nation communities could be incorporated without changes in the principles of the program. Furthermore, this program allowed for discussion of “alternate” treatments for arthritis in addition to the traditional Western medical health model: such a program allowed for experimental sharing and supports the oral traditions and elder wisdom valued by First Nations communities.

A second study was carried out simultaneously with the trials of the newly adapted First Nations Arthritis Self-Management Program in sixteen communities. The outcomes evaluated in this second study were based on information elicited in the first study and once again used health promotion principles. The purpose was to determine the effectiveness of the First Nations Arthritis Self-Management Program on health and quality of life in the participant communities. A combination of qualitative and quantitative methodologies was initiated to determine how to study the impact of the program. The partners determined that these methods would best enable the communities to evaluate both health and social (or quality of life) benefits.

The results from both methodologies, when compared, showed a high degree of congruency, and provided the basis for choosing the following nine outcome measures for the testing of the First Nations Arthritis Self-Management Program: health status; pain; disability; stress; fear; anger; depression; self-efficacy related to symptoms; and self-efficacy related to pain. Widely-applied, validated tests were used to assess these outcomes, including visual analogue scales to determine pain, stress, fear and anger outcomes.

Tests were conducted before, immediately after, and four months following the program to obtain data from 167 program participants. Cultural sensitivity, education level, and comfort with self-administered paper and pencil tests were considered in preparing the questionnaire.

In the second study, significant improvements in all nine areas – health status; pain; disability; stress; fear; anger; depression; self-efficacy related to symptoms; and self-efficacy related to pain – were shown at the end of the six week course. All improvements were maintained with minor variations four months later.

At a progress meeting almost one year following implementation of the First Nations Arthritis Self-Management Program in the communities, native leaders indicated additional changes were taking place and attributed these to the program. The leaders described eight additional impacts that seemed to be occurring in the communities and that seemed to have positive effects on arthritis and health care generally. Interview questions were designed to test these observations in a third study. Native leaders were trained as research associates and travelled to the involved communities and interviewed 31 course participants. Analysis of the questionnaires showed that the program did have positive effects in the eight areas identified by the native leaders.

Participants reported improved interactions and relationships with physicians through improved communication and deepening interpersonal relationships. Social support networks were developed and strengthened and People found that they were able to carry out daily activities more easily. The realization that specific management strategies could be employed led to an increased frequency of exercise and higher motivation levels. Generally, participants found the course to be helpful and responses toward it were positive.

Finally, to obtain information on how the program was implemented, and to learn what it meant to participate in the program, project staff carried out a fourth study. They developed 18 questions and interviewed the 13 course leaders who had provided the First Nations Arthritis Self-Management Program in their communities.

This information from the fourth study, from the perspectives of the course leaders, confirms the ability of communities to tackle their own health and welfare issues.

The information from the total project provides a comprehensive picture of what the communities experienced as a result of the project. One of leaders interviewed states it eloquently:

“We have more questions to ask and we’re not just going to say “thank-you very much for your help” and that’s it, you know. We want to know why, and what, and how… This kind of program needs to be offered to elderly people, to middle aged people, to teenagers, to little people… because it’s an education and education is learning… A lot of our First Nation People… never asked any questions… and now we’re asking questions.”

TABLE OF CONTENTS

FIRST NATION PARTNERS

The following people are responsible for making The First Nations Arthritis Self-Management Program a success. The knowledge, expertise, and time they contributed in planning, implementing, evaluating, and disseminating the project is greatly appreciated by the thousands of people with arthritis in First Nations communities.

Karen Agur	CHR, Sliamin Reserve, Powell River
Rachel Andrew	Mt. Currie Band, Mt. Currie
Rose Andrew	Mt. Currie Band, Mt. Currie
Florence Atleo	Ahousaht Band, Ahousaht
Esther Bob	Paquachin Band, Brentwood Bay
Irma Bos	Native Friendship Centre, Port Alberni
Mary Brown	ASMP Trainer, White Rock
Ina Campbell	Ahousaht Band, Ahousaht
Bunt Crammer	Tsawaayuus Gardens, Port Alberni
Cindy Dan	Mt. Currie Band, Mt. Currie
Ben David	United Native Nations, Port Alberni
Grace David	Port Alberni
Tom Dick	Mowachaht Band, Gold River
Veronica Dick	Mowachaht Band, Gold River
Pam Elliot	Mt. Currie Band, Mt. Currie
Debra Foxcroft	Nuu chah nulth Community & Human Services
Trudy Frank	CHR. Ahousaht
Kuldip Gill	University of B.C.
Phil Hall	Native Health, Ministry of Health
Grace Hans	Nuxalt Nation, Bella Coola
Sheila Henry	Paquachin Band, Brentwood Bay
Barbara Hill	CHR, Westbank
Ian Hinksman	B.C. Aboriginal Network on Disability Society
Anita Jack	Kyuquot Band, Kyuquot
Margaret Jack	Kyuquot Band, Kyuquot
Lois Jacks	CHR, Paquachin Band, Brentwood Bay
Jennie Joe	University of Arizona, Tuscan
Muriel Joe	Cowichan/Chemainus Band, Duncan
Carol John	Fountain Band, Lillooet
Fred John	Fountain Band, Lillooet

Judy Joseph	United Native Nations, Port Alberni
Florence Martin	Arthritis Society Board of Directors
Joe Mitchell	Band Manager, Sliamin Band, Powell River
Bill Mussell	Sal’i’shan Institute, Naramata
Gail Madriga	Cariboo Friendship Centre, Williams Lake
Gail Madriga	Cariboo Friendship Centre, Williams Lake
Gloria Nicholson	Professional Native Women’s Association
Maxine Nookemus	Ohiat Band, Bamfield
Pat North	CHR, Ittatsoo Band, Ucluelet
Irene Seward	CHR, Nanaimo Band, Nanaimo
Lillian Siwallace	Nuxulk Nation, Bella Coola
Myoung Soon Lee	U.B.C. Institute of Health Promotion Research
Debbie Tallio	CHR, Nuxulk Nation, Bella Coola
Theresa Thorne	Cowichan/Chemainus Band, Duncan
Bev Touchie	Ittatoo Band, Ucluelet
Jeanette Watts	Nuu chah nulth Community and Human Services
Margaret Waite	Allied Indian and Metis Society
Darleen Watts	CHR, Tseshaht Band, Port Alberni
Courtney Watts-Boucher	Tseshaht Band, Port Alberni
Audrey Whitmore-Atleo	Ahousaht Band, Ashousaht
RoseAnn Williams	Sliamin Reserve, Powell River
Connie Wilson	Sliamin Band, Powell River
Dorothy Wilson	Tseshaht Band, Port Alberni
Mish Vadasz	Arthritis Society, BC and Yukon Division

PROJECT TEAM

Principal Investigators

Patrick McGowan	The Arthritis Society (BC & Yukon Division)
Lawrence W. Green	Institute of Health Promotion Research, University of British Columbia

Project Coordinators

Cathay Loadman	The Arthritis Society (BC & Yukon Division)
Marietta Einarson	The Arthritis Society (BC & Yukon Division)

Project Consultants

Kate Lorig	Stanford Arthritis Centre, Stanford University, Palo Alto, California
Jennie Joe	Native American Research Training Centre, University of Arizona, Tucson, Arizona
Jeannette Watts	Nuu chah nulth Community and Human Services Program, Port Alberni, B.C

Qualitative Analysis

Gail Zuk	School of Social Work, University of British Columbia
Michelle Calloway	Institute of Health Promotion Research, University of British Columbia

Quantitative Analysis

Bob Uttl	University of British Columbia

Project Assistant

Lisa Richardson	The Arthritis Society (BC & Yukon Division)

FIRST NATIONS ARTHRITIS SELF-MANAGEMENT PROGRAM

SUMMARY REPORT OF PROJECT

ARTHRITIS AND FIRST NATIONS PEOPLES

British Columbia has approximately 127,000 native persons, representing 4.4% of the provincial population. The Arthritis Society, B.C. and Yukon Division, has made several attempts during the last decade to deal with the health care needs of native people as they relate to arthritis. A preliminary review of the literature indicated that the prevalence of rheumatic disease among native peoples in Canada occurs at about the same rate as in the general population, with the exception of the high occurrence of ankylosing spondylitis among Haida Indians of the Queen Charlotte Islands. Research studies examining the coping ability of native persons with arthritis were not found in the literature, but the experience with native people of The Arthritis Society. B.C. and Yukon Division, has shown that entry to the health care system is usually delayed and that, on entry, progressed symptoms were very common. Whether arthritis in the native community is more or less prevalent, it apparently presents with greater salience.

Early intervention and proper self-management of rheumatic disease can offset high costs of reparative hospital days and rehabilitative services needed when the condition is not treated early. Early entry into the health care system for treatment of arthritis and better knowledge of self-management techniques not only benefits those who suffer from the disease, but also benefits the whole community and helps contain health care costs.

Emphasis in the past, however, has been on education of health care professionals so that they could take care of native persons with arthritis instead of empowering native people to take care of themselves. Traditional didactic educational approaches have attempted to convey knowledge to the caregivers so that they could provide better treatment to persons experiencing arthritis. Lecture content usually included etiology, pathology, treatments (i.e., medication, physiotherapy, occupational therapy), and description of The Arthritis Society and its services. This information, however medically important, could not be used in programs and services at the community level with First Nations peoples. A service infrastructure did not exist in native communities and most health care workers who worked with native people in the communities were not trained or qualified to provide these types of services. In 1991, The Arthritis Society trained native Community Health Care Workers so that they would implement the program in their community. However, although 150 native workers were trained, the Arthritis Self-Management Program was implemented in fewer than five native communities.

In the fall of 1990, the British Columbia Ministry of Health conducted a Delphi survey of First Nation Leaders to assess their perception of social problems or issues facing First Nation populations of the province. Arthritis was identified as a serious health issue and was the only problem in the top ten priorities not related to alcohol or drug misuse. In the needs assessment study to identify native health problems, issues, and concerns, the following four problems were identified:

Lack of Native Health Care Workers: Many communities did not have access to native workers who can provide service in the context of day to day life in the community. Additionally, the workers who were available often did not have adequate support, training, and educational materials.

Problems Using the Health Care System: Translators, interpreters, and advocates for older and more isolated native people were needed when they attended medical clinics, hospitals, or even doctors' offices. Professionals have difficulty explaining medical concepts and treatments in a manner which is understandable. As a result, native people do not get a clear understanding of the explanations and directions and therefore become frustrated and discouraged and fail to follow-up their care. In some cases, hospital emergency departments are used when other more appropriate facilities should be used.

Inaccessible or Inappropriate Health Education Programs: Health education programs often are not available in native communities and Native Health Care Workers often do not have access to quality education materials that are "packaged" for delivery in community areas.

Breakdown in Communication Skills: Many native persons, especially the elderly, may lack the ability to communicate with doctors and other health care workers. Health professionals usually cannot speak the native language.

BACKGROUND TO THE PROJECT

In September 1991, four separate native groups approached The Arthritis Society requesting assistance with the problems caused by arthritis:

Nuu-chah-nulth Health Board (Port Alberni)
Pauquachin Band Council (Brentwood Bay)
Sliamin Band (Powell River)
Cariboo Friendship Society (Williams Lake)

A plan was arranged whereby the communities and The Arthritis Society would work together to identify needs, develop a program, and, in collaboration with the UBC Institute of Health Promotion Research, determine appropriate implementation and evaluation methodologies, participate in program implementation and evaluation, and interpret results. A research grant application (i.e., “Letter of Intent”) was submitted to the British Columbia Health Research Foundation Special Research Demonstration Program, Native Health Competition. The “Letter of Intent” was approved for progress to the next stage, with the following additional recommendations:

- i. Demonstrate community support for the project;
- ii. Encourage involvement from natives in the designing of the program; and
- iii. Ensure that the research design and the demonstration are culturally sensitive.

An Advisory Committee was established, with the following members:

Margaret Waite, Allied Indian and Metis Society
Phil Hall, Community Liaison, Native Health. B.C. Ministry of Health
Bill Mussell, Sal'i'shan Institute

On Saturday, October 19, 1991 this Advisory Committee met with the research team:

Patrick McGowan, B.C. Arthritis Society, Principal Researcher
Lawrence Green, University of British Columbia, Co-Principal Researcher
Kate Lorig, Stanford Arthritis Centre, Stanford University, Palo Alto, California, developer of the original Arthritis Self-Management Program and advisor to the Research Project
Cathay Loadman, B.C. Arthritis Society, Coordinator of the Arthritis Self-Management Program
Kuldip Gill, an anthropologist from University of British Columbia.

The purpose of the meeting was to discuss the proposed demonstration program, the recommendations made by the British Columbia Health Research Foundation when they reviewed the Letter of Intent, and ways to begin work on a project to help those in the native communities to manage their arthritis problems more effectively. It was agreed the Phil Hall would contact the chiefs or band mangers of the four native communities that had made the original approach to inquire if they were interested in participating in a demonstration project. All four communities agreed.

The Advisory Committee, working with the research team, developed focus-group questions to examine:

a) how back pain, joint pain, and/or arthritis affected people's lives,

b) the types of things that made it better or worse

c) the types of things they would do to help people with arthritis, and

d) the number of their friends and relatives who had back pain, joint pain, and/or arthritis.

The resultant questionnaire developed by the team following this meeting would help determine the kind of project that might be needed.

The questions were pilot tested at a Community Health Representative training course at the Sal'i'shan Institute where the group brainstorming method seemed productive.

The focus-group questionnaire then was administered four ways:

i. Group Brainstorming Method

Sliamin Reserve – by Joe Mitchell (Band Manager) and Cathay Loadman – December 4
Paquachin Band – by Lois Jacks (Community Health Representative) and Patrick McGowan – December 12

ii. Survey Method

Cariboo Friendship Society – Gail Madriga, Executive Director

iii. Group Discussion Format

At the Sal'i'shan Institute the group discussed the questions and the facilitator recorded responses

iv. Questionnaires completed individually by Sal'i'shan class members

According to Sal'i'shan class members, the percentage of persons with back pain, joint pain, and/or arthritis was extremely high in each of the communities:

Sliamin – 61%
Cariboo Friendship Society – 40%
Pauquachin – 34%
Sal'i'shan – 43%

The analysis showed that joint pain and arthritis seemed to have the greatest impact on lifestyle and emotional well-being. People from Sliamin reported difficulty fishing, digging clams, dancing, and doing handicrafts as well as having mobility difficulties. Depression was the major emotional effect that was reported at least once in each of the groups. The inability to complete family chores and loss of independence were cited, especially by the Pauquachin Band. In general, people reported that pain slowed them down, made them enjoy life less, and contributed to anger and frustration.

Of the things that made pain better, rest was the most common response. Other popular responses included cultural activities such as the swear lodge (with cedar bark), dressing warmly, hot baths, exercise, and good nutrition. Commonly reported things that made the pain worse were fatigue, cold, changes in the weather, and “overdoing it”.

Of the things they would like to do to help others with arthritis, providing information and education were the most common responses. Other things reported more than once included workshops, self-help groups, help with daily tasks, building a recreation complex, holding exercise groups, and building sweat lodges.

The overall high prevalence of arthritis (average 45%) suggested by the questionnaire, the request for assistance from The Arthritis Society, and the willingness to participate in the project were indications of community support for the project.

With this information at hand, a research grant application was prepared and submitted to British Columbia Health Research Foundation. The project was approved through the peer reviewed competition for health promotion grants in visible minority communities and received $125,000 in March, 1992.

PROJECT RESEARCH QUESTION

The research question submitted for funding and used to guide this project was:

“Does participation in an Arthritis Self-Management Program have an effect on the health status and managing ability of persons with arthritis?”

This question was similar to that used in testing the Arthritis Self-Management Program in other B.C. and Canadian communities. The difference in this research project, which was based on a Health Promotion Model, was that the Arthritis Self-Management Program would be adapted for use in First Nations communities and would be measured using goals determined by native community leaders.

In the project application it was stated that successful implementation of the project would have positive effects on the program participants, the leaders who deliver the program, the community, and the health care delivery system. The following descriptions are taken from the submission for research funding:

Program Participants

By participating in self-management program, participants will:

- gain knowledge and understanding of arthritis;
- learn ways of reducing pain and stress;
- learn ways that they can manage their arthritis (i.e. exercise, relaxation, pain management);
- learn ways of evaluation treatments that are suggested by family and friends;
- learn communication skills (i.e. how to talk to doctors, health care workers, family, and friends);
- learn problem-solving skills day-to-day living; and,
- learn community resources and ways of accessing health care.

These new skills and understanding that participants acquire through the program will benefit them in their ongoing struggle with arthritis in that they will:

- experience less pain and depression;
- be more active in managing their activities by practising more health related behaviours;
- be able to talk to doctors, health professionals, family, and friends about their arthritis, their needs, and problems;

- be able to solve arthritis-related problems in activities of daily living;
- use the health care system more effectively (reduced doctor visits, mediation usage);
- have a higher confidence in their ability to manage the day-to-day problems related to arthritis; and
- be more interested in participating in managing their overall health.

Program Leaders

After learning to lead the program, and then giving the course in the community, leaders will:

- learn and be able to use leadership skills;
- learn and use group work skills;
- learn practical medical knowledge of arthritis and its treatment;
- learn ways of encouraging others to help themselves.

The benefits accrued through leader involvement will also be felt in the community as a whole because they:

- will have an increase in self-confidence in their ability to facilitate groups;
- will be seen as a competent persons and as a resource within their community;
- will experience greater learning and be able to help others to learn;
- acquire confidence to become involved in other types of social and community action;
- will be able to transfer these skills into other areas of community life (i.e. advocacy).

Community Benefits

Communities will realise the benefits of the demonstration in several ways.
Communities will:

- have the expertise to plan and deliver arthritis patient education programs;
- have opportunities for people to become involved in self-help and social support activities;
- have programs created that are conductive to healthier lifestyles;
- have greater awareness of the prevalence and negative impacts of arthritis which will encourage involvement in advocacy and social action; and
- become involved in planning and implementing programs that deal with the health problems that they identified.

Benefits to the Health Care System

Successful participation in a Arthritis Self-Management Program by First Nations people may bring about positive benefits to the overall health care system. Native persons will access the health care system at an earlier stage and through the most effective manner. This will lead to a reduction in doctor visits and medication use, and less acute care hospital and rehabilitation centre utilisation.

The following figure shows where and at which stage the benefits of this proposal can be realised.

	Direct Benefits	Secondary Benefits	Ultimate Benefits
Persons with arthritis and their family	●	●	●
ASMP Leaders	●	●	●
Communities/Bands		●	●
Health Care System		●	●

The ultimate outcomes of the program are in an improved quality of life, an independence of participants, and communities being able to identify and manage chronic health problems.

INITIAL PROJECT ACTIVITY

The research project officially started in May 1992. The first task was to hire a First Nations Coordinator. A selection committee was struck with members: Margaret Waite, Allied Indian and Metis Society: Phil Hall, Community Liaison, Native Health, B.C. Ministry of Health: Gail Madriga, Cariboo Friendship Centre: Jeannette Watts, Nuu-chah-nulth Community and Human Services: Cathay Loadman, Arthritis Society Arthritis Self-Management Program Coordinator: and Patrick McGowan, The Arthritis Society and Principal Investigator. The committee was chaired by Gail Madriga.

Eight candidates were interviewed and Marietta Einarson was chosen as the half-time First Nations Arthritis Self-Management Program coordinator. Marietta Einarson would work closely with Cathay Loadman, who was also assigned half-time to work on the project.

The first activity that took place was a four-day structured focus group held in Vancouver. Ten First Nations leaders, the coordinators, the principal investigator, and a student observer. The activity during the four-day workshop was led by Dr. Jennie Joe and Dr. Kate Lorig. Dr Joe is from the College of Medicine, University of Arizona, Tucson, and is medical anthropologist and an experienced community health worker with special expertise in education and research. Dr. Lorig is from the Stanford Arthritis Centre, Stanford University, and is the developer of the Arthritis Self-Management Program . Dr. Joe and Dr. Lorig had experience working together other Native Health projects.

During the workshop, participants described the problems people with arthritis were expecting and the shortcomings of existing programs in addressing these needs. Several First Nations leaders had had experience with the Arthritis Self-Management Program that was being offered throughout the province. The previous research activity in testing this program with First Nations communities is described in Appendix A.

There was a general consensus that the Arthritis Self-Management Program was the right type of program because it taught people to be more reliant and active in taking care of themselves. The Program was reviewed in detail and participants suggested several changes and modifications in the information, the way the information was presented, the activities, processes, and techniques.

The First Nations Coordinators then took the suggested modifications and incorporated them into the First Nations Programs Manual (Appendix B).

The funding agency had specified that appropriate research methods needed to be used in this project. The advisory committee and the research team agreed that both quantitative methods (e.g., questionnaires) and qualitative methods (e.g., person-to-person interviews) should be used in combination.

This project followed a Health Promotion Model, whereby community participation is central to the project. Because of this, an initial study had to be carried out to choose outcome measure that should be used. Evaluation of the First Nations Arthritis Self-Management Program (the main project) was carried in the second research study. As well, other outcomes were noted during the administration of the programs and the follow-up phase, which lead to another study to determine whether these outcomes were related to the project. A final study was carried out to assess the recommendations of the course leaders.

Thus, during the project, four studies were carried out:

Study 1 – Interviews were conducted with 18 people from the native communities to get information about what they wanted a community arthritis program to bring about. This information was needed to help determine outcomes measures and to develop the questionnaire to be used to assess and evaluate the main project (ie., Study 2).

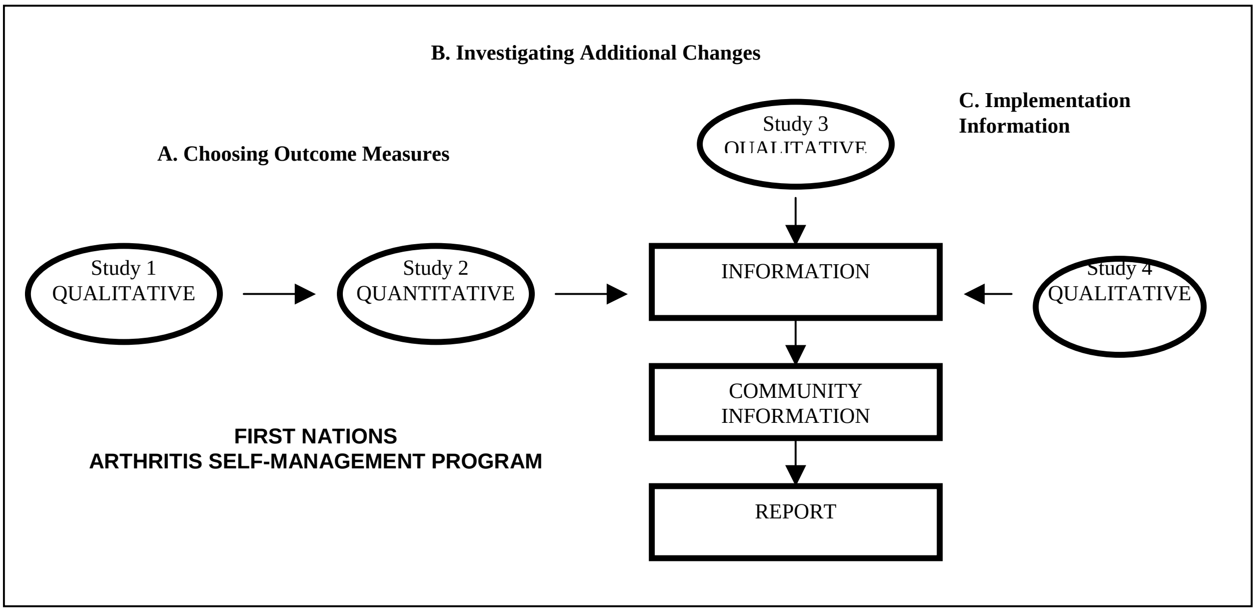
Study 2 – A pre-program, post-program, and four months follow-up questionnaire survey was completed by 167 program participants. These questionnaires were administered before the participants started the program, after they completed the program six weeks later, and again four months later. These produced valuable information about the impact of the program.

Study 3 – Interviews were conducted with 31 program participants to investigate additional benefits in the communities that had been reported to the research team by native leaders. These additional outcomes were assessed to see if they occurred as a result of the program.

Study 4 – Interviews were conducted with 13 persons who had led the program in their community to obtain information that might be useful in implementing the program in other native communities.

The sequence and the different research methods used is shown in Figure 1.

Figure 1. *Data collection by means by qualitative and quantitative designs at various phases of the First Nations Arthritis Self-Management Program.*



These information gathering stages used a combination of quantitative and qualitative research methods. This allowed a comprehensive picture of program impact to be developed. This information was returned to the communities for their assistance with interpretation for a summary of the overall project.

RESULTS OF STUDY 1 – DETERMINING PROGRAM MEASURES

With participatory research, a first principle is that the affected population should influence, if not control, the framing of the research question in terms meaningful to the group. A first step in the participatory research approach, therefore, is to decide jointly what matters to the community itself. This social diagnosis is not defined biomedically only, but also in relation to quality of life (social, emotional, and economic well-being).

To determine how to measure the success of the project, interviews were conducted with 18 community leaders in eight communities. These leaders were asked about things they wanted a community arthritis program to bring about. This activity took place during the fall of 1992. Exploration with native groups concerning quality of life and the subjective meanings they attach to arthritis included the following questions:

1. *"Can you tell me a little bit about yourself, what do you do, your role in the community."*

   This question asks about personal involvement in the community, whether the leaders saw themselves primarily as individuals involved with their family or having larger responsibility in the community such as being an Community Health Representative (CHR).

2. *"You're heard people talk about "quality of life". I guess this means what's really important to you in your own life, What things are really important to you, in your life?"*

   With this question respondents were asked to specify the things they felt were part of "quality of life" to them.

3. *"When you think of arthritis, what do you think about?"*

   This question was included in the interview to tap the most relevant and important thoughts and feelings about experiencing arthritis. The same question has been used in other qualitative surveys with arthritis and has produced good results.

4. *"What about other people in your community, what are their experiences with arthritis?"*

   This is an "experience/behaviour" question, and acts as a prompt to further expand on the previous question.

5. *“How have you been involved with the First Nations Arthritis Self-Management Program so far?”*

   This question helps respondents remember how they became involved in the program, and more importantly, prepares them for the next question, which is:

6. *“What do you think about the program?”*

7. *“If this program was going to have any effects on the people who take it, what kinds of effects would they be?”*

   Respondents who are intimately familiar with the daily struggle with arthritis, and who are familiar with the program, are asked their opinion of what impacts they believe the program will bring about.

   Question eight, the last question, was added after the first version of the questionnaire was pre-tested. It asks:

8. *“After the research is done, we will be coming back to share the results. What do you think is the best way to do that?”*

In past relations between the medical community and First Nations communities, there have been several research projects in which participants have been unpaid experimental subjects. In almost all cases the research team has not returned to the communities to discuss the results and to get assistance with the interpretation. In this project the plan for involving each community in sharing the results and participating with the interpretation was made clear right from the start when the communities agreed to participate in the project. This question served as a reaffirmation that this would take place, as well as get ideas for organising it.

Eighteen persons from eight communities agreed to be interviewed (see Table 1).

Table 1. Location of Bands and Number of Persons Interviewed

Ahousaht	1
Bamfield	1
Brentwood Bay	3
Campbell River	1
Gold River	2
Port Alberni	4
Powell River	5
Vancouver	1

Interview Results

The interviews identified outcome measures that were important to the native communities. The interview information was analysed in two ways: by an advisory committee and by the principal researcher using standard methodology. A complete description of the analysis procedure is contained in Appendix C.

Analysis of the responses found three main "themes" that needed to be measured:

Quality of life. The most important quality of life components to those interviewed were: **one's health, the family, caring for others, culture, and one's independence.**

Social meaning of arthritis. When allowed to range beyond biomedical perspectives on a health problem, people generally discuss it in terms meaningful to their social lives and quality of life. For the First Nations participants interviewed, the six most important themes or meanings associated with arthritis were: **pain, the inability to do things they used to do, medications and treatments, crippling, being afraid and scared, and the need to learn how to deal with it.**

Desired effects of the program. Also reflected in this stage of the participatory planning and research were desired effects of the program besides those reflected in the social meanings attached to arthritis. Concretely, they wanted **better understanding of arthritis, to "learn how to take care of myself," to**

learn about diets, medications, and exercises, and to learn to deal with stress, anger, and frustration.

These themes in the qualitative analysis helped formulate and adapt outcome measures and program content that would give the program relevance and the participants a greater sense of ownership of it.

The interviews led to the outcome measures. The principal researcher then chose various measuring tools that could be used to evaluate the effects of the First Nations Arthritis Self-Management Program in terms of these outcomes.

The outcome measures chosen included visual analogue scales measuring pain, stress, fear and anger, and standardised measures of disability (functional limitation scale), depression, and self-efficacy (i.e., confidence in one's ability to handle a problem in the future). The standard measurement tools are described in Table 2.

Table 2. *Tools Selected to Measure Outcomes Identified in Study 1*

QUANTITATIVE MEASUREMENT TOOLS

Health Status (MOS)

Visual Analogue Scales to measure:

……………………………………….. Pain
……………………………………….. Stress
……………………………………….. Fear
……………………………………….. Anger

Functional Limitation (HAQ Functional Ability Scale)

Depression Scale (CES-D)

Self-Efficacy Scale to measure one's confidence to manage Pain and Other Symptoms (Arthritis Self- Efficacy Scale)

These tools were incorporated into a questionnaire (see Appendix D). These questionnaires formed the base for Study 2, the main project, and were completed by those who participated in the First Nations Arthritis Self-Help Management Program. The questionnaires were completed by participants at the start of the program, a second time when they completed the program six weeks later, and again six months later.

PROGRAM IMPLEMENTATION

The First Nations Arthritis Self-Management Program is a six-session course which is given once a week for six weeks in a row. It is led by two trained leaders who receive a three-day training workshop that shows them how to teach the program. The teacher training workshops were arranged and given by the two project coordinators. In total, 121 interested persons took the teacher training during the project period. Of the 121 persons, 75 persons completed the training workshop and agreed to lead the program in their community. Table 3 shows the dates, locations, and number of persons in the training workshops.

<u>Table 3.</u> ***First Nations ASMP Leader Training Workshops***

Date	**Band/Location**		**Number Attended**	**Number Trained**
April, 1992	Ittatsoo Band	Ucluelet, BC	22	11
June, 1992	Amalgamated	Port Alberni, BC	23	9
October, 1992	Amalgamated	Port Alberni, BC	10	3
October, 1992		Campbell River, BC	21	16
November, 1992	Paquachin Band	Brentwood River, BC	7	6
November, 1992		Williams Lake, BC	11	5
March, 1993	Sliammin Band	Powell River, BC	7	6
June, 1993	Nuxalk Nation	Bella Coola, BC	7	6
October, 1993	Mount Currie Band	Mount Currie, BC	9	9
October, 1993	Fountain Band	Lillooet, BC	4	4
Totals			**121**	**75**

Once trained, the leaders organised and led the course in their own community. Leaders received $150 each for each course they implemented and led. In total 170 persons completed the course. A greater number were registered in the courses but were unable to attend all sessions for various reasons (e.g., moved, went fishing, became ill).

Table 4 shows the times, the Bands and locations, and the number of persons who completed the course.

Table 4. ***First Nations ASMP Courses***

Date	Band/Location		Number of Participants
TIME 1	Ahousaht Band	Ahousaht, BC	5
April 19, 1993	Ahaminaquus Band	Gold River, BC	6
	Kyuquot Band	Kyuquot, BC	6
	Sliammin Band	Powell River, BC	7
	Ohiat Band	Ucluelet, BC	5
	Musqueam Band	Vancouver, BC	3
	Westbank Indian Band	Westbank, BC	11
TIME 11	Ohiat Band	Bamfield, BC	9
May 24, 1993	Pauquachin Band	Brentwood Bay, BC	9
	Amalgamated Bands	Port Alberni, BC	6
	Squamish Band	North Vancouver, BC	7
	Sliammin Band	Powell River, BC	6
TIME III	Ahousaht Band	Ahousaht, BC	9
June 28, 1993	Pauquachin Band	Brentwood Bay, BC	5
TIME IV	Sliammin Band	Powell River, BC	3
October, 1993	Ittatso/Toquaht Band	Ucluelet, BC	3
	Nuxalk Nation	Bella Coola, BC	10
	Pauquachin Band	Brentwood Bay, BC	6
	Namaimo Band	Namaimo, BC	2
TIME V	Chowichan/Chemainus	Duncan, BC	5
November/	Mount Currie Band	Mount Currie, BC	7
December, 1993	Chowichan/Chemainus	Duncan, BC	5
	Chowichan/Chemainus	Duncan, BC	5
	Chowichan/Chemainus	Duncan, BC	5
	Fountain Band	Lillooet	3
	Fountain Band	Lillooet	6
	Nuxalk Nation	Bella Coola, BC	6
	Mount Currie Band	Mount Currie, BC	10
	TOTAL PARTICIPANTS		**170**

RESULTS OF STUDY 2 – PROGRAM IMPACT

The First Nations Arthritis Self-Management Program was based on a program that had been extensively tested with controlled trails. The partners could use, therefore, an evaluation design based on significant pre-test differences within the new populations. Such differences provide sufficient evidence of the effectiveness of the adapted program as long as the differences are greater than those observed in pre -test and post-test control subjects in the previous trials.

The main questionnaire was based on highly standardised measurement instruments used to assess outcomes in arthritis treatment and self-management, and the further assurance that the pre-testing effect on post-test scores is similar for different populations. Given these assumptions, simple pre-test/post-test designs combined with qualitative observations can serve far more efficiently to answer the research questions of adaptation, implementation, and dissemination for those program approaches that have been validated in previous controlled trials.

Subjects

In total, 167 participants completed the questionnaire, however, not all participants completed the pre-program, post-program, and follow-up questionnaires. Twenty-three subjects did not complete the first questionnaire (6 did not fill it out, 17 did not complete more than 2 critical sections), 52 did not complete the second questionnaire (48 did not fill it out, 4 did not complete more than 2 critical sections), and 46 did not complete the third questionnaire (46 did not fill it out). There were 101 subjects who completed both the first and second questionnaires, and there were 87 subjects who completed all three questionnaires. A questionnaire was considered complete and thus included in the analyses if subjects completed and if they provided data on at least 7 out of 9 outcome variables. For all critical analyses, the missing values were replaced by group means for each critical measure.

Of 101 subjects who completed both the first and second questionnaires, 28 subjects did not have any disability as evidenced by their zero score on the disability scale. The data were analysed two ways. The first set of analyses included all subjects, whereas, the second set of analyses included only the subjects with at least some disability. The demographic data on all participants, and participants who completed pre- and post-program questionnaires are shown in Table 5.

Table 5. *Demographic data of persons who completed questionnaires in First Nations Arthritis Self-Management Program. All subjects and subjects with disability.*

			Completed Pre- and Post- program questionnaire			
	All participants		All		Disabled only	
	M	*SD*	*M*	*SD*	*M*	*SD*
Age (years)	45.97	16.29	46.65	16.23	49.58	15.47
Gender						
Male (%)	13		16		11	
Female (%)	87		84		89	
Education (years)	9.57	3.01	9.61	2.91	9.06	2.86
Years with arthritis	13.62	11.71	14.53	12.01	14.72	12.59
Taking medication (%)	35		40		53	
Arthritis type (%)						
Rheumatoid Arthritis	15.0		15.8		19.2	
Osteoarthritis	6.0		6.9		9.6	
Other	3.6		6.0		8.2	
Don’t know	38.9		38.6		43.8	
Don’t have	18.6		15.8		4.1	
Missing data	18.0		16.8		15.1	
N	167		101		73	

Overview of statistical analyses

Because there were more subjects who completed the first two questionnaires (i.e., pre- and post-program) than those who completed all three questionnaires (i.e., pre- and post-program and four months follow-up), analyses were conducted in two steps. First, the impact of the First Nations Arthritis Self-Management Program was examined using only pre- and post-program scores on as many subjects as possible (101 who completed first two questionnaires). Second, the impact of the First Nations Arthritis Self-Management Program and the durability of the impact examined using the data from subjects who completed all three questionnaires (87 subjects).

The data were analysed using multiple analysis of variance (MANOVA) with 9 dependent variable (outcome measures): health status, pain, stress, fear, anger, disability scale, depression scale, self-efficacy symptoms subscale, and self-efficacy pain subscale. Whenever appropriate, a significant MANOVA was followed by a single analysis of variance to elucidate the effect of the Arthritis Self-Management Program on each outcome variable considered by itself.

MANOVAs on 9 outcome variables with pre- and post-program data as repeated measures showed a significant effect of treatment. F(9.92) = 3.91, p < .001. effect Seize = .277. The results of ANOVAs with pre-program and post-program data as repeated measures are shown in Table 6.

Table 6. *Pre- and post-program mean scores and standard deviations for 9 outcome measures, and the results of univariate ANOVAs.*

Pre-program			Post-program		
	M	*SD*	*M*	*SD*	*F (1.100)*
Health VAS	3.16	1.13	2.96	1.08	5.89*
Pain VAS	4.55	4.00	3.35	3.16	12.18**
Stress VAS	3.90	4.05	2.67	2.95	9.49*
Fear VAS	2.49	3.39	1.82	2.40	3.98*
Anger VAS	3.65	3.98	2.69	3.05	6.12*
Disability	.46	.51	.45	.51	.41
Depression	1.11	.43	1.02	.40	5.90*
SE symptoms	67.24	17.95	73.70	18.29	22.81**
SE pain	63.54	23.07	72.09	20.47	19.94**

*p < .05, **p < .001
N = 101

The 9 outcome variables were also examined to show the relationships between the pre-program, post-program, and the follow-up mean scores (see Table 7).

Table 7. *Pre-program, post-program, and follow-up mean scores and standard deviations on 9 outcome, and results of univariate ANOVAs testing the difference between pre-program and post-program scores, and between pre-program and follow-up scores.*

	Pre-program		Post-program		Follow-up		Pre vs Post	Pre vs Follow up
	M	*SD*	*M*	*DF*	*M*	*DF*	*G(1.86)*	*F(1.86)*
Health VAS	3.16	1.16	2.96	1.09	2.97	1.02	4.58*	4.37*
Pain VAS	4.81	4.06	3.35	3.11	3.38	3.03	15.12**	14.23**

2Stres2 Stress VAS 403.637 >>BD/MCID 4.01 4.10 4(2)Tj12 2.72 2.06 0 12 406.937 >>BD/MCID 4(2)Tj12 0 0

Table 8. *Pre-program and post-program mean scores and standard deviations for 9 outcome measures, and the results of univariate ANOVAs, for participants with disability only.*

Pre-program			Post-program		
	M	*SD*	*M*	*SD*	*F(1.72)*
Health VAS	3.53	.90	3.26	.97	8.07*
Pain VAS	5.83	3.55	4.27	3.18	14.77**
Stress VAS	4.84	3.99	3.42	3.10	7.98*
Fear VAS	2.87	3.54	2.17	2.58	2.85[a]
Anger VAS	4.49	4.14	3.37	3.24	4.97*
Disability	.64	.49	.61	.52	.92
Depression	1.17	.45	1.10	.41	2.10
SE symptoms	63.20	16.41	69.73	17.58	18.70**
SE pain	58.00	21.62	68.66	19.13	24.34**

*p < .05, **p < .001

[a] p = .10

N = 73

<u>*Table 9.*</u> *Pre-program, post-program, and follow-up mean scores and standard deviations on 9 outcome, and the results of univariate ANOVAS testing the differences between pre-program and post-program scores, and between pre-program and follow-up scores, for participants with disability only.*

	Pre-program		Post-program		Follow up		Pre vs Post	Pre vs Follow up
	M	*SD*	*M*	*SD*	*M*	*SD*	*F(1.61)*	*F(1.61)*
Health VAS	3.55	.94	3.26	1.02	3.27	.85	7.17*	6.14*
Pain VAS	6.21	3.47	4.36	.3.08	4.24	2.96	17.66*	20.21**
Stress VAS	5.01	4.00	3.54	3.09	3.58	2.86	7.71*	7.95*
Fear VAS	3.06	3.61	2.25	2.56	2.09	2.35	3.47[a]	4.61*
Anger VAS	4.79	4.23	3.56	3.27	2.87	2.83	5.20*	14.18**
Disability	.68	.49	.64	.55	.60	.52	1.92	5.24*
Depression	1.16	.45	1.13	.37	1.15	.41	.61	.06
SE symptoms	62.12	16.08	68.23	16.75	68.29	17.86	15.04**	8.28*
SE pain	57.46	21.05	68.26	18.94	67.97	19.23	29.78**	13.05**

*p < .05, **p < .001

[a] p = .07

N = 87

Overall MANOVAs on 9 outcome variables with pre-program, post-program, and follow-up scores as repeated measures showed a significant effect of time of measurement. F (18.44) = 3.38. p < .001. ES = .580. Follow-up MANOVAs were conducted to find out whether participants improved as a results of the Arthritis Self-Management Program and whether the benefits accrued during the Arthritis Self-Management Program were still present at the follow-up session four months later. A MANOVA on pre- versus post-program data showed a significant effect of time of measurement. F (9.53) = 4.55. P < .001. ES = .436, and MANOVAs on pre- versus follow-up data also showed a significant effect of time of measurement. F (9.53) = 4.08. p < .001. ES = .410. In contrast, a MANOVA conducted on post versus follow-up data was not significant. F (9.53) = .61. p > .50. ES = .095.

The end result is that the analysis shows statistically significant improvements in all nine variables: pain level, self-efficacy symptoms, and self-efficacy pain, and additional improvements in health status, stress, fear, anger, and depression.

Figure 2 shows these improvements in terms of “effect size”. The impact of the program was evaluated using several different scales that differ widely in terms of range of values and, therefore, there is a spread of the scores (or variability) across the scales. For example, the range of possible values on the self-efficacy scales is from 0 to 100, whereas the range of possible values on the health scale is 0 to 4. To examine the **relative** impact of the program on the areas of health status measured by each scale, it is necessary to obtain an index of the program effect that is free of the specific properties of each scale. This index is provided by the effect size measure. This is computed as the difference between pre- and post-program performance relative to the variability of each scale.

The effect size index allows direct comparison among improvements and/or deteriorations on any number of scales. In general, an effect size of .2 is considered small, .5 medium, and .8 large. However, even a very small effect size, for example .1, may indicate enormous clinical benefits for a target population. This point is especially true when dealing with long-term disability and chronic illness that carries substantial costs to the individual and to society.

Figure 2. Effect of ASMP on quality of life. (First Nations)

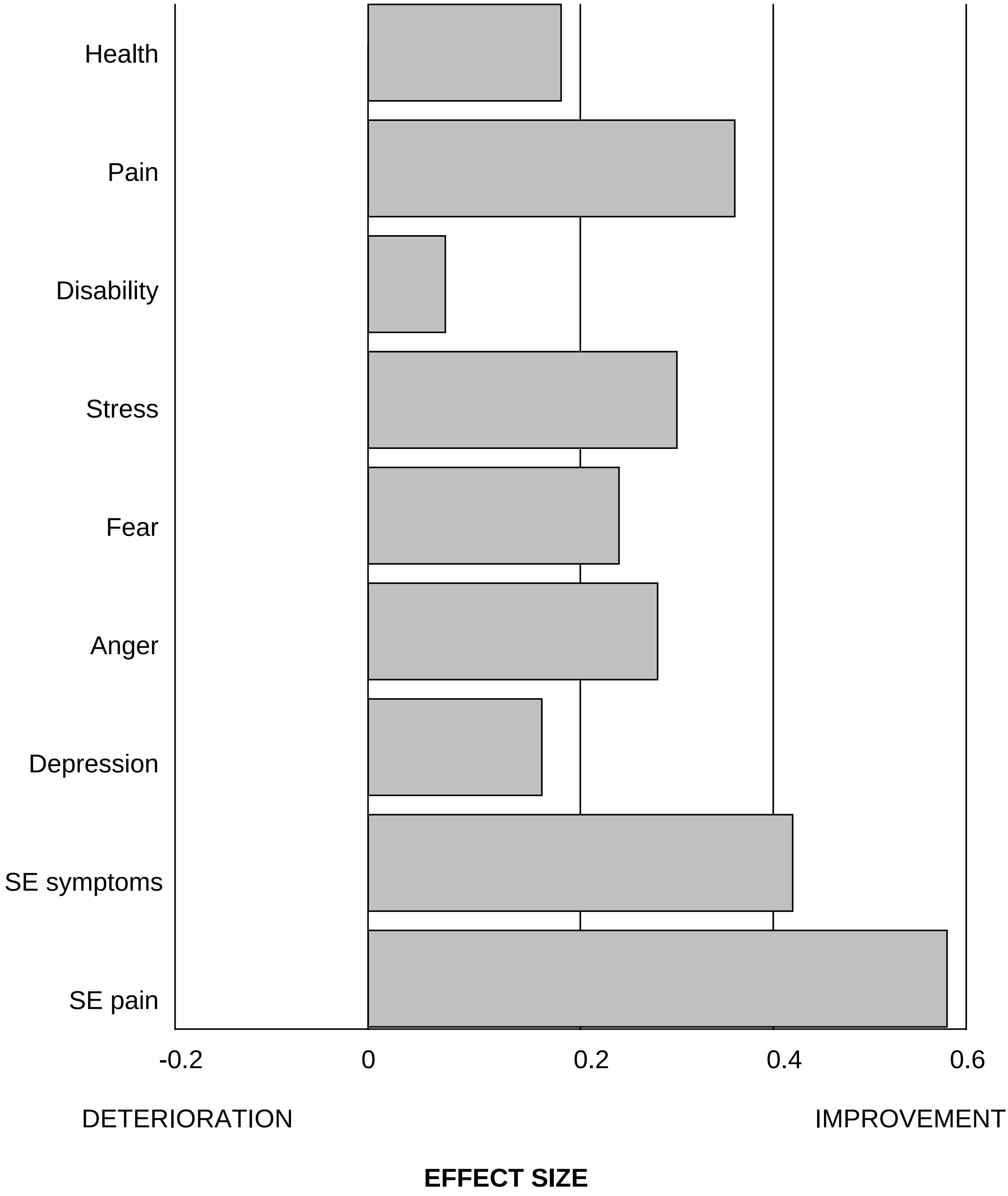
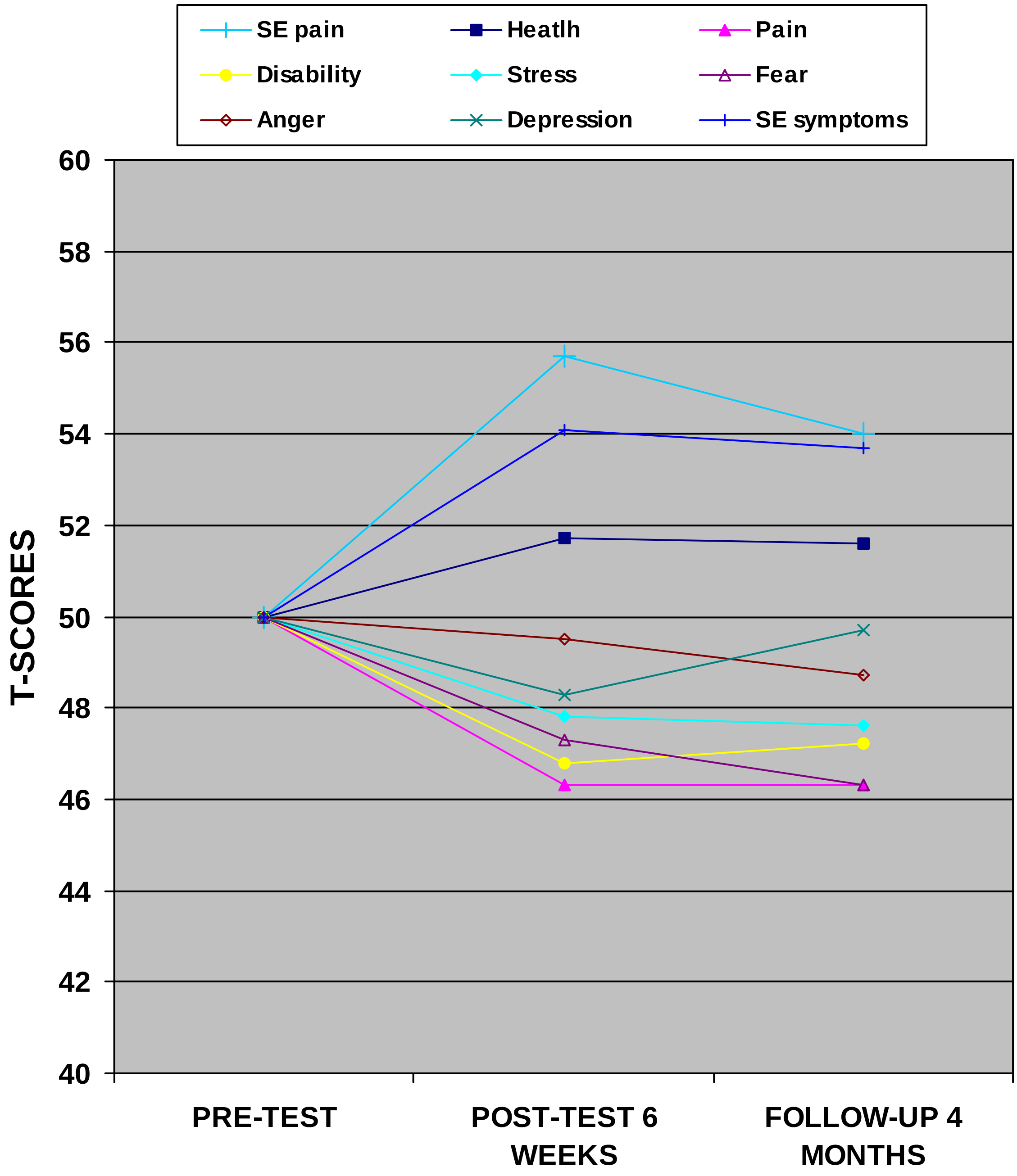


Figure 3 illustrates the changes in outcome measures between the pre-program scores, the post-program scores, and the scores four months later. These results show that Arthritis Self-Management Program resulted in improved well-being of the participants, and that these improvements did not diminish over time (that is, they lasted at least four months). The results of ANOVAs conducted as follow-up analyses to significant MANOVAs indicated that improvements occurred in all outcome measures except two: the disability scale and the depression scale. However, the disability represents improvements on pre-PROGRAM vs follow-up. One possible explanation is that it may have taken longer than six weeks for this benefit to appear.

<u>Figure 3.</u> *Pre-test, post test, and follow-up for ASMP outcome measures. (First Nations)*



RESULTS OF STUDY 3 – ADDITIONAL BENEFITS

In November 1993, a committee of First Nations teachers met at The Arthritis Society to review project progress. Attending the meeting were: Karen Agur, Connie Wilson, RoseAnn Williams, Bunt Cranmer, Barbara Hall, Cathay Loadman, and Patrick McGowan. At this meeting, these leaders indicated that at least eight additional changes were taking place as a result of the program, and these changes were different from the things being measured by the questionnaires. They articulated what they felt these changes were and these comments are shown in Table 10.

Table 10. *Additional Impacts Identified by Course Leaders*

1. Better and more communication with doctors (health professionals).
2. Developed a new support system. *"Realisation they were not alone, that a lot of people in their community had arthritis."*
3. Less loneliness, less isolation. *"People wanted to help each other, and were more concerned about each other."*
4. There was a change in the way people understood the concept/meaning of exercise.
5. More understanding of arthritis – what they were able to do themselves.
6. More control, not so helpless.
7. People realised they were able to do things they used to do.
8. People who took the course were more understanding and supportive towards each other.

These course leaders were hired to become researchers to investigate these observations. They developed a series of eight questions that they would ask persons who completed the program. The leaders travelled to the involved communities (other than the community where they had taught the course) and interviewed 31 persons who had completed the program. The interview results were summarised by Michelle Calloway. The interview questions developed are shown in Table 11.

Table 11. Interview Questions Developed

1. "Since you have been involved with the Arthritis Self-Management Program, could you tell me about what your visits and talks with your doctor or other health professional have been like."

2. "Some people with arthritis feel that they are all alone – you know, no one else understands, or feels they are all by themselves. What are your feelings about this now that you're been involved with the Arthritis Self-Management Program?"

3. "Since you've taken the arthritis course what has your contact been like with other people who have arthritis?"

4. "Since taking the arthritis course, have your ideas about exercise changed? Can you please explain."

5. "Since taking the arthritis course, can you tell me how your understanding about arthritis has changed?"

6. "Since taking the arthritis course, how are you managing your day-to-day activities (you know, getting dressed, cooking, handicrafts)?"

7. "Since taking the course, how are other people who have also taken the course acting towards you and other people who have arthritis?"

8. "Is there anything else you would like to say about the First Nations Arthritis Self-Management Program?"

Results of the interviews

Question 1. *Since you have been involved with the Arthritis Self-Management Program, could you tell me about what your visits and talks with your doctor or other health professional have been like.*

The course had a positive impact on the physician – patient relationship. The resultant changes in health professional visits since the implementation of the course were increased physician support and improved patient comprehension. Physicians became more supportive, offering encouragement and positive reinforcement at both the individual and community level. One patient reported that a physician had said:

> ***"This is the best thing that happened on the reserve."***

Patients had increased comprehension of what their physician was telling them because they had a better understanding of arthritis. To one course participant, the outcome of this increase in knowledge meant that:

> ***"I know what I was talking about."***

Improved comprehension was also the result of perceived clearer communication on the part of the physician, who:

> ***"Explained everything thoroughly".***

Question 2 *Some people with arthritis feel that they are all alone – you know, no one else understands, or feels they are all by themselves. What are your feelings about this now that you're been involved with the Arthritis Self-Management Program?"*

There has been a reduction in the sense of isolation and an increase in the level of social support among the participants in the course. One community member came to the realisation that:

> ***"I'm not alone in my suffering."***

which minimised feelings of loneliness and abandonment. The heightened levels of empathy displayed by family members and the ability of participants to disclose more information are indicators of improved social support. One woman commenting on the change in her husband's behaviour after she completed the course, noted that:

> ***"My husband has been really understanding."***

<u>Question 3</u>. *Since you've taken the arthritis course what has your contact been like with other people who have arthritis?*

The contact that participants have had with others who have arthritis after the course has improved in that interpersonal communication has been enhanced and social support networks strengthened. The disclosure of more personal information is an indication of this improvement in communication. Many participants previously found it difficult to share their feelings with others exclaimed that:

> ***"I can talk to others."***

The strengthened social support network is evidenced by group cohesiveness, mutual empathy and the willingness of participants to assist each other. According to group members:

> ***"We grew more close.", "We understand each other,"*** *and,* ***"We help each other along."***

<u>Question 4</u>. *Since taking the arthritis course, have your ideas about exercise changed? Can you please explain.*

The course resulted in increased frequency of exercise. This may be attributed to the learned knowledge that exercise is possible, important and beneficial for the arthritis sufferer. An overall increase in motivation to exercise occurred, as one participant noted:

> ***"I motivate myself to … keep exercising."***

For some, this increased desire to exercise was due to the fact that they found that:

> ***"The exercises are helpful."***

For others, learning that:

> ***"You could do exercises"*** *and* ***"Exercising is so important"***

was an influential factor in their decision to exercise.

<u>Question 5.</u> *Since taking the arthritis course, can you tell me how your understanding about arthritis has changed?*

A general increase in knowledge about arthritis, including the associated emotional responses and the existence of various forms, resulted after taking the course. Participants commented that:

> ***"It expanded my knowledge"*** *and* ***"I'm more aware (of) …. inner feelings."***

Furthermore, there was an understanding of the chronic nature of the disease.

> ***"Knowing that it's not going to go away."***

made acceptance of the disease easier. Learning about the triggers and coping strategies was an empowering experience, as evidenced in comments like:

> ***"There's a lot of thing I can do for myself" and "We have the means…. Coping with it."***

<u>Question 6</u>: *Since taking the arthritis course, how are you managing your day-to-day activities (you know, getting dressed, cooking, handicrafts)?*

The ability to manage daily activities improved. Participants indicated that they felt motivated to try and do activities which they previously though they could not do. This increase in motivation is captured in one person's response:

> ***"I was one of those people who lay around and feel sorry for myself, but not anymore."***

Furthermore, the exercises and techniques learned in the course facilitated the ease with which certain activities could be performed. This is illustrated in the case of a participant who was able to perform daily activities that were previously difficult to do:

> ***"Now that I've got my exercise program ….. down pat, it's been o.k."***

<u>Question 7</u>: *Since taking the course, how are other people who have also taken the course acting towards you and other people who have arthritis?*

The response to this question was much like the response to question number three. The course changed the way in which participants acted towards one another in that they became more communicative and supportive of each other. The course also enabled them to talk about their difficulties with one another. Heightened empathy, acceptance of each other and a sense of group cohesiveness, contributed to the development of this social support network. Feelings that people with arthritis:

> ***"Have accepted us"*** *and* ***"Have more respect for one another"***

are examples illustrating this increased sense of acceptance.

Question 8: *Is there anything else you would like to say about the First Nations Arthritis Self-Management Program?*

The general comments about the course referred to the course structure and quality, the knowledge and skills learned, being able to talk about one's feelings, the importance of maintaining a positive attitude, and the need from more aggressive advertising to market the course. Two suggestions for improving the course included a stratification of the course by age as a means of facilitating participation and disclosure:

> ***"There should be different age groups, ……they'd be able to express themselves more"*** *and to:* ***"Have more people (in the class)"***

in order to allow more community members to join. Aside from one participant, who felt that her teacher was unorganised, praise was given for high-quality instruction:

> ***"The teachers were good"*** *and* ***"Knew what (they) were talking about."***

Some participants enjoyed the course enough to claim:

> ***"They should have a lot more."***

The students benefited from the knowledge gained about arthritis, such as the influence of diet. For example, one student:

> ***"Realised the nutritional value and how much it could help me."***

Others found the relaxation and exercise techniques to be quite helpful. The impact of attitudes on one's illness and the importance of:

> ***"Thinking positive."***

was also emphasised.

In summation, the First Nations Arthritis Self-Management Program appears from qualitative feedback from program participants to have had a positive impact on relationships by improving the quality of the physician – patient interaction and deepening interpersonal relationships. Social support networks appear to have been developed and strengthened and communication was enhanced. The level of knowledge about arthritis increased and people found that they were able to manage their daily activities more easily. The realisation that specific management strategies could be employed led to an increased frequency of exercise and increased levels of motivation. Generally, participants found the course to be helpful and the response towards it was positive. To quote one participant:

> ***"It was the best thing that ever happened to me …… it helps me to express myself about how I was feeling and I would go home feeling that much lighter every day …. I think it's a really big help."***

RESULTS OF STUDY 4 – IMPLEMENTATION INFORMATION

The fourth study in the project involved interviews with 13 course leaders who had led the course at least once in their community. The purpose of these interviews was to obtain additional information regarding implementation processes used as well as to augment the information obtained in the third interview. The interview questions were developed by Patrick McGowan, the Principal Investigator. Interviews were carried out by Cathay Loadman of The Arthritis Society, and the analysis was completed by Gail Zuk of The UBC School of Social Work. Eighteen questions were used in the interviews, which took approximately 45 minutes each to complete. They were:

1. *"How did you become involved in the First Nations Arthritis Self-Management Program, and how many courses have you led?" (Get people to talk about how, when, and in which ways they became involved.)*

2. *"Tell me about the training you took to become a leader?" (When, where, who arranged it, what arrangements were made, the training experience itself, the best parts, the worst parts, etc.)*

3. *"What were the reasons why you actually decided to organise and give a course in your community?" (Who facilitated or suggested the position? Did someone phone her and apply pressure? Was it an expected part of another job? Did the person really feel it would be beneficial?)*

4. *"After you took the training, tell me all the steps you took to organise and give the course in your community?" (A detailed blow by blow description is needed here – as much detail as possible.)*

5. *"What sorts of things made it easier or helped to organise and give the course in your community?" (Peers, chief, council, band officials, etc.)*

6. *"What sort of things made it difficult for you to organise and give the course?" (Politics, other members, the culture, the mind set of the people, mistrust, previous experience with the medical profession, etc.)*

7. *"What sort of skills or talents do you think a leader needs to have to be able to organise and deliver the course in their community?"*

8. *“Why do you think the people came and took the course?’*

9. *“What sorts of thing made it difficult or hard for the people to take the course?”*

10. *“What sorts of things can be done to make it easier for the people to come out and take the course?”*

11. *“How comfortable were you (i.e., how secure or how confident were you) in giving the course in your community?”*

12. *“Why did you become a leader and give the course in your community (details needed)?”*

13. *“What sorts of skills do you have that made it possible for you to organise and lead the course in your community?”*

14. *“Was there anything that you learned in the training that helped you to organise and lead the course in your community?”*

15. *“Why did you give the course a second time in your community (or why didn’t you give the course a second time in your community)?”*

16. *“You were paid to give this course in your community, and people were paid $20 to complete the questionnaires. Do you think that being paid made a difference to either yourself or the participants?” (A lot of explanation and detail is needed here.)*

17. *“Can you describe what was actually happening during the sessions?” (Was it a social event, a sharing, a bitch session, a ritual, a ceremony, describe instances and events, etc.?)*

18. *“Can you tell me what your thoughts and feelings were when you were giving your class(es)?” (Lots of prodding may be needed to get the person to talk about what the experience was like. Get as many examples as possible.)*

Thirteen face-to-face interviews were conducted with First Nations peoples who lead the First Nations Arthritis Self-Management Program within their communities in British Columbia. The interviews were transcribed, a content analysis conducted, and common themes extrapolated across the interviews to augment and enhance other findings from other research. All 13 interviews were conducted after the respondents had lead at least one course in their respective communities (six respondents had led two or more), and all occurred at a location of their choice, usually within their homes.

The content analysis revealed common experiences among the native leaders and provides valuable information about the First Nations Arthritis Self-Management Program itself, its applicability to native culture, and some of the benefits of having health care courses offered by and for First Nations community members. Cultural beliefs and practices are prevalent throughout the interviews and is discussed throughout different sections of this qualitative analysis.

The sample was composed of ten females and three males. While a few had formal training in the health field, the majority were concerned family members or persons who had arthritis themselves. All the respondents had attended a training seminar on the Arthritis Self-Management Program prior to leading the course in their communities.

This report will address the major findings, using illustrative verbatim examples from the transcripts, followed by a brief discussion of implications. The findings are presented in a logical flow format and are reflective of the respondents' process in leading the course. The sections of this report are: **training** to lead the course, which then provided the impetus or **motivation** to offer the course to members of their community, **the course** itself (preparation, organisation, and delivery), **leader skills**, and **outcomes**. A section on **recommendations** was then added which is inclusive of the First Nations leaders' ideas to improve both the overall Arthritis Self-Management Program and the research itself.

The Training Course

A prerequisite to delivering the First Nations Arthritis Self-Management Program within the community was attendance at a training workshop which provided information about arthritis and teaches facilitation of the course. All 13 respondents attended such a training prior to leading the course within their own communities.

The majority of respondents were recruited for the program from contact with their Community Health Representative, newsletters, or advertising in the band office and were initially motivated to attend because they either have arthritis themselves, or through their employment were in contact with others who have arthritis. Two of the respondents attended the initial training because their spouses suffered with arthritis:

> ***Let's see … I first heard … I was sent a letter from the health workers and they – they just let me know they were having a workshop … since I have arthritis … I was very interested in going to listen.***
> ***" … they had in our newsletter saying that you know, for people that were interested … so naturally I figured well this is a whole new lifestyle for me – sure it would help so I just heard about it through our band office and went ahead and took it."***
>
> ***"myself (might get) it (arthritis) from sports injuries and … the line of work I do … looking after elderly people with arthritis and learning how to deal with them on a day to day basis … how to deal with people and their stress and pain and hurt."***
>
> ***"My wife asked me to go and she wanted me to find out – that's the reason why I went to find out you know … how bad it really is, I have a cousin that goes through hell because her husband doesn't believe she really suffers from it."***
>
> ***"I don't know (why I got involved) … probably because I took a nurse's aide course and I thought … that would better my course if I were ever to look for a job and I've that to add on."***

All the respondents who attended the initial training were genuinely interested in the subject area and believed it would help them. For example, they believed it would assist them in understanding a spouse, in their employment, or in coping with their own arthritis. While the training provided the tools and information necessary to facilitate the course, the respondents themselves were the ones to transform this experience from basic content into something meaningful and worthwhile for them as individuals and as members of the First Nations community. This process of personalising the positive experience and carrying it forward into their respective native communities is evidenced in the following section "motivation to lead."

Motivation To Lead

The positive experience of the training course provided one aspect of the respondents' motivation to deliver the Arthritis Self-Management Program course within their own communities. That is, upon completion of the training, the participants believed they had increased their knowledge and understanding of arthritis and had personally benefited from the experience.

> ***"Because I was given a lot of good information through the workshop that I went to … it helped me to realise what I was capable of … I thought that whole concept was worth passing on to other people who also feels so trapped … It made me feel inspired – It made me feel empowered and I thought that was really worth sharing."***

> ***"… what we looked at too was that they're willing to pay us for it … it's always expected for the Native First Nations people to do it voluntarily … but when non-natives come in, they get paid an awful lot. … It kind of gives us a lift in a way of respect."***

This positive experience, in combination with other factors, appears to have formed the basis of the respondents' motivation to lead the course within their respective communities. In addition to motivation arising out of attendance at the arthritis self-management training course, respondents also reported the following:

> ***"After … the training … I thought that's not a bad idea and if this can work for some other people I'm willing … (and) I could really use the money, I need the money, in a bad way."***

> ***"… there is now a very high percentage of arthritis within the First Nations people and this is one way … a group of people can come together and share what they have put up with every day and then they can become a support group to each other."***

> ***"The reason me and my wife decided to put one here is because there's quite a bit of people that have it … at an early stage really, and we figured that if we put the workshop up it would help them in the future."***

> ***"To start helping people that have arthritis problems – help them understand it more and how to deal with it – that they're not alone and a lot of other people have it … I would like to help them ease the pain."***

> ***"Because I knew a lot of family members that had arthritis and I know that eventually I'm going to get it … and like I said, I'm interested and I'm a nurse."***

In summary, respondents appear to have been motivated initially out of personal and/or professional interest to attend the original training course, and, once they had the tools to do so, became motivated to offer the course to members of their own communities. The motivational factors included: as an outcome of training; community need; desire to help others; to increase understanding; financial incentive; and as part of role in the community. Underlying all of these factors is the belief that given the appropriate opportunity, people can take charge of their physical health. The respondents appear to have to have recognised the pervasiveness of arthritis within the First Nations population and felt a sense of personal responsibility in addressing this health issue. The training course for the Arthritis Self-Management Program appears to have provided these respondents with information and tools, giving them the opportunity to take constructive action in combating the impact of arthritis in First Nations communities.

The training course itself, and the motivation factors discussed by the respondents, provided the fundamental foundation upon which to begin the task of organising and delivering the arthritis self-management course within the community.

Course Preparation/Organisation

The organisation of and preparation for facilitating the arthritis self-management course was also addressed by those interviewed. While the transcripts reveal common methods used to recruit participants to the workshop, respondents appear to differ in terms of what elements of preparation served as barriers or obstacles to course delivery, and those that served as enablers for the workshop.

The most common method of participant *recruitment* was informal, usually word of mouth, or telephone calls to people that were known to have arthritis. This informal recruitment was influenced by the size of the community as well as the connections and relationships among its people.

> ***"… just if I'm seeing somebody I just ask them if they'd like to come … I didn't do any advertising or anything like that."***
>
> ***"…just word of mouth and phoning and talking to people … we also put some posters up … and I put a little blurb in the (local paper) which is a paper that goes out to First Nations people in the (location) region."***

> ***"…I went right to see them … and I asked them about it … that we're going to do this and we would like them to come – then the people that were there, I asked if they knew others and then they asked the other people around if they would like to come too, so they brought some more."***
>
> ***"…I sent out a newsletter …I put it on our wheel."***
>
> ***"A lot of phone calls – I made a lot of phone calls … and I would say well, I'm not just teaching this course, I said I have arthritis also … and I found it very helpful. …I knew a lot of people that had arthritis and they would say well, maybe my sister could come … you know I would tell my friend and she would tell her sister and I would tell my sister and you know … it just got around."***
>
> ***"… well, the (two of us) got together and made it a list of all the people we knew that had arthritis … and then we made phone calls and some we made personal house visits and we passed out those pamphlets that mentioned the arthritis workshop…"***
>
> ***"…the first thing was posters … made phone calls and um …. talked to people and asked them – it was quite easy to get people because a lot of them didn't know much about arthritis."***

The methods chosen to recruit participants for the Arthritis Self-Management Program illustrate the importance of using local First Nations people to deliver educational courses within the communities. These people have a working knowledge of their communities, and their strong connections to other community members make successful recruitment more likely, particularly given the remote settings where formalised recruitment is difficult if not impossible. Of those respondents who led the workshop more than one, all agreed it was due to the effect of having participants recruit others through word of mouth.

A further aspect of course preparation/organisation involved asking participants what they believed helped or hindered this process. What was revealed in the interviews was the commonality of perceived barriers across communities. These barriers are*: location, transportation, timing,* and *food.*

The isolation and distance between homes in some of these communities, as well as road conditions, often made it difficult for participants to attend the workshop and was often reported to be an extra consideration of the native leaders. Due to *transportation* concerns (many participants would walk to attend the workshop), a central and accessible *location* was an additional consideration for many of the native workshop leaders. The workshops were typically held in schools, meeting halls, private homes, or the medical centre. In one instance, a church was used as this was considered to be the most convenient location.

> ***"… it's (location) pretty centralised in town … I picked up two of the ladies … and one of the other ladies walks a lot. And the time … we had it in daylight you know … I was always available to give people rides if they needed it because I think that was one of their concerns."***
>
> ***"… a lot of the people are very closed in and a lot of them refuse to stray too far from home … and that was a challenge you know, trying to get them to stray a little further, walk a little further."***
>
> ***"Rides. I had to arrange ride too … and during the winter time it was … it was hard during the winter time because it was like freezing weather …"***
>
> ***"… just for me was transportation - that's my deal and it's personal … we don't have a vehicle ourselves, so we had to look for ways to get there and that …"***

This illustrates the importance of looking beyond traditional ideas when planning to offer health education programming in remote, isolated First Nations communities. Transportation concerns were anticipated due to the leaders' familiarity with the community and overcome by their creativity and determination.

Another factor that appears to have been an additional consideration for the workshop leaders was that of *time.* This time consideration is inclusive of the time of day as well as the time of year for the workshop.

> ***"Like summertime, you're thinking of people that are canning fish and smoking fish … I mean, - it depends on what region you come from … what food gathering happens in what season – I mean, you always ask the people."***
>
> ***"… there was a lot of things going on at the time – there was the long house and memorials and stuff like that."***
>
> ***"Like I said, the time of year, that seemed to be the biggest drawback at all was the time of year … In the fall, early fall or spring sometime are two good times. People don't have lots of other things to do – fishing and all in the summer – summer's not a good time because there's lots of gardening and fishing."***

> ***"Christmas was the wrong time of year … there were concerts all over town… and they also had to travel out of town to get ready for Christmas…"***
>
> ***"It (time) was a struggle because the lady that organises the elder groups she lives two houses away ... so we would juggle our schedules and ... that's another hard part … trying to fit into their schedules."***
>
> ***"… the first time we got together with all the people who were going to attend we told them – asked them what days would be better for them because some of us work …"***

Again, the timing consideration was overcome only because the First Nations workshop leaders knew their local communities and cultural practices as well as any seasonal barriers which may impede the successful delivery of the Arthritis Self-Management Program.

Many of the workshop leaders held informal planning meetings or solicited input from prospective participants in advance of the workshop to overcome some of the potential barriers to workshop attendance. One respondent discussed the importance of soliciting input:

> ***"I mean, you always ask the people, you know, ok, we're going to give this course about this – now what is a good time, what is a good day, how many hours do you think you could sit through – you have to have some kind of input from the people that will be a part of this course, you know, because then they'll think, "well, gee, I helped to organise it with time of the day and I can't really let the leader down and myself down for not going, so they feel a part of it… because they were part of the organising."***

Clearly, doing an informal needs assessment increases the sense of community ownership of the workshop and increases participants' investment in the overall success of the program.

In addition to the factors already mentioned, *food* was also frequently mentioned by many of the workshop leaders. Clearly, for this type of workshop, it is important to offer refreshments and nutritional snacks, partly as an incentive to those attending, and, more importantly, it allows the leaders to model what they are teaching about self-management of arthritis.

> ***"But the refreshments really attract them too… and it's really good to serve refreshments – a real nutritious meal and we went into nutrition too which was the best part of it and we tried – tried serving the meal the way we were preaching you know."***

The importance of the factors which hindered respondents in the organisation of the workshop was greatly relieved if the respondents were able to *recruit support* from others in offering the course in their communities.

> ***"My oldest daughter… She helped with the coordinating, setting up tables and putting the stuff together… Just the setting up – a lot of the things I can't really do."***

> ***"…we'd split the arrangements so that way one person is not doing most of the work… [and] with the elders' cooperation, … by agreeing to go try it out."***

> ***"…we even approached the hospital for… to soak in the swimming pool and they were quite receptive and [name] has a hot tub and… buy bathing suits through the band funding…but you know, anything that could help them…"***

> ***"…the health representatives were excellent in promoting this workshop and…they did the leg work, you know, when it came to putting it together…"***

The most significant factor about recruiting support in terms of health care is that the community becomes actively involved in taking charge of its health. As one respondent described it, offering this type of program within First Nations communities is crucial to heightening awareness and breaking the isolation of people who have arthritis.

"…it brings it out you know, it's ok to talk about it, and it's a problem, you know, rather than pretending it doesn't exist, it just makes people aware I guess…"

Once the First Nations leaders had received training in the Arthritis Self-Management Program, and prepared for and organised a similar course within their native community, the next step was to deliver the program.

Course Delivery

The 13 respondents were asked to describe the sessions they held in leading the Arthritis Self-Management Program. The most prevalent aspect of the emergent themes was the integration of the all aspects of the workshop into the cultural beliefs and practices of the First Nations community. While the content of the sessions arose out of handbooks and flip charts, the process was one of reciprocal learning which involved a component of experiential sharing, where leaders assumed a position of non-expertness and respect for the wisdom of others.

> ***“We used to point out to a person and say, …hey, you read this part – we made them all involved in the reading and the contracts… They were communicating and sharing…about their pain, how they were feeling.”***
>
> ***“Following the outline of the lessons in the binder…I’d go through that and then we’d kind of go through it slowly and speak to it and discuss it…we had a very open group they spoke to issues very open.”***
>
> ***“I don’t believe in leading something to feed my ego, I believe in leading as to being more of an organiser, to listen to people, and get their feedback. People tell you kind of what they need and want and you help them or assist them…”***
>
> ***“They told of some of their experiences, like sometimes they’d wake up and they’d have an ache and pain and they’d compare to one another…they’d start getting into a storytelling thing like that.”***
>
> ***“They all had a turn to express themselves, give their ideas and feelings and things like that…so we left it open to them, to share and talk.”***

The *process* of the workshops given by the Fist Nations leaders was clearly one of mutual respect, where experiential sharing provided the vehicle for information acquisition. This type of process supports the First Nations cultural belief in the value of oral traditions to gain knowledge and wisdom. The Arthritis Self-Management Program, where the content is proscribed but the process in which it is transmitted is left to workshop leaders, allows the information to acquire its meaning from the group. It follows then that the First Nations leaders are able to tailor the process to complement the culture, rather than trying to force the culture into a prescribed learning format. This cultural sensitivity encourages the integration of knowledge, making long-term positive impact more likely.

Other *cultural practices* and *beliefs* were also prevalent throughout the Arthritis Self-Management Program workshops.

> ***"We've always thought of our elders to be our books of knowledge…because they've lived for so many years…you're kind of taking the native and non-native traditions and kind of putting them on an equal path you know, and kind of living side by side."***
>
> ***"Treatments…there's a lot of people who have their ideas about…things that have been handed down for generations…they like to pass them on."***
>
> ***"Just knowing the people, knowing how to speak Indian…understanding our culture…traditional native food – what to eat and the long houses and that's what I explained to them."***

In addition to the discussion of "alternative" treatments and the value of elders, the First Nations workshop leaders also discussed the importance of knowing the *native language*, and many chose to conduct the workshop using their dialect.

> ***"I was all right because I speak fluently…they really listened and asked questions in Indian."***
>
> ***"you definitely need to know your language down here…that's so important…that was one of their comments to me – 'oh, we just love it so much because you can speak our tongue – we can talk to you."***

The leader's comments are illustrative of the additional, and often unanticipated, outcome of this type of community health workshop – that it can serve as a vehicle for the transmission of First Nations culture. One respondent described the sessions as similar to a potlatch:

> ***"I think we as First Nations people are very…sociable kind of people, human beings, where you come together at a gathering…well this was kind of a potlatch feeling where you came together and witnessed what each other had to put up with on a day-to-day basis in regard to their arthritis, and witnessed what people had to say and listened…it was a time to come together and be happy about something that was bad, so it was a gathering of…family and friends, and it was a gathering of human beings coming together and talking about something that affected them all…sharing your knowledge with each other and not outdoing each other because you are all at the same level in dealing with something that affected your everyday life."***

The workshop leaders were also asked about aspects of the course which served as either barriers or enablers for facilitation. The only barrier frequently mentioned was the research questionnaires, which will be discussed in the recommendations section of the report on this Study. In terms of what the leaders thought was helpful, practical items were mentioned, such as the flip chart, manuals, and participant books. The respondents also discussed facilitator skills as important to the deliver of the First Nations Arthritis Self-Management Program. The following section of the report will address leader skills.

Leader Skills

The 13 First Nations leaders of the Arthritis Self-Management Program were also asked to discuss skills they believed to be significant to leading the program within their community. In addition to being fluent in the native language of the community, the respondents also frequently talked about *communication, organisation*, and *listening skills* as being important for workshop leaders to possess.

"Just being able to talk to a person, with ease, and they can talk to you and…that's

> ***"I think, just trying to – trying to deal with this issue of arthritis and trying to…make some fun instead of being serious – like I said before, you know, you got to talk about funny things and serious things to kind of balance things out and to turn negatives into positives…we had a lot of laughter, and to have a lot of laughter is to be happy and that kind of takes away the stress."***
>
> ***"I guess you need a little bit of laughter in there to…just ease it out, I guess."***
>
> ***"listening skills, very important because you had to sit there, you had to listen to people – a sense of humour was always important, if you don't have humour I don't know how you can make it through things like that."***

The appropriate use of humour allowed the workshop leaders to address serious issues in a manner more appealing to participants. Humour also provided the participants with some hope and a more positive outlook, thereby increasing the likelihood of successfully coping with their arthritis. Literacy, knowledge of arthritis, and an open, non-judgemental posture were other skills respondents deemed important for workshop facilitation.

The First Nations Workshop Leaders were also asked about the experience with facilitating the Arthritis Self-Management Program. The majority of the respondents discussed how their initial feelings of anxiety, fear, and uncertainty became transformed during the workshop to feelings of confidence and comfort.

> ***"I was nervous at first – first time – and…got confident…It got easy for me – I could communicate better with them…I don't know, I just didn't have confidence in myself and then after things went on I got confident and I could say hey, I could do it and …it got easy for me."***
>
> ***"I guess…anticipation, I guess, wondering – I wonder if they'll accept me…I was scared at first – the first time…Once they started asking questions and I was able to answer questions I felt more comfortable."***
>
> ***"Believe in what you learned…Know it's right and relay it…you can't seem unsure, you have to be sure of yourself and what you're trying to say."***

The experience of facilitating a group allowed the respondents to view themselves as competent, valuable individuals who had something to offer the group

These leaders believed in what they were communicating, and, as members of the community, knew the language and the customs of their culture.

In summary, the First Nations workshop leaders brought their knowledge of arthritis and their knowledge of the First Nations culture to each of the Arthritis Self-Management Program sessions. This integration of health education with traditional culture resulted in a process of story-telling, reciprocal learning, and information exchange that valued each participant's unique history and experience with arthritis.

One of the advantages of training community members in the facilitation of health education such as with the training course for the First Nations Arthritis Self-Management Program, is that the workshop leaders remain a part of the community and can therefore often perceive the impacts of such programs more readily and can promote their continuation. The First Nations leaders interviewed perceived the program as having a positive impact, of having "made a difference" on a number of different levels. The next section explores these outcomes from the perspective of the 13 workshop leaders interviewed.

Outcomes

All 13 First Nations people interviewed talked about the impact of the Arthritis Self-Management Program. The outcomes involved positive benefits for the *leader,* the *participants,* the *community,* and the *culture.* Another major impact involves the impact of the workshops on *health care* as participants became informed consumers the medical system. Each of these areas will be addressed in this section.

An often unanticipated outcome of workshops involves the positive impact on the *leader*. The respondents discussed feeling pride and a sense of accomplishment as a result of facilitation.

> ***"I felt really good that I could help people understand what arthritis is and…to understand it more…Proud of myself…because I accomplished something."***
>
> ***"I'm just excited and happy and glad…that I did something…It just makes you feel like that you can go on, you know, no matter how many walls you hit, you can always go on. That's the way I see it and that's how I felt about the course and giving the course, you know. Even though there was a lot of walls I ran into to get it going…and to finish it off, you know, it was just the fact of achievement."***

> ***"I felt good. I felt secure. I felt like I'd reached a little bit more beyond what I normally do and that felt good, so…I felt like I was accepted more."***
>
> ***"It was good. I felt like I accomplished something each day, you know…and it made me feel good to know that I was able to help them to understand a lot of that…have confidence that I, hey, I must be doing ok here."***

The sense of accomplishment experienced by the workshop leaders is significant given that the majority of them suffer from some type of arthritis themselves. The accomplishment allowed them to contribute meaningfully to their communities in spite of their disability, recognising that they can overcome the limitations of the disease.

According to the First Nations workshop leaders interviewed, the *participants* also experienced positive outcomes in health and overall well-being. Many choose to being regular exercise and a proper diet to offset physical impact of arthritis. Others reported an increase in their social supports available and a sense of new connections to others who have arthritis.

> ***'When you see a young person that never use to…that used to just keep it all to herself and…then all of a sudden she's talking to you…"***
>
> ***"She was in a car accident a long time ago…she had developed arthritis…when I was talking to her she had said you know…just from going to the course I find now that I deal with my pain mentally instead of popping the pills I used to pop…"***
>
> ***"You know, the exercises were really beneficial to her and she'd been practising them and the other one stated it helped her in her – helped her see some stuff personally…just the issues of how you're seeing things…beneficial effects in their personal stuff."***
>
> ***"…as the course unfolded and they talked about the different aspects of arthritis they started to realise they weren't alone and that…they didn't need to feel so self-conscious."***
>
> ***"…every time I showed them exercises, everybody jumped up and started doing it and that was their exercise and they loved it. And up-to date I know of one lady – she still walks – that's all she can do, she just walks circles around her house – she still does it today and she loves it."***

The content of the Arthritis Self-Management Program provided participants with beneficial strategies in managing the physical aspects of arthritis. The process of the workshop encouraged participants to share their struggles and successes to the group, enhancing their ability to manage the psychological impact of arthritis. The experimental component to the program provided participants with the opportunity to expand their informal support networks, adding to the resources available to assist them in managing their arthritis, and in forming new community connections.

Another benefit to the participants from the perspectives of the workshop leaders is that the medical information provided encouraged participants to be *informed consumers* of the medical system. Several respondents interviewed discussed how, as a result of the workshop, participants were now asking their doctors and pharmacists questions, making informed choices about their health care.

> ***"…communicating with professionals…a lot of Native people don't like to put anybody out of their way…[doctors] you don't get a word in edgewise until you leave because he's talking…and then you're walking out with a piece of paper and you haven't said anything…[in the group] I was telling them…that he doesn't know if there's anything else wrong with you if you don't tell him…use the "I" message…"***

> ***"I think a lot of First Nations people are afraid to communicate what they're feeling and I think this program has helped them be more confident in speaking out and I also think it taught them how to deal with their doctors and their community health workers because now they know what questions to ask."***

Being an informed consumer means workshop participants will communicate effectively with their doctors, making beneficial treatment more likely. It also encourages participants to begin to take responsibility for their overall health and well-being. Rather than relying on the expertness of others, the First Nations Arthritis Self-Management Program teaches participants to become their own expert, and to explore alternative options to medications.

The *community* was also impacted by the Arthritis Self-Management course. The positive outcomes for the workshop leaders and participants, led to an increased sense of community participation, of working together, and community ownership in addressing physical health issues.

> ***"I think a lot of people don't know their priorities on their band…they tend to…unless it's a real personal thing, they'll go to a place but they don't…we have a really hard time trying to have our community work together on a lot of stuff…somebody in each household has somebody with arthritis."***

> ***"…we're all trying to work towards the same thing – for people to live comfortably with an ailment such as arthritis or diabetes or something like that…I think that the Arthritis Self-Management Program is a start and I think that native people now are going to say, hey, you know – there is this program now, what other program can we bring to teach us how to deal with this…[the] program has opened the doors and …actually has paved a path for positive things to happen within the native population."***
>
> ***"We would see each other in town and…HI…and a big smile before it was just a nod…that felt good. To get to know people a little better and to have them being more open and…friendly."***

The impact of the Arthritis Self-Management Program on the community is, from the leaders' perspectives, one of enhancing a sense of belonging and community self-responsibility. The program can serve as a model for the community to develop similar programs and courses to address other health issues. As the workshop leaders were also members of the community in which the program was offered, these individuals can be viewed as a resource in the development of similar programs.

The workshop leaders also discussed how the Arthritis Self-Management Program served as a vehicle for the transmission and strengthening of *native culture.*

> ***"…saying, you are a native group, you have different beliefs, you have, you know, a different way of doing things and I find that works the best and I find that all – a lot of learner type teaching…[in] the medical field – like you have a lot of boundaries and that you can't talk about cultural things…so I felt like it [arthritis program] was far more open-minded and it said First Nations so that was kind of – of us as people that we were a different society of people…just having the title is saying that somebody out there in the medical field…Arthritis Society actually is interested in what makes…First Nations different and how can we mould this program to fit them."***
>
> ***"Wrote everything down that they [elders] said, all these different stories and sitting there writing away [later]…It made me feel closer to my people…it's passing on knowledge…"***

From the perspectives of the workshop leaders, this type of health course, in which people from the community are trained to facilitate, encourages an overall sense of pride in oneself, in others, in the community, and with one's culture. In the past, First Nations people have experienced a sense of hopelessness and dependence with Western models of health care. The format for the Arthritis Self-Management Program is supportive of First Nations cultural practices and beliefs. This model recognises the ability of communities to come to grips effectively with their own health and welfare issues, instilling a sense of competence and accomplishment among community members. The workshop leaders also had suggestions to improve the program. These will be addressed in the next section of the report.

Recommendations

Some of the 13 First Nations workshop leaders interviewed recommended changes to the Arthritis Self-Management Program, covering a variety of issues which emerged for them as they delivered the program in their communities. These recommendations ranged from having a refresher course to allow people to "keep on top of things"; and as some participants are unable to read or write, videotaping the more detailed parts of the content from the books would increase the accessibility of the material. Another leader suggested adding an outreach component to the program.

"We brought this relaxing tape instead of doing it verbally, we used the tape and that tape was really excellent…it even helped me as an instructor."

"A video tape would help a lot…just more information of what we had on those charts [due to literacy barrier]"

"I'm sure the health reps are aware of some people in the community who…could use this type of information, and maybe the6y could be sent letters…"

"Maybe we could offer to go and see them…it needn't be in a group of people, …it would help them overcome the worst part, where they don't need to feel alone, they don't need to just be stuck…it would give them hope"

The most discussed recommendation for change involved the mandatory completion of pencil and paper research questionnaires by workshop participants. It must be emphasised that a research component was a necessary requirement to have the program funded and was in no way connected to the content or format of the First Nations Arthritis Self-Management Program. Each workshop participant was required to complete a package of measures at three different time intervals and, in exchange, were paid a small monetary stipend. The respondents were unanimous that offering financial incentive in no way influenced participation or attendance and reported that it was appreciated by participants. Several leaders, however, believed that the monetary compensation to facilitators was insufficient, given that they often supplied the food and transportation.

The questionnaire as a data collection instrument was considered to be culturally inappropriate given the cultural value in the oral tradition. The questions themselves were also seen as culturally nonsensical to many participants. Again, the feedback received by respondents concerns the research component, which was added to the First Nations Arthritis Self-Management Program.

> ***"We went through the questionnaires because some of these ladies – some of them spoke only Indian…and have to explain to them…we had to go over it one by one with them 'cause they didn't know how to write or know how to read."***
>
> ***"A lot of our people, I think, like to be spoken to and asked questions that way instead of filling it out on paper…I think they kind of feel uncomfortable…if there's some other way of receiving the information…maybe a quick phone call where you press one or two or something would be better."***
>
> ***"The questionnaires…they were very lengthy – the questions were repetitive…Like who would ask a question 'are you afraid of arthritis"? Because when we posed this question to our elders or to anybody else they looked at each other and their mouths fell open…well, maybe if the other girls I work with and the other leaders…make it a point to get them to a certain meeting spot even if it's here…maybe we could…like put together a workshop and go over you know, what else, what would you like to see rather than these lengthy questionnaires. [Later] a lot of the people down here couldn't read…lot of them couldn't write…one lady couldn't see."***
>
> ***"…some of the questions we had to ask them…I think a lot of them had a hard time understanding them…we'd have to explain it to them in different ways because some of the words are higher words."***

The comments from the workshop leaders illustrate the importance of a community research participation model which encompasses all aspects of the research, including types and content of the measurement instruments.

In summary, the recommendations from the 13 leaders of the First Nations Arthritis Self-Management Program arose out of their experiences delivering the program within their communities and can be viewed as future considerations for programs being offered by and for First Nations communities.

Summary and Conclusions to Study 4

The analysis of the interviews with leaders of the First Nations Arthritis Self-Management Program revealed the overall congruence of this program to the cultural practices and beliefs of the First Nations communities of British Columbia. From the respondent's perspectives, this program provides valuable information and coping strategies about arthritis. Further, the content of the program is easily adaptable to the First Nations culture as it allows for different or "alternative" treatments for arthritis in addition to the traditional Western medical health model. The respondents also discussed how the group format and process encourages experimental sharing, supportive of the oral tradition and elder wisdom valued by First Nations communities.

The First Nations Arthritis Self-Management Program appears to enrich community participation and ownership of health issues by providing training to community members. This affords the community the opportunity to develop resources and expertness among its own members in an effort to combat the physical and mental health issues faced by First Nations people.

DISSEMINATION ACTIVITY

The first and most important dissemination activity is to provide information and research results to the people who participated in the study. This provides an opportunity for participants both to provide feedback and to help interpret results.

Three main methods were used to share the results with those who participated; presentations in First Nations Communities; presentations by participants at First Nations meetings; and giving all participants a summary of research results.

Presentations and Information Fairs in First Nations Communities

During May and April 1994, public meetings were held in Powell River, Mount Currie, and Port Alberni. At these meetings a customary lunch was provided, participants were thanked for their participation, and the results were explained. Then participants were given an opportunity to ask questions and provide explanations and interpretations of the results. These meetings also provided excellent opportunities to discuss future plans for arthritis services in the communities. Approximately 100 people attended these meetings.

On July 8 and 9, 1995, an information booth was set-up for two days in the Health Unit at the Ittasoo Reserve at Port Albion. The display was staffed by Dorothy Wilson, student with Nuu-chah-nulth Community and Human Services. Florence Martin, The Arthritis Society Board of Directors, and Patrick McGowan, the Principal Investigator. This event was held in conjunction with the Nuu-chah-nulth Tribal Council Meeting, which takes place every six months. During the two-day meeting participants visited the display to discuss problems and difficulties arthritis was causing in the community and to try the hot wax bath. They were given explanations about arthritis treatment, given information brochures, and told about the First Nations Arthritis Self-Management Program. Participants were invited to offer their opinion on what was needed in the community.

On July 31 and August 1, 1995, an Arthritis Information Fair was held at the Friendship Centre in Port Alberni. The event was held on these dates to coincide with the Native Games that were taking place in Port Alberni and was sponsored by the Nuu-chah-nulth Community and Human Services Program, the Port Alberni Friendship Centre, and the Arthritis Society. During the two days people were invited to stop by the centre to sample refreshments, to hear the speakers, and to ask questions and get information on arthritis. Talks and demonstrations were provided as follows:

TOPIC	PRESENTER	ORGANISATION
Massage	Wilma Doxtdator Community Health Nurse	Nuu-chah-nulth Community and Human Services Program
Nutrition	Cindy Calvert Outreach Nurse	Nuu-chah-nulth Community and Human Services Program
Disability Services	Ian Hinksman President	BC Aboriginal Network on Disability Society
First Nations Arthritis Self-Management Program	Patrick McGowan Community Researcher	The Arthritis Society
Arthritis Medications	Nest McGraw	Community Pharmacist
Lupus	Maureen Brechin	Port Alberni Arthritis Branch
Therapeutic Touch	Sara Derocher	Port Alberni

Those who stopped by the Centre were also asked about the problems arthritis was causing in their communities and what kinds of services and programs were needed. Approximately 150 persons participated in the two-day event.

Presentations by Participants at First Nations Meetings

On Sunday, October 2, 1995, eight people from the Port Alberni and Ahousaht areas made a presentation at the Annual Meeting of the Aboriginal Nurses Association of Canada. The meeting took place in the Tsa;Kwa;Luten Lodge on Quadra Island. The eight presenters provided a one-hour talk on “The First Nations Arthritis Project,” and this was within the Meeting Theme of “Environmental Management and Disability.”

Bunt Cranmer, from Port Alberni, introduced the session and presenters. Bunt is a First Nations Arthritis Self-Management Program trained leader who has given the course in Port Alberni at the Rainbow Lodge. Florence Martin and Judy Joseph provided testimonials of what it was like to be stricken with arthritis and the problems and difficulties they experienced in obtaining proper treatment. Particularly important

Was being able to communicate as equal partners with doctors and health care workers. Florence Martin had recently joined The Arthritis Society, B.C. and Yukon Division as a Board Member.

Trudy Frank, Audrey Whitmore-Atleo, and Bunt Cranmer then related their experiences in becoming trained program leaders, setting-up, and delivering the program to others experiencing arthritis in their community. They stressed the communication and sharing aspects of the program and emphasised that “fun” could be part of the process. Bunt Cranmer and Trudy Frank had also participated as researchers in the project.

The audience then previewed 10 minutes of a video tape of a training session that taken place this summer at Paper Mill Dam in Port Alberni. The video had been prepared by a film crew from San Francisco working with Bill Mower. Bill Mower was the host of a television program called “The Healing Mind.”

Patrick McGowan, from The Arthritis Society and the Principal Investigator of the Research Project on the First Nations Arthritis Self-Management Program, provided a review of how the program initially began and the shared involvement of First Nations representatives through all the stages. The research results clearly showed that participants were interested in participating in their own arthritis care, and their health status had been improved.

Ben David and Grace David provided a powerful and thoughtful closing for the workshop. Ben Davis stressed that all too often programs had come and gone and the community had been left with nothing. Also, in this time of high health care costs there needed to be innovative and imaginative solutions. He stressed that traditional caring and sharing that had always been important characteristics within First Nations communities were key factors to solving today’s problems. He was optimistic that the First Nations community would develop a successful plan of action.

During November an information booth was set up at the Nuu-chah-nulth Tribal Council Annual Assembly in Campbell River. Program leaders Bunt Cranmer and Judy Joseph provided information on arthritis and about the First Nations Arthritis Self-Management Program to those attending the Assembly. Ben David and Grace David assisted with the display. As well, Florence Martin made a presentation about the program to the Assembly.

Giving all participants a summary of the results

During October, 1995, an executive summary of the study was sent to each person who participated in the project.

Professional and scientific dissemination

A second responsibility in disseminating research results is to share the research processes, methods, design, results and lessons learned with other researchers and planners. This is done through presentations at scientific meetings and through publications. During the course of this project several presentations were made by the researchers. These relate to participatory research, qualitative and quantitative methods, health promotion, self-management, and self-help. These presentations are listed in Appendix E.

One of the presentations has been published in the Canadian Journal on Aging and others are being prepared for submission to professional and scientific journals. The project has also enable the BC Consortium for Health Promotion Research to obtain a grant from the Seniors Independence Research Program of Health Canada to extend the ASMP to other communities and to study some of the issues in self-care and mutual aid raised in this project. Further analysis of data from this and a related national study will form the doctoral dissertation of the Principal Investigator, Patrick McGowan, to examine issues specifically surrounding the role of self-efficacy in bring about some of the benefits observed in this and other applications of the ASMP. The Institute of Health Promotion Research has entered discussions with the Aboriginal Health Research Association at the UBC Longhouse on future collaboration on health promotion in First Nations populations.

PROJECT DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

This report has described results of four interrelated research projects conducted jointly by The Arthritis Society, the UBC Institute of Health Promotion Research, and sixteen native communities to introduce, test, and determine the effectiveness of a First Nations Arthritis Self-Management Program. As well, the project has identified areas where the program can be strengthened.

This project began when representatives from four native communities in B.C. requested The Arthritis Society work with them on the problem of arthritis. The native communities themselves had identified arthritis as a priority. Earlier attempts by The Arthritis Society to introduce the Arthritis Self-Management Program had met with limited success, but several respondents believed that this program could be adapted with success and had initiated the meetings with The Arthritis Society.

After initial discussions, grant funds were obtained from the British Columbia Health Research Foundation to support the collaboration and finance the development of a new program under strict research conditions.

The Arthritis Society and native representatives negotiated appropriate methods that included the native communities as full partners. To do this, a Native Advisory Committee was set up to oversee all parts of the projects and a team of expert research advisors was established to ensure that the project was valid.

A major decision was to use the participatory research process, using a health promotion planning model. With participatory research, the guiding principle is that the affected population should influence, if not control, the framing of the research question and to participate as full partners throughout the research calling on qualified researchers as advisors. The first step, therefore, was to determine what mattered most to the community itself. This social diagnosis was based on concerns of “quality of life” (social, emotional, and economic well-being and not just biomedical concerns).

The first study therefore was to determine what community leaders wanted a community arthritis program to do. Analysis of the responses found three main “themes” that needed to be measured.

Quality of life. The most important quality of life components to those interviewed were: **one’s health, the family, caring for others, culture, and one’s independence**.

Social meaning of arthritis. When allowed to range beyond biomedical perspectives on a health problem, people generally discuss it in terms of meaningful to their social lives and their quality of life. The six most important themes or meanings associated with arthritis were: **pain, the inability to do things they used to do, medications and treatments, crippling, being afraid and scared, and the need to learn how to deal with it.**

Desired effects of the program. Also reflected in this stage of the participatory planning and research were desired effects of the program besides those reflected in the social meanings attached to arthritis. Concretely, the community leaders wanted **better understanding of arthritis, to learn how to take care of oneself, to learn about diets, medications, and exercises, and to learn to deal with stress, anger, and frustration.**

The research team, aided by the information gathered and by input from the advisory committee, then worked on ways that the Arthritis Self-Management Program could be adapted for use in the First Nations communities. A First Nation Program Coordinator was hired and native leaders were recruited and trained to introduce the First Nations Arthritis Self-Management Program in eight communities. Local groups were established.

Finally, the program was evaluated using the native communities' own standards. The themes in the qualitative analysis helped formulate the outcome measures for the research project. The principal researchers and the research team chose various measuring tools that could be used to evaluate the effects of the First Nations Arthritis Self-Management Program in terms of these outcomes. Both qualitative and quantitative tools were used.

Tested and validated research tools were used to measure the selected outcomes. Visual analogue scales were used for measuring pain, stress, fear and anger. Other standardised measures included the functional limitation scale, the CES-D depression scale, and self-efficacy scales related to pain and to other symptoms. Nine specific variables were identified; health status; pain; disability; stress; fear; anger; depression; self-efficacy related to symptoms; and self efficacy related to pain.

The tools used for these variables have been used to test arthritis in other studies. These tools were incorporated into questionnaires that were given to all participants before the introduction of the program, immediately following the program, and four months following the program.

This second study was considered the main one for this project. The data indicated significant improvements in all nine areas at the end of the six-week course and the improvements were maintained four months later.

In the project application, it was postulated that successful implementation of the project would have positive effects on the program participants, the leaders who delivered the program, the community, and the health care deliver system. The data from Study 2 revealed that benefits were clearly visible in the first groups, and could be shown to persist at statistically significant levels of improvements four months after the program.

Participants gained knowledge and understanding of arthritis and learned was of reducing pain and stress. The also learned ways to manage their arthritis (i.e. exercises, relaxation, pain management) and ways of evaluating treatments that are suggested by family and friends. As well, responses indicated the participants had learned better ways to communicate with health professionals and had learned more about community resources and ways of accessing health care.

It was also postulated that the program leaders themselves would benefit, as would the participating communities. Two follow-up studies (Studies 3 and 4) indicate that these project goals were met. Program leaders reported increased leadership skills and greater self-confidence and were seen as a competent persons and as a resource within their community. It appeared that they were able to transfer these skills into other areas of community life (i.e. advocacy).

Communities also report having realised benefits from the demonstration project. In addition to having representatives able to plan and deliver arthritis patient education programs, the programs were conducive to healthier lifestyles generally.

It has been more difficult to demonstrate benefits to the Health Care System at this stage. However, some responses in Studies 2, 3 and 4 indicate that members of these First Nations communities now will access the health care system at an earlier stage and in a more effective manner.

At a progress meeting almost one year following completion of the First Nations Arthritis Self-Management Program in the communities, native leaders indicated additional changes were taking place and attributed these to the program. The information from the fourth study, from the perspectives of the course leaders, confirms the ability of communities to tackle their own health and welfare issues.

The overall results indicate that the First Nations Arthritis Self-Management Program has had significant positive results on health (arthritis control) and quality of life in sixteen first nation communities in British Columbia. Results suggest that the program could be implemented with similar success in other First Nations communities in Canada.

Recommendations

1. That The Arthritis Society (British Columbia & Yukon Division) make The First Nations Arthritis Self-Management Program a permanent program within the Division.

2. That The First Nations Arthritis Self-Management be considered for implementation in the other Canadian Arthritis Society Divisions, especially those with large First Nations populations.

LIST OF APPENDICES

A. Previous ASMP Research Activity in First Nations Communities.

B. First Nations Arthritis Self-Management Program Manual.
(under separate cover)

C. Group Qualitative Analysis Process.

D. Pre-program, Post-Program, and Four-month Follow-up Questionnaires.

E. Presentations at Scientific Meetings.

FIRST NATIONS
ARTHRITIS SELF-MANAGEMENT PROGRAM

REPORT ON THE PROGRAM

APPENDIX A

PREVIOUS ASMP RESEARCH ACTIVITY WITH FIRST NATINS

Since 1989, the Arthritis Society had been implementing the ASMP in British Columbia, Alberta and the Yukon. On the national scale, planning for complete implementation of the ASMP in every Canadian province began in 1992.

In February, 1991, responding to a request made by the Provincial Health Unit in Hazelton, B.C., we held a three-day leader training workshop for twelve Native Community Health Representatives (CHR's). Two of the CHR's then delivered the course in their bands.

In March, 1991 the Arthritis Society sponsored a three-day training workshop at Naramata, B.C. as part of the Sal'i'shan Institute training for CHR's and Alcohol and Drug Counsellor workers.

Previous training of (ASMP) leaders has been largely limited to middle-class Anglo-Saxons. To explore the ability of First Nations people to teach the ASMP, the Arthritis Society arranged were made with the Sal'i'shan Institute to incorporate the three-day ASMP Leader Training into their ongoing program. This research examined the effectiveness of the three-day workshop in enhancing Community Health Representatives and National Alcohol and Drug Assistance Program workers' perceived level of self-efficacy in their ability to carry out the tasks that would be required in leading the ASMP on their reserves.

Workers from rural reserves with populations of generally less than 300, and representing the Sto:lo, Carrier, Chilcotin, and Shuswap cultural groups participated. The group of 60 people consisted of 80% females and 20% males who had an average educational level of 10.5 years, and the average length of employment in this capacity of 21months.

Participants completed questionnaires measuring level of self-efficacy in 10 areas at the beginning of the workshop and again at the end of the three days. The information was summarised and paired t-tests were conducted for the 31 subjects who completed both pre and post tests. The average difference in self-efficacy levels between the pre and post test scores for the 10 items showed a statistically significant increase of 19.35 percentage points (range of 12.58% to 27.74%). Reliability tests were completed with the questionnaire, and yielding a Cronbach's Alpha of .927. Then, demographic variables were correlated with the amount of change in self-efficacy to determine levels of association.

Conclusions reached were; 1) that ASMP training enhanced self-efficacy of First Nations people for conduction arthritis patient education; 2) efficacy enhancement was not dependent on sex, age, education level, type of job, or the length of time in their position; 3) like their middle-class Anglo counterparts, First Nations people were able to execute self-efficacy scales and demonstrated enhanced self-efficacy from teaching the ASMP. This suggested that self-efficacy may be applicable across cultures, and that the ASMP may have the same positive impacts it has had with the Anglo-Saxon population.

In the four month period following the ASMP leader training workshop for First Nations persons, five ASMP courses have been given by the Fist Nations leaders to persons on their reserves.

APPENDIX C

GROUP QUALITATIVE ANALYSIS PROCESS

Interview Instrumentation

As three persons were involved in conducting the interviews (i.e. two project coordinators and the researcher), a standardised open-ended interview type was chosen. This would increase the comparability of response information and increases the likelihood for complete data on the topics addressed. As well, it reduces interviewer bias. Weaknesses of this approach include little flexibility for the interviewers which may limit the naturalness of the responses.

Sample Selection

One hundred and one First Nations persons had participated in the three-day teacher training workshops, and fifty-six persons graduated and expressed interest in teaching the program. Based on the availability of project staff, resources, geographic location of the communities, and the time-line of project activities, it was decided that a total of twenty interviews would be conducted with teachers from Bands most involved in the project. Individuals were chosen on the basis of their availability during the specified time period and their willingness to be interviewed. Thirteen persons were available and agreed. Table 1 shows the Band locations and number of individuals interviewed.

Table 1. Location of Bands and Number of Persons Interviewed

• Ahousaht	1
• Bamfield	1
• Brentwood Bay	3
• Campbell River	1
• Gold River	2
• Port Alberni	4
• Powell River	5
• Vancouver	1

The average age of respondents was fifty-one years (S.D. 9.5 years) and average level was nine years (S.D. 1.75 years). There was a wide range of the number of years they have had arthritis, from ten to forty-two (mean of 34 years). Thirteen of the eighteen respondents were married and eight were employed full-time. Sixteen were female.

Interview Process

Meetings between the researcher and project coordinators took place prior to the coordinators conducting interviews. After a thorough explanation of the purpose of the qualitative research, role playing took place with the researcher being the interviewer and coordinator pretending to be the respondent. The complete interview guide was followed. Once the role playing was completed, there was an extensive discussion of the types of prompts that should be used. The prompts discussed during this training included; uh huh's; mm hmm's; and…and…and…; silence; head nods; eye contact; facial expressions which indicated encouragement, understanding, compassion, concern, admiration, querying, pensiveness; repeating back what was said; and simply saying "I'm sorry, but can you explain that". The training took approximately two hours to complete.

Both coordinators were issued miniature tape recorders, a supply of blank tapes and spare batteries. This was done two to three days prior to the interviews with instructions to "play-around" with them to become comfortable using the tape recorder.

The coordinators made telephone contact with respondents, explained the purpose of the interview, and mad arrangements with them regarding the time and place of the interviews. Coordinators travelled to the designated locations, which most often turned out to be the respondent's home, and conducted the interviews. Prior to beginning the interviews, the respondents were read a Consent Form to ensure they understood their rights, and once signed, were given the respondent's copy.

RESULTS AND ANALYSIS

A total of eighteen interviews were completed. The full text was transcribed word for word onto numbered sheets. The typist was instructed to type the exact words spoken, and to use dots (.) to indicate a one second lapse in the conversation. For example, the sentence "and then she said….." indicates that there was approximately a five second interval in the respondent's conversation.

Analysis of the transcripts followed two separate processes; A – a process in which a group of eight persons (i.e…two First Nations members from the Advisory Committee, four project staff members, and two key individuals familiar with all aspects of the program) met for three hours and followed a group process to choose important elements that should be included in the outcome measures; B – a process in which the researcher analysed the transcripts following the methodology specific to qualitative research.

The Group Process

The committee members were: Marjorie White, Gloria George, Mary Brown, Mish Vadasz, Marietta Einarson, Cathay Loadman, Lisa Richardson, Myoung Soon Lee, and Patrick McGowan.

The eighteen interview transcripts were separated into three separate piles by the researcher. They were separated on the basis of length of interview and geographic location of the respondent. At the meeting each person received one envelope containing six interviews, so that each transcript would be analysed by three persons.
Table 2 shows how the groups and transcripts were arranged.

Table 2. Transcripts Reviewed by Each Group

GROUP 1 (3 persons)	GROUP 2 (3 persons)	GROUP 3 (2 persons)
Envelope containing interview transcripts 1……6	Envelope containing interview transcripts 6……12	Envelope containing interview transcripts 13……18

Once the researcher gave an explanation of what the research was all about and what it hoped to find out, each person was instructed to work individually on question number two (Quality of Life question). They were instructed to list the indicators (i.e., exact words) on the right hand side of the transcript. Once this was done, they were asked to list the indicators on a separately prepared coloured sheet. When everyone was finished doing this the sheets were collected and items listed on flip charts. The group then placed the items into groupings that seemed to fit together.

The group process used allowed individual analysis without being influenced by the larger group as well as the involvement of the First Nations research partners in the process of determining outcome measures.

APPENDIX D

PRE-PROGRAM, POST-PROGRAM AND FOUR MONTH FOLLOW-UP QUESTIONNAIRES

FIRST NATIONS ARTHRITIS SELF-MANAGEMENT RESEARCH PROJECT

Welcome to the First Nations Arthritis Self-Management Program. This is a research project being carried out by The Arthritis Society (B.C. and Yukon Division) and the Institute of Health Promotion Research at the University of British Columbia.

The research is tyring to find out if this program helps First Nations people manage their arthritis better.

As part of the research, we would like you to complete the attached questionnaire – even if you don't have arthritis. We would like you to complete the questionnaire today, another questionnaire that the teacher will give you when the course finishes in six weeks, and a third questionnaire that we will send you in four months. If you complete the questionnaires (all three of them) we will give you $20.00 for your help.

As this is a research project, you do not have to pay for this course, or for "The Arthritis Helpbook", which you will get free.

When you complete the questionnaire, please put it in the enclosed envelope, seal the envelope to keep it private, and give it to the course teacher who will send it to us.

IMPORTANT

> The information that you provide will be kept completely confidential, and will not be used for any other purpose other than this research project. When we receive your questionnaire your name will be removed from the questionnaire and replaced by a confidential I.D. number. The questionnaire will be kept in a locked filing cabinet and will be destroyed at the end of the research project.

If you agree to take part in this research project, please sign your name on the line below.

I agree to take part in this research project by completing the three questionnaires.

____________________________ ____________________________

Signature Date

If you do not wish to take part in this research project, you may still attend the six-week course, but you do not have to fill out the questionnaire, and you will not receive the $20.00 for your help.

The results of this research project will be sent out to everyone who takes part.

Thank you for your help. If you have any questions please call me collect at 879/7511.

____

Patrick McGowan, Investigator

FIRST NATIONS ARTHRITIS SELF-MANAGEMENT PROGRAM QUESTIONNAIRE

Name: ____

Address: ____ (postal code)

Telephone Number: (home) ______________________ (work) ______________________ **Male** ________ **Female** ________

Band: ____ **Birthdate:** ________ month ________ day ________ year

Please circle the <u>highest</u> year of school completed.

1 2 3 4 5 6 7	8 9 10 11 12	13 14 15 16 17 18
(grade school)	(high school)	(college or university)

What kind of arthritis do you have? ____

In what year do you think your arthritis began? ____

Are you taking medication for your arthritis? Yes ______________ No ______________

The last time I saw a doctor to talk about my arthritis was: (any doctor) ________ month ________ year

Do you live….: (check only one)

☐ Alone ☐ With others

Are you: (check only one)

1. Working Full-Time ________ 2. Working Part-Time ________ 3. Not Working Now ________

4. Retired ________ 5. On Permanent Disability ________

If employed, what kind of work do you do? ____

If retired, what kind of work did you do mostly? ____

PART I

IN GENERAL, WOULD YOU SAY YOUR HEALTH IS:

	(circle one)
Excellent	1
Very Good	2
Good	3
Fair	4
Poor	5

PART II

HOW DO YOU FEEL ABOUT ARTHRITIS?

ON THE LINES BELOW, PUT AN "X" THAT SAYS HOW YOU HAVE BEEN FEELING THIS PAST WEEK.

- **How much arthritis pain this past week?**

No Pain ____ **Pain as bad as It can be**

- **How much stress caused by arthritis this past week?**

No Stress ____ **Lots of Stress**

- **How frightened or scared of arthritis have you been this past week?**

Not Scared At All ____________________________________ **Very Scared**

- **How angry or mad has your arthritis made you this past week?**

Not Angry At All ____________________________________ **Very Angry**

PART III

DURING THE PAST MONTH, HOW DIFFICULT WAS IT FOR YOU TO DO THE FOLLOWING THINGS?

PLEASE PUT AN “X” IN THE RIGHT BOX.

1. Dress yourself, including tying shoelaces and doing buttons	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
2. Brush or comb your hair.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
3. Stand up from a chair that doesn’t have arm rests.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
4. Get in and out of bed.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
5. Get up off the floor.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
6. Cut your food with a knife or fork.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**

7.	**Lift a full cup or glass to your mouth.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
8.	**Walk outdoors 100 steps flat ground.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
9.	**Walk outdoors 500 steps on flat ground.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
10.	**Climb up five steps.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
11.	**Climb up 15 steps.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
12.	**Wash and dry your whole body.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
13.	**Get on and off the toilet.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**

`

14.	**Take a bath in the tub.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
15.	**Reach up and get something that weighs five pounds (such as a bag of sugar) from just above your head.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
16.	**Bend down to pick up clothing from the floor.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
17.	**Open jars which have already been opened.**	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**

PART IV

BELOW IS A LIST OF SOME OF THE WAYS YOU MAY HAVE FELT OR BEHAVED. PLEASE INDICATE HOW OFTEN YOU HAVE FELT THIS WAY DURING THE PAST WEEK BY CHECKING THE APPROPRIATE SPACE.

1.	**I was bothered by things that don’t usually bother me.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
2.	**I did not feel like eating; my appetite was poor.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
3.	**I felt that I could not shake off the blues even with the help from my family.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
4.	**I felt that I was just as good as other people.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
5.	**I had trouble keeping my mind on what I was doing.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**

6.	**I felt depressed.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
7.	**I felt that everything I did was an effort.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
8.	**I felt hopeful about the future.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
9.	**I thought my life had been a failure.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
10.	**I felt fearful.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
11.	**My sleep was restless.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**

12. I was happy.	☐ Rarely or none of the time	☐ Some or a little of the time	☐ Occasionally or a moderate amount of time	☐ All of the time
13. I talked less than usual.	☐ Rarely or none of the time	☐ Some or a little of the time	☐ Occasionally or a moderate amount of time	☐ All of the time
14. I felt lonely.	☐ Rarely or none of the time	☐ Some or a little of the time	☐ Occasionally or a moderate amount of time	☐ All of the time
15. People were unfriendly.	☐ Rarely or none of the time	☐ Some or a little of the time	☐ Occasionally or a moderate amount of time	☐ All of the time
16. I enjoyed life.	☐ Rarely or none of the time	☐ Some or a little of the time	☐ Occasionally or a moderate amount of time	☐ All of the time
17. I had crying spells.	☐ Rarely or none of the time	☐ Some or a little of the time	☐ Occasionally or a moderate amount of time	☐ All of the time

18.	**I felt sad.**	☐ **Rarely or none of the time**	☐ **Some or a little of the time**	☐ **Occasionally or a moderate amount of time**	☐ **All of the time**
19.	**I felt that people disliked me.**	☐ **Rarely or none of the time**	☐ **Some or a little of the time**	☐ **Occasionally or a moderate amount of time**	☐ **All of the time**
20.	**I could not get “going”.**	☐ **Rarely or none of the time**	☐ **Some or a little of the time**	☐ **Occasionally or a moderate amount of time**	☐ **All of the time**

PART V

HOW SURE ARE YOU THAT YOU CAN DO THE FOLLOWING THINGS RIGHT NOW?

Please circle the number that shows how sure you are.

1. How sure are you that you can control your fatigue? (tiredness)

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

2. How sure are you that you can do the things you need to do without making your arthritis worse?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

3. How sure are you that you can do something to help yourself feel better if you are feeling blue?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

4. When you compare yourself with other people with arthritis like yours, how sure are you that you can manage arthritis pain during your daily activities?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

5. How sure are you that you can manage your arthritis so that you can do the things you like to do?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

6. How sure are you that you can deal with the frustration of arthritis?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

7. How sure are you that you can reduce your pain quite a bit?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

8. How sure are you that you can do most of your daily activities?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

9. How sure are you that you can keep arthritis pain from bothering your sleep at night?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

10. **How sure are you that you can make your arthritis pain go down a small to medium amount using other ways instead of medication?**

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

11. **How sure are you that you can make your arthritis pain go down a large amount using other ways instead of medication?**

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE.

YOUR HELP IS VERY MUCH APPRECIATED!

Please check that all the questions have been answered.

BRITISH COLUMBIA
AND YUKON DIVISION

THE
ARTHRITIS
SOCIETY
BC and Yukon Division

EXECUTIVE DIRECTOR

FIRST NATIONS ARTHRITIS SELF-MANAGEMENT RESEARCH PROJECT

Dear: ___________________________

Thank you for completing the questionnaire before you started the program. I sincerely hope that you found the First Nations Arthritis Self-Management Program to be helpful.

Now that you have completed the program we would like you to complete this questionnaire and return it to your course teacher.

In about 2 1/2 months the course teacher will give you another questionnaire to complete. Once you have completed all three questionnaires, we will arrange to send you $20.00 to thank you for participating.

Thank you for your help. If you have any questions, please call me collect at 879-7511.

Sincerely,

Patrick McGowan, Investigator

PMG/lmr

To be completed at the end of the course

FIRST NATIONS ARTHRITIS SELF-MANAGEMENT PROGRAM QUESTIONNAIRE

Name: ____

Address: ____ (postal code)

Telephone Number: (home**)** ______________________ (work) ______________________

Are you taking medication for your arthritis? Yes______________ No ______________

The last time I saw a doctor to talk about my arthritis was: (any doctor) _________ month _________ year

Do you live….: (check only one)

☐ Alone ☐ With others

Are you: (check only one)

1. Working Full-Time __________ 2. Working Part-Time __________ 3. Not Working Now __________

4. Retired __________ 5. On Permanent Disability __________

If employed, what kind of work do you do? ____

If retired, what kind of work did you do mostly? ____

PART I

IN GENERAL, WOULD YOU SAY YOUR HEALTH IS:

	(circle one)
Excellent..	1
Very Good	2
Good..	3
Fair	4
Poor...	5

PART II

HOW DO YOU FEEL ABOUT ARTHRITIS?

ON THE LINES BELOW, PUT AN “X” THAT SAYS HOW YOU HAVE BEEN FEELING THIS PAST WEEK.

Example:

How much loneliness has arthritis caused this past week?

No Loneliness ____ **A Lot of Loneliness**

- **How much arthritis pain this past week?**

No Pain ____ **Pain as bad as It can be**

- **How much stress caused by arthritis this past week?**

No Stress ____ **Lots of Stress**

- **How frightened or scared of arthritis have you been this past week?**

Not Scared At All __________________________________ **Very Scared**

- **How angry or mad has your arthritis made you this past week?**

Not Angry At All __________________________________ **Very Angry**

PART III

DURING THE PAST MONTH, HOW DIFFICULT WAS IT FOR YOU TO DO THE FOLLOWING THINGS?
PLEASE PUT AN “X” IN THE RIGHT BOX.

1.	Dress yourself, including tying shoelaces and doing buttons	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
2.	Brush or comb your hair.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
3.	Stand up from a chair that doesn’t have arm rests.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
4.	Get in and out of bed.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
5.	Get up off the floor.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
6.	Cut your food with a knife or fork.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do

7.	Lift a full cup or glass to your mouth.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
8.	Walk outdoors 100 steps flat ground.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
9.	Walk outdoors 500 steps on flat ground.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
10.	Climb up five steps.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
11.	Climb up 15 steps.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
12.	Wash and dry your whole body.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do
13.	Get on and off the toilet.	☐ No difficulty	☐ Some difficulty	☐ Much difficulty	☐ Unable to do

14. Take a bath in the tub.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
15. Reach up and get something that weighs five pounds (such as a bag of sugar) from just above your head.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
16. Bend down to pick up clothing from the floor.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**
17. Open jars which have already been opened.	**☐ No difficulty**	**☐ Some difficulty**	**☐ Much difficulty**	**☐ Unable to do**

PART IV

BELOW IS A LIST OF SOME OF THE WAYS YOU MAY HAVE FELT OR BEHAVED. PLEASE INDICATE HOW OFTEN YOU HAVE FELT THIS WAY DURING THE PAST WEEK BY CHECKING THE APPROPRIATE SPACE.

1.	**I was bothered by things that don’t usually bother me.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
2.	**I did not feel like eating; my appetite was poor.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
3.	**I felt that I could not shake off the blues even with the help from my family.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
4.	**I felt that I was just as good as other people.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
5.	**I had trouble keeping my mind on what I was doing.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**

6.	**I felt depressed.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
7.	**I felt that everything I did was an effort.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
8.	**I felt hopeful about the future.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
9.	**I thought my life had been a failure.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
10.	**I felt fearful.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
11.	**My sleep was restless.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**

12.	**I was happy.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
13.	**I talked less than usual.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
14.	**I felt lonely.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
15.	**People were unfriendly.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
16.	**I enjoyed life.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**
17.	**I had crying spells.**	**☐ Rarely or none of the time**	**☐ Some or a little of the time**	**☐ Occasionally or a moderate amount of time**	**☐ All of the time**

18.	**I felt sad.**	☐ **Rarely or none of the time**	☐ **Some or a little of the time**	☐ **Occasionally or a moderate amount of time**	☐ **All of the time**
19.	**I felt that people disliked me.**	☐ **Rarely or none of the time**	☐ **Some or a little of the time**	☐ **Occasionally or a moderate amount of time**	☐ **All of the time**
20.	**I could not get “going”.**	☐ **Rarely or none of the time**	☐ **Some or a little of the time**	☐ **Occasionally or a moderate amount of time**	☐ **All of the time**

PART V

HOW SURE ARE YOU THAT YOU CAN DO THE FOLLOWING THINGS RIGHT NOW?

Please circle the number that shows how sure you are.

1. How sure are you that you can control your fatigue? (tiredness)

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

2. How sure are you that you can do the things you need to do without making your arthritis worse?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

3. How sure are you that you can do something to help yourself feel better if you are feeling blue?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

4. When you compare yourself with other people with arthritis like yours, how sure are you that you can manage arthritis pain during your daily activities?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

5. How sure are you that you can manage your arthritis so that you can do the things you like to do?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

6. How sure are you that you can deal with the frustration of arthritis?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

7. How sure are you that you can reduce your pain quite a bit?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

8. How sure are you that you can do most of your daily activities?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

9. How sure are you that you can keep arthritis pain from bothering your sleep at night?

10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**
Very unsure				**Moderately sure**					**Very sure**

10. How sure are you that you can make your arthritis pain go down a small to medium amount using other ways instead of medication?

10	20	30	40	50	60	70	80	90	100
Very unsure				Moderately sure					Very sure

11. How sure are you that you can make your arthritis pain go down a large amount using other ways instead of medication?

10	20	30	40	50	60	70	80	90	100
Very unsure				Moderately sure					Very sure

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE.

YOUR HELP IS VERY MUCH APPRECIATED!

Please check that all the questions have been answered.

APPENDIX E

PRESENTATIONS AT SCIENTIFIC MEETINGS

1. **26th National Scientific Meeting, Arthritis Health Professions Association**
   Boston Massachusetts, November, 1991.
   'Arthritis Self-Management Leaders Training: First Nations (Native American Experience)' McGowan, Lorig, Mussell.

2. **International Conference on Self-Help/Mutual Aid, Canadian Council on Social Development –** Ottawa, Ontario, September, 1992.
   'Self-Help and the Management of Arthritis Among the Elderly'
   McGowan, Brown, Frank, Lee

3. **American Evaluation Association.** Seattle, WA, November, 1992
   'Synthesis of Qualitative and Quantitative Methods' Green

4. **3rd National Conference of the American Journal of Health Promotion.**
   Hilton Head. SC, February, 1993
   'Methodological Challenges in Health Promotion Research' Green

5. **Health Promotion: What Works and Why – 2nd National Conference on Health Promotion Research.** Institute of Health Promotion Research.
   University of British Columbia, Vancouver, British Columbia, March, 1993.
   'Self-Management for Chronic Health Conditions: Experience with First Nations Communities of B.C.' (Workshop) Lorig, McGowan, Watts

6. **Universitè de Laval.** Quebec City, Quebec, April, 1993
   'The PRECEDE-PROCEED Model Applied to Chronic Disease Control'
   Green

7. **Centre for Research in Women's Studies and Gender Relations.** Graduate Student Presentation Day, University of British Columbia, Vancouver, British Columbia, May 1993.
   'Health Promotion Planning with First Nations' Communities'

8. **Kauffman Foundation,** Kansas City, Missouri, May, 1993
   'Diffusion and Adaption of Health Innovations' Green

9. **School of Social Work Research Conference.** University of British Columbia, Vancouver, BC, May, 1993
   'The Democralization of Research' Green

10. **First International Congress of Health Psychology.** Tokyo, Japan, July, 1993
'Approaches to Assessment and Evaluation in Health Promotion' Green

11. **Annual Conference – Society for Public Health Education. San Francisco.** California, October, 1993
'Health Promotion Planning with First Nations Communities' (Round Table Session) McGowan

12. **28th National Scientific Meeting, Arthritis Health Professions Association.** San Antonio, Texas, November, 1993
'*Qualitative Methodology as a Strategy In Collaborative Programm with First Nations Communities'* (Research) McGowan

    'Participatory Action Research: An Innovative Strategy for Enhancing the Relevance of Practice Research' (Research) Maxwell, McGowan

13. **University of Montreal Health Promotion Research Centre. Montreal,** Quebec, February, 1994
'Participatory Research' Green

14. **Alberta Heritage Foundation for Medical Research.** Edmonton, Alberta, April, 1994
'Future of Health Promotion Research' Green

15. **Symposium on Methological Diversity and Quality in Applied Social and Health Research on Aging and Seniors' Issues.** Alymer, Quebec, April, 1994
'Health Promotion Research Methods in Seniors Research: Weaknesses, strengths, and challenges' Green, McGowan

16. **International Patient Education Conference.** Phoenix Arizona, April, 1994
'Patient Education Models in a Changing Health Care Environment' Green

17. **First International Symposium on Qualitative & Quantitative Methods in Health Care Research.** Banff, Alberta, May, 1994
'Facilitating Community Participation in the Planning and Delivery of Arthritis Programs with First Nations Communities' McGowan

18. **Prospects for Health Gains, Canadian Public Health Association 85th Annual Conference.** Edmonton, Alberta, June, 1994
'Facilitating Community Participation in the Planning and Delivery of Arthritis Programs with First Nations Communities' McGowan

19. **First UBC Summer Institute on Health Promotion Planning and Evaluation.** Vancouver, BC June 20-24, 1994. Green, McGowan et al.

20. **Canadian Association on Gerontology 1994 Annual Meeting.** Winnipeg, Manitoba, October 13-16, 1994
'Planning and Evaluating the First Nations Arthritis Self Management Program' McGowan

21. **Second Annual Conference on the Victoria Health Foundation.** Melbourne, Australia, November, 1994
'Planning Models for Health Promotion: Moving beyond the disease paradigm' Green

22. **American Public Health Association 122nd, Annual General Meeting,** Washington, D.C., Oct, 20 – Nov, 3, 1994
'Collaborative Planning and Evaluation with First Nation Communities: The First Nations Arthritis Self-Management Project' McGowan, Green, Lorig

23. **Health Conference 94 – Coming to Terms.** Vancouver, B.C., Nov, 17 – 18, 1994
'The First Nations Arthritis Self-Management Project' McGowan

24. **Royal Society of Canada Report of Participatory Research in Health Promotion,** Ottawa, December, 1994.
'Presentation and Workshop' Green, Frankish, Rootman

25. **McCreary Lecture.** University of British Columbia, March, 1995
'Getting Health Promotion Research Out of the Test-Tube' Green

26. **World Conference of the International Union of Health Promotion and Education.** Makuhari, Japan, April, 1995
'Brining Health to Life Means Brining People Back to Health' Green

27. **"Preparing for the 21st Century" People-Policy-Prevention-Promotion National Health Education Colloquium, US Department of Health & Human Services, Indian Health Service**. Seattle, WA, September 1995
'Methodological challenges in health promotion research' McGowan

'The PRECEDE-PROCEED Model: How to start and when to end' Green

28. **Association of Rheumatology Health Professionals,** San Francisco, CA, October, 1995
'Qualitative Evaluation: First Nations Arthritis Self-Management Program' McGowan

29. **Evaluation '95, Vancouver, BC, November, 1995**
'Collaborative Evaluation with First Nations Communities' McGowan
'Participatory Health Promotion Research: Defining the Field' Green, George, Cargo, Bowie, Frankish, Daniels, Herbert, Millisan, McGowan, Rootman (Panel)

For more information contact:

Patrick McGowan, Community Researcher
The Arthritis Society, BC and Yukon Division
895 West 10th Avenue
Vancouver, BC V5Z 1L7
Tel. (604) 879-7511
FAX (604 871-4500
e-mail: PMcGOWAN@UNIXG.UBC.CA

ISBN# 1-895364-04-3