Our Journey:
First Nations Experience in Navigating Cancer Care

On behalf of the Mi’kmaq Health Research Group:

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Acknowledgements

On behalf of the Mi’kmaq Health Research Group, we would like to extend our sincere thanks to all of the First Nations persons and health professionals who participated in this important study. Your courage and commitment to sharing your stories about this critical health issue will provide valuable information to Cancer Care Nova Scotia, as well as to those in the cancer care system in Nova Scotia.

We are also very grateful to Jean Knockwood, who served as the research assistant for this study. Jean was extensively involved in organizing and facilitating the small group sessions and also in undertaking the interviews with health professionals.

The strategies required in pursuing this research in a way that was respectful of community protocols and sensitive to individual’s experiences made the process more time consuming and complicated. However, we feel confident that the findings, which reveal barriers faced by First Nations people attempting to navigate the cancer care system, will make a valuable contribution to cancer care policies, programs, education and services for First Nations people in Nova Scotia.
Executive Summary

The purpose of this qualitative study was to explore the cancer care experiences of First Nations people in Nova Scotia. The overall design of this study was qualitative in nature, with group discussions and telephone interviews representing the primary methods of data collection. Extensive recruitment took place in all 13 Mi’kmaq communities in Nova Scotia. A total of seven group discussions were held in Cape Breton, Annapolis Valley, and the Truro area with 9 First Nation adults, 18 and older, who had been diagnosed with cancer in the past five years, and with 17 caregivers of persons who had been diagnosed with cancer in the past five years. Telephone surveys were conducted with 13 health professionals who interact with First Nations cancer patients as well as their families and caregivers. Under the direction of the Mi’kmaq Health Research Group, a trained community facilitator assisted in advertising the study in Mi’kmaq communities, recruiting participants for group discussions and interviews, as well as arranging and facilitating data collection. Analysis was enhanced through a qualitative data management software program (Atlas ti) and was conducted by the Principal Investigators. Broad and fine level coding assisted in the organization of data into categories and themes, which emerged through inductive techniques. The qualitative data were coded to reveal common themes, with particular emphasis on identifying needs, barriers and gaps related to cancer care during diagnosis, treatment and post-treatment.

The findings for patients and caregivers have been organized around three major themes: pre-diagnosis, diagnosis, and treatment. These themes are supported by sub-themes related to informational, emotional, and social needs and supports, as well as interactions with health professionals and decision-making around treatment options. Findings emphasize the barriers faced by First Nations people within the cancer care system. In particular, participants reported the following: lack of knowledge about cancer and distrust of the cancer care system; miscommunication with health professionals; inappropriate, complex, insufficient, or excessive information; lack of resources to adequately navigate the cancer care system; lack of cultural competence on the part of health professionals; a reductionist approach to health by Western medicine; and lack of consideration for traditional healing.

Recommendations focus on improving the knowledge base of Mi’kmaq communities about cancer and the cancer care system, reshaping the kind of information that is provided, organizing workshops and support groups, addressing the distrust that often exists between Mi’kmaq communities and medical personnel, shortening the time frame between the onset of a health problem and being seen by a specialist, appointing a resource person to act as a liaison between Cancer Care Nova Scotia and the First Nations of Nova Scotia, and providing much-needed training for the health professionals who work in Mi’kmaq communities.
Chapter I  Introduction

The Importance of Cancer

Although there have been relatively few studies related to the incidence and mortality of cancer among First Nations in Canada, disease patterns appear to be considerably different in this population, relative to Euro-Canadians (Mao, Moloughney, Semenciw, & Morrison, 1992). In general, First Nations people tend to be diagnosed with and die from cancer less often than other groups, particularly from cancer of the lung, breast, prostate and colon. However, a study of First Nations in Ontario revealed that cancer is the third leading cause of death, after heart disease and preventable deaths (i.e. accidents, suicides, and homicides) in that population (Marrett & Chaudhry, 2003). Other research indicates that First Nations people are more likely to be diagnosed with cancers of the cervix, gallbladder, and kidney (Mahoney & Michalek, 1991). Based on the most recent demographic and disease trends, the incidence of cancer among First Nations people is expected to rise over the next decade. Indeed, with smoking rates and exposure to second-hand smoke well above the Canadian average, it can be anticipated that certain kinds of cancer will increase in the First Nations population. Consequently, cancer is increasingly becoming a priority health concern among First Nations people in Canada.

During the past 50 years, epidemiological trends among First Nations have shifted from infectious to chronic diseases such as diabetes and cancer. Socio-cultural determinants which have influenced this change include: smoking, diet, physical activity, obesity, reproductive trends, socio-economic status, environmental contaminants and increased cancer screening (Marrett & Chaudhry, 2003). Some of these determinants may also represent obstacles for many First Nations people attempting to access support within the cancer care system yet, little qualitative data exists about their experiences. In particular, the complex federal/provincial health system may create barriers for First Nations people attempting to access diagnosis and treatment of cancer. Reduced prevalence of most cancers among First Nations people as well as cultural concepts of disease management may also negatively influence access to cancer surveillance and care (First Nations Cancer Research and Surveillance Workshop, 2003). Finally, interactions between Aboriginal peoples and health professionals within the health care system may be premised on inter-cultural and inter-class inequities in social power, which disadvantage those seeking cancer care (Hanrahan, 2002).

Goals and Objectives

Since its inception by the Nova Scotia Department of Health in September 1998, Cancer Care Nova Scotia (CCNS) has worked collaboratively with individuals and organizations to assess and enhance cancer care services and programs in Nova Scotia. In addition to providing programs such as Patient Navigation, which is based on the recognized needs of individuals, families, and communities, CCNS has made an effort to determine the extent to which programs and services are meeting the needs of diverse ethno-cultural communities. Following a successful needs assessment conducted in African Nova Scotian communities, CCNS asked the Mi`kmaw Health Research Group to pursue a similar inquiry into the cancer care needs and related barriers faced by First Nations individuals, families, and communities in Nova Scotia.
The purpose of this qualitative study was to explore the experiences of First Nations people in navigating the cancer care system in Nova Scotia. In particular, the following objectives guided the study:

1. Identify the cancer care needs of First Nations individuals, families, and communities in Nova Scotia.
2. Identify barriers that First Nations individuals, families, and communities encounter in accessing cancer care programs and services.
3. Identify gaps in the cancer care system that might affect the cancer care experience of First Nations people.
4. Determine ways in which Patient Navigators might facilitate access to cancer care for First Nations people.
5. Determine ways in which First Nations people might benefit from the Patient Navigator Program.
6. Identify potential avenues of change within the cancer care system, which might reduce barriers and enhance the experience of First Nations individuals, families, and communities.

**Chapter II Methodology**

The overall design of this study was qualitative in nature. Group discussions and telephone interviews represented the methods of data collection. Data collection for this project took place between September 2003 and November 2004. Under the direction of the principal investigators and the Mi’kmaq Health Research Group, a qualified First Nations Research Assistant coordinated and facilitated all of the recruitment and data collection.

**Sampling Strategy**

Recruitment for the study took place in all 13 First Nation communities in Nova Scotia. The sampling strategy was developed in consultation with Cancer Care Nova Scotia as well as with senior health advisors for the Confederacy of Mainland Mi’kmaq and the Union of Nova Scotia Indians (both of whom are members of the Mi’kmaq Health Research Group). Seven focus group discussions were held across Nova Scotia (Cape Breton, Annapolis Valley, and the Truro area). The individuals included 9 First Nation adults 18 years of and older, who have been diagnosed with cancer in the past five years, as well as 17 family members/caregivers of individuals who have been diagnosed with cancer in the past five years. Telephone interviews were conducted with 13 health professionals who provide health services and/or programs to First Nations people. Attempts were made to ensure diversity with respect to age and gender.

**Recruitment**

Recruitment material included posters in Band offices, health centres and the Halifax Native Friendship Centre. We also announced the study over community bulletins, radio and other media (Appendix B) as well as seeking the assistance of health professionals in the recruitment process (Appendix C). Information packages, including a recruitment poster (Appendix D) and an introduction letter both with contact information, were sent to all on-reserve health
professionals as well as urban health centres (e.g. North End Community Centre, QEII Health Centre) and organizations that serve First Nations people living off reserve (e.g. Native Council of Nova Scotia). Health professionals’ participation was recruited through direct phone calls from the Research Assistant, following their receipt of the information packages.

Consent

The Mi’kmaq Health Research Group, which includes senior health advisors for the Union of Nova Scotia Indians and the Confederacy of Mainland Mi’kmaq (CMM) gave their consent for this project. During initial contact with potential participants, the Research Assistant provided information about the purpose of the study, the process of data collection, the risks/inconveniences and benefits of participation, issues of confidentiality, and any additional information potential participants required or requested. Each participant also received a copy of the information letter (Appendix A). This project also received approval from the Mi’kmaq Ethics Watch and Dalhousie University’s Ethics Committee.

Before each interview, the Research Assistant ensured that informed consent was obtained from individual participants, in which they acknowledged their understanding of the nature and purpose of the study; the benefits, risks, or inconveniences of participation; their role and responsibilities in the inquiry process; their right to withdraw at any time without penalty; and the degree of confidentiality that will be maintained. Participants were asked to sign two copies of the consent form (one for their records and one for the project records), which includes their consent to participate in the study, to be audio-taped and to have their direct quotes published.

Direct quotes have been used in the report for illustration but are not attributed to individuals and do not provide details that might identify an individual or their home community.

The consent process honours OCAP principles (ownership, control, access, and possession) (National Aboriginal Health Organization, 2002). In particular, we made an effort to ensure that cultural knowledge (e.g. traditional healing practices, ceremonies, and/or medicines) is protected, that First Nations communities were involved in the research process, that participants have access to their own data, and that communities, leaders, and participants will receive a complete report of the research findings.

Data Collection Process

A total of seven focus groups and 13 telephone interviews were conducted in various Mi’kmaq communities across Nova Scotia. At each of four locations in Nova Scotia, one focus group was conducted with individuals who have been diagnosed with cancer in the past five years and one with family members or caregivers of someone diagnosed with cancer\(^1\). First Nation community centres such as health centres were a convenient and appropriate place to conduct the groups; the Research Assistant and health staff negotiated the dates and times of each group meeting. Individual interviews with health professionals were conducted by telephone.

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\(^1\) Eight groups were originally planned but, in one community no patients turned up.
Before each session, participants were asked to complete a short demographic survey that has been used to describe the research sample. Group discussions lasted approximately 1.5 – 2 hours and individual interviews with health professionals lasted approximately 30 minutes. While Cancer Care Nova Scotia provided focus group guides for cancer patients, we adapted these to suit the First Nations context and our own sense of what would work best with the groups in question (Appendices F and G). We also modified the interview guide for use with health professionals (Appendix H). In addition to each group being audio-taped, flip charts were used to record major themes of the discussion. In addition, one of the Principal Investigators attended each of the group sessions and took detailed notes. Individual interviews with health professionals were not audio-taped; during these interviews, the Research Assistant took detailed notes of the participants’ responses to questions related to their experience with the cancer care system.

Analysis

In consultation with the Mi’kmaq Health Research Group, the Principal Investigators conducted an analysis of the data. The goal of the data analysis was to develop an in-depth understanding of First Nation individuals’ perception and experience of the cancer care system in Nova Scotia. In particular, through content analysis, we identified the cancer care needs of First Nations individuals, families and communities, identified barriers that First Nations individuals, families, and communities encounter in accessing cancer care programs and services and identified gaps in the cancer care system that might affect the cancer care experience of First Nations people.

Quantitative data were analyzed using an Excel program, which generated charts. Qualitative data were aggregated for the purpose of thematic analysis. The data management software program Atlas ti was used to facilitate initial coding and analysis of the qualitative data. Textual data was coded to reveal common themes, with particular emphasis on identifying needs, barriers and gaps related to cancer care during diagnosis, treatment and post-treatment. Unique cultural contexts within which First Nations people access information and support for cancer care were also examined. The product of this analysis will shape further phases of the Cancer Care Patient Navigation Program.

Confidentiality

All discussion groups and interviews were held in a private space such as a boardroom or an office. The Research Assistant signed a confidentiality agreement (Appendix I), related to her involvement in facilitating individual interviews and focus groups. Unfortunately, participation in a group discussion cannot be anonymous, and we could not guarantee that participants would keep identities or comments private. Therefore, in the case of these discussions, participants were made aware of this potential and asked to respect the privacy of others in the group. The written field notes of each discussion do not include the participants’ names, nor does this report reveal their identity through use of their real name, the name of their community or any other information that might identify them or their home community.

The original tapes, typed notes, and related confidential materials are stored in a locked file cabinet in Dr. Loppie’s office in the School of Health and Human Performance, Dalhousie
University. All confidential electronic files are kept on the password-protected computer of Dr. Loppie. In order to protect the privacy of participants, the Principal Investigators and the Research Assistant are the only people who have access to the entire set of tapes, flip charts and field notes. However, participants will have access to the tape and/or field notes of their own interview or group discussion through the principal investigators. The audio-tapes, field notes and related project materials will be kept for five years after the findings of the study are published, in accordance with research ethics policy at Dalhousie University. At that time, the audio-tapes will be destroyed, the paper files will be shredded and the electronic files will be permanently deleted.

**Characteristics of Patients and Caregivers**

The following charts provide information on some basic characteristics of the cancer patients and caregivers who attended the focus groups. They reveal that the patients who took part were mostly female and in their 50’s or early 60’s. A variety of types of cancer and years since diagnosis were identified by cancer patients as well as caregivers. The four types of cancer most frequently reported were breast, lung, lymphoma and colorectal, but a range of other cancers were also identified. For most patients, the diagnosis has been made fairly recently, that is, within the past three years.

### Patients’ Demographic Information

**Gender of Patient**

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Age of Patient

![Age of Patient Bar Chart]

Years Since Diagnosis

![Years Since Diagnosis Bar Chart]
The caregivers who attended our focus groups were female, with one exception. Compared to the patients, they came from a broader age spectrum, from young adult to seniors. They usually had a close family relationship to the patient, being a sibling, a child, parent or partner.

**Gender of Caregiver**

![Gender of Caregiver Chart]

**Age of Caregiver**

![Age of Caregiver Chart]
This concludes our discussion of the methodology of the project, and the characteristics of those who took part in it. We turn now to our findings, beginning with patients and caregivers who attended the small group discussion sessions.
Chapter III: Findings: Patients and Caregivers

Pre-Diagnosis

A Wall of Silence: Pre-Diagnosis Feelings

When asked to describe the feelings they experienced during the pre-diagnosis period, participants of this study talked extensively about how lack of knowledge about cancer, as well as fear and apprehension, created a barrier to getting the help they needed, particularly with respect to diagnosing cancer early, when the effectiveness of treatment can be maximized. For some, several months might have passed before they made a visit to the doctor about their symptoms. Many were simply afraid to make the appointment, while others believed that their symptoms were caused by something that they could treat themselves. In some cases, people have had very little experience with doctors and were often fearful of the procedures involved in diagnosing cancer. In fact, many participants reported that pre-diagnosis testing could be very stressful, yet felt that doctors are unaware of how difficult this process can be.

Some participants talked about an inequality of power between doctors and patients, which created discomfort around questioning the doctor’s advice. Consequently, many First Nations patients do not assert their desire to seek a second opinion or a specialist, if the doctor does not suggest this course of action. This imbalance of power can create additional stress, particularly for people already concerned about the possibility that they might have cancer. Unfortunately, some participants sensed that their symptoms might be a sign of something very serious for weeks, months, or even years before they sought medical advice. For some, rather than motivating them to seek help, the fear of cancer acted as a deterrent. They often hid their symptoms or refused to talk about their illness. Many of these people have previously lost someone to cancer, so for them, diagnosis represented a death sentence, thus, creating little incentive to visit the doctor. This resistance sometimes manifested itself in their reluctance to receive recommended tests, which might confirm the doctor’s suspicion.

Just out of Reach: Pre-Diagnosis Information

The majority of First Nations people who participated in this study, reported a general lack of knowledge about cancer prior to their involvement in the cancer care system. Unfortunately, many of them received very little useful information while attempting to navigate this system. With limited prior knowledge, they often did not know what questions to ask and most revealed that their doctor was not forthcoming with information, or educational materials prior to diagnosis. Although some participants received adequate information during the pre-diagnosis period, many others were promised additional information that they did not receive. Others expected information in the form of follow-up calls that sometimes did not come. In a few cases, symptoms were initially erroneously attributed to illnesses such as diabetes or respiratory illnesses, which are prevalent in First Nations populations.

Many participants reported receiving somewhat conflicting information, which made it more difficult to understand their illness and the procedures that were being recommended. The
perception of misinformation also diminished their trust in physicians and increased their scepticism about the medical system. According to most participants, the initial information they received was vague and conditional, in as much as physicians suggested that their symptoms might be caused by cancer. The obvious exception occurred when the symptoms were clearly advanced, in which case, patients and caregivers were advised immediately to pursue treatment.

Most participants rated doctors’ communication skills as poor. Some claimed that their doctor treated them disrespectfully, providing them with little or no information about why a particular diagnostic procedure or treatment was chosen. Many did not feel that they were adequately involved in decisions related to the diagnosis or treatment of their disease. Many doctors were unavailable for consultation; yet, alternative sources of information were not always available or accessible. Finally, beyond the physical manifestation and treatment of cancer, physicians did not appear to acknowledge other aspects of health, and seemed unaware of the impact of cancer on emotional, spiritual, and social well-being.

The time between the appearance of symptoms and a pre-diagnosis visit varied considerably among participants. For some, pre-diagnosis occurred as a result of visiting the doctor about an unrelated illness, while others were aware of their symptoms and attended to them immediately. A few participants reported that they were encouraged by family or friends to seek immediately medical attention for their symptoms; yet, others waited a few weeks or a few months before seeing their doctor. Unfortunately, a small number of those who did seek medical advice, waited many months for treatment because of an initial misdiagnosis. Similarly, some caregivers, still grieving loved ones lost to cancer, reported that their family member had waited many months or even years before agreeing to see a doctor about their symptoms.

Diagnosis

Lost in the wilderness: Receiving a diagnosis of cancer

The majority of First Nations participants who had been diagnosed with cancer were told by either their family doctor or by an oncologist, both having shared the diagnosis in a very direct manner. Family members were often with the patient when the diagnosis was made and, due to the initial shock on the part of many patients, family members were more likely to seek information from the physician during this discussion. A few physicians had the foresight to advise patients to bring a friend or family member with them to this visit. However, some people had no one with them at the time of diagnosis and had to go home and share the news with their family or were sent immediately to see a specialist alone. In a small number of cases, the physician shared the diagnosis with a patient’s partner, or in the case of a young person, with their parent, who then conveyed the diagnosis to the patient.

According to the First Nations people who participated in this study, health professionals, who tend to focus on physical diagnosis and treatment, often overlook the emotional aspects of cancer. Yet, these participants claim that the emotional trauma and psychological fatigue resulting from diagnosis can be very detrimental to overall health.
Participants’ feelings during diagnosis ranged from emotional upset to calm acceptance; yet, all of them experienced intense fear. Many also experienced an overwhelming sense of helplessness; for them, a diagnosis of cancer felt like a death sentence because they were aware of so many First Nations people who had died of cancer. Family members in particular, struggled with the diagnosis, attempting to understand why their loved one should suffer. Some experienced intense anger at a system, which they perceive to have perpetuated the ill health of First Nations people. Older people in particular, talked about a renewed feeling of hostility toward the residential school system, in which so many had already suffered so much. They believe that they have been through enough and that the diagnosis was outrageously unfair.

Despite an indisputable diagnosis of cancer, some people continued to deny their illness or the illness of a family member, which made it more difficult to grasp or retain important information. Others simply did not believe the doctor, quite likely as a result of past misdiagnoses or a general lack of trust in doctors or in the western medical system.

Some people tried to hold their feelings in, so their families would not suffer. This was particularly true for the parents of young children. A strong sense of independence kept others from showing outward signs of grief or a loss of control. They believed that they should face this disease alone and many turned their focus to issues related to treatment options and quality of life issues.

Although most people felt initially overwhelmed by the diagnosis, adequate information and support seemed to enhance their sense of control and diminish their fears. It becomes evident through listening to First Nation peoples’ stories, that those who lack strong support, either through formal or informal systems, experience the most difficulty.

Several participants revealed having experienced a deep depression following the diagnosis, and often this sadness settled around entire families. In fact, many of the participants who had been diagnosed with cancer seemed to be more worried about how the diagnosis would affect their family than about themselves. Some family members simply refused to talk about it or they became emotionally upset to the point that the patient worried for their physical safety or emotional well-being.

**Fact or fiction? Information provided at the time of diagnosis**

Participant discussions regarding information shared at the time of diagnosis, tended to focus on themes of access and comprehension. Participants revealed that, while many physicians attempt to ensure that patients and family members are adequately informed, others do not incorporate this component of care in their practice, in as much as they do not appear to consider or provide information related to the emotional elements of this disease. One participant claimed that physicians seem to view cancer patients as “as a broken down vehicle in need of repair - just fix the physical body”.

With the exception of videos provided by the cancer unit, information provided at the time of diagnosis typically took the form of written material, which was not always easy to understand, particularly at such a stressful time. For many people, reading material was too lengthy, too
complicated, or was perceived as ‘work’ they did not have the energy to do during the distressing time of diagnosis. Similarly, the lapse in time between testing and diagnosis, combined with the anxiety experienced during this time, is such that details are often forgotten or confused. A few people did not receive any written information; instead, they talked with their physician, usually because they did not want a lot of information or because they were still in denial about the diagnosis. Others felt as though the physician had given them the “run around” in terms of information, which diminished their trust and increased their stress and feelings of helplessness.

Whether as a result of negative past experiences or a general distrust of the medical system, some people revealed that they did not feel comfortable talking to their doctor or asking questions, so they relied on other sources of information. A few participants took the initiative to research their illness through the internet, some approached their community health nurse, while others sought out another doctor to get the information they needed. However, not everyone possesses the capacity for independent research and many people simply did not know where to turn for information.

Among those who did receive adequate information at the time of diagnosis, the content varied across health professionals and ranged from descriptions of specific types of cancer, the impact of cancer on health, treatment options, risks and side effects of alternative treatments, as well as long term prognosis potentials. Recognizing the emotional impact of the initial diagnosis, certain doctors scheduled a follow-up meeting to discuss subsequent treatment options. Despite the well-intentioned effort of these physicians, several participants felt that the information they received was filtered through the shock of the diagnosis, thus diminishing its usefulness.

In addition to one-on-one information sessions with a physician, a few participants described how information was also shared with family members, who found this process very helpful. A holistic approach, which includes health professionals from diverse health care disciplines, was viewed as most beneficial. One patient in particular, expressed a great deal of satisfaction with the information and support she and her family received. She described the information as very comprehensive, including printed material, diagrams, as well as details about on-line support.

Yet, this was not the case for everyone, many of whom felt that information is not tailored to diverse levels of literacy and cultural groups, nor is the cognitive impact of diagnosis adequately considered. Similarly, without adequate emotional, social, and spiritual support, the majority of participants agreed that information is not particularly useful. This is especially true for elders, who may require more informational support, aimed at enhancing their knowledge of health issues in general and cancer in particular.
Timing of Pre-Diagnosis and Oncology Appointment

The chart below describes the time between initial pre-diagnosis and the appointment to see an oncologist. This data was shared by 19 of the participants.

![Bar Chart](chart.png)

Easing the Burden: Supports that Help

Participants offered several suggestions related to supports that would assist First Nations people through the difficult period of diagnosis and treatment of cancer. These discussions centred mainly around the provision of informational, emotional, affirmational, and instrumental support.

Informational Support

Having someone with them during the diagnosis was very important to almost every participant in this study. In most cases, this person was viewed as not only a source of emotional support but also of informational support at a time when the patient’s capacity to acquire and retain information might be diminished. In particular, patients and caregivers require someone who knows the right questions to ask and can explain tests and treatments in lay language. Ideally, this person would also understand the diagnostic process and related procedures, so they could explain to patients and caregivers what to expect and could provide advice outside of doctor visits. Additional advice on how diet and lifestyle adjustments can improve quality of life and healing was viewed as an important component of informational support. Parents were especially interested in obtaining information and skills about how to talk to their children about cancer, especially about how to discuss end of life issues. Ideally, informational support would be provided by a person who speaks Mi’kmaq fluently because, aside from difficulties with the technical language of medicine, patients and caregivers sometimes have difficulty interpreting English terms into Mi’kmaq.
As mentioned above, most participants agreed that information should be tailored for a First Nations audience. Specifically, they recommended visual information, in the form of DVDs or videos, which focus on Aboriginal people’s cancer needs and experiences. Most importantly perhaps, this information must be comprehensible and accessible to First Nations people.

Workshops represent an ideal forum for patients and caregivers to gain the knowledge and skills they need to adequately prepare for the physical, emotional, and spiritual demands of cancer. They also envisioned a person who is trained in the cancer care system, working closely with community health nurses and health representatives, to develop and coordinate prevention initiatives, which might encourage people to seek medical attention at the first sign of problems. This person would have to be familiar with and supportive of traditional healing remedies and ceremonies.

**Emotional Support**

Emotional support during the pre-diagnostic, diagnostic, and treatment phases of cancer was reported to be one of the most important elements of care among the participants of this study. If possible, this support occurs in conjunction with informational support, and is provided in individual, family, or community settings. Counselling for individuals, families and particularly for young children was cited as a priority. However, having a person designated to provide support, not just about diagnosis and treatment but also around grieving, was considered critical to individual, family, and community wellness.

**Affirmation Support**

Patients and caregivers alike recognize the importance of affirmation and validation of their suffering throughout this traumatic experience. One of the ways which affirmational support can be provided is through videos of survivors who describe their feelings, as well as the diagnosis and treatment procedures in their own words. Participants claimed that it would be most helpful if these people understood the experience from a First Nations’ perspective. This would help to validate their feelings and experiences, in addition to providing some comfort through the knowledge that other First Nations people have survived cancer and have achieved wellness. Many participants believed that a support group, including First Nations cancer patients, family members, caregivers, and survivors, could provide emotional as well as affirmational support. In particular, survivors could play a counselling role in groups such as these.

**Instrumental Support**

Lack of resources was viewed as a major barrier for First Nations people who are navigating the cancer care system. For many, instrumental support received through home care and palliative care represented an important source of assistance. Participants also claimed that transportation issues created a barrier to accessing medical services during diagnosis and treatment, and suggested that medical transport, provided through the Non-Insured Health Benefits Program, Health Canada, give priority to cancer patients. We heard, for example, about the rigidity in the system requiring transport arrangements to be made well in advance. We also heard about cars
that did not arrive and about those that broke down. Finally, participants suggested that communities need to develop networks that support travel, childcare, and respite care for cancer patients and caregivers during diagnosis and treatment. Additionally, Band funding for alternative and traditional healing would provide additional support for cancer patients and their families who choose this route.

**Treatment**

*Give and take: Making treatment decisions*

Decisions regarding treatment were typically made by physicians. Sometimes this involved consultation with patients and caregivers, but sometimes it did not. Similarly, the degree to which participants were engaged in these consultations varied across health professionals.

A few participants reported that they were not consulted at all about treatment options, while others were told that there were no alternative treatments except the one offered by their physician. In some cases, the physician made a strong recommendation regarding one particular route of treatment, and the patient agreed, based on that recommendation. In other cases, physicians consulted extensively with patients and caregivers, who then made the ultimate decision about which treatment option to pursue. Due to risk factors associated with treatments, in some cases, only one treatment option was available. Likewise, the extent of the cancer often determined treatment options, and in these cases, patients were not given a choice.

There was a small group of participants who pursued treatment alternatives outside the formal cancer care system, often without the knowledge of their physician. In fact, some did not follow physicians’ recommendations about a particular treatment regimen, including to remain in hospital. This was particularly true for those with terminal cancer who wanted to die at home. Many sought out traditional healers or attended traditional ceremonies in an attempt to promote healing and wellness. A small number even sought treatment outside of Canada, travelling many miles, at great expense, to pursue herbal/naturalistic cancer treatment that they had heard or read about.

*Treatment Information*

The type and amount of information shared during the treatment phase varied across health professionals and ranged from insufficient to considerable. For some, treatment information included description of specific procedures, details about various treatment options and related effectiveness, as well as short and long-term side effects. In a few cases, treatment was presented as a cure, and in other cases, this eventuality was not assured. One patient indicated that, although the physician provided a rationale for the best treatment choice, and encouraged the patient to ask questions, which were answered fully, he did not support any alternatives, even though the patient indicated an interest in them.

Several people talked about receiving what they perceived to be misinformation, particularly around treatment options. Similarly, mix-ups and delays in treatment left some people feeling a loss of control over the process. For many, having to ask for more information or further
clarification increased the stress and frustration they were already experiencing during this phase of the illness. Similar to the diagnosis phase, many did not know what questions to ask, so were not sure if they had received accurate or useful information. For some, information that turned out to be less than accurate was perceived to be motivated by a desire to comfort patients and their family members, rather than to provide truthful information.

Frequently, physicians were reported to have only provided information once during diagnosis; this information was not absorbed due to the initial shock described earlier in this report. Participants felt that, to be most beneficial, this information should be repeated at subsequent visits to ensure clarity. According to most, physicians did not probe patients or caregivers for questions or concerns regarding treatment. The ensuing relational tension was often compounded if physicians became annoyed with patients or caregivers who needed further clarification, as was the case for two participants in this study.

In much the same way that receiving only written information is insufficient for effective dissemination during the diagnosis phase, the treatment phase can be an equally unfavourable time for extensive reading. Furthermore, one of the patients explained that First Nations culture is based on oral traditions and that, perhaps health professionals should be made aware of this. Participants also expressed a desire for more information during the post-treatment phase, so they could return home with a feeling of security, rather than apprehension, particularly about potential side effects of treatment.

Preparing for Treatment

In terms of perceptions of their preparedness for treatment, the participants of this study fell into two groups; those who felt adequately prepared and those who did not. The participants who were most sufficiently prepared, were those who received relevant, comprehensible information in a form that was useful to them. One participant received a video about treatment procedures and effects that was very helpful. Others relied on their family members to ask questions, which helped them to feel more prepared for treatment. A small number of participants reported that they had accessed information from the Internet, books, and chat rooms to get prepared for the treatment.

Among the participants who reported feeling inadequately prepared for treatment, the major barriers were too little information, too much information, or inappropriate/confusing information. Once again, many patients and caregivers did not know what questions to ask, so were often unprepared for treatment procedures and subsequent side effects. A lack or limited amount of information left many people feeling helpless and out of control, thus amplifying their anxiety, which made it more difficult to prepare for the treatment. Yet, too much information left people feeling overwhelmed and consequently, less prepared as well.

A few participants revealed that health professionals were not always aware of some treatment regimens and so, patients and caregivers had to search for information related to some treatment options for themselves. Conducting this type of independent research is obviously not a capacity that everyone possesses, particularly at a time when their emotional, physical, and spiritual resources are strained.
**Turned inside-out: Feelings about cancer treatment**

When asked to talk about their feelings during the treatment phase of illness, patients’ and caregivers’ discussions centred around three main themes: their relationship with health professionals, their interactions with those outside the cancer care system, and their own emotions.

Although a few participants claimed that the treatment phase of this illness was enhanced by a positive relationship with health professionals in the cancer care system, many did not share this perception. A number of people felt resentful toward physicians, who did not inspire much in the way of hope around treatment regimens. This apprehension often diminished their trust in the entire cancer care system. Many were also fearful about the actual treatment procedures as well as intimidated by the physical environments in which treatment is carried out. Most participants experienced an increased sense of vulnerability in relation to health professionals and a few perceived a lack of respect on the part of some individuals within the cancer care system.

Treatment procedures were made additionally challenging by language difficulties, whether they resulted from confusing technical terminologies or from physicians whose first language was not English.

Participants often talked about how the treatment phase of cancer was affected by or affected those outside the cancer care system. For those with few supports, this was a very lonely time. For others, the isolation was self imposed, motivated by an attempt to protect loved ones from having to suffer with them through the effects of treatment. Lack of resources created additional stress for those who have to curtail or terminate their employment in order to make time for treatment and/or caregiving responsibilities. For some, this meant depending on welfare for the first time in their lives. For others, it meant an increased and often vital dependence upon a medical transportation system that did not meet their needs. In both instances, the result was an erosion of their sense of control and well being. Despite the emotional hardships created by cancer in general, and the treatment phase of the disease in particular, many participants expressed a desire to help raise awareness among other First Nations people about cancer and the importance of early diagnosis and treatment.

Whether they were a patient or a caregiver, all of the participants talked about how their own emotions influenced the treatment experience. For many, a loss of control, either over their own body or the treatment process in general, created additional stress during this phase of the illness. They often clung to the hope that treatment would be successful and that they, or their loved one, would be healed. Yet, they remained fearful that the treatment would not work or that the cancer would return. Unfortunately, many people simply lost hope if the initial treatment was not successful. Their hope was further diminished by the systems’ neglect of the emotional and spiritual aspects of the cancer experience. This was often expressed as frustration at a system that does not seem to understand their unique needs.
Chapter IV: Findings: Health Professionals

Profile of Participants

The health professionals who participated in this study included: a Health Manager, Health Directors, a Home Care Co-ordinator, a Community Care Program Co-ordinator, Community Health Nurses, and Community Health Representatives. The services provided to First Nations cancer patients and family members by these health professionals include:

- home care and home visiting
- educational information
- support and resources
- provision of cancer nursing care (i.e., administering medications, supplies)
- accompanying patients to palliative care clinics
- providing transportation to appointments
- community health nurse involved from the first suspected problem
- in small clinics “we all do everything”
- home visits to conduct assessments and palliative care
- general support (e.g., shopping, making appointments, transportation, prescription pick-up)
- social visits and comfort
- ensuring adequate home care is in place

As the following chart indicates, the health care professionals who participated in the study had, for the most part, several years of experience working with cancer patients and their caregivers. Indeed the majority of respondents had at least four years of experience.

Number of Years Working with First Nations Cancer Patients and Caregivers

![Bar Chart showing the number of years worked with First Nations cancer patients and caregivers. The chart indicates that most respondents had more than 10 years of experience.](chart.png)
The large majority had seen cancer patients in the past year, often dealing with more than one patient per year. Within the clinic or health care facility in which these professionals worked, the wait time for an appointment is relatively short, in the order of one to two weeks.

**Number of First Nations Cancer Patients Seen in the Past Year**

<table>
<thead>
<tr>
<th>None</th>
<th>1-3 Patients</th>
<th>4-7 Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

**Average Wait Time for an Appointment**

- [2-3 weeks](#) 9
- [3-4 weeks](#) 2
- [no response](#) 2

**Training**

As the following chart indicates, most of the health professionals participating in the study have not received any training that would help them guide patients or caregivers through the cancer care system. One respondent said that “We go to a lot of conferences, but we never hear about cancer. We need more training with cancer and cancer treatment”.

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When asked to describe what type of training, if any, they received that assists them in guiding First Nations patients through the cancer care system, health professionals responded with the following:

- palliative care – but not specific to First Nations people
- a one day cancer workshop - three years ago
- working with palliative Care
- if the Palliative Care Society is not required, the types of treatments and their side affects, treating those side affects
- Chemotherapy & Side Effects workshop
- Home & Community Care
- nine participants had received no training

**Pre-Diagnosis and Diagnosis Phase**

While patients can usually access a health professional fairly readily at their local clinic or medical centre, as we saw above, it may take some time to be referred to a specialist and to receive the diagnosis. The health professionals we interviewed were in most cases not able to put a time frame on this period. We asked, for example, what is the average length of time from ordering tests to receiving the diagnosis. While a few respondents mentioned a wait of between two to four weeks, most were not able to answer the question.

According to the health professionals, it is the patients’ physician or an oncologist who shares a diagnosis of cancer. When asked who they thought should share this information, they all agreed that the physician is the most appropriate person. The following reasons were given for this opinion:

- it is the physician’s responsibility to talk to clients about health matters
- physicians have the medical documentation to support the diagnosis
• physicians have the reports and they know about the treatment
• “it is the physician’s job, it is better to get the information from the doctor; the
doctor is more believable”
• the doctor knows the type of cancer the patient has and can offer options for cure
or treatment
• “I feel the doctor should tell the individual with loved one with them for support”
• “the person needs the support of a loved one at this time; physicians have the
evidence to support the diagnosis but it is important to have another set of ears”
• only the specialist knows how treatment could/should proceed and gives an
accurate timeline
• “it is the doctor’s job, but the patient will not be taking in all the information – as
nurses we do go with clients”

Do First Nations patients and caregivers receive consistent messages from health professional? The following chart reveals that a majority of those responding to this question are of the opinion that consistent messages are not given by health professionals.

**Giving Consistent Messages to Patients and Caregivers**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
<td>3</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>No response</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

When asked to describe the types of information and resources they provide to First Nations patients and families at the time of cancer diagnosis, the health professionals reported the following:

• time to talk one-on-one
• literature
• palliative care and general support
• information about what is available in terms of care
• nursing care
• travel assistance
• “I have never had to do this. If I did, I would ask the Patient Navigator for assistance”
• printed pamphlets – videos
• care in the home with the help of the Palliative Care Association
• information about patient navigator system and/or the Patient Navigator’s phone number
• Cancer Care Nova Scotia resources
• suggest talking to cancer patients who have already been through the system and had treatment
• whatever they want/need based on interview and assessment
• support group information

According to these health professionals, First Nations cancer patients and their families are generally looking for:

• reassurance
• information about pain management; alternative medicine
• information about their cancer, where it is located, what treatments can be accessed
• “what happens now?”
• timelines, survivor stories, what to expect in the future
• “something to give them hope”
• types of cancer and death rate

On the other hand, the kinds of information gaps identified by health professionals included:

• literature pertaining to First Nations
• a person to interpret the information
• someone to walk clients and families through the system

The information perceived to be most useful to these health professionals includes:

• the CCNS newsletter – “it is easy to read and current”
• printed material and videos
• up-dates regarding types of treatments for cancer
• “The Patient Navigator is a great support”
• information about different types of cancer, treatments/cures
• pamphlets, websites
• information about healthy living

If they access cancer information and resources, it is through the following mechanisms:

• internet and email
• phone calls and networking
• health centres, doctors, hospitals
• pharmacists
• printed materials
• linkages with outside agencies
• Cancer Care Nova Scotia
• Patient Navigator

Health professionals refer First Nations patients to additional resource, information sources, and supports such as:

• reading material
• spiritual/traditional healers
• religious groups
• palliative care/cancer clinic, emergency care
• Cancer Care Nova Scotia
• a nature healer or a healing centre
• cancer support groups from Halifax
• oncology department at local hospital
• dietician
• community members

The Treatment and Post-Treatment Phase

When health professionals are asked to indicate what kinds of resources they provide to patients and their families prior to treatment, most replied by saying that this is usually a matter that is discussed between the patient and his/her doctor. A few mentioned that this might be raised with a nurse advocate, a cancer care navigator, or with the interpreter. At this stage, patients and families want:

• a time to talk and to know the options
• how much time they have so they can plan their last months
• information about the chosen treatment, including side effects, emotional impacts, and what services are available through the hospital
• help in understanding specialist jargon. Someone to lay everything on the table and not use big words they don’t understand.

Health professionals are almost evenly divided on whether they can provide the kind of information patients are looking for in this stage, in a manner that is understandable so they are aware of the process and treatment they are about to undertake. If they are not able to provide the necessary information, it is because:

• the health professionals do not have the up-to-date treatment plans, or have not been contacted by the cancer specialist
• they have not had the training necessary to provide the desired information, and they would appreciate having in-services to deal with this
• there should be persons available who have been trained to deal specifically with patients who have cancer and who is able to answer all their questions
In response to a question about what their role is in the treatment process, health professionals say it includes the following:

- providing support to the patient and their care givers – moral, personal, financial
- attending to tasks such as making appointments for patients and reminding them to go, overseeing care and picking up supplies including equipment or drugs when needed
- interpreting if the patient does not understand fully
- assuring client of comfort and as much freedom from pain as we can provide

In terms of additional supports that are required but which are not (always) currently available, health professionals mentioned:

- the need for interpreters in that medical terms are confusing at the best of times
- the patient navigator program
- having spiritual healing available in the hospitals
- easy to read literature and time to talk
- in service programs for health professionals
- more support for caregivers, who may have other roles and responsibilities
- a support group for patients and caregivers
- more psychological support in the form of counsellors, palliative care resources

Once treatment is complete, health professionals indicate that patients need to have:

- follow-ups and reassessment
- their mental health needs addressed (depression, anger, etc.)
- some may need a prosthesis such as an artificial leg
- reassurance to help them move on the best they can, or to accept that nothing else can be done

Available supports include nursing care (for example, VON), spiritual or religious support, respite and palliative care, Aboriginal healing supports, and community health workers. However, not all of these services are available in all locations. Health professionals said what is missing in their situation is:

- a social worker,
- respite care for caregivers,
- training for the health professionals themselves,
- support groups,
- mental health/emotional supports
- traditional healing
- more time, better communication
Future Directions

When asked what kind of information they need in order to deliver quality services to First Nations cancer patients and their families, the health professionals suggested these areas:

- palliative care/oncology support
- culturally appropriate workshops
- appropriateness of support groups
- clinical pathways used in hospitals
- information about the process from diagnosis to treatment to aftercare
- logarithmic chart or management charts
- support for the care giver
- a list of supports across Nova Scotia
- patient-family-nurse workshops with questions and answers
- increased awareness and education for First Nations people – particularly around survival
- support for health care professionals
- updated information, including new procedures for diagnosis and treatment
- binder for quick reference for various cancers

When asked to identify specific elements of care that are lacking in the cancer care system of Nova Scotia, health professionals suggested the following:

- support for families and health staff
- adequate palliative care
- First Nations content
- more health staff in communities
- qualified person to assist patients and family members cope with the cancer - need more information on research and up-to-date statistics
- early detection
- increase First Nation people’s awareness and prevention
- First Nations Patient Navigator
- more local/rural resource centres
- traveling mobile units to deliver information locally
- workshops and presentations
- more resources – financial and human
- doctors must be more sensitive to individuals’ emotional needs
- lacking in First Nation culture and information
- information if too difficult to understand
- awareness and detection of prostate cancer for men
On a positive note, when asked to identify areas within the cancer care system that are working well, health professionals reported:

- care and treatment
- cancer centre
- screening clinics
- cancer care newsletter is very informative and up-to-date
- hospital treatment (e.g. Chemo, blood work)
- Patient Navigators
- Palliative care
- VON
- cancer centre in Sydney – patients do not have to go to Halifax for treatment
- a lot of First Nations community support and family support. The community comes together to deal with death and dying

Finally, in their own communities, health professionals reported that the following would make the greatest difference in improving the provision of cancer care for First Nations patients and family members:

- regular workshops
- a 24 hour hot line
- First Nations patients could rely more on the home and community care nurse.
- Support for nurses
- support for family members
- more health staff to relieve the burden that currently exists
- a cancer centre or palliative care centre for First Nations people
- training for family members to help people at home
- more VON nurses
- more people trained in home care
- more up-to-date information
- cancer care staff
- meetings to discuss problems and to hear of success stories
- earlier detection (especially for men) is needed
- a patient advocate, similar to the Patient Navigator
- having support closer to home
- more dependable transportation for treatments and appointments
- support for caregivers and extended families
- an advocate with some medical knowledge and the confidence to ask questions and who speaks the language
- more education around earlier diagnosis
Chapter V: Conclusions and Recommendations

In the Canadian context, any group of people are likely to have a range of experiences with the health care system, some very positive and others negative. The Mi’kmaq are no exception, and those participating in our study of experiences with the cancer care system reported a range of opinions.

It is also clear from our interviews and small group discussions that there are a number of areas relating to Mi’kmaq experiences with the cancer care system that could be substantially improved. The following recommendations are based on suggestions made by First Nations people who have been diagnosed with cancer, caregivers of First Nations people who have been diagnosed with cancer, and health professionals who interact with First Nations cancer patients, their families, and caregivers.

1. There is a need to improve the knowledge base of the Mi’kmaq population in general, and especially those who experience cancer and their caregivers, about cancer and the cancer care system. Areas that need to be covered include knowledge about prevention, screening, the signs and symptoms of cancer, the benefits of early diagnosis and treatment, options and alternatives in treatment, the post-treatment stage and side effects, and the prospects of survival, among other topics.

2. There are many shortcomings in the quality, relevance and availability of information about cancer. We recommend that information about cancer and the cancer care system be:

   - more culturally appropriate, geared to particular age groups, and cognizant of the levels of literacy of the receiving population
   - more holistic in content, including not only factual information but also content on the emotional and spiritual components of dealing with cancer
   - inclusive of information that deals with the impact on the family of the person who has cancer, and how that impact can be addressed
   - available not only in printed form but also in the form of videos. The latter should include affirmational support – that is, stories from survivors describing their journey, their thoughts and feelings, their experiences with diagnosis and treatment, from a First Nation perspective

   Information is optimal when delivered in small doses and at various milestones along the cancer care journey.

3. Communities are encouraged to organize workshops and support groups for cancer patients and their caregivers. Bringing people together to share experiences and to provide mutual support is an excellent way not only to provide information about cancer and the cancer care system, but also to reduce isolation and ease the strain of this experience. Resource persons who could provide technical information should be included in the workshops, but there should also be opportunities for participants to share their experiences.
4. Effective steps need to be taken to address the distrust that often exists between members of the Mi’kmaq community and doctors. The issues have to do with imbalances of power and knowledge, with cultural difference and insensitivity, and with interpersonal skills. We recommend that:

- doctors become more familiar with the communities they serve, through organized opportunities where medical personnel and community members can socialize
- the training of medical personnel is improved, both through their degree education and through continuing medical education. Improvements need to be made in communication skills, in doctors providing options and alternatives for treatment and in leaving room for patient participation in decision-making, in the value of indigenous health practices, and in cultural competence generally
- Faculties of Medicine in particular, but also other health science disciplines, increase the number of Aboriginal graduates

5. Appropriate measures are taken to shorten the time frame between individuals who have health concerns that may be related to cancer and their meeting with their doctor, and also in obtaining an accurate assessment and referral to a specialist.

6. Communities should have available to them a person trained in and knowledgeable about cancer and the cancer care system. This person would work with community health representatives and nurses to encourage persons in the community to seek medical attention at an early stage; to help people navigate the cancer care system; to provide information and support as required; to help educate medical personnel, and to liaise with Cancer Care Nova Scotia, among other duties. Such persons should be Mi’kmaq and should speak the Mi’kmaq language fluently.

7. Cancer patients and their caregivers noted a number of areas where improvements could be made in support services. These included:

- Increasing the availability of home care, palliative care and other forms of counselling support in the area of mental health services. This includes building networks to assist persons with travel, child care and respite care
- Addressing inadequacies in the health transportation system for persons who do not have any alternative
- Providing funding for alternative and traditional healing approaches

8. Health care professionals indicated that, for the most part, they have received no training that would equip them to meet the needs of cancer care patients and their caregivers. They repeatedly noted the need for workshops in this area, and we recommend that they be provided.
Appendices
Appendix A: Information Letters and Consent Forms

Patient Information Letter and Consent Form

Project: Cancer Care and Patient Navigation – A First Nations Experience

Researchers: On Behalf of the Mi’kmaq Health Research Group

Dr. Fred Wien
Maritime School of Social Work, Dalhousie University
6414 Coburg Road, Hfx, NS  B3H 2A7
(902) 494 –1326
frederic.wien@dal.ca
and
Dr. Charlotte Loppie
School of Health and Human Performance, Dalhousie University
6230 South Street, Hfx., NS  B3H 3J5
charlotte.loppie@dal.ca

Hello,

We would like to invite you to participate in a research project called “Cancer Care and Patient Navigation: A First Nations Experience”, conducted by the Mi’kmaq Health Research Group (Union of Nova Scotia Indians, Confederacy of Mainland Mi’kmaq and Dalhousie University) and funded by Cancer Care Nova Scotia. Your participation in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconveniences, or discomfort, which you might experience.

Purpose

The purpose of this study is to gather information about First Nations peoples’ experience with the cancer care system in Nova Scotia. You may participate in this study if you are a First Nations person, 18 years or older, who has been diagnosed with cancer in the past five years.

Study Design

Under the supervision of the Dr. Fred Wien, Dr. Charlotte Loppie, and the other members of the Mi’kmaq Health Research Group, our Research Assistant, Jean Knockwood, will guide a discussion in which you will join five other people in talking about their experiences with the cancer care system in Nova Scotia. You will first be asked to work with another group member (who you may or may not know) to create a summary of your experience in the cancer care system. Then, you will join the rest of the group in a discussion that will last between one and a half and two hours and will take place at a health centre in your home community or in a First Nations community in your region. You will also be asked to complete a short demographic survey before your group discussion. You may choose not to complete this survey if you wish.

The Research Assistant will tape-record the discussion and later, the information will be recorded in writing. You may look at the written summary of your discussion at any time. The tapes and all confidential written material will be kept in a locked cabinet and on the password-protected computer at Dalhousie University until they are destroyed and/or permanently deleted, five years after a report of the
study is published. The Research Assistant will ask you to sign a consent form before the discussion. However, your participation in this study is voluntary and you may withdraw at any time without losing your honorarium. Also, if you do agree to participate, you may choose not to discuss any issues that make you feel uncomfortable.

All of the information we gather from participants who have been diagnosed with cancer in the past five years will be combined and the researchers will try to identify the similarities and differences in peoples’ experiences in the cancer care system. The information gathered during this study may be used in presentations, journal articles, newsletters, and workshops. We will also be providing a full report of the research findings to the Confederacy of Mainland Mi’kmaq, the Union of Nova Scotia Indians, the Atlantic Policy Congress of First Nations Chiefs, and First Nations communities in Nova Scotia. Some of these reports will include direct quotes from the participants. However, these reports will not include your real name, nor will any report reveal your identity or that of your home community.

**Compensation**

Each group participant will receive an honorarium (gift) of $20.00.

**Risks and Benefits**

Your participation in this study intends no harm or discomfort to you: the questions are mainly focussed on your thoughts, feelings, and experiences with the cancer care system in Nova Scotia. You may or may not benefit from sharing your experiences at the time of your participation. However, your input will contribute to our knowledge about how the cancer care system might better serve the needs of First Nations people. You should discuss any questions you have about this study with Jean Knockwood at (phone number, fax and email).

When discussing sensitive topics, some participants might need personal support, which may be provided by the other members of the group. For instance, some people may experience stress related to talking about their experiences with cancer and the cancer care system. In addition, participants might also need information about community resources and supports. The Research Assistant will have a list of community resources available for those who may require support as a result of their participation in this study.

Cancer Care Nova Scotia may wish to collaborate with the Mi’kmaq Health Research Group in future projects related to First Nations people’s cancer care experiences and needs. Therefore, with the appropriate ethical approval, the findings of this study may be used to help them develop those future projects.

**Confidentiality**

Although the Research Assistant and the researchers will keep your participation in this study private, we cannot guarantee that others in your group will keep your identity or comments private. Therefore, we ask that everyone who participates in a group discussion respect the privacy of others in the group.
Contact Information

If you have any questions or concerns, please feel free to call Charlotte Loppie by phone at (902) 494-6620 or by email at charlotte.loppie@dal.ca or Fred Wien at (902) 494-1326. We would be happy to discuss any questions or comments you have. Please be assured that we will keep you informed about any new information that might affect your decision to participate in this study and you will be contacted in the unlikely event that this study is terminated.

Many thanks,

Fred Wien
Mi’kmaq Health Research Group

I have read the above explanation of this study. I realize that my participation is voluntary and that I am free to withdraw from the study at any time. I have been given the opportunity to discuss this information and my questions have been answered to my satisfaction.

I hereby consent to take part in this study and to be audio-taped. □ Yes □ No

___________________________________________________________________
Participant's Signature Date

___________________________________________________________________
Signature of Person Obtaining Consent Date

In the event that you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Human /Research Ethics/Integrity Co-ordinator at Dalhousie University’s Office of Human Research Ethics and Integrity for assistance.
Phone: (902) 494-1462.
Hello,

We would like to invite you to participate in a research project called “Cancer Care and Patient Navigation: A First Nations Experience”, conducted by the Mi’kmaq Health Research Group (Union of Nova Scotia Indians, Confederacy of Mainland Mi’kmaq and Dalhousie University) and funded by Cancer Care Nova Scotia. Your participation in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconveniences, or discomfort, which you might experience.

**Purpose**

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**Study Design**

Under the supervision of the Dr. Fred Wien, Dr. Charlotte Loppie, and the other members of the Mi’kmaq Health Research Group, our Research Assistant, Jean Knockwood, will guide a discussion in which you will join five other people in talking about their experiences with the cancer care system in Nova Scotia. You will first be asked to work with another group member (who you may or may not know) to create a summary of your experience in the cancer care system. Then, you will join the rest of the group in a discussion that will last between one and a half and two hours and will take place at a health centre in your home community or in a First Nations community in your region. You will also be asked to complete a short demographic survey before your group discussion. You may choose not to complete this survey if you wish.

The Research Assistant will tape-record the discussion and later, the information will be recorded in writing. You may look at the written summary of your discussion at any time. The tapes and all confidential written material will be kept in a locked cabinet and on the password-protected computer at Dalhousie University until they are destroyed and/or permanently deleted, five years after a report of the study is published. The Research Assistant will ask you to sign a consent form before the discussion. However, your participation in this study is voluntary and you may withdraw at any time without loosing
your honorarium. Also, if you do agree to participate, you may choose not to discuss any issues that make you feel uncomfortable.

All of the information we gather from participants who care for someone who has been diagnosed with cancer will be combined and the researchers will try to identify the similarities and differences in peoples’ experiences in the cancer care system. The information gathered during this study may be used in presentations, journal articles, newsletters, and workshops. We will also be providing a full report of the research findings to the Confederacy of Mainland Mi’kmaq, the Union of Nova Scotia Indians, the Atlantic Policy Congress of First Nations Chiefs, and First Nations communities in Nova Scotia. Some of these reports will include direct quotes from the participants. However, these reports will not include your real name, nor will any report reveal your identity or that of your home community.

**Compensation**

Each group participant will receive an honorarium (gift) of $20.00.

**Confidentiality**

Although the Research Assistant and the researchers will keep your participation in this study private, we cannot guarantee that others in your group will keep your identity or comments private. Therefore, we ask that everyone who participates in a group discussion respect the privacy of others in the group.

**Risks and Benefits**

Your participation in this study intends no harm or discomfort to you: the questions are mainly focussed on your thoughts, feelings, and experiences with the cancer care system in Nova Scotia. You may or may not benefit from sharing your experiences at the time of your participation. However, your input will contribute to our knowledge about how the cancer care system might better serve the needs of First Nations people. You should discuss any questions you have about this study with Jean Knockwood.

When discussing sensitive topics, some participants might need personal support, which may be provided by the other members of the group. For instance, some people may experience stress related to talking about their experiences with cancer and the cancer care system. In addition, participants might also need information about community resources and supports. The Research Assistant will have a list of community resources available for those who may require support as a result of their participation in this study.

Cancer Care Nova Scotia may wish to collaborate with the Mi’kmaq Health Research Group in future projects related to First Nations people’s cancer care experiences and needs. Therefore, with the appropriate ethical approval, the findings of this study may be used to help them develop those future projects.

**Contact Information**

If you have any questions or concerns, please feel free to call Charlotte Loppie by phone at (902) 494-6620 or by email at charlotte.loppie@dal.ca or Fred Wien at (902) 494-1326. We would be happy to discuss any questions or comments you have. Please be assured that we will keep you informed about any new information that might affect your decision to participate in this study and you will be contacted in the unlikely event that this study is terminated.

Many thanks,
I have read the above explanation of this study. I realize that my participation is voluntary and that I am free to withdraw from the study at any time. I have been given the opportunity to discuss this information and my questions have been answered to my satisfaction.

I hereby consent to take part in this study and to be audio-taped. □ Yes □ No

Participant's Signature

Date

Signature of Person Obtaining Consent

Date

In the event that you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Human /Research Ethics/Integrity Co-ordinator at Dalhousie University’s Office of Human Research Ethics and Integrity for assistance. Phone: (902) 494-1462.
Dear Health Professional,

We would like to invite you to participate in a research project called “Cancer Care and Patient Navigation: A First Nations Experience”, conducted by the Mi’kmaq Health Research Group (Union of Nova Scotia Indians, Confederacy of Mainland Mi’kmaq and Dalhousie University) and funded by Cancer Care Nova Scotia. Your participation in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconveniences, or discomfort, which you might experience.

Purpose

The purpose of this study is to gather information about First Nations peoples’ experience with the cancer care system in Nova Scotia. You may participate in this study if you are a health professional, working on or off reserve with First Nations people who are diagnosed with cancer.

Study Design

Under the supervision of the Dr. Fred Wien, Dr. Charlotte Loppie, and the other members of the Mi’kmaq Health Research Group, our Research Assistant, Jean Knockwood, will guide a one-on-one interview with you about their experiences as a health professional working with First Nations people and the cancer care system in Nova Scotia. The discussion will last approximately 30 minutes and will take place over the phone or in your office. The Research Assistant and the researchers will keep your participation in this study private.

The Research Assistant will write down your responses to questions from a guide developed by Cancer Care Nova Scotia. You may look at the written summary of your discussion at any time. All
confidential written material will be kept in a locked cabinet and on the password-protected computer at Dalhousie University until they are destroyed and/or permanently deleted, five years after a report of the study is published. The Research Assistant will ask you to sign a consent form before the discussion. However, your participation in this study is voluntary and you may withdraw at any time without penalty. Also, if you do agree to participate, you may choose not to answer any questions.

All of the information we gather from health professionals will be combined and the researchers will try to identify the similarities and differences in peoples’ experiences in the cancer care system. The information gathered during this study may be used in presentations, journal articles, newsletters, and workshops. We will also be providing a full report of the research findings to the Confederacy of Mainland Mi’kmaq, the Union of Nova Scotia Indians, the Atlantic Policy Congress of First Nations Chiefs, and First Nations communities in Nova Scotia. Some of these reports will include direct quotes from the participants. However, these reports will not include your real name, nor will any report reveal your identity or that of your home community.

Risks and Benefits

Your participation in this study intends no harm or discomfort to you: the questions are mainly focussed on your thoughts, feelings, and experiences with the cancer care system in Nova Scotia. You may or may not benefit from sharing your experiences at the time of your participation. However, your input will contribute to our knowledge about how the cancer care system might better serve the needs of First Nations people. You should discuss any questions you have about this study with Jean Knockwood.

Cancer Care Nova Scotia may wish to collaborate with the Mi’kmaq Health Research Group in future projects related to First Nations people’s cancer care experiences and needs. Therefore, with the appropriate ethical approval, the findings of this study may be used to help them develop those future projects.
Contact Information

If you have any questions or concerns, please feel free to call Charlotte Loppie by phone at (902) 494-6620 or by email at charlotte.loppie@dal.ca or Fred Wien at (902) 494-1326. We would be happy to discuss any questions or comments you have. Please be assured that we will keep you informed about any new information that might affect your decision to participate in this study and you will be contacted in the unlikely event that this study is terminated.

Many thanks,

Fred Wien
Mi’kmaq Health Research Group

I have read the above explanation of this study. I have been given the opportunity to discuss this information and my questions have been answered to my satisfaction. I hereby consent to take part in this study and to have the information that I share published in a report of the research findings. However, I realize that my participation is voluntary and that I am free to withdraw from the study at any time.

Participant's Signature          Date

Signature of Person Obtaining Consent         Date

In the event that you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Human /Research Ethics/Integrity Co-ordinator at Dalhousie University’s Office of Human Research Ethics and Integrity for assistance. Phone: (902) 494-1462.
Appendix B: Mi’kmaq Maliseet News Article

Mi’kmaq Health Research Group and Cancer Care Nova Scotia to study the experiences of Mi’kmaq people in the cancer care system of Nova Scotia.

Cancer is becoming a major health concern for First Nation people in Canada. According to a 2003 study, cancer is the third leading cause of death among First Nation peoples and researchers expect these rates to rise over the next decade. Following a successful study in African Nova Scotian communities, Cancer Care Nova Scotia asked the Mi’kmaq Health Research Group (MHRG) to conduct a similar study among the First Nations in Nova Scotia. During August and September of 2004, the researchers will conduct group discussions in several First Nation communities, where they will ask cancer patients, family members and caregivers, and health professionals to talk about the cancer care needs, experiences and barriers for First Nation individuals, families, and communities in Nova Scotia. Cancer Care Nova Scotia hopes that the results of this study will generate recommendations for improving cancer diagnosis, treatment and post-treatment for Mi’kmaq people.

For more information, please contact your health centre or one of the MHRG Co-Chairs:
Sally Johnson (Union of Nova Scotia Indians) at (902) 539-4107
Charlotte Loppie (Dalhousie University) at (902) 494-6620
Dear Health Director or Community Health Representative,

Enclosed you will find a package of information about a research project being conducted by the Mi’kmaq Health Research Group, in collaboration with Cancer Care Nova Scotia. The purpose of this project is to:

1. Identify the cancer care needs of First Nations individuals, families, and communities in Nova Scotia.
2. Identify barriers that First Nations individuals, families, and communities encounter in accessing cancer care programs and services.
3. Identify gaps in the cancer care system that might affect the cancer care experience of First Nations people.
4. Determine ways in which Patient Navigators might facilitate access to cancer care for First Nations people.
5. Determine ways in which First Nations people might benefit from the Patient Navigator Program.
6. Identify potential avenues of change within the cancer care system, which might reduce barriers and enhance the experience of First Nations individuals, families, and communities.

Since its inception by the Nova Scotia Department of Health in September 1998, Cancer Care Nova Scotia (CCNS) has worked collaboratively with individuals and organizations to assess and enhance cancer care services and programs in Nova Scotia. In addition to providing programs such as Patient Navigation, which is based on the recognized needs of individuals, families, and communities, CCNS has made an effort to determine the extent to which programs and services are meeting the needs of diverse ethno-cultural communities. Following a successful needs assessment conducted in African Nova Scotian communities, CCNS has asked the Mi’kmaq Health Research Group to pursue a similar inquiry into the cancer care needs and related barriers faced by First Nations individuals, families, and communities in Nova Scotia.

Cancer is increasingly becoming a priority health concern among First Nations people in Canada. In fact, cancer is the third leading cause of death among First Nations populations and based on current demographic and disease trends, the incidence of cancer among First Nations people is expected to rise over the next decade (Marrett & Chaudhry, 2003). Although it appears that

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2 The Cancer Care Patient Navigation Program was established in 2001 by the Minister of Health, “to support the work of family physicians and others, while ensuring that cancer patients and their families have the information, knowledge and support they need as they journey through the cancer system” (Cancer Care Nova Scotia, 2004).
specific socio-cultural circumstances represent obstacles for many First Nations people attempting to access support within the cancer care system, little is known about these experiences. In particular, the complex federal/provincial health system may create barriers for First Nations people attempting to access diagnosis and treatment of cancer. Beliefs about the reduced prevalence of cancer among First Nations people as well as cultural concepts of disease management may also deleteriously influence access to cancer surveillance and care (First Nations Cancer Research and Surveillance Workshop, 2003). Finally, interactions between First Nations people and health professionals within the cancer care system may be premised on inter-cultural and inter-class inequities in social power, which disadvantage those seeking cancer care (Adams, 1995).

Our Research Assistant, Jean Knockwood, will contact you in the near future to discuss the participation of members of your community in this important research. Thank you in advance for your consideration of this project.

Sincerely,

Charlotte Loppie
Mi’kmaq Health Research Group
Has Cancer Touched Your Life?

The Mi’kmaq Health Research Group and Cancer Care Nova Scotia are looking for your help.

We would like to invite you to take part in a discussion (focus group) about your journey through the cancer care system. This discussion will last about 1.5 – 2 hours. Cancer Care Nova Scotia hopes that these groups will help them improve the cancer care system for First Nations people.

Come with your thoughts, feelings, and experiences

Come with ideas to make things better!

Focus groups will be held in a number of First Nation communities

The date, time and place of the groups will be announced at a later date.

Please call now, if you are interested in learning more about this study and if you are:

- A First Nations person, 18 years or older, who has been diagnosed with cancer within the past five years
- A family member or caregiver of someone who has been diagnosed with cancer in the past five years

Please call Jean Knockwood at (758-3187) between the hours of 8 am and 4 pm. or e-mail Jean at jean.knockwood@ns.simpatico.ca
Appendix E: Family Member/Caregiver and Patient Demographic Surveys

Family Member/Caregiver Demographic Survey

1. Gender:
   Female ........................................
   Male ..............................................

2. Do you currently work outside of the home?
   Yes ........................................
   No ........................................

   If you are employed, what is your occupation
   ________________________________.

3a. What is your relationship to the person who has been diagnosed with cancer?
   ____________________________________________________________

3b. In which of the following age groups does your family member fall? Are they...

   18-30 ........................................
   31-40 ........................................
   41-50 ........................................
   51-64 ........................................
   65-74 ........................................
   75+ ...........................................

4. What type of cancer does/did your family member have?
   Cervical Cancer ................................
   Breast Cancer ...............................
   Prostate Cancer ............................
   Colorectal Cancer ..........................
   Lung Cancer ................................
   Other (Please specify)______________________

5. When was your family member diagnosed with cancer?
   Less than 1 year ago ..................
   1 – 3 years ago .........................
   More than 3 years ago ...............
1. **Gender:**
   - Female ........................................
   - Male ...........................................

2. **Do you currently work outside of the home?**
   - Yes ........................................
   - No ...........................................

   If you are employed, what is your occupation __________________

3. **In which of the following age groups do you fall? Are you...?**
   - 18-30 ....................................
   - 31-40 .....................................
   - 41-50 .....................................
   - 51-64 .....................................
   - 65 -74 ...................................
   - 75+ ........................................

4. **What type of cancer do/did you have?**
   - Cervical Cancer ........................
   - Breast Cancer ...........................
   - Prostate Cancer ........................
   - Colorectal Cancer ........................
   - Lung Cancer .............................
   - Other (Please specify_________________________)

5. **When were you diagnosed with cancer?**
   - Less than 1 year ago ..............
   - 1 – 3 years ago ......................
   - More than 3 years ago ............
1. Opening Prayer

2. Background Information from Fred/Charlotte on the MHRG

3. Introduction of Participants, Informed Consent and Demographic Survey

4. Explanation of Format for the afternoon

5. We are going to begin by asking each of you to talk for 5-10 minutes about your journey with someone who has cancer, from the time that you first knew something was wrong with him/her through diagnosis, treatment and follow-up. We are most interested in knowing what are the key events that took place, what are the milestones in this journey that stand out for you?

6. In this next phase, we are going to ask each of you some questions about each period in this journey with cancer, beginning with the time before the illness was diagnosed:

(a) Pre-diagnosis: how long was it from the time you knew something was wrong with your family member or friend until he/she was diagnosed?

(b) Diagnosis: Who told your family member that she/he had cancer, and how were they told? Were you with them at the time? How did you feel? Was there anyone or anything that made receiving this information easier for you, and if yes, who/what was it? What information did you receive about cancer and how useful was it? How long was it from the time your family member was diagnosed until he/she was referred to a specialist and started treatment?

(c) Treatment: How did your family member decide about what treatment option to choose? Do you think that you and your family member were you adequately prepared for this treatment? What information did you want to have, if any? Where did you look for it?

(d) Post treatment/Follow-up: What information, if any, did you want in this phase? Where did you look for it?

7. Next, we are going to ask each of you about the key supports that sustained you (the caregiver) on this journey. Key supports are the things or persons from which you drew your strength or depended upon – a place, a group, an activity or object. Did your supports change at different times? Were there any gaps in your support system?

8. To conclude, we would like you to identify three areas where there were gaps, where things need to be improved to make the journey through cancer a little less difficult and more bearable. What are the solutions that need to be implemented? Think about what could have made a difference for you.
Appendix G: Moderator’s Guide for Patients

1. Opening Prayer

2. Background Information from Fred/Charlotte on the MHRG

3. Introduction of Participants, Informed Consent, Demographic Survey

4. Explanation of Format for the morning

5. We are going to begin by asking each of you to talk for 5-10 minutes about your journey with cancer, from the time that you first knew something was wrong through diagnosis, treatment and follow-up. We are most interested in knowing what are the key events that took place, what are the milestones in this journey that stand out for you?

6. In this next phase, we are going to ask each of you some questions about each period in your journey with cancer, beginning with the time before you were diagnosed:

(a) Pre-diagnosis: how long was it from the time you knew something was wrong until you were diagnosed?

(b) Diagnosis: Who told you that you had cancer, and how were you told? How did you feel at the time? Was there anyone or anything that made receiving this information easier for you, and if yes, who was it? What information did you receive about your cancer and how useful was it? How long was it from the time you were diagnosed until you were referred to a specialist and started treatment? How many health professionals did you see and how did you feel about that?

(c) Treatment: How did you decide about what treatment to take? Were you adequately prepared for this treatment? What information did you want to have, if any? Where did you look for it?

(d) Post treatment/Follow-up: What information, if any, did you want in this phase? Where did you look for it?

7. Next, we are going to ask each of you about the key supports that sustained you on this journey. Key supports are the things or persons from which you drew your strength or depended upon – a place, a group, an activity or object. Did your supports change at different times? Were there any gaps in your support system?

8. To conclude, we would like you to identify three areas where there were gaps, where things need to be improved to make the journey through cancer a little less difficult and more bearable. What are the solutions that need to be implemented? Think about what could have made a difference for you.
Appendix H: Health Professional Interview Guide

Participant Profile

Before we begin, I would like to find out a little information you.

1. Position/title ______________________________________

2. What is your involvement with First Nations cancer patients/family members?
   __________________________________________________________________________
   __________________________________________________________________________

3. How long have you been working with First Nation cancer patients/family members? ______

4. Approximately how many First Nations cancer patients did you see in the past year? ______

5. What is the average waiting time for an appointment in your clinic/practice?
   □ 1-2 weeks       □ 3-4 weeks       □ 5-7 weeks       □ 8 or more weeks

Current Cancer Care

The next few questions have to do with the process leading up to and including diagnosis.

6. In your experience, what is the average length of time from ordering the tests, to the patient actually
   being told the diagnosis? ______________

7. In your experience, who tells patients they have cancer? ______________________________
   In your opinion, who should tell patients they have cancer? __________________________
   Why do you feel that way?
   __________________________________________________________________________
   __________________________________________________________________________

   If you are the person who tells patients: Are you comfortable telling them? Yes ____ No ______
   What would assist you in this task?
   __________________________________________________________________________

8. Do First Nations patients and their families receive consistent messages from health professionals?
   Yes ________ No __________

9. When diagnosed with cancer, what types/kinds of information and resources do you provide to First
   Nations patients and their families?
   __________________________________________________________________________
What types of information are they generally looking for?  
Is what they are looking for or require available? Yes ___ No _______

What is missing?  _______________________________________________________

10. What information do you find most useful and why?  ______________________________________ 
________________________________________________________________________________

How do you learn about these resources?  __________________________________________________

How do you access these resources?  ___________________________________________________

11. Do you refer First Nations patients to additional resources, information sources, supports? 
Yes _____ No _________

If yes, which resources?  __________________________________________________________

The next few questions have to do with the treatment and post-treatment process.

13. Thinking about the time prior to treatment, what resources, if any, do you provide to assist First 
Nations patients and their families in choosing an appropriate treatment option? ________
____________________________________________________________________________
____________________________________________________________________________

What do First Nations patients and their families want or require at this time? ______________
_______________________________________________________________________________
_______________________________________________________________________________

14. In general, do you feel that you are able to provide First Nations patients with the kind of information 
they are looking for in a manner that is understandable so they are aware of the process/treatment that 
they are about to undertake?  __________________

If no: What sorts of information, resources, and supports do you require to overcome this problem?
_________________________________________________________________________________
_________________________________________________________________________________

15. What is your role in the treatment process?  _____________________________________________
________________________________________________________________________________

16. What, if any, further supports are required, both from your professional perspective and the First 
Nations patients’ perspective?  ______________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

17. How do First Nations patients’ needs change once treatment is complete?
_________________________________________________________________________________

What supports are available?  _________________________________________________________

What is missing?  _________________________________________________________________
Education

I would now like to ask you about education, specifically as it relates to cancer care.

18. Have you received any training that assists you in guiding First Nations patients through the cancer care system?  Yes ________       No _______

If yes: What type/s of training have your received? ______________________________________
________________________________________________________________________________

Future Directions

19. What types of information would be helpful to you in delivering quality service to First Nations cancer patients and their families? _____________________________________________________
_________________________________________________________________________________

20. What, if anything, do you think Nova Scotia’s cancer care is lacking today? ____________________
_________________________________________________________________________________
_________________________________________________________________________________

21. Overall, what areas of cancer care are currently working well? ______________________________
_________________________________________________________________________________
_________________________________________________________________________________

22. In your community, what would make the greatest difference in improving the provision of cancer care for First Nations patients and family members? _______________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

On behalf of Cancer Care Nova Scotia and the Mi’kmaq Health Research Group, I would like to thank you for taking the time to take part in this study. Your comments and suggestions have been very helpful.
May 11, 2004

This is to confirm my agreement to maintain, in the strictest confidence, information to which I have access in the course of my employment with the Mi’kmaq Health Research Group and Dalhousie University. This information shall not be disclosed to any party within or outside the Mi’kmaq Health Research Group or the University, except as directed in the course of my employment.

Name: Jean Knockwood

Signature: ________________________________

Date: _________________________________
References


