

Final Report

Premier's Consultation for Improved
Cancer Care in Northern BC
July 2006



Premier's Consultation for
IMPROVED CANCER CARE
in **NORTHERN BC**

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From the Co-Chairs

Dear Premier:

A little over a year ago, you asked us to lead a comprehensive consultation process on access to cancer care in the north. We took on the responsibility because we believe this is one of the most pressing health care concerns facing Northern BC, where we have the highest rates of cancer of any region in the province, and where cancer is the second leading cause of death.

We would like to thank you for the opportunity. It has been a great honour to travel widely in the region, to meet northerners, and to listen to their honest and well-presented stories, concerns and recommendations on cancer care and cancer prevention. It has not been an easy task, however. It has been a highly personal experience at times for us. Each of us, like most families, has had our own experiences with the cancer journey.

The document you hold in your hands is not so much a report as an accumulation of voices, the voices of northerners who have had direct experience with cancer, the voices of health care professionals struggling to provide care in difficult circumstances, and the voices of regular people who want to know the care will be available when they need it. Sometimes those voices told stories of hope and triumph. Often they cracked with emotion as they related tales of tragedy. We hope we have honoured these voices by recording their experiences faithfully.

What has become clear to us during this process is that British Columbia has a cancer care system that, while of the highest quality, is difficult for Northerners to access without encountering significant obstacles of distance, time and personal expense.

As far back as 1989, the BC Cancer Agency recognized this disparity, and emphasized the need to address the pressures on the system that it estimated would reach critical levels some time after 2001. In its Review of Cancer Services in BC (1989) it recommended that local cancer services in smaller communities be enhanced and, specifically, that cancer facilities be expanded to meet the expected growth in demand in the new millennium. It is now time to take up this challenge.

The challenge, however, is not just in creating a cancer care centre in Prince George. Rather, it is fundamentally rooted in improving care and access for all northern communities. The commitment to and establishment of a centre in Prince George will only be the completion of an overall integrated vision of what cancer care needs to be for all residents of Northern British Columbia.

Respectfully,

Dr. Charles Jago, Co-Chair

Jeff Burghardt, Co-Chair



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Executive Summary

Significant work has been done recently to examine cancer care in Northern BC, the region of the province with the highest rates of cancer and the least successful treatment outcomes for many forms of cancer.

In March 2005 Northern Health and the BC Cancer Agency released a report entitled the *Northern Cancer Control Strategy*. The report focused on expanding cancer control services in Northern BC in a coordinated way, but explicitly did not recommend a full-service cancer care centre for Prince George.

In April 2005, following the release of this report, Premier Gordon Campbell asked Dr. Charles Jago, President of the University of Northern BC, and Jeff Burghardt, Chair of Northern Health, to lead a comprehensive community consultation process on access to cancer care in the north.

At the same time, Northern Health and the BC Cancer Agency began exploring the viability of a comprehensive cancer care centre in Prince George (including radiation therapy). Their report, the *Radiation Therapy Review*, was released in February 2006. It concluded that, provided significant challenges are addressed, a full-service cancer care centre for Northern BC “is both desirable and feasible.”

Building from the information contained in the *Northern Cancer Control Strategy* report and the *Radiation Therapy Review*, Jeff Burghardt and Charles Jago undertook a broad consultation process by visiting seventeen communities in Northern BC in March and April 2006. Public meetings, focus groups and written comment forms provided forums for northerners to share their unique perspectives on cancer care, to consider what might be done to improve the cancer care system, and to communicate directly with the consultation leaders.

The fundamental question for consideration in the consultation was: How can we design a comprehensive and integrated cancer care system that best meets the unique needs of the people of Northern BC?

Almost 1,000 people participated in the consultation and provided honest, heartfelt and clear comments to the two co-chairs. There were positive expressions of gratitude for what worked well in cancer care; there were also critical comments on what must be improved.

Participants’ views reflect a desire among northerners to see enhancements and improvements in the following areas of the current system:

- prevention of cancer and health promotion activities;
- screening and early detection services – locally and regionally;
- diagnostics, treatment, follow-up to treatment in cancer centres, and end of life care;

- effective coordination of cancer care in the north;
- information sharing and guidance for patients;
- the cancer nurse navigator role and local chemotherapy services;
- consistency and quality of physician care for cancer;
- patient choice in deciding where to go for cancer treatment;
- assistance to offset the financial, physical and emotional burden of travel for cancer treatment;
- cancer care training and education, particularly for physicians;
- the use of technology to improve service and waiting times (for tests, for example);
- culturally relevant services, meeting the needs of all northerners, including the Aboriginal population; and,
- a comprehensive cancer care centre in Prince George.

As a result of the insights gained from participant comments, this report proposes four principal recommendations for improving cancer-related services in Northern BC.

Recommendation 1

Develop a unique and fully integrated system of cancer care in Northern BC with a network of care that extends from smaller communities to the largest centre.

There is an opportunity at hand for British Columbia to become a leader in the field of northern and rural cancer care. As was the case with the Northern Medical Program, this will take commitment, patience and vision.

A fully integrated system, based on a single, comprehensive plan for cancer care, will provide effective coordination at all levels (local, regional, provincial) and will provide services and supports for a continuum of cancer services in the north.

Guiding principles for this integrated system include:

- Clearly assigned leadership, with responsibility to create and develop a system of cancer care for the BC Northern and Central Interior that is second to none.
- A system of care in which patients and their families become knowledgeable and engaged partners in their own care.
- Local capacity to support all stages of cancer care as close to a patient's community as possible.
- A focused northern cancer prevention strategy.
- Strong research partnerships between the BC Cancer Agency, the University of Northern BC and Northern Health, focused on the incidence and causes of cancer rates in the north.
- Application of technology to improve access to cancer care and reduce the impact of travel distance and challenges.
- Culturally relevant services for the significant Aboriginal population in the north.
- Community cooperation and a network of care that creatively meets the challenges of serving a widely dispersed population in a vast geography.
- The right of patients to choose the most appropriate cancer centre for their needs.

Out of the consultation process, a number of clear strategies for creating this integrated system arose. They are described in some detail in the report and include proposals for moving forward in these broad areas:

- increasing prevention and health promotion;
- supporting northern physicians in providing better cancer care;
- improving community-based care across the whole cancer care continuum; and,
- expanding the use of technology to reduce patient travel and to better coordinate timely care.

Recommendation 2

Create a full-service BC Cancer Agency cancer care centre in Prince George as the foundation for development of the services and expertise required to achieve a fully integrated system of cancer care for Northern BC and the Central Interior of the province.

Northern BC has the highest rate of death in the province from all forms of cancer, and cancers are the second leading cause of death among northerners. Rates of some cancers are higher than the provincial average and outcomes after treatment are poorer on average. And the number of people expected to get cancer in Northern and Central BC is expected to increase by forty percent in the next ten years, from 1,000 new cases per year now to 1,400 new cases by 2015.

There is substantial support from northerners for a comprehensive northern cancer care centre in Prince George. The consultation team also heard from people in Williams Lake and other areas in the Central Interior, who support this. A Prince George Cancer Centre will attract patients from outside of the Northern Health area (see Appendix II). It is expected that Northern Health would work cooperatively with the Interior Health Authority and the BC Cancer Agency to coordinate this care. This is reflected in this report.

It was acknowledged in every community that, in addition to the obvious benefit of reduced travel for many northerners, a cancer care centre could also be a hub for improved services and would help generate northern solutions to the cancer care needs throughout Northern BC.

It was recognized, through the consultation, that a northern cancer care centre has the potential to:

- enhance the development of health care services in Northern BC and the Central Interior of the province;
- provide health care services in a manner that recognizes and understands the different realities of living in Northern BC and the Central Interior of the province;
- ease the financial burden of accessing care;
- allow for better choices of treatment options, leading to better outcomes for patients;
- provide direct support to community cancer clinics and other staff throughout the north (training, clinical support, building a network, adapting services);
- build on efforts to attract and retain health care professionals in the north;
- become an integral part of the medical research and education sector, particularly through the University of Northern British Columbia; and
- reduce wait times for diagnosis, treatment and follow up.

The consultation process has reaffirmed the findings of the Radiation Therapy Review, and confirms the support of most northern residents for taking the steps needed to proceed to development of a cancer centre in the north.

This includes the associated steps and resources required for Prince George Regional Hospital to have the capacity to support an increased number of cancer patients. It also includes the construction and operation of a cancer lodge for patients needing accommodation that would be built and operated in partnership with the Canadian Cancer Society and other private support. Travel support for those who need financial assistance to access the centre should also be provided.

Most importantly, a northern cancer centre will be expected to support the cancer care services in local communities through the development of innovative models of care delivery, including the use of technology.

The proposed centre must embrace as its primary goal the creation of a fully integrated system of cancer care for Northern BC and the Central Interior of the province based on the principle of providing as many services as possible to patients as close to their homes as possible.

The 1989 BC Cancer Agency Review of Cancer Services in BC recommended that “The Board of Trustees of the Cancer Control Agency, in partnership with the Ministry of Health, recognize the needs for cancer care services in the smaller communities of British Columbia, particularly in terms of the expansion of Cancer Control Agency facilities beyond 2001.”

It is now time to take up this challenge, and to seize this opportunity to demonstrate strong national leadership in northern and rural health care by developing a distinctively northern centre for cancer care that is part of a comprehensive approach to this disease.

Recommendation 3

Appoint the BC Cancer Agency, under the jurisdiction of the Provincial Health Services Authority and in partnership with Northern Health, as the lead agency for managing improvements to cancer care in the North and Central Interior of BC.

An essential element in improving cancer care in the north will be the establishment of a framework for leadership. This will be critical to move forward with the strategies for improving cancer care outlined in Recommendations 1 and 2 in this report, as well as those contained in the Northern Cancer Control Strategy and the Radiation Therapy Review. Clear leadership is required in order to manage complex change in a coordinated, effective and timely manner. The responsibility for leading these changes resides with the Provincial Health Services Authority – through the BC Cancer Agency.

The BC Cancer Agency needs to apply its provincial leadership role to this northern initiative. There is already a good working relationship between the BCCA and Northern Health. A continued joint executive group involving the two organizations requires specific mandated responsibilities and accountabilities. A fully integrated network of care through all communities will require coordinated and shared use of staff and resources. Northern Health is already operat-

ing much of that capacity. A well-established and close working relationship between both groups will assure progress on the strategy. The individual performance agreements between the Province and each these organizations should reflect these responsibilities.

Additionally this joint executive group should work in close collaboration with the medical advisory groups of the North, the Canadian Cancer Society, the University of Northern BC and other relevant organizations. Those ongoing and working relationships will help ensure the unique northern aspects of the full strategy will be appreciated and addressed.

Recommendation 4

Develop policy and practical solutions to achieve equitable access to cancer care, by addressing the obstacles to health care access caused by distance and personal financial circumstances.

In addition to the lack of availability of adequate cancer care close to home, travel to access those services in other communities was consistently identified as the greatest obstacle to equitable access to care. In fact many stories were told of patients electing surgery (mastectomy, for example) over the burden of traveling for radiation therapy, and even some tragic cases in which patients chose to not take any treatment at all.

People in the Northern and Central Interior of BC must travel far away from their homes and communities for specialized cancer care. This creates a financial and emotional burden, and results in a weakening of the principle of equal access to health care. A cancer care centre in Prince George will reduce the distances and time away from home for many northern residents.

Even with a Prince George cancer centre, however, many patients will still need to travel for care and even Prince George remains a long journey for some. Therefore, they should continue to have a choice of treatment locations.

The emotional and psychological burden of travel is exacerbated for those who don't have the financial resources to pay for airfares, accommodation, meals, medications and other expenses. The Canadian Cancer Society provides limited financial support to those who qualify. Even so, it was clear from these consultations that this support, although appreciated by those who receive it, does little to reduce the inequities in access to services.

When reviewing travel support policies in BC, it would be reasonable to compare them to policies from other northern regions of Canada (such as the Yukon, the Northwest Territories and Northern Manitoba). Those living in northern and rural parts of this province have more in common with residents of those regions than with people living in the more densely populated southern parts of BC.





Introduction

Residents of Northern BC are a strong, independent people who are used to facing challenges and coping with difficulties unique to people living in a vast, largely rural area.

During public meetings and in smaller focus groups held as part of the consultation process, residents provided honest and direct comments on the state of cancer care, including strong, but realistic, views on what needs to be improved, and concrete suggestions on how this might happen. The consultation team heard moving, often heart-wrenching stories of living with cancer in the north.

The purpose of this report is to summarize what was heard during consultations with almost 1,000 people throughout Northern BC and to translate their thoughts and experiences into recommendations on how to improve cancer care in the north. It begins with a brief background to the consultation, provides an overview of the process, a summary of findings (including a community by community summary) and concludes with key recommendations.

This document is not a scientific survey. It is, however, the result of a rigorous exploration of the views of hundreds of northern residents who have had direct and indirect experience with the cancer care system as it is today. Nor is this document a catalogue of complaints. People praised the BC Cancer Agency, the supports received when away from home for treatment, and local cancer care services. The highest praise was often reserved for local cancer care staff, who, according to patients, work selflessly for long hours in challenging conditions, often isolated from the rest of the cancer care system.

Stories of quick and successful treatment were heard, as were tales of tragedy. Mostly, though, people's experiences with the cancer care system fall somewhere in between these two opposing constellations.

What has become clear from this consultation process is that cancer care in northern BC is highly variable. What is also clear is that, in many ways, the current standard of cancer care in the north is inadequate.

*The Board of Trustees of the
Cancer Control Agency,
in partnership with the Ministry
of Health, recognize the needs
for cancer care services in the
smaller communities of British
Columbia, particularly in terms
of expansion of Cancer Control
Agency Facilities beyond 2001.*

BC CANCER AGENCY REVIEW OF
CANCER SERVICES IN BC, 1989



Background

Cancer affects citizens across the province. Yet, in Northern BC, rates of some cancers are higher than the provincial average and outcomes after treatment are poorer, on average. Northern BC has the highest rate of death in the province from all forms of cancer, and cancers are the second leading cause of death among northerners.

Residents of Northern British Columbia have grown increasingly concerned about the impact of cancer on health and on the range and accessibility of cancer care services available in the north. This concern – and the desire for solutions – is shared by health care providers and political leaders, and has been for some time.

In fact, a 1989 BC Cancer Agency review of cancer services in British Columbia described many of the same concerns as were raised during this consultation process. Recommendation IV of that report states: *That the Board of Trustees of the Cancer Control Agency, in partnership with the Ministry of Health, recognize the needs for cancer care services in the smaller communities of British Columbia, particularly in terms of expansion of Cancer Control Agency Facilities beyond 2001.*

More recently, the BC Cancer Agency and Northern Health jointly conducted two reviews of the cancer care system in the year prior to the present consultations. *The Northern Cancer Control Strategy*, released in March 2005, focused on reviewing and expanding cancer care services in a coordinated way, while the *Radiation Therapy Review*, released in February 2006, looked specifically at the need for and feasibility of a comprehensive regional cancer care centre in Prince George. That review concluded that, provided significant challenges are addressed, a full-service cancer care centre for Northern BC “is both desirable and feasible.”

In April 2005, Premier Gordon Campbell asked Dr. Charles Jago, President of the University of Northern BC, and Jeff Burghardt, Chair of Northern Health, to lead a comprehensive community consultation process on access to cancer care in the north.

The consultation team visited seventeen communities in Northern BC in March and April 2006. Public meetings, focus groups and written comment forms provided forums for residents of Northern BC to share their unique perspectives on cancer care, to consider what might be done to improve the cancer care system, and to communicate directly with the consultation leaders.

The fundamental question for consideration in the consultations was:

***How can we design a comprehensive and integrated cancer care system
that best meets the unique needs of the people of Northern BC?***

Snapshot of Community Input

Community	Public Meeting	Focus Group	Written Input
Burns Lake	X	X	X
Cluculz Lake			X
Dawson Creek	X	X	X
Fort Nelson	X	X	X
Fort St James			X
Fort St John	X	X	X
Hazelton	X		X
Hudson's Hope			X
Houston			X
Kamloops			X
Kitimat	X	X	X
Kitkatla			X
Lax Kw'Alaams			X
McBride	X	X	X
Nakazdli			X
Prince George	X	X	X
Prince Rupert	X	X	X
Queen Charlotte Village	X	X	X
Quesnel	X	X	X
Smithers	X	X	X
Stewart			X
Tatlayoko Lake			X
Terrace	X	X	X
Unknown			X
Valemount	X	X	X
Vanderhoof	X	X	X



Consultation Process

During the months of March and April 2006, the consultation team traveled across Northern BC, hosting meetings and discussions with residents of communities from the Village of Queen Charlotte to Valemount, and from Fort Nelson to Quesnel.

Focus groups were held in sixteen communities. These were small group discussions with people who have had direct experience with cancer, either as patients themselves or as caregivers for loved ones. Larger, public meetings were also held in seventeen northern communities.

Participants in focus groups and public meetings were invited to comment on the entire cancer care system – what is referred to as the cancer care continuum – from prevention and health promotion through to treatment and end of life care. They were asked to describe their experiences, what worked well, and what could be improved.

They were also given the chance to respond to the vision for improved cancer care put forth in the discussion paper, *A Northern Vision*, and in an accompanying video presentation.

All northerners were invited to submit their thoughts on a comment form, made available through Northern Health facilities and through the consultation website: www.northern-cancercare.ca.

The consultation team set out to understand northerners' responses to three distinct, but interrelated questions:

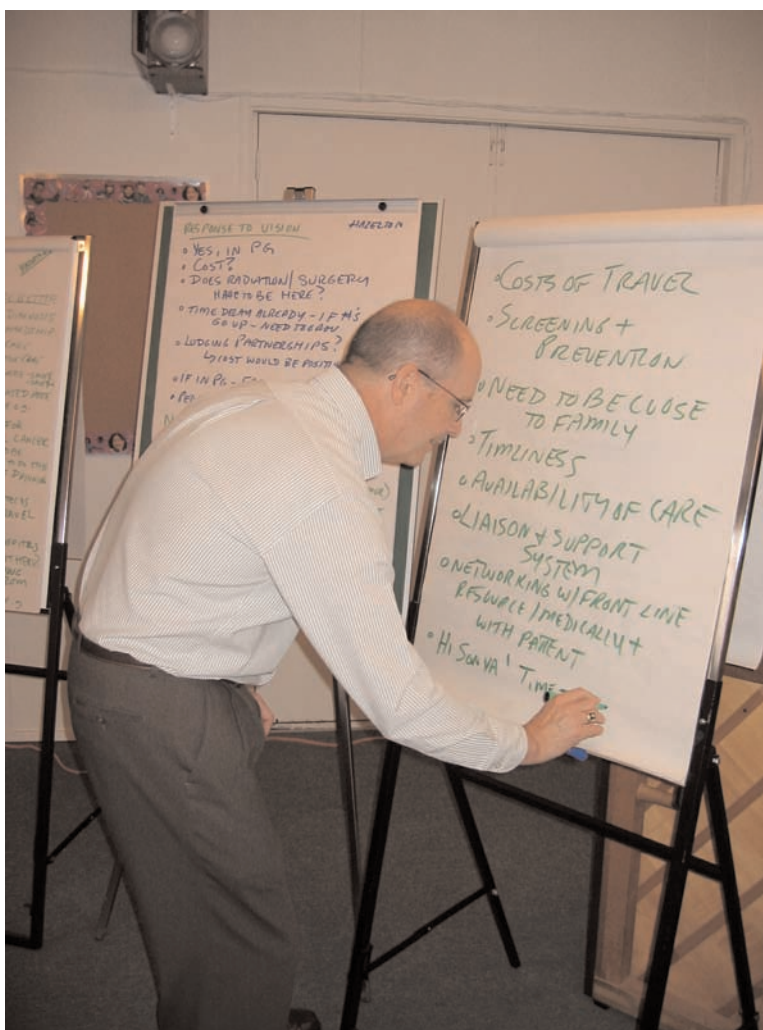
- Current state of cancer care in Northern BC: How well do you feel the cancer care needs of Northern BC and the Central Interior are being served today?
- Response to *A Northern Vision* (a discussion paper prepared for the consultation): What are the positive elements? What are the challenges?
- Considering a Northern Cancer Centre: What is your specific response to the possibility of building a northern cancer care centre in Prince George?

There was a wide range of responses across the north, with different reactions regionally, and even within communities. The team also received unsolicited input from some people in the Central Interior area, just south of the Northern Health jurisdiction. This report seeks to reflect this diversity of opinion in all of its findings, and by including a brief summary of what specifically was heard in each community.

While there were regional and local differences of opinion, common themes began to emerge over the course of the two-month consultation. Issues, experiences and opinions were repeated in community after community. We have tried to capture these common

themes in the findings below, beginning with those related to current cancer care services, followed by more broad themes, and then to the specific issue of a cancer care centre in Prince George.

In doing so, we draw a distinction between findings and recommendations. The latter are found at the conclusion of this report and reflect the consultation co-chairs' answer to the Premier's request for advice on how to improve cancer care in Northern BC. The findings are an attempt to reflect accurately what the consultation team heard from participants and respondents.





Findings

1. Current Cancer Care Services

Residents of Northern BC are generally very appreciative of being able to receive some services in or near their home community, and recognize the challenges inherent in delivering those services to a small population in northern and rural communities.

Without exception, however, every community expressed the desire – indeed, the demand – for improvements to local cancer care services.

The following gives a sense of what northerners think of the level of cancer care services available to them now.

Prevention and promotion

Prevention of cancer was discussed at every meeting and in many written submissions.

Northern residents would like to see more emphasis on all aspects of prevention and health promotion related to cancer care.

The Vision document and consultation video highlighted that up to fifty percent of all cancers are preventable. Most people are aware of the messages about risk behaviour that may lead to cancer (tobacco use, sun exposure, nutrition). However, respondents said the health care system and its partners, such as the Canadian Cancer Society and First Nations Health Services, should do more to provide health promotion activities, especially to young people. They also suggested that offering people more support to change behaviours would help reduce the incidence of cancer.

The consultation team also heard from a significant number of participants who felt there are other, less well understood environmental causes of the high rates of cancer in Northern BC. They recommended more research be done on the relationship between cancer and the conditions of their water, air, food, workplace environment, and the impact of industrial pollutants. A few participants wanted to see this research into environmental causes take priority over research on treatment.

Regardless of the type of research, residents would like to see more emphasis on partnerships between Northern Health, UNBC and the BC Cancer Agency.

Screening and early detection

There was a strong message from participants that, in their experience, doctors (and the health care system in general) are not fully promoting or offering enough cancer screening. Their question was essentially this: would it not be money well-spent to catch cancer in its earliest, and therefore, most treatable stages?

There is access to mammography services in most communities, although for many northern communities it is a traveling service that visits only once or twice a year. Access to other procedures such as prostate and colorectal cancer screening is highly variable, and is perceived at times to depend more on good luck and strong personal advocacy than on any interest by the health care system in promoting the screening.

“You can’t say enough about the nurses in this hospital, and the doctors too. They’re not miracle workers – nobody can be – but they sure do what they can.”

People questioned why a more comprehensive system of cancer screening is not in place and consistently applied by doctors regardless of location. There was acknowledgement that the difficulty communities have recruiting and retaining family physicians limits access for patients to preventative screening and early detection.

There were many stories of delays in obtaining tests and test results (which often must leave the region for analysis) and subsequently poor communication of information from tests. Challenges in maintaining human resources, equipment and providing services across a vast area were acknowledged as a

major factor in the breakdown of information sharing.

Diagnostics, treatment, follow-up and end-of-life care

The variability in peoples’ experiences of diagnosis, treatment, follow-up and end of life care was remarkable.

In some communities and with some types of cancer, the standard of care is excellent. Often, however, patients told stories of feeling like no one was listening to them, resulting in their symptoms either being ignored or action delayed, and, tragically, allowing the cancer to spread. There were stories of delays in treatment, test results being sent to the wrong community and a lack of knowledge by local health care providers regarding treatment and follow up care.

Problems identified by respondents as contributing to this variability in care were:

- the shortage of physicians and the inconsistency in physician coverage across the north;
- problems with physicians not making accurate and timely diagnoses;
- the challenges local health care providers face in keeping knowledge and skills current;
- the lack of oncology-trained physicians in northern communities;
- gaps in services – the need for as full a range of chemotherapy services as possible; for adequate physical space for services; for adequate pharmacy services; to increase surgeries provided locally; to improve support for families and to improve end of life care;
- breaks in communication – the a flow of information between care providers and institutions that is prone to problems, resulting in patients and caregivers having to oversee these processes for themselves; specifically, most complaints were directed at doctors and their offices for providing inadequate guidance and follow-up;
- ineffective use of available technology;
- a lack of recognition and support for alternative or complementary approaches and therapies; and,

- a lack of information on specific cancers and treatment options; for many the benefits of speedy access to treatment are negated by a feeling of being rushed and not given time and guidance to understand their choices; doctors need to take more time and care in helping patients with both the educational and emotional elements of dealing with cancer, especially in the initial stages following diagnosis.

2. Coordination of care

Many patients and families feel there is a lack of integration and coordination of cancer care, both within the north, and between the north and cancer centres in the south. Services are fragmented and patients say they are all too often left to figure things out for themselves.

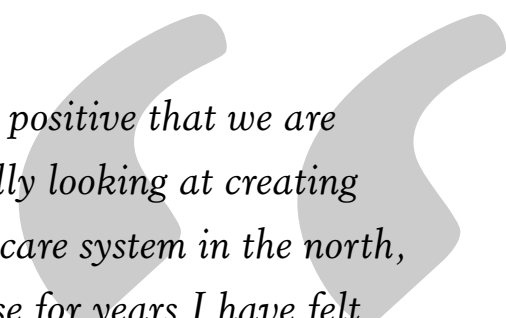
As a result many of them find themselves having to advocate for their own care at a time when they are least able to cope with such responsibility – from requesting screening tests, to researching cancer care information, to locating specialists, to arranging treatment.

It quickly became apparent during the consultations that in communities where there is a nurse navigator there is significantly less personal advocacy required. Patients are grateful for this support. Unfortunately even within the health care system, not everyone is aware of the role of the nurse navigator, and, for whatever reason, local doctors often demonstrate a lack of knowledge of the service, and a reluctance to refer patients to it.

Community cancer clinics and their staff are deeply appreciated, as are community pharmacy services. There was strong support for expanding services offered by existing clinics, to do prevention, promotion and outreach around their home communities, and to improve networks with other clinics and with cancer centres. Increasing the number of clinics around the north was also supported.

Participants identified the following areas where they said coordination of care can be improved:

- Many patients and family members find they must be their own advocates for care. To do this well, they need ready access to information, and guidance on their care options.
- There was support for improving the flow of clinical information between Northern Health, physicians and the BC Cancer Agency. The Clinical Information System being developed by Northern Health will make the sharing of patient records and information more efficient and give care providers up-to-date information when and where they need it. This is well supported by patients.
- Patients and families value the cancer nurse navigator where this role is available, and there is interest in seeing it expanded, including incorporating increased training in and access to administration of chemotherapy drugs.



“It’s positive that we are actually looking at creating a cancer care system in the north, because for years I have felt so alone up here.”

3. Choice of treatment location

In almost every community, but especially in those areas furthest from Prince George, people demanded the right to maintain choice in where they receive treatment.

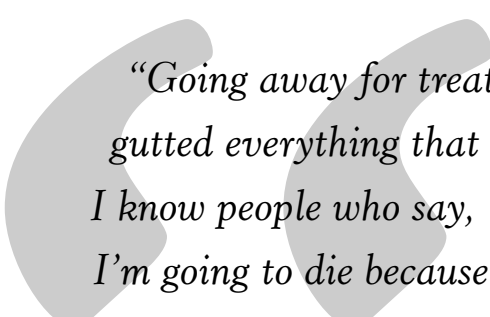
Patients and their families consistently expressed the importance of having the ability to choose where to go for treatment. Their choice of treatment location appears to be determined by three main factors: the proximity of family supports, including their ability to have family join them (i.e. distance to be traveled); having the financial ability to travel for care and be away from home; and the desire to be allowed to seek out the best treatment for their particular cancer.

Participants in the consultation were adamant that they not be forced to seek treatment in a particular location. Health professionals who participated in the consultations echoed the desire to maintain freedom of choice.

4. The burden of travel

Financial, physical and emotional costs

The fact that residents of Northern and Central BC must travel for a majority of cancer diagnoses and treatment is the most obvious example that equal access to cancer care does not presently exist for northern and rural patients in British Columbia.



“Going away for treatment gutted everything that I had. I know people who say, ‘I guess I’m going to die because I don’t have the money to go.’”

The most frequently noted challenge in obtaining timely and effective treatment was the cost associated with traveling great distances for services available to the typical urban resident for the cost of a taxi ride. Without an employee assistance plan or eligibility for Canadian Cancer Society funding, those costs – often in the thousands of dollars – fall to the patient.

Often patients from remote parts of the province are asked to travel hundreds of miles on multiple occasions, often on short notice. In addition, there are costs for accommodation and meals during often long stays in Vancouver, as well as lost time at work. The consultation team heard a number of stories of people deciding against treatment due to the cost.

In addition to the financial burden of travel, there are associated emotional and psychological costs. It’s difficult for anyone to receive a diagnosis and begin the long and arduous cancer journey. It’s exponentially more difficult to do so alone, far from home, family and friends.

The new Northern Health Connections travel service was acknowledged by some to be a positive travel support. Many participants, however, see it as a difficult and unsuitable option for long distance travel (for cancer patients).

Participants in the consultation were generally very pleased with the care they received from the BC Cancer Agency and the support the cancer lodges and staff provided for them once they arrived for treatment. But there is also a shared sense that government and those at the province's urban cancer centres don't understand what it's like to live in remote, rural and northern communities – in terms of both geographical and psychological distance. There was extreme frustration with the apparent lack of concern for issues such as travel, distance, weather and costs for northerners.

5. Support

While local cancer clinic staff were praised for their professional and caring support, people expressed the need for quick and relatively easy access to information and support at all stages of the cancer journey.

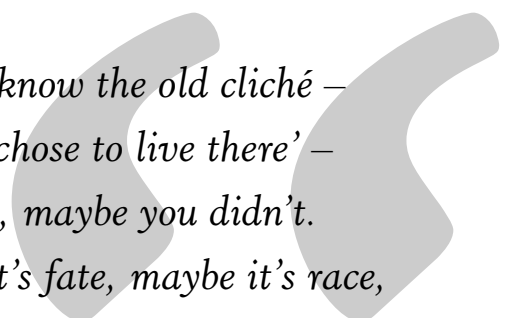
Once there is a diagnosis of cancer, there is an immediate need for information and support, some of it specific to a particular cancer and some of it emotional support from those who have been through the experience.

Through treatment and post-treatment, there is a need for support groups, more information and a way to ask questions and share experiences. There is also a great need for support and information for loved ones and caregivers, especially around end of life care.

Access to these kinds of information and support becomes scarce the rarer the form of cancer a patient has, and the more distant a patient lives from the centres of cancer care.

For the most part, participants told the consultation team that they do not see this continuum of support being provided in a consistent, coordinated or effective manner. In many cases, physicians and other care providers have not even referred cancer patients to the Canadian Cancer Society or the Northern Health cancer navigator in town. The Cancer Connections program (run by the Canadian Cancer Society) was heralded as a tremendous support by those who have used it; however, few seem to be aware of it.

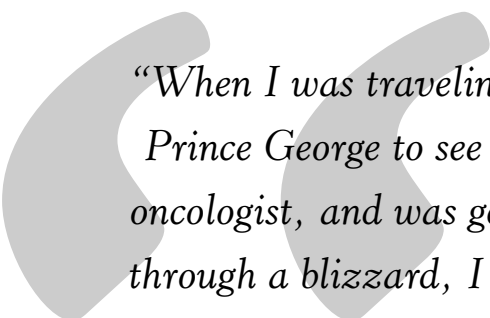
Patients often reported returning from receiving treatment at a cancer center to local services that are unfamiliar with the treatment they have received, the need for follow-up care, and the side effects that they are experiencing.



*“You know the old cliché –
‘you chose to live there’ –
well, maybe you didn’t.
Maybe it’s fate, maybe it’s race,
maybe the job’s here.
We could all use the support.”*

6. Training and education

Investing in the education and training of local health service providers in cancer diagnosis and treatment, and post treatment support and care was consistently identified as a need. Physician knowledge of cancers, approach to screening and diagnosis, support to patients, provision of information and other care is not consistent.



“When I was traveling to Prince George to see my oncologist, and was going through a blizzard, I was wondering why am I not talking to him via telehealth?”

7. Technology

Residents generally supported greater use of technology within the framework of a comprehensive cancer care system in two specific ways. There is support for using telemedicine – telephone, video and satellite diagnostics and consultation – to reduce wait times, eliminate unnecessary travel, and improve communication. There is also support for the Clinical Information Systems framework presently being developed by Northern Health.

8. Cultural Relevancy

These consultations did not include a separate, parallel process for First Nations. And it is with regret that the consultation team was not able to engage a larger proportion of the Aboriginal population through the public consultation process that did take place in seventeen communities. However, the Aboriginal voices present at many meetings, and those heard in the written submissions received from First Nations, made it clear that the cultural sensitivity of the health care system in general is in need of improvement. Cancer care is no different.

There is an opportunity to develop a system that is relevant to the unique culture of First Nations in Northern BC and that will help improve cancer care among the Aboriginal population, which currently has some of the worst outcomes in Canada. Partnerships with the University of Northern BC and with First Nations would be critical in both medical research and in developing cultural understanding.

It should be noted that there is a distinct “culture of the north” as well. This is a culture that respects nature, weather, distance, isolation and community. It’s a culture that breeds resilient, good-humored and strong people. Participants feel that, in other parts of BC, life in the north and the people who live here are not fully appreciated or understood. There is some hope that a distinctively northern approach to cancer care will improve upon a health care system in which northerners have some of the highest rates of cancer in the province, and the worst outcomes.

9. A Northern Cancer Centre

The development of a cancer care centre in Prince George is generally supported throughout the north. Not surprisingly, the level of enthusiasm grows the closer one gets to Prince George.

Participants noted that one obvious benefit of a cancer centre in Prince George would be that it would eliminate or reduce travel for many northern patients, and make it easier for families to support loved ones who must leave home for treatment.

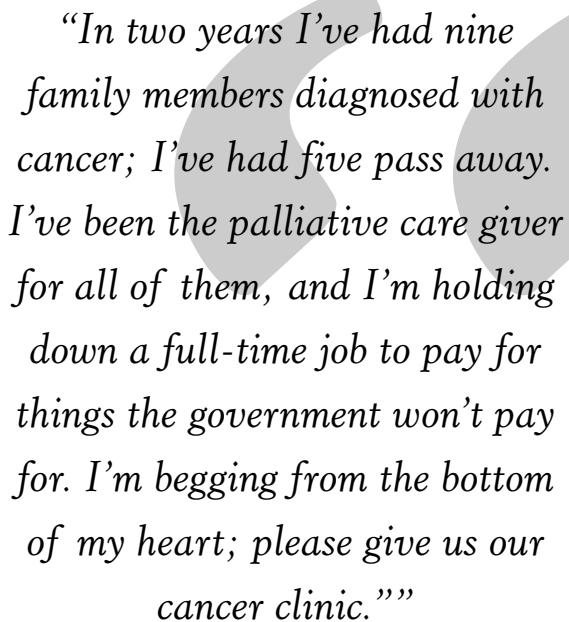
It was recognized that a northern cancer care centre has the potential to benefit many aspects of cancer care in the North (see Recommendation 2).

Participants also raised good questions and made useful comments about challenges that need to be addressed should a cancer centre be built.

Concerns were expressed, in the northwest and northeast areas particularly, that the creation of a cancer centre might draw resources away from outlying communities. People in communities such as Prince Rupert, Masset and Fort Nelson were clear that a centre in Prince George should not detract from local services. As noted above, they were equally intent on ensuring patients and physicians still have the option to choose the most appropriate location for specialized cancer care.

In order to fulfill the increased demands put on it to support a successful cancer centre, participants recognized that Prince George Regional Hospital will need to be given additional resources. Many northerners who have had occasion to go to Prince George for treatment were clear in stating that PGRH is, in their opinions, already inadequate as a regional referral centre, even in the short term.

Residents from throughout the north, including in Prince George, agreed that affordable accommodation attached to or near a centre is critical. To this end, the Canadian Cancer Society has made an offer of support for the construction of such a centre (see Appendix III). There has also been a strong indication of private philanthropic support.



“In two years I’ve had nine family members diagnosed with cancer; I’ve had five pass away. I’ve been the palliative care giver for all of them, and I’m holding down a full-time job to pay for things the government won’t pay for. I’m begging from the bottom of my heart; please give us our cancer clinic.””





Recommendations

Northern British Columbia is a vast area, where the majority of the population lives in small, rural and often isolated communities. It has been said many times before – but bears repeating here – that there is distinctiveness in Northern BC, evident in the people, in the land, in culture, in human spirit, and in living with the difficulties created by distance, weather and geography. This distinctiveness has created historical challenges to the health care system. These consultations show that it continues to be a challenge.

But it also presents us with an opportunity, an opportunity to develop a distinctive approach to the provision of cancer care, an approach that recognizes and affirms those qualities particular to the north, and uses them to its best advantage.

This approach will require a commitment to do things differently, and will require a close partnership between Northern Health, the BC Cancer Agency, the Ministry of Health and the people of Northern BC. Done right, however, it could set a new standard of cancer care in Northern Canada.

Recommendation 1

Develop a unique and fully integrated system of cancer care in Northern BC with a network of care that extends from smaller communities to the largest centre.

Rationale

There is an opportunity at hand for British Columbia to become a leader in the field of northern and rural cancer care. As was the case with the Northern Medical Program, this will take commitment, patience and vision.

A fully integrated system, based on a single, comprehensive plan for cancer care, will provide effective coordination at all levels (local, regional, provincial) and will provide services and supports for a continuum of cancer services in the north.

Guiding principles

Guiding principles for this integrated system include:

- Clearly assigned leadership, with responsibility to create and develop a system of cancer care for the BC Northern and Central Interior that is second to none.
- A system of care in which patients and their families become knowledgeable and engaged partners in their own care.
- Local capacity to support all stages of cancer care as close to a patient's community as possible.

- A focused northern cancer prevention strategy.
- Strong research partnerships between the BC Cancer Agency, the University of Northern BC and Northern Health, focused on the incidence and causes of cancer rates in the north.
- Application of technology to improve access to cancer care and reduce the impact of travel distance and challenges.
- Culturally relevant services for the significant Aboriginal population in the north.
- Community cooperation and a network of care that creatively meets the challenges of serving a widely dispersed population in a vast geography.
- The right of patients to choose the most appropriate cancer centre for their needs.

To develop this integrated system of cancer care, there are a number of improvements that will need to be made to the present system.

Participants in the consultation process provided insight into the system of cancer care from a patient, family and community viewpoint. Some of the strategies described below (or similar ones) are found in the proposed Northern Cancer Control Strategy; some are not. All of them, however, arise directly from input from residents of Northern BC. This is not a long laundry list for improvement. Rather it is a number of critical leverage points that, if addressed, will support the goal of an integrated system.

An essential element of improving cancer care in the north is going to be a framework for leadership. Who will be responsible for leading and managing change in a coordinated and effective manner? A new relationship between the provincial government, the Ministry of Health, Northern Health, the BC Cancer Agency and medical advisory committees may have to emerge as these strategies are addressed.

Strategies to support this recommendation

Prevention and health promotion

Pursue relevant research partnership opportunities between the University of Northern BC, the BC Cancer Agency and Northern Health in order to better understand the causes of cancer in the north and to find northern strategies to reduce cancer rates.

Work with partners (such as the Canadian Cancer Society) to develop a coordinated cancer health promotion campaign in the north with a focus on risk factors and recommended screening tests (breast, prostate, colorectal etc). Coordinate this in and for Northern BC.

Support physicians in providing cancer care

In addition to the broad goal of improving access to physicians across the north, support the capacity of doctors to provide cancer care with a concerted education effort around cancer care. Increase the number of family physicians with additional oncology training (in each region). Physician practice should include:

- recommending and providing cancer screening tests based on known best practice;
- automatically referring patients with cancer to the nurse navigator (where available);
- and,
- automatically referring patients with cancer to the Canadian Cancer Society.

Improve community-based care

There are a number of strategies suggested and informed by this consultation which will help develop an integrated northern approach to the continuum of cancer care. These are:

- expand the capacity of community cancer clinics to address the growth in service required in the coming years, specifically to add more chemotherapy and potential surgical services, and provide linkages between all Northern Health clinical staff to aid information and learning;
- continue to expand the cancer nurse navigator role and ensure physicians are aware of and support it;
- improve outreach services through increasing (and coordinating) the use of visiting cancer care specialists;
- recognize that patients and families are often their own advocates, provide consistent and accurate information on cancer and cancer treatment to every patient (and family) upon diagnosis, consider creating a standard, plain language and culturally-sensitive information package on cancer care for northern residents (paper and electronic);
- implement region-wide standards for obtaining tests, getting test results and communicating results to patients in a timely and sensitive manner and ensure that implementation is monitored in some fashion;
- improve coordination of information and scheduling between local physicians, cancer centre staff and patients;
- expand the capacity of communities to provide quality end of life care; and
- link the improvement in cancer care directly to Northern Health's plans to improve primary care services.

Expand the use of technology

Expand the use of telemedicine technology to reduce travel for patients and to better coordinate timely care, particularly with specialists and family physicians.

Ensure that the development of the Northern Health integrated medical information management system (underway) includes cancer care providers.

Recommendation 2

Create a full-service BC Cancer Agency cancer care centre in Prince George as the foundation for development of the services and expertise required to achieve a fully integrated system of cancer care for Northern BC and the Central Interior of the province.

Rationale

Northern BC has the highest rate of death in the province from all forms of cancer, and cancers are the second leading cause of death among northerners. Rates of some cancers are higher than the provincial average and outcomes after treatment are poorer on average. The number of people expected to get cancer in Northern and Central BC is expected to increase by forty percent in the next ten years, from 1,000 new cases per year now to 1,400 new cases by 2015.

There is substantial support from northerners for a comprehensive northern cancer care centre in Prince George. The consultation team also heard from people in Williams Lake and other areas in the Central Interior, who support this. A Prince George Cancer Centre will attract patients from outside of the Northern Health area (see Appendix II). It is expected that Northern Health would work cooperatively with the Interior Health Authority and the BC Cancer Agency to coordinate this care. This is reflected in this report.

It was acknowledged in every community that, in addition to the obvious benefit of reduced travel for many northerners, a cancer care centre could also be a hub for improved services and would help generate northern solutions to the cancer care needs throughout Northern BC.

It was recognized, through the consultation, that a northern cancer care centre has the potential to:

- enhance the development of health care services in Northern BC and the Central Interior of the province;
- provide health care services in a manner that recognizes and understands the different realities of living in Northern BC and the Central Interior of the province;
- ease the financial burden of accessing care;
- allow for better choices of treatment options, leading to better outcomes for patients;
- provide direct support to community cancer clinics and other staff throughout the north (training, clinical support, building a network, adapting services);
- build on efforts to attract and retain health care professionals in the north;
- become an integral part of the medical research and education sector, particularly through the University of Northern British Columbia; and,
- reduce wait times for diagnosis, treatment and follow up.

Strategies to support this recommendation

In February 2006, the Radiation Therapy Review noted that if certain challenges are addressed, a full-service cancer care centre for Northern BC “is both desirable and feasible.” This consultation process has reaffirmed the findings of the Radiation Therapy Review, and confirms the support of most northern residents for taking the steps needed to proceed to development of a cancer centre in the north.

This includes the associated steps and resources required for Prince George Regional Hospital to have the capacity to support an increased number of cancer patients. It also includes the construction and operation of a cancer lodge for patients needing accommodation that would be built and operated in partnership with the Canadian Cancer Society and other private support. Travel support for those who need financial assistance to access the centre should also be provided.

Most importantly, a northern cancer centre will be expected to support the cancer care services in local communities through the development of innovative models of care delivery, including the use of technology.

The proposed centre must embrace as its primary goal the creation of a fully integrated system of cancer care for Northern BC and the Central Interior of the province based on the principle of providing as many services as possible to patients as close to their homes as possible.

The 1989 BC Cancer Agency Review of Cancer Services in BC recommended that “The Board of Trustees of the Cancer Control Agency, in partnership with the Ministry of Health, recognize the needs for cancer care services in the smaller communities of British Columbia, particularly in terms of the expansion of Cancer Control Agency facilities beyond 2001.”

It is now time to take up this challenge, and to seize this opportunity to demonstrate strong national leadership in northern and rural health care by developing a distinctively northern centre for cancer care that is part of a comprehensive approach to cancer care.

Recommendation 3

Appoint the BC Cancer Agency, under the jurisdiction of the Provincial Health Services Authority and in partnership with Northern Health, as the lead agency for managing improvements to cancer care in the North and Central Interior of BC.

Rationale

An essential element in improving cancer care in the north will be the establishment of a framework for leadership. This will be critical to move forward with the strategies for improving cancer care outlined in Recommendations 1 and 2 in this report, as well as those contained in the Northern Cancer Control Strategy and the Radiation Therapy Review. Clear leadership is required in order to manage complex change in a coordinated, effective and timely manner. The responsibility for leading these changes resides with the Provincial Health Services Authority – through the BC Cancer Agency.

Strategies to support this recommendation

The BC Cancer Agency needs to apply its provincial leadership role to this northern initiative. There is already a good working relationship between the BCCA and Northern Health. A continued joint executive group involving the two organizations requires specific mandated responsibilities and accountabilities. A fully integrated network of care through all communities will require coordinated and shared use of staff and resources. Northern Health is already operating much of that capacity. A well-established and close working relationship between both groups will assure progress on the strategy. The individual performance agreements between the Province and each these organizations should reflect these responsibilities.

Additionally this joint executive group should work in close collaboration with the medical advisory groups of the North, the Canadian Cancer Society, the University of Northern BC and other relevant organizations. Those ongoing and working relationships will help ensure the unique northern aspects of the full strategy will be appreciated and addressed.

Recommendation 4

Develop policy and practical solutions to achieve equitable access to cancer care, by addressing the obstacles to health care access caused by distance and personal financial circumstances.

Rationale

In addition to the lack of availability of adequate cancer care close to home, travel to access those services in other communities was consistently identified as the greatest obstacle to equitable access to care. In fact many stories were told of patients electing surgery (mastectomy, for example) over the burden of traveling for radiation therapy, and even some tragic cases in which patients chose to not take any treatment at all.

People in the northern and Central Interior of BC must travel far away from their homes and communities for specialized cancer care. This creates a financial and emotional burden, and results in a weakening of the principle of equal access to health care. A cancer care centre in Prince George will reduce the distances and time away from home for many northern residents.

Even with a Prince George cancer centre, however, many patients will still need to travel for care and even Prince George remains a long journey for some. Therefore, they should continue to have a choice of treatment locations.

The emotional and psychological burden of travel is made worse for those who don't have the financial resources to pay for airfares, accommodation, meals, medications and other expenses. The Canadian Cancer Society provides limited financial support to those who qualify. Even so, it was clear from these consultations that this support, although appreciated by those who receive it, does little to reduce the inequities in access to services.

When reviewing travel support policies in BC, it would be reasonable to compare them to other northern regions of Canada (such as the Yukon, the Northwest Territories and other regions such as Northern Manitoba) as those living in northern and rural parts of this province have more in common with residents of those regions than with people living in the more densely populated southern parts of BC.



Community Summaries

Burns Lake

The Experience of the Community

Burns Lake, approximately two and a half hours west of Prince George, is a forest-dependant community with a population of approximately 2,700 with a large regional surrounding population, of which a significant portion is First Nations.

Residents in the Burns Lake area receive some of their health services locally but must travel for many others, including specialized cancer care.

While there are promotion and prevention activities, they seem to be sporadic in nature and not always appropriately linked to screening services. There was, however, considerable praise for the mobile mammography unit that comes to the community twice per year and, a sense that the service was being utilized by more and more people. Some patients wondered if twice yearly access was sufficient – particularly in the case of aggressive breast cancer.

Some participants reported that the current system is working well, and that they received timely referrals for diagnostic testing and care. Some residents felt there is inconsistency in the level of knowledge from doctor to doctor with respect to cancer diagnosis and treatment information, and that there was a subsequent lack of continuity of care.

Burns Lake residents reported significant wait times between detection, diagnosis and referral. In addition, while care received in Vancouver or Prince George was often rated as very good, required care and follow up in the community was not always available – particularly in relation to home care nursing.

Support groups and associated support resources are not available to Burns Lake residents experiencing cancer. And patients who must travel long distances to secure cancer treatment often do so without the support and presence of family members.

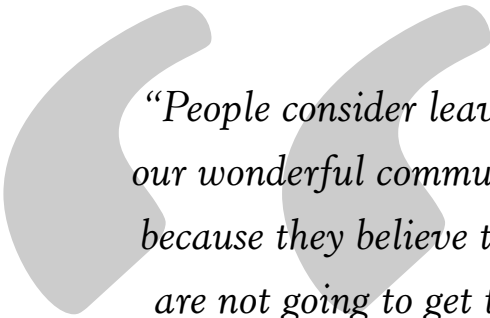
A recurring theme throughout the community consultation process was the level of personal advocacy and fortitude necessary to navigate the cancer care system – especially in the absence of support systems. Many felt there was insufficient support for patients and families across all phases of the cancer care continuum, including end of life care. While there is a hospice room and local hospice organization, not everyone knows about it – particularly because of the high turnover of health care professionals.

Recommendations from the Community

Local services

Burns Lake residents would like to see better integration of cancer care services between all communities in the north. They view it as important to improving local services throughout

the north. There was recognition of the value associated with having local GPs with oncology training. However, there was also an acknowledgment that it may be necessary to consider incentives to attract interest and participation by already overworked doctors.



“People consider leaving our wonderful community because they believe they are not going to get the care they need.”

Coordination and information

A coordinated system of providing useful information, especially upon diagnosis, is desirable.

While a nurse navigator would play an integral role in service integration, Burns Lake residents

would also like to see the establishment of an overall coordinating resource or committee that would work at all points of the cancer care continuum to facilitate improved access to both information and service. For example, travelling prevention and promotion resources that are scheduled to be in one community could perhaps be made available to other communities through this coordinating function.

Support systems

There is a strong desire to improve the spectrum of support services available to cancer patients and their families in Burns Lake. Unlike many other northern communities, there are no cancer support groups in Burns Lake, and Cancer Society presence and service in the community is limited – although the presence of a Cancer Connections volunteer was acknowledged.

Travel

Residents would like cancer care closer to Burns Lake to help alleviate the financial and emotional burdens associated with travel. Transportation for treatment is seen as an obstacle for people in Burns Lake – particularly when costs of being away from home and work, in a community where self-employment continues to be a growing sector, are considered.

Response to the Vision

There was strong support in Burns Lake for the cancer care strategy as presented, with a full-service cancer care clinic in Prince George.

Residents were quick to point out the importance of service integration, not only between communities and a cancer centre but across communities and along the entire cancer care continuum.

Many saw the opportunity for the enhancement of local services and stressed that a clinic must also be integrated with Northern Health to ensure that it can develop its cancer care services throughout the north in a coordinated and supportive manner.

Dawson Creek

The Experience of the Community

Dawson Creek is forty-five minutes from Fort St John and sits near the Alberta border. As such, there are strong ties between the residents of Dawson Creek and Alberta, a relationship reflected in residents' choice of Edmonton and Grand Prairie for specialized cancer care services.

Residents reported overall satisfaction with the level of care in Dawson Creek, noting things have improved in recent years. Local health care staff were described as caring and diligent. Residents did note local physicians appeared reluctant to refer patients early enough in the process, even if they were unable to make a diagnosis themselves.

Surgery that could be received in Dawson Creek was rated highly, as was the ability to receive chemotherapy, home care nursing, and follow-up care back in their home community. There are now two GP oncologists and chemotherapy-trained nurses in Dawson Creek, and an oncologist visits the community every eight weeks.

"I don't know how anybody could do it without support. This is the biggest hearted community in the world."

All of that said, Dawson Creek residents reported widely varying experiences with the cancer care system. Some patients met with delays at every stage of the process, sometimes amounting to months. Others reported quick diagnosis and treatment.



The majority of the delays occurred at the local level, specifically in the detection and diagnosis stages. Once diagnosed and referred to other centres, patients reported rapid and top-notch service. The reasons for the variability of service at the local level are not clear, although there were a number of stories of records going missing, slow diagnosis, misdiagnosis and slow follow-up.

Dawson Creek residents experience "fragmented care." Because cancer patients go to a number of different locations outside of Dawson Creek where the oncologists might not know the local doctors, there is a lack of integration of care.

A unique experience of a number of Dawson Creek patients is that they have experienced more than one diagnosis of cancer, many of them in spite of living healthy lifestyles. This has left them with the belief that, in addition to education on lifestyle causes of cancer, more research and education is needed on chemical and environmental causes.

Almost everyone commented on the lack of travel and accommodation assistance and the subsequent financial burden of cancer care, especially for low- to middle-income earners who can't afford to travel on their own, yet who are not eligible for Cancer Society assistance.

Recommendations from the Community

Local services

Dawson Creek residents are appreciative of the oncology training some of the local doctors and nurses have received. They want to see the level of expertise locally maintained and enhanced.

They would also like to see more frequent visits to the community by specialists. They see this as an less expensive option – financially and emotionally – than constantly sending patients out of the community.

Information, coordination and communication

The breakdown in information sharing – between agencies, and between the health care system and patients – is considered one of the biggest problems in Dawson Creek. They would like to see much more emphasis put on providing reliable, timely information to patients. They also want to see the different professionals within the health care system communicating and working together more effectively.

Choice

Like people in other parts of the north distant from Prince George, people in Dawson Creek want to maintain the right to choose where they receive treatment.

Screening, prevention and promotion

Residents recommended regular screening be available on demand or on a routine basis. A story of throat cancer being detected by the screening done in the dentist's office was used as an example of how incorporating routine screening into other allied services can increase chances of early detection.

Palliative care

Residents would like to see an increase in the amount of palliative care available in Dawson Creek, and a full-fledged hospice somewhere in the Peace River region.

Response to the Vision

Dawson Creek residents predominantly support a northern cancer centre located in Prince

“Every time I drive by that sign in Abbotsford that says they’re getting another cancer clinic, it makes me so angry. They’ve got three, and we’ve got none.”

George, based on the belief it will strengthen cancer care throughout northern BC. An alternative response was that consideration should be given to building on the existing partnerships with Alberta, since that is where a large number of northeastern patients go for treatment.

If a cancer centre were to be built in Prince George, Dawson Creek residents would also like to see the following:

- Peace River communities would need to be true partners in the centre of excellence with equal access to training and resources, and a recognition of their community as a service satellite to the centre;
- increased investment in local services to ensure follow up care is excellent;
- improved travel and accommodation assistance;
- the decision whether to build a centre must be made based on what is best for all northern BC residents, not just on what is best for Prince George, and certainly not on politics.

Fort Nelson

The Experience of the Community

Fort Nelson is a geographically remote community ten hours by road from Prince George. Most cancer care services must be accessed outside the community. As such, living with cancer in Fort Nelson comes with significant personal, financial, emotional and physical challenges.

While individual stories of the cancer journey vary, a common experience for the people of Fort Nelson is the need to take responsibility for all aspects of one's own care, from navigating the cancer care system, to planning travel for care, to financing all related expenses.

Residents report that the level of service to cancer patients locally is deteriorating, that there is a shortage of general practice physicians and that the support system is less effective than it used to be.

Local cancer services include some prevention and awareness activities, extremely limited chemotherapy, and mobile screening mammography. Financial support through the Canadian Cancer Society is limited, and residents report difficulty in accessing it. Hope Air flies patients requiring treatment out of Fort Nelson twice a year, although the service is not well-known. There is a hospice society in town, and home care and the hospital provide good palliative care.

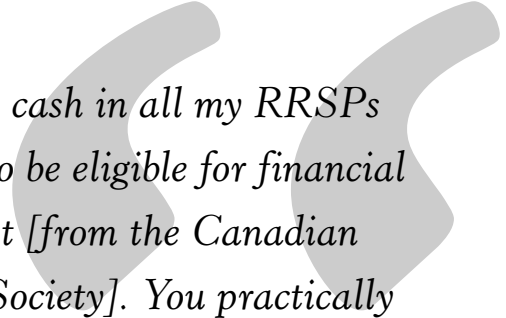
There were significant variations in the speed and quality of care received. While some people received prompt and well-coordinated care immediately following diagnosis, others felt the length of time from diagnosis to treatment was too long, that the process often felt rushed, and that they were not well-informed.

As with other communities in the northeast, Fort Nelson residents generally identify more closely with Alberta than BC. Grand Prairies is three hours closer than Prince George, and the experience of Fort Nelson residents is that access to care is easier in Alberta than in BC. Therefore, most cancer patients seek care in Alberta, although the ability to be close to friends and family is almost always the first consideration in choosing where to get care.

Recommendations from the Community

Local services

The number one priority for Fort Nelson residents – regardless of where they receive primary cancer care services – is to see local services strengthened, including: increased access to screening, chemotherapy, physiotherapy, and cancer support groups. It was recommended that regular visits to the community from a traveling specialist would go a long way to improving local access to cancer care.



I had to cash in all my RRSPs in order to be eligible for financial support [from the Canadian Cancer Society]. You practically had to be destitute to qualify.



Education and training

Improved training opportunities, and the time and financial assistance to allow local service providers to access them, are viewed as extremely important to improving cancer care in Fort Nelson.

Navigation

Residents report receiving little assistance in navigating their way through the often complex and intimidating cancer care system. They recommend training someone (not necessarily a medical professional) who can help people navigate the system.

Information, coordination and communication

Residents report difficulty in finding information to help them through the process.

Communication between local service providers and those at cancer centres needs to be

improved. There was also a specific recommendation that coordination of on-reserve services to First Nations (federally-administered) and off-reserve services be improved.

Financial assistance

The financial burden from loss of employment, travel and accommodation costs increases the further from cancer care centres one is. Fort Nelson residents would like to see increased assistance for remote communities. Increased funding to run local programs is also considered important.

“It’s like you step into a revolving door, and when you’re done you’re shot out into the street. It’s like, ‘Good luck to you.’ That’s what you hear going in, and that’s what you hear going out.”

Prevention and promotion

In addition to increasing education and awareness about cancer, there was a recommendation that more research be done on why the rates of cancer are so high in Fort Nelson.

Response to the Vision

There is qualified support from Fort Nelson residents for a full-service cancer care centre in Prince George. There would need to be a clear demonstration that such a centre would also add to and improve services locally in Fort Nelson for people to support it fully.

It was generally agreed that a northern cancer centre would improve training and networking opportunities for northern professionals, and also strengthen the network of local services.

Fort Nelson residents sounded a strong note of caution, however, that political and financial commitments to a northern centre, if they are made, should not take away from other health care services in the north.

They also want to ensure patients and physicians still have the option to receive treatment at the cancer care facility of their choice.

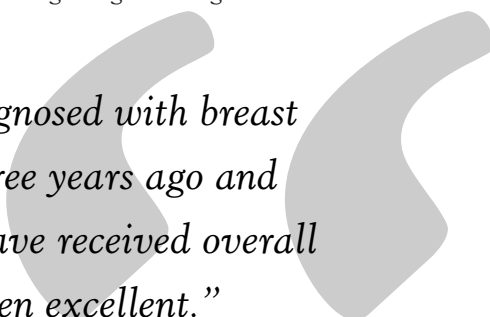
Fort St John

The Experience of the Community

Fort St John's is a regional centre for the northeast of the province. Because it is a great distance from other parts of the province, both geographically and psychologically, and because of its proximity to Alberta, the cancer care experiences of Fort St John residents are unique, and highly variable.

The cancer room at the Fort St John hospital has made a big difference for people to be able to receive chemotherapy in their home community, and patients have nothing but good things to say about the cancer care staff.

A large number of cancer patients still have to travel outside Fort St John for diagnosis and treatment. Stories of spending thousands of dollars on travel, accommodation and other expenses associated with getting treatment are not uncommon.



“I was diagnosed with breast cancer three years ago and the care I have received overall has been excellent.”

Once diagnosed and referred outside Fort St John, people reported good care and appreciate the option to choose the location for their treatment from a number of cancer centres, including Edmonton and Grand Prairie, Alberta.

Local care – initial screening and diagnosis, as well as follow-up care – was also the cause of much frustration. There is a GP-oncologist in Fort St John, but patients indicated a general frustration with the level of knowledge and “bedside manner” of other local doctors.

Many felt that “not being heard” by their family doctors may have increased the length of time it took to obtain a diagnosis. Causes for the delays included symptoms not being recognized as cancer, a lack of access to second opinions, a lack of access to family doctors, delays in accessing specialists, and delays in accessing diagnostic tests.

Communication and coordination between local health care services and those in other centres seems to be where some of the biggest problems occur. Fort St John residents told many stories of unacceptable delays between screening, diagnosis and treatment. A lack of communication between physicians and patients, and between local health care providers and central agencies, appears to be at the heart of the problems.

As a result of communication difficulties, people found they needed to take on the role of an advocate – for themselves and for their family member – which increased the stress of the experience.

Overall, there seemed to be a lack of information available locally. Again, the level of access to information was highly variable, and often dependent on local physicians as gatekeepers of the information.

Recommendations from the Community

Local services

Regardless of whether a cancer centre is built in northern BC, Fort St John residents want to see continued improvement and enhancement of local services, specifically more dedicated space for cancer programs, an increase in palliative care, and expanded therapy space. Other suggestions included:

- a reconsideration of the boundaries for home care nursing support,
- more cancer support groups,
- increased support for transportation, and
- increased redundancy built into the system in the form of equipment, backup staffing and professional support.

Coordination and communication


A “web” of services that not only coordinates services between major cancer centres and regional cancer clinics, but also improves the number and coordination of services in all communities was recommended. A local advocate or nurse navigator is also considered imperative to help better coordinate services.

Information

Fort St John residents want to see a general increase in the amount and availability of information on cancer care at all points on the cancer care continuum, and to all people within the system, including patients, their families and caregivers, and health care professionals.

Education and training

Variability in quality of care led Fort St John residents to recommend local health care providers be given better access to cancer care training, and that they be pushed to pursue greater knowledge.



“There was a fellow from Fort Nelson who came down to Fort St John and he was planning on driving home after having his treatment. He didn’t have the money for a hotel room and he was going to sleep in his truck after chemotherapy.”

Prevention and promotion

Residents want to see an increased emphasis on cancer prevention, education and health promotion, and the importance of early detection.

Response to the Vision

Fort St John residents support the vision for an integrated system of cancer care in the north. They agree that the biggest benefit from a Prince George based cancer centre is that it would strengthen the whole system of care in the north. They were adamant, however, that developing a cancer centre in Prince George must not detract from the investment and development of local services. Building a centre in Prince George must only take place while at the same time developing other services at the local level, much of which could begin now.

Some Fort St John residents saw the benefit of having a centre closer to home, although still a five-hour drive away on treacherous roads. Others suggested the money to develop a northern centre would be better spent expanding services at existing cancer centres and supporting patients in the north to travel to those centres, and to improve local services.

The priority for residents of Fort St John would be improving and enhancing services they receive at home, and better linking them to cancer services elsewhere, wherever they may be.



Hazelton

The Experience of the Community

The Hazeltons are situated along the Yellowhead highway, just inside the majestic Coastal Mountains at the junction of the Skeena and Bulkley rivers. The area has been inhabited for some 10,000 years and is renowned for its natural beauty and cultural heritage.

Wrinch Memorial Hospital and its attached clinic, run by the United Church of Canada, provide health services to more than 7,000 people of both native and non-native descent in the region. The nearest cancer clinic is in Smithers.

“We need nurses who are educated in caring for returning patients. I had to give myself a crash course to help my son. It would really help if there was a cancer nurse in each community to help.”

In Hazelton, there are supports for prevention and reduction of tobacco use, including the NIC program. A visiting mobile mammography service provides support for breast cancer screening. Wrinch Memorial provides some basic surgery services and there is a limited local chemotherapy. There is a Hospice Palliative Care Society in the community.

While there is a strong sense of support (and praise) for the services provided by Wrinch Memorial Hospital and the clinic, there are also concerns about the care available for people at risk of, or suffering from cancer. Home care services are perceived to be inadequate to provide the support needed for a family with someone living with cancer.

As with others in northern BC, area residents must go south for most specialized cancer consultations and treatments. Most patients go to the Cancer Centre in Vancouver, while some may go to Kelowna or Victoria. There is a great appreciation for the caring staff and quality of the cancer lodges in the south and a great hope that a centre in Prince George will also offer this.

In spite of a funeral for a well-known local man being held at the same time as the consultation session, a good number of area residents came out to listen and comment on the future of cancer care in their area. Many concerns were raised and the possibility of a cancer centre being established in Prince George was well-discussed.

Recommendations from the Community

Local services

If cancer services in general are to be improved, residents believe that as many services as possible must be delivered as close as possible to Hazelton. For example, they would like to have better quality home care and a nurse navigator role locally, or at least more accessible to them.

Prevention

Residents would like to see enhanced information on prevention of cancer, as well as increased support for people wanting to change their lifestyle. There was also discussion around the

increased prevalence of cancer, and the suggestion that more needs to be done to investigate environmental causes, rather than focusing only on lifestyle.

Transportation and family support

The cost and hardship of traveling south for cancer appointments and treatments was described as a heavy burden. Even traveling to Prince George will add to the burden for families already dealing with the illness. Hazelton residents consider family support critical to patient well-being. Therefore they recommend improving travel assistance, even if a clinic is in Prince George. A cancer centre in Prince George is supported in part because it would be easier for Hazelton residents to travel to visit relatives receiving cancer treatment.

Recruitment and retention

Hazelton residents expressed concern at the lack of continuity of care as a result of difficulties in keeping a stable population of health care professionals. There is support for the BC Cancer Agency to train a local nurse to provide at least some chemotherapy locally, as well as to provide navigation services.



Response to the Vision

There is reasonably strong support in the Hazelton area for a full service cancer centre to be built in Prince George. It was recognized that such a centre will make it easier for families to support each other and that it is “psychologically closer” to them than the south. Participants agreed such a centre could be a uniquely northern solution for northern residents that could provide care not found anywhere else.

Concerns related to establishing a centre include the difficulty of highway travel at some times during the year and a worry that the costs of this centre might erode local services in some way. It was also stated, then, that for such a centre to be a success, it must enhance services in other communities; it must not take away from local services or divert health care funding from local areas.

There is hope that a cancer centre, with an accompanying lodge, will make the cancer journey less difficult for people from the Hazelton area. There is also hope that it will assist with staff training, be sensitive to northern issues and “speak our language.”

Kitimat

The Experience of the Community



Kitimat is located less than an hour south of Terrace. It is a community proud of both its industrial heritage and access to nature. Like many other northern communities, economic challenges are affecting the population and the range of local services the community receives.

Residents are served by a local hospital, which provides a range of services. There is also relatively ready access to additional health services in Terrace and Prince Rupert (a two-and-a-half

to three-hour drive away). The Hospice Palliative Care Society is active in the community, as are Canadian Cancer Society volunteers. The Northern Health nurse who provides assistance to cancer patients is greatly appreciated.

“Going to Vancouver was a blessing. We went to Ronald McDonald House and were surrounded by other families with kids with cancer. I wouldn’t have wanted to be anywhere else.”

There are some local cancer screening and prevention activities. There is a mammography centre, although it has often not been in operation due to the fact a technician has not always been available to run it. There is stereotactic breast biopsy technology available and access to basic surgery and limited

chemotherapy services. There are also physicians with oncology training practicing in Kitimat.

Like many patients in the northwest, when residents of Kitimat think of travel for specialized cancer care, they think of the north-south corridor and traveling to Vancouver. Some residents described a “two-tier” system, in that some people have the means (or health plan) to travel without great personal cost and others must spend everything they have to access treatment in the south.

There were concerns expressed about the lack of continuity and integration of cancer care. Treatment received at the BC Cancer Centre was widely praised. Screening, diagnosis and follow-up services were described as weak and poorly coordinated.

Some residents related harrowing experiences. For example: waiting months for a diagnosis; missing one out of every four chemotherapy treatments because the drug simply can’t be delivered in time from the lab in Prince Rupert; being ignored by a family physician, and later dealing with advanced breast cancer.

Residents agreed that support services are stronger when they go to a larger centre for treatment; however, being far from family and friends is difficult. Conversely, once home, there are few support mechanisms for patients dealing with the outcomes of treatment, and the feeling of isolation can be extreme, especially, in one case, for the parent of a child with cancer.

Recommendations from the Community

Local services

Whether a cancer care centre is built in the north or not, Kitimat residents would like to see local services for cancer improved. Examples of short-term solutions include ensuring the

mammography equipment is in good condition and that there is staff to operate it. Another example is ensuring prompt delivery – before expiry – of chemotherapy drugs sent from the lab in Prince Rupert to the hospital in Kitimat.

Education and training

Closely linked to the provision of services locally is the level of expertise of the local professional health care staff. Patients find value in having physicians with oncology training and nurses with chemotherapy and navigation training and would like to see incentives or other means to ensure more local people have this training.

Screening, prevention and promotion

Another approach to providing better service locally that was recommended is to have travelling programs, such as screening and health promotion, or specialist visits.

Information, coordination and communication

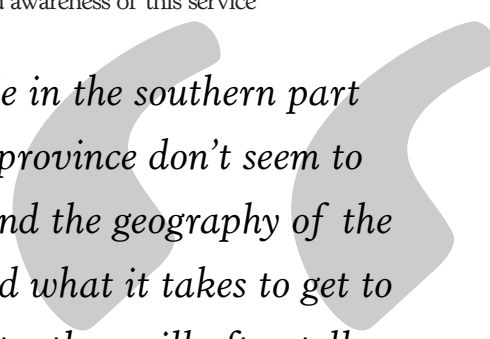
There is a sense in Kitimat that there are gaps in information and communication. There needs to be a coordinated system to provide useful information to patients, especially upon diagnosis. This information needs to be communicated through physician offices, as they are the first line of primary care and often are helping coordinate treatment.

Support systems

The local breast cancer support group is appreciated, while other forms of cancer either don't have support groups or are rare locally (such as children's cancers). The Cancer Connection service is a good source of information and support, although there is not widespread awareness of this service and some physicians don't seem to know about it or refer to it.

Travel assistance

Residents recommended some consideration be given to providing a higher level of travel and accommodation assistance to residents forced to leave their communities for care, regardless of whether a cancer centre is built in Prince George.



“People in the southern part of the province don’t seem to understand the geography of the north and what it takes to get to treatment - they will often tell us to be in Vancouver the next day.”

Response to the Vision

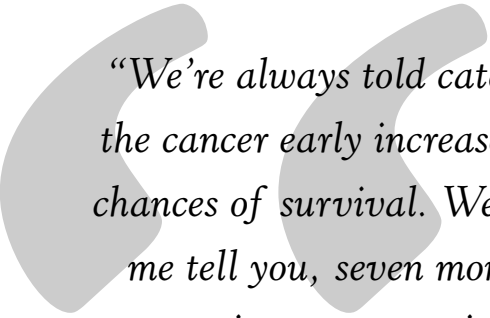
Kitimat residents support the creation of a high quality, full service cancer centre in Prince George on the assumption that it would be a positive development for the entire north. They believe it would offer options for patients, that it may speed up access to care, and that it would make it easier for friends and family to visit and offer support during cancer treatment. They did recommend that such a facility be conceived, developed and promoted as a provincial facility open to all, just as other centres are.

The option to choose where they receive specialized treatment is very important to the people of Kitimat. They sent a strong message that people in the north deserve equal health treatment options as those in larger, urban centres – and that this means there should be a greater level of support for northerners to help them access those services.

Mackenzie

The Experience of the Community

The community of Mackenzie, served by the Mackenzie Hospital, is located two hours north of Prince George at the southern end of Williston Reservoir, created with the construction of the WAC Bennett Dam.



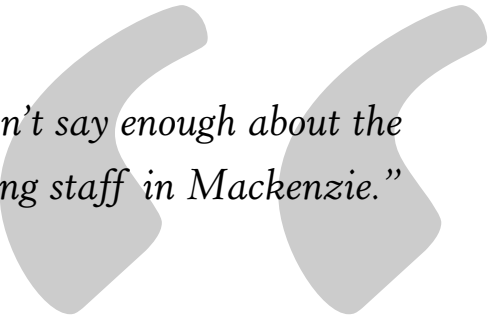
“We’re always told catching the cancer early increases the chances of survival. Well, let me tell you, seven months to receive treatment is just not acceptable.”

Residents reported that there is very little information on health promotion and cancer prevention available. What little there is tends to be incomplete and lacks cohesiveness.

The mobile mammography unit travels to Mackenzie twice per year but some reported that unless an appointment is booked immediately, access is not assured. Beyond mammography there are limited screening options, and residents reported that personal advocacy is often required to gain access to screening tests.

The inability to retain a regular complement of physicians appears to be at the core of many concerns Mackenzie residents have with current cancer care. They report a lack of continuity of care, misdiagnosis, non-diagnosis, delays between screening, diagnosis and treatment, and lack of follow-up care. A long term battle with cancer means having to inform each new doctor of the circumstance, and although the local doctors give the best care they can, they may not be familiar with the system or the specialists they must work with in other communities. This results in an extremely long period of time between screening, detection and diagnosis – months in the experience of many of the participants.

Travel and the associated financial and emotional burden for those dealing with cancer is also of concern for Mackenzie residents. Many patients are away from family for long stretches of time as they receive specialized cancer services in Vancouver and often find that a return to Mackenzie is problematic given winter travel and the lack of available beds at the local hospital.



“I can’t say enough about the nursing staff in Mackenzie.”

For caregivers and patients alike, there is limited support and information. There was much praise for palliative care at the Mackenzie hospital; doctors and nurses are considered very helpful and caring. However, limited numbers of staff means that family members are often depended upon to provide many services.

Recommendations from the Community

Local Services

Whether a cancer care centre is built in the north or not, Mackenzie residents would like to see effort put into stabilizing health care services in their community. Examples of solutions that

need to be found in the short term include ensuring there is a consistent complement of local physicians, GPs with oncology training, and an enhancement of chemotherapy options at the local hospital.

Training

Mackenzie residents suggested the province should consider offering incentives to physicians to take on oncology training as well as regular medical training and that doctors need to be supported in their training, perhaps by making it easier to take training close to home.

Information, communication and coordination

Gaps in information and communication were noted – beginning from the prevention and screening end of the continuum, right through to support after treatment. Mackenzie residents, therefore, want to see a better coordinated system of providing useful information to patients, especially upon diagnosis. This information needs to be communicated through physician offices. Many people spoke of a lack of coordination that resulted in their arriving in Vancouver and learning that a designated appointment or treatment had been cancelled or rescheduled without their knowledge.

“If I was still living in Vancouver and hadn’t moved to Mackenzie, my wife would still be alive today, and that’s a fact.”

Travel and financial assistance

Mackenzie residents recommended the implementation of a transportation system to support low-income families, or those without the support of family and friends. And special mention was made of the need to locate as many cancer care services as possible close to home in order to decrease the financial and emotional stress that accompanies repeated trips to either Vancouver or Prince George.

Response to the Vision

Mackenzie residents fully support a northern cancer centre in Prince George, and conveyed a sense of urgency in their desire to see one built. Additionally, however, they would also like to see some effort put into stabilizing health care services in their community, beginning immediately.



McBride

The Experience of the Community

Cancer care in the experience of residents of McBride, a community of about 900 at the western end of the Robson Valley, was generally described as good, although there were some concerns about the level of service available and coordination of care.

“I’ve been sent to Prince George twice for tests. The last set of tests, I haven’t even got the results yet. And that was in December. I don’t know where they are.”

Residents said local health care providers respond to patient concerns with quick follow up, and referrals to diagnostics and treatment in Prince George or Vancouver. One patient who has had three experiences with cancer said the care has improved greatly since her first diagnosis twenty-five years ago.

The two-and-a-half hour drive to Prince George can be dangerous, especially in the winter. But

most people are used to it, and therefore don’t see it as a major obstacle to receiving treatment.

However, with no airport, residents of McBride must drive to Prince George in order to get to Vancouver or Kelowna for radiation therapy. One patient described choosing to have a mastectomy instead of taking on the burden of travel for radiation treatment.

People felt that follow up care in McBride was good and having family to support you during treatment was very helpful. However, there was some concern that the cancer-specific knowledge of local health care providers may not be sufficient.

Integration of services and communication between medical professionals was seen as a weakness, and McBride residents expressed the sense that doctors in Prince George don’t always seem to be willing to make the time to meet with patients from outlying communities.

With a high percentage of McBride residents working shift work or in the bush, many people can’t take advantage of health care services, which are generally offered only on weekdays.

Prevention programs have not been as well promoted in the community as they used to be. They used to be provided through regular health fairs that were organized by the community.

Palliative care services were described as good, if limited, in McBride. A palliative care room is being developed at the local hospital.

Recommendations from the Community

Local services

McBride residents would like to see enhancements to local treatment and support options, including expanded diagnostic services and trained staff to undertake diagnosis.

Screening, prevention and promotion

Although there is now a wellness clinic in McBride which is involved in health promotion and



awareness, it was described as having become “routine.” McBride residents would like to see more public awareness and promotion done through avenues such as open houses, lectures and public screening sessions, preferably when more residents can access them.

Coordination and communication

There was a recommendation that integration of services between larger centres and outlying communities, as well as between doctors and other health care providers throughout the system be improved. Effort is especially needed to foster more teamwork among health care professionals – teamwork that looks after patient care needs first.

A specific request was made to improve the process of discharge planning back to home communities. The unique needs of rural residents need to be recognized by the health care professionals. For example, people in rural areas may not have basic necessities such as electricity and running water; people may have large distances to travel with no support to get there; or they may not even have the option of receiving home support.

Response to the Vision

Overall the citizens of McBride thought the integrated nature of the vision that took into account the need to improve cancer care services throughout the north was appealing.

There was unanimous support for the vision and specifically for the development of a full service cancer centre in Prince George. Benefits of such a facility identified by McBride residents included reduced referral wait times, improved accessibility and improved communication. An attached accommodation option was also supported.

They did want to make sure a northern cancer centre would create opportunities for local physicians to receive training in diagnosis and detection and that it would also be a resource for local communities to bring visiting specialists in for consultations. They said a northern centre must not take resources away from other communities, nor should it draw resources from the other cancer centres in BC.

There was also a recommendation that, in an area where there are different cultures (e.g. First Nations and non-First Nations) those cultural differences must be acknowledged and accommodated – people’s individual needs and wants must be able to be met.



Prince George

The Experience of the Community

Prince George is the largest city in Northern BC and has the highest concentration of specialized health services. In terms of cancer care, there are a range of services, some of these include:

- Prevention – tobacco reduction programs.
- Screening – a permanent mammography centre.
- Detection and diagnosis – stereotactic breast biopsy technology available.
- Treatment, care and rehabilitation – a full range of surgery is available (except thoracic and neurosurgery); family practice oncology network physicians are available; a full time oncologist and a community cancer clinic (which includes chemotherapy support); the Canadian Cancer Society regional office is in Prince George.
- Palliative and end of life care: an in-patient hospice unit, hospice palliative care society, palliative care coordinator.

In spite of this array of services, there are significant strains on the system in Prince George, as elsewhere, including a shortage of family doctors. Prince George residents must leave the area for specialized cancer consultations and treatment. Most go by vehicle or by air to the cancer centres in Vancouver, Kelowna, and sometimes Victoria. The most frequent drawbacks noted in care are the cost and stress (and indeed ill-health) that result from long-distance travel.

Some elements of cancer care received significant praise, including the work done by the lone oncologist in the city (Dr. Winston Bishop). The chemotherapy service in Prince George is

perceived as overworked, yet extremely supportive. As well, the perception of treatment and support at any of the BC Cancer Agency centres is that it is compassionate, caring and of a very high quality. The same appreciation is expressed for the quality of support received at cancer lodges.

Closer to home, there are variations in the speed and quality of care received. A great deal of concern was expressed around support for regular screening, the slowness in attaining diagnostic appointments, and, in some cases, very poor communications and delays in obtaining the results.

Prince George residents also noted frequent breakdowns in communication between the different parts of the system, and a lack of consistency in care.

“Once diagnosed and referred to the BC Cancer Agency in Vancouver, the level of care I received was excellent and timely. A plan was immediately put in place and my treatment was started in a matter of weeks.”

Recommendations from the Community

A cancer centre

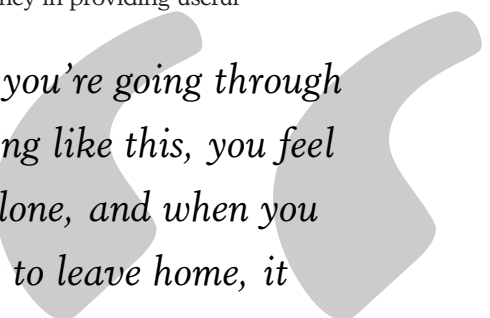
The priority for Prince George residents is certainly the establishment of a cancer centre, with radiation therapy, in their city.

Diagnostics

According to Prince George residents, the whole continuum of care around diagnostic services needs to be improved, from reducing the waiting time for diagnostic and specialist appointments to eliminating delays (and sometimes miscommunication) of test results.

Information and coordination

Once a diagnosis is made, there appears to be a need for more consistency in providing useful information to patients. For some patients there is also a need for the follow up to be better coordinated. Residents believe that information management must be improved so that there are less delays or botched communications.



“When you’re going through something like this, you feel very alone, and when you have to leave home, it makes it even worse.”

Travel and financial assistance

Improving the financial support available for travel costs incurred by cancer patients in the north is considered a priority by Prince George residents. Costs associated with treatment include travel, accommodation, extraordinary medications and lost income. Cancer patients who travel south pay for these themselves (unless they have a supportive benefits package). While the Canadian Cancer Society provides limited support for those who qualify, almost all patients experience some degree of hardship.

Support systems

Residents of Prince George believe that a cancer centre will alleviate most of this stress associated with leaving home for treatment, at least for residents of their immediate area. Other recommendations for reducing stress include better communications, increased use of technology for medical consultations, more specialist recruitment, and increasing the level of local services.

Local services

While there were some positive stories about care received locally, there were also a number of concerns. It was recommended that physicians commit to more routine screening tests, and offer higher levels of compassion to patients. Improved communication and coordination between local physicians, southern cancer centres, and the Canadian Cancer Society was also recommended.

The sole oncologist currently in Prince George is greatly appreciated, but more specialists are urgently required. Prince George residents would also like to see the number of local physicians with oncology training increased.

Prevention and promotion


In addition to programs for reducing the use of tobacco products, recommendations were made to further study the causes of cancer in the north, including research into air quality in Prince George. While personal choices account for some cancer risk, residents pointed out that environmental factors also play a role. While there is information available on self-screening for cancer, it is felt that this should be promoted better, as well as general promotion of the work of and by the Canadian Cancer Society.

Response to the Vision

It's not surprising that Prince George residents strongly support the development of a cancer centre in their city. It is clear that they expect it to be of equal or better quality to the centres they now travel to. They share the concern that recruitment of specialized staff will be a challenge, and they recognize that to be successful it must support and enhance cancer care services across the north.

Concern was expressed that Prince George Regional Hospital must receive the upgrades and budget increases it would need to support a cancer centre. It was also suggested that a cancer centre in Prince George would enhance other sectors of the community as well, including economic, educational and social.

Residents of Prince George expressed understanding of the challenges that remain for residents of other parts of northern BC who will still have the hardship of travelling for specialized care. There was enthusiastic support for doing whatever it takes to make it attractive to other residents of the north – including building a high quality cancer lodge and providing community support in any other ways that might ease the burden (from volunteers to free parking, for instance).



“We used to all sit around in the evenings at the lodge in Vancouver, and the one thing we all agreed was we never want to have to come back here again. And that’s the dream of a Prince George cancer centre – so that we never have to go there again.”



Prince Rupert

The Experience of the Community

Prince Rupert, located at the far western point of the Yellowhead Highway, is a resilient community that has been hit hard by economic and social challenges over the years. It is the health care centre for many smaller surrounding communities, including a significant number of First Nations communities, as well as for many residents of the Queen Charlotte Islands/Haida Gwaii.

Cancer care services available in Prince Rupert include tobacco prevention, a permanent mammography unit (although it is not always operational), stereotactic breast biopsy technology, and some specialty cancer surgery.

There is also a community cancer clinic providing chemotherapy and other support. This clinic and its staff are obviously highly regarded and valued by patients. The nurse navigator role is greatly appreciated and is the single link to all information on cancer at this time. Unfortunately, a large number of physicians don't seem to refer patients to this service.

Local Canadian Cancer Society volunteers provide information, some financial support and links to support through Cancer Connections. Local awareness of Cancer Society services is not great, however.

While there are some positive stories about quick diagnosis and effective treatment, there was a strong message that information is hard to come by, whether this is information on preventing cancer and obtaining early screening or information for a person who has a cancer diagnosis.

*“The cancer care I received
was both horrific and fantastic
at the same time.”*

With the exception of some shared services with Terrace, residents must travel long distances for specialized care. There is currently no direct airline service from Prince Rupert to Prince George.

Some residents spend thousands of dollars and many weeks to receive cancer treatment in the Lower Mainland, which naturally comes with the added emotional burden of being away from family and community supports. Prince Rupert residents report excellent care once they reach cancer treatment centres in Vancouver or Victoria.

Recommendations from the Community Choice

It is clear that, in terms of specialized health care, area residents think in terms of the north-south corridor to Vancouver, not the east-west corridor to Prince George, and they do not consider Prince George the centre of northern BC. The number one message from Prince Rupert

residents was that they will continue to demand the right to choose where they receive specialized services.

“I have seen so many people who, rather than deprive their children, they wouldn’t take the care they needed because they couldn’t afford to travel to get it, and they died because of it.”

Travel and financial assistance

If Prince George were to be considered a preferred treatment location for some patients, it was recommended that train travel for patients be supported, and that reasonably-priced flights be made available. The road is considered a poor option, especially in bad conditions. Increased financial support for travel was recommended as

something that should be offered immediately, regardless of the result of these consultations.

Local services

While most residents recognize it is not feasible to have a full service cancer centre in the north-west, they would like to see creative use and enhancement of existing services. For example:

- greater intercultural education and outreach to help First Nations in accessing cancer care,
- more family physicians taking oncology training, as well as visits from oncology specialists,
- more cancer care training for all health care providers,
- increased use of telehealth.

Information

Residents said better information on cancer should be made available, perhaps in the form of a checklist to explain what to expect of the cancer journey and to link patients to the resources that exist.

Coordination and communication

Currently there appears to be a lack of coordination of the different parts of the health care system (between health care providers, between north and south, at different stages of the process). It was recommended that the nurse navigator role be enhanced and that doctors be urged to make use of it in the interests of patients.

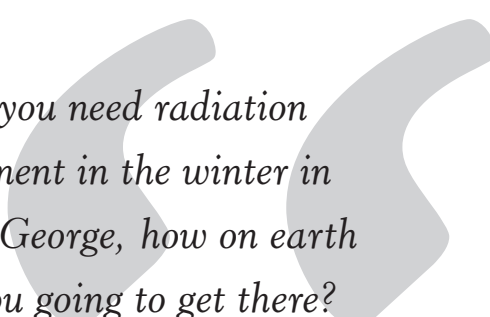
Screening, detection and diagnosis

Residents recommended putting more resources in place to be sure every physician knows which cancer screenings to recommend for patients and how to complete them in a timely manner. It was also recommended that special attention be paid to ensuring First Nations residents in the area receive the same level of early screening and diagnosis.

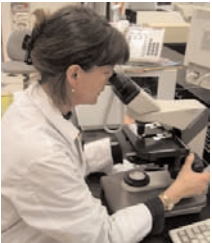
Response to the Vision

Prince Rupert is a great distance from Prince George and residents express some doubts about the value of a full service cancer centre in that location being of any benefit to them.

Those doubts include a concern that they (and their physicians) will lose the choice of traveling to Vancouver or Victoria for cancer care (which many would prefer) and that creating a centre in Prince George will reduce the availability of services in smaller communities such as Prince Rupert. According to Prince Rupert residents, cancer care needs to be improved by first supporting and improving local services – from promotion and screening through to access for specialized services – and it's only in this context that a cancer care centre in Prince George will be successful.



“If you need radiation treatment in the winter in Prince George, how on earth are you going to get there? The roads are so bad.”



Some residents do support having the option of a cancer centre in Prince George, but there is a strong feeling that if a cancer care centre is developed in the north, it must enhance and increase local services – not take away from them.

There must be the same high quality of care provided by the BC Cancer Agency as it provides elsewhere and there should be supporting services in place such as information, transportation, accommodation, financial and increased navigation assistance. If a northern centre is established, its oncologists should be willing to travel to other communities.

Queen Charlotte Islands/ Haida Gwaii

The Experience of the Community

Residents of the Queen Charlotte Islands, also known as Haida Gwaii, braved an early spring snowstorm to attend consultation meetings in the communities of Masset and Queen Charlotte Village, and to describe their experiences with the cancer care system.

“The waiting time between diagnosis and treatment was very emotional – my friend who had had cancer was really important to me in helping me through my experience.”

The geographic isolation of the islands is the first and most obvious challenge for residents. Health care services in general are basic on the islands. And transportation off the islands is limited to air travel and ferry travel. The recent sinking of the Queen of the North ferry has served as a reminder of the fragility of the transportation links on which islanders depend.

In spite of the difficulties, people spoke proudly of the excellent care they receive from many of their health providers, the willingness of physicians to

provide house visits, and the compassionate end-of-life care their loved ones have received.

They also expressed appreciation for the services that are available, however limited in scope. Specific services mentioned included the mobile screening mammography program, the breast cancer support group on island, the fact that about one-third of the chemotherapy needed can be provided on-island, and the excellent palliative and end-of-life care.

There was much discussion about the extraordinary distances that must be traveled, the length of time away from home and the expense individuals and families incur to receive diagnosis, treatment and follow-up care off-island, whether in Prince Rupert or Vancouver. Courses of treatment often require multiple trips. And travel has become more expensive since Air Canada discontinued its travel assistance program. The challenge of coordinating appointments with accommodations and transportation is also difficult.

Recommendations from the Community

Local services

Above all else, Haida Gwaii residents want to see local cancer care services enhanced. Specific suggestions included:

- find a way to increase the amount of chemotherapy that could be done on-island;
- support local health professionals to enhance clinical skills;
- improve access to technology; and
- bring specialists on-island on an outreach basis.

Each of these tactics was seen as a way to reduce the amount of travel involved in the average patient's course of treatment.

Travel and financial assistance

In cases where it isn't feasible to offer cancer care services locally, residents said the next best thing would be a better system of financial assistance for travel, and more information about the financial assistance that is available. The efforts of Northern Health to improve travel options was acknowledged and praised.

A specific recommendation was also made that the ferry design be reconsidered with patients in mind. For example, there is presently only one wheelchair-accessible cabin on the ferry.

“I would be apprehensive of the islands being marginalized if the centre goes to PG and QCI continues to receive services from Vancouver.”



Prevention, promotion and screening

Residents of Haida Gwaii recommended more be done to increase awareness of cancer. It was recommended that better and earlier screening be done to reduce the number of cases of cancer, especially when there is a family history.

Physician recruitment and retention

The difficulty in retaining full-time health care staff on the islands has created a lack of continuity of care. Residents felt that more could be done to improve programs to recruit and retain physicians, and to offer additional training in screening diagnosis and other oncological services.

Information, coordination and communication

There were a number of specific suggestions from Haida Gwaii residents on how to make improvements to the quality and availability of information to help cancer patients through their journey:

- a video showing what treatment involves,
- a central location for where information on cancer can be found,
- speaking visits from experts in cancer care,
- a meeting place at the Vancouver Cancer Centre where northerners could meet and network.

Response to the Vision

The response of Queen Charlotte Islands/Haida Gwaii residents to a northern cancer centre was neutral. Although they could see the potential for it to benefit the whole north, they likely wouldn't make use of it, as transportation to Vancouver would still be an easier option than traveling to Prince George.

Residents did acknowledge that people may become more comfortable with the idea of Prince George as an option for treatment, especially as more young people attend UNBC. They also saw the potential for a Prince George centre to take some of the pressure off other cancer centres in the province.

The elements of the vision of which they were very supportive were enhanced travel support, the opportunity to improve chemotherapy locally, and the opportunity to access more screening services in Prince Rupert.

Quesnel

The Experience of the Community

Experience with the cancer care system has been mixed at best in Quesnel. While some people described excellent care, many shared stories that pointed to a number of areas in need of improvement.

A number of residents shared stories of being refused screening tests, even after having had cancer once before. Detection and diagnosis was also described as being hit and miss, with many stories of delays in receiving test results and other information critical to making a timely and accurate diagnosis.

Some of the problems in the early stages of the cancer journey were attributed to the attitude of physicians, poor communication between parts of the system, delays in follow-up tests, and in some cases a lack of support staff. Residents emphasized that it would have helped to have a person in an advocacy role for patients and families.

There appears to be a fairly good number of surgeries done in Quesnel, thus offering residents the opportunity to receive treatment in their home community. People receiving surgery in Quesnel said the time between diagnosis and surgery was generally quick, although there were some examples of surgery being delayed because of bed pressures.

Residents reported excellent care in Vancouver and Kelowna, and having a choice about where to go for treatment was viewed positively. And while there were some communications challenges between Kelowna and Quesnel, local follow-up care was also considered caring and compassionate. Having access to affordable and well located accommodations (e.g. a cancer lodge) was considered essential.

“My road to diagnosis was filled with frustration, and I work in the system. I know enough to be my own advocate, but can’t imagine what it’s like for people who don’t know their way around.”

according to some participants, as is the working relationship between Quesnel and Prince George. There was also one story of a successful experience accessing naturopathy services to detect and treat a cancer.

Going away for care is hard on patients and families, from both a support system perspective and from a financial perspective. There were indications that many people decide not to get certain treatments because of the distances they have to travel, because of feeling intimidated in a big city, and because of the financial and emotional burden. Financial support from the Canadian Cancer Society was described as “too little too late.”

The integration of services appears to be getting better since the formation of Northern Health,



Recommendations from the Community

Education and training

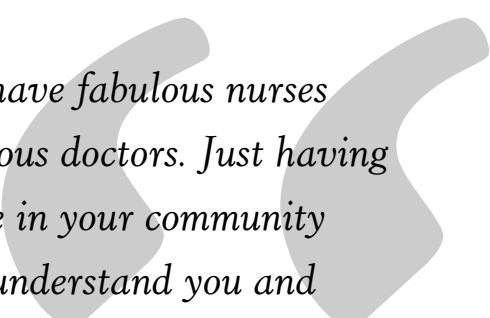
Quesnel residents would like to see health care providers better trained in all aspects of the cancer continuum, as well as having at least three GP oncologists (currently there are none in Quesnel). They would also like to see physicians receive training in how to treat patients with compassion and respect.

Advocacy and information

Quesnel residents would like to see better information and support for patients to help them advocate for their own needs as they navigate the cancer journey.

Screening, detection and diagnosis

Specific suggestions for improving the lag time between screening/detection and diagnosis include: improving access to scans, ensuring lack of support staff and infrastructure do not contribute to the delay, and maintaining a good flow of patient information between providers.



“We have fabulous nurses and fabulous doctors. Just having people in your community who understand you and who understand the community is a big help.”

Prevention and promotion

Quesnel residents want northerners to have access to the same consumer-friendly information as the rest of the province.

Local services

Participants want a full-time chemotherapy nurse in the community (with ongoing education and funding). There were also indications that better working relationships need to be developed between local caregivers and administrators, and outside specialists in order to build a trusting working relationship. In addition to staff, a dedicated and appropriate treatment area was also recommended.

Palliative care

Currently there are no hospice palliative beds in Quesnel. In addition to a hospice, access to a palliative team that is knowledgeable in pain and symptom control and management is seen as a real need.

Travel assistance

Quesnel residents want to see financial support and transportation assistance improved immediately whether or not a cancer centre is built.

Response to the Vision

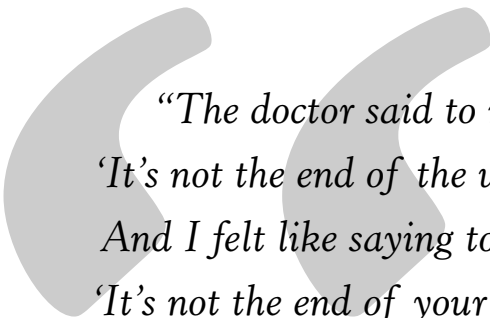
Because it is just over an hour south of Prince George, Quesnel residents are used to accessing health care services in Prince George, and therefore they fully support the vision, including a cancer centre in Prince George, as being a benefit to the whole north.

They believe a northern cancer centre would create opportunities for local physicians to receive training, and they believe a Prince George-based staff would understand the network of services available in each community, and therefore be better able to support patients returning to their home community.

At the same time, Quesnel residents wanted assurances that it would be a centre of choice for northerners, that it would be a fully integrated BC Cancer Agency system, that a nurse navigator role would be created for Quesnel, that the capacity at PGRH and in Quesnel would be increased to handle the additional work, and that access to programs and diagnostic services would improve.

The primary concerns about the vision were whether or not Prince George's recruitment of specialists would negatively impact Quesnel's recruitment efforts, and the amount of time it will take to see the vision fulfilled.

Two additional suggestions were offered: (1) that the Williams Lake and south area should be canvassed to see if they support the vision and a cancer centre in Prince George; and, (2) that BCCA, the University of Northern BC and the College of New Caledonia work to improve training opportunities for physicians and nurse in cancer care, as well as provide programs for the support staff needed to sustain the vision.



*“The doctor said to me,
‘It’s not the end of the world.’
And I felt like saying to him,
‘It’s not the end of your world;
it is the end of mine.’”*

Smithers

The Experience of the Community

Residents in the Smithers area receive some of their cancer care locally at the highly regarded and much appreciated cancer centre in the hospital, as well as from local physicians, including a GP oncologist and chemotherapy nurse/navigator. The cancer care centre services the immediate region around Smithers as far as the Hazeltons in the west and Houston and Burns Lake in the east.

Cancer centre staff are active in health promotion in the community, including offering a tobacco reduction program, and have initiated a colorectal screening program. The mobile mammography service stops in Smithers. Some specialty surgery is available in Smithers, with local services enhanced by visiting specialists.

There is a Hospice Palliative Care Society active in end of life care. The Canadian Cancer Society provides education, some travel assistance and peer support through the Cancer Connections program.

Specialized treatment requires travel, usually to Vancouver. Residents described the emotional and financial challenges in having to travel such a great distance. While Prince George is a much shorter drive than Vancouver or Kelowna, there is a natural tendency to look south for specialized cancer care (and to fly when possible).

Many residents expressed frustration at the fact that so much of the cancer care discussion focuses on diagnosis and treatment. They felt that more attention should be paid to understanding and addressing the causes of cancer. These include personal risk factors, such as tobacco use, nutrition and activity levels, but also the often overlooked environmental causes of cancer – water and air quality for example.

There is a significant component of the Smithers population interested and experienced in integrated cancer care – a system of care that includes a range of health practices, from massage therapy and nutritional counselling to non-traditional complementary health approaches. There is great interest in building upon this in any future cancer care that is offered.

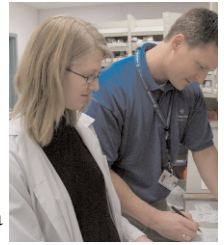
Recommendations from the Community

Prevention

There was concern expressed that cancer prevention activities are too often limited to lifestyle factors such as smoking at the expense of more far-reaching environmental causes. Many participants spoke to the need for more emphasis on research into the underlying environmental causes of cancer, and subsequent public policy decisions to address them.

Local services

Concern was expressed that, with an expected growth in cancer diagnoses, the local cancer clinic will become overwhelmed if it is not offered increased resources. It was also recommended



“We need to expand our view of cancer care. We can add so much more than just a cancer clinic in PG.”

that if a cancer centre is built in Prince George, it must help improve the local clinic, not take away from it.

Residents from Houston expressed a specific concern about developing palliative care services in their community.

Screening and diagnosis

In terms of health promotion and screening to detect risk of disease, residents felt physicians could play a more effective role and provide better information.

Communication and coordination

There was a sense that physicians do not all seem to have the same level of knowledge about cancer and that there isn't a consistent approach to communication within the health care system. Residents also want to see stronger links between physicians' offices and the Canadian Cancer Society.

Choice and integrated services

Smithers was unique among northern communities in these consultations in the amount of support for integration of non-traditional health care approaches with the present traditional medical model. Some local practitioners, including a GP with oncology training, are trained in integrative approaches and have seen great benefits. There was a strong recommendation that patients be allowed the choice and encouraged to pursue non-traditional health care approaches as a complement to traditional approaches.

Travel and support

Financial support for northerners to receive approved treatments for cancer is clearly a priority for Smithers residents. While the Canadian Cancer Society travel assistance program is appreciated for what it is able to do, it is perceived to be inadequate in addressing the need for equitable assistance.

Technology

Increased use of telehealth was suggested as way to reduce travel and take advantage of emerging technology.

Response to the Vision

Reaction from Smithers residents to establishing a cancer care centre in Prince George is mixed. Some people felt the money and resources needed to build a cancer centre might be better spent on research and prevention of environmental and societal causes of cancer, while at the same time subsidizing travel costs for residents to continue heading south for specialized treatment. Others, particularly those who have experienced cancer care first-hand, are more supportive of a cancer centre in the north and indeed, some feel it is long overdue.

Regardless of their position, people in Smithers want to be sure that local services in Smithers are further enhanced; that any centre built by the Cancer Agency is not inferior to those in the south; that there is confidence specialized staff will be able to be recruited; and that there must be accommodation in Prince George for patients and families. There was also a recommendation that the patient must retain the choice of location for treatment.



Terrace

The Experience of the Community

Like Fort St John in the northeast, Terrace is a regional centre in the northwest of the province, especially for the large rural and First Nations population. And like Prince Rupert, it feels a general disconnection from other parts of northern BC. It is six hours from Prince George, and a fifteen-hour drive from Vancouver.

The local cancer clinic provides information, navigation support and some chemotherapy services. In addition, residents have access to some prevention and promotion programs, a permanent mammography unit and some specialty surgeries. There are a Hospice Palliative Care Society and active Canadian Cancer Society volunteers in Terrace.

Experiences in cancer care in Terrace vary from excellent to catastrophic. Some residents reported early detection, quick diagnosis and effective, well-coordinated treatment. Others told heart wrenching stories of delays and a lack of information in each of those stages (including, in one case, being incorrectly diagnosed and treated for non-existent cancer).

There is pride in local health care services, including the cancer treatment clinic, although there is a sense that services have been weakened in recent years.

Residents have concerns about the lack of good information and coordination of care once a diagnosis is made. There does not seem to be a coherent practice for this at all – from the doctor's office on.

Locally, developing expertise and a proposed “centre of excellence” for breast cancer is supported throughout the northwest and is a model of cooperation that will provide better care in the area. A local GP, with oncology training, is providing leadership in improving local services and in working to a vision of a more integrated system of cancer care.

People in Terrace travel south for specialized cancer consultations and treatment, usually to Vancouver. They are quick to praise the quality of care they receive through the BC Cancer Agency and the support they receive from the lodge, but do feel there is a disconnect between their care in the south and services in Terrace. There is also a sense that most care providers in Vancouver don't have a clue about the distances and geography in the north, let alone the obstacles to treatment.

“I have a doctor here in Terrace who, since I started going to him in 1979, has never done a single breast exam on me – even when I’ve had an oncologist put it in writing that I needed one.”

Recommendations from the Community

Local services

Residents of Terrace want to see the direction of cancer care in the north move to a seamless and integrated system – including local services. They want their cancer services to be

enhanced, so that as much as possible, diagnostic and treatment services are available locally. This includes the need for more local physicians to receive oncology training, the need for navigation services to be expanded and the need for better information. Telehealth must be implemented and supported across the north and is seen to be a uniquely suitable solution for such a large area with dispersed communities.

Information

Residents in Terrace feel that good information, provided early on, is critical not only to make treatment choices, but also to address the emotional distress and isolation a cancer patient experiences. Good information on screening, widely promoted through the community, would also reduce the impact of cancer.

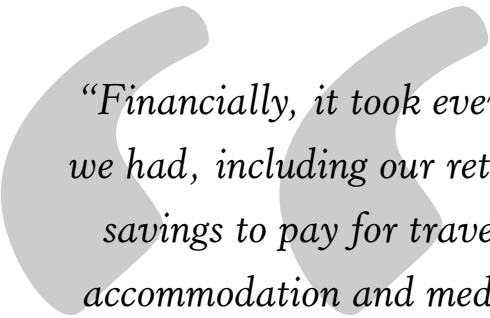
Communication and coordination

Coordination of services will be improved by providing useful information, and by better communication between the cancer centre staff, the local GP and the patient. Some residents feel they are left on their own to sort through the choices and to search for information that should be automatically provided to them.

Screening and diagnosis

Terrace residents often experience long delays between screening, detection and diagnosis. (For example, one breast cancer patient had her diagnosis and surgery – in Calgary – all before her mammogram appointment could be scheduled in Terrace.)

Teleconferencing, better information systems, tracking of test data and better coordination by physicians were all recommended as areas for improvement.



“Financially, it took everything we had, including our retirement savings to pay for travel and accommodation and medicine.”

Financial assistance

As in other communities in the north, residents of Terrace face expensive travel and long periods away from home and community when they require specialized cancer care. They face this with dignity and

strength, but it is difficult to cope both emotionally and financially with these challenges. They, like others, recommend greater financial support during the cancer care journey.

Response to the Vision

Terrace residents are generally supportive of a cancer centre in Prince George, mainly based on the benefits they see to cancer care throughout the north, including the ability to recruit, train and retain professionals and technicians.

However, they are adamant that patient choice over treatment options (and locations) must be maintained and that a cancer centre must be part of improving cancer care across the region. Many people would still prefer to receive cancer care in Vancouver than in Prince George.

The bottom line for Terrace residents is that they want cancer services to improve in northern BC and want that to be through a seamless, integrated system that begins at the local level. They don't want to see the development of a cancer centre at the expense of other services and supports.

Valemount

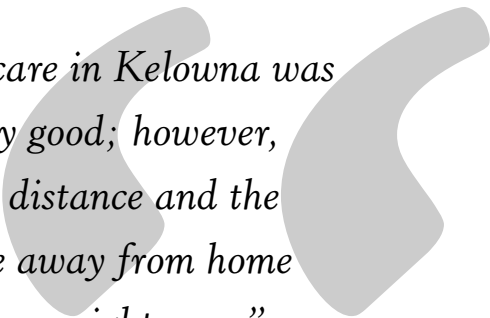
The Experience of the Community

Valemount is located at the southeastern end of the Robson Valley, three and a half hours east of Prince George and about four hours north of Kamloops.

When they must travel for cancer care services, residents of Valemount may go to any one of Prince George, Kamloops, Kelowna or Hinton, Alberta. For some specialized services, travel to Vancouver may be required. Not unexpectedly the main challenge for the residents of Valemount in accessing care is the travel required, and the subsequent distance from home and family supports.

Two widely opposing experiences with quality of care were described by participants. On one hand, a family experienced significant delays in detection and diagnosis, and, because the cancer was aggressive, the patient died within days of the eventual diagnosis.

Communication, coordination and care at Prince George Regional Hospital was described as poor and uncaring. The level of care only improved when the family advocated on its own behalf. There was also concern about the level of knowledge and skill of the local care providers, as well as the difficulty in getting help at PGRH when one doesn't have a family doctor in Prince George.



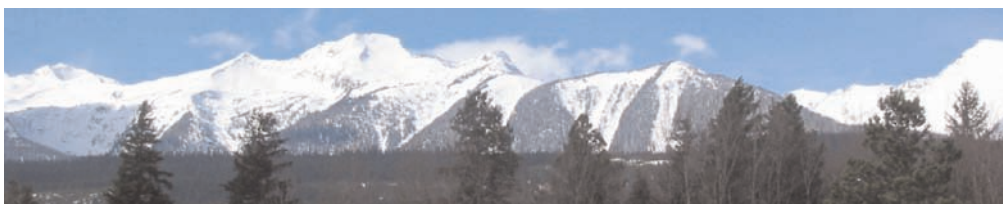
“The care in Kelowna was very good; however, the distance and the time away from home was a nightmare.”

Another very different experience involved quick diagnosis, choices in seeking treatment, and excellent care in Prince George. Information sources that really helped were the local physician, the cancer society and the 1-800 help line.

Generally, comments on speed of access to treatment varied from some wondering why it takes so long to get to treatment, to others saying the speed to treatment was so fast that they didn't actually have time to process what was happening – which brought emotional turmoil of its own.

Other services and supports available in Valemount include annual mammography screening. Although there is a grief support group, there is no cancer-specific support group in the area. Currently there is little capacity for diagnosis and treatment in the community and access to services seems to be quicker in Hinton than it is in Valemount.

End of life care locally is provided at the hospital in McBride, and through the local Home Support and Home Care services. Residents noted that the presence and support of the Hospice Society in Prince George really helped with understanding the pain and symptom control measures available.



Recommendations from the Community Choice

Given that they are located quite a distance from all major cancer centres, one of the biggest concerns of Valemount residents was the issue of choice. Being able to choose a location where there is family or a support network is vital from a financial and emotional perspective.

Local services

Where possible, Valemount residents would like to see improvements and enhancement of local service provision, including training local staff in diagnostics and in chemotherapy where practical.

Transportation and Accommodation

As with most communities beyond the range of easy travel to Prince George, Valemount residents pointed out that travel, and often overnight stays, would still be necessary if a cancer centre is built in Prince George. Therefore, travel assistance will need to be addressed, and accommodations provided.

Response to the Vision

Valemount appears to be just within the radius of support for a cancer clinic in Prince George. Participants did note, however, that their support of such a centre would be dependent on there being better integration between local, regional and provincial services.

The distance they would have to travel to get to Prince George is more acceptable than the distance to Kelowna. Additionally, the option to travel to Vancouver is not easy in Valemount, since they must drive to Prince George or Kamloops to fly anywhere.

Valemount residents' response to the vision also focused on the challenges faced on the way to establishing a cancer centre in Prince George. These were seen as:

- the challenges of physician recruitment,
- the lack of current diagnostic capacity in Prince George,
- ensuring the centre is as good as other centers.

Discussion of the vision did allay some of the fear that the care that would be received in Prince George would be inferior, and it was agreed that "anything that will make health care even a little bit more accessible will help."

It was thought to be important for the vision to address the following:

- the need for accommodation at the centre for people from out of town,
- the need to improve travel assistance, and,
- the need to create a network of services that integrates with and improves local services (there needs to be better internal connections in the system).

Vanderhoof

The Experience of the Community

Vanderhoof, served by St. John Hospital, is located an hour west of Prince George on Highway 16. Most residents must travel to obtain cancer diagnosis and treatment.

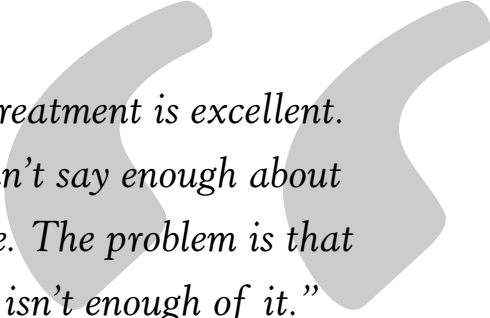
There are limited promotion and prevention initiatives in the community. However, there is a desire for increased activity along with the effort required to raise awareness of these initiatives. While screening mammography has become much more accessible, there is a sense that other available screening services (such as colonoscopy) are not part of regular health care, but should be.

While residents, for the most part, reported having good experiences with local physicians, they stated that it is very difficult to access the limited number of community based GPs, thus creating the biggest challenge to successful cancer treatment for Vanderhoof residents – unacceptably long delays in diagnosis. It can take up to six weeks to see a family doctor, and then there is often a further delay if a referral to a specialist outside of the community is required to complete the diagnosis.

Once a diagnosis of cancer is made, patients report rapid entry into the cancer care system – often at a time when they are searching for immediate support and information that is not readily available. There was praise for cancer treatment services in both Prince George and Vancouver, but concern about follow-up care in Vanderhoof.

Expenses associated with having cancer treatment outside of the community is also an issue for Vanderhoof residents, to the extent that some opt not to seek adequate treatment. Some patients reported unnecessary trips to Vancouver caused by a lack of coordinated and timely information sharing between medical professionals in the south and those in their home community.

There is an informal support network for cancer patients and survivors in Vanderhoof that is not associated with the Canadian Cancer Society. In addition, many participants shared examples in which the community (churches, co-workers, neighbours etc.) had mobilized to provide support where there would otherwise be none. Still, there is a sense that there is not enough support for patients and their caregivers locally. Palliative care in Vanderhoof is mostly taken care of by family and close friends.



“The treatment is excellent. You can’t say enough about the care. The problem is that there isn’t enough of it.”

Recommendations from the Community

Local Services

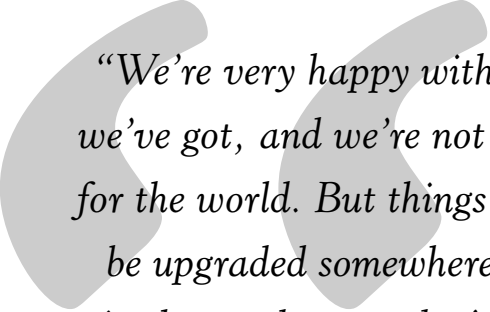
Vanderhoof residents suggested many ways in which local services along the whole length of the cancer care continuum could be enhanced. There was a call for more local health promotion activities, greater access to a diverse range of screening services and improved cancer information services within the community.

Recruitment and education

They would also like to see an increase in the number of physicians locally, and they want local physicians to receive the BC Cancer Agency oncology training. From screening and detection to diagnosis often takes a long time for cancer patients in Vanderhoof. The delays come from long waits to access local physicians and diagnostic tests.

Communication and coordination

Recommendations related to treatment included improved communication and coordination between health care professionals throughout northern BC.



“We’re very happy with what we’ve got, and we’re not asking for the world. But things should be upgraded somewhere here in the north so we don’t have to travel so far.”

Travel and financial assistance

As elsewhere in the north, residents of Vanderhoof face expensive travel and long periods away from home when they require specialized cancer care, such as radiation therapy.

Support

In the absence of established information and support services in the community, the emotional impact of being away from home and family is intensified. While many patients indicated they received great support from the community, others

(including caregivers) felt isolated and unable to connect with the support or information necessary to face the challenges of service access in rural areas. Participants said they would like to see more attention paid to improved palliative care funding and support.

Alternative therapies

There was also a call for consideration of how alternative, but complementary, cancer therapies may be incorporated to encourage access to treatment and improve outcomes.

Response to the Vision

Vanderhoof residents fully support the establishment of a northern cancer centre in Prince George and see many associated benefits, including the opportunity to recruit, train and keep professionals in the north.

They want to see improved local services, particularly in the area of information and support for patients dealing with a cancer diagnosis.

As well, there was a call for improved follow-up services in the local community, with an emphasis on improvements in the coordination and transfer of information between cancer care professionals outside of the community and local physicians.

Appendix I

Consultation Data Collection Summary



Number of individuals represented

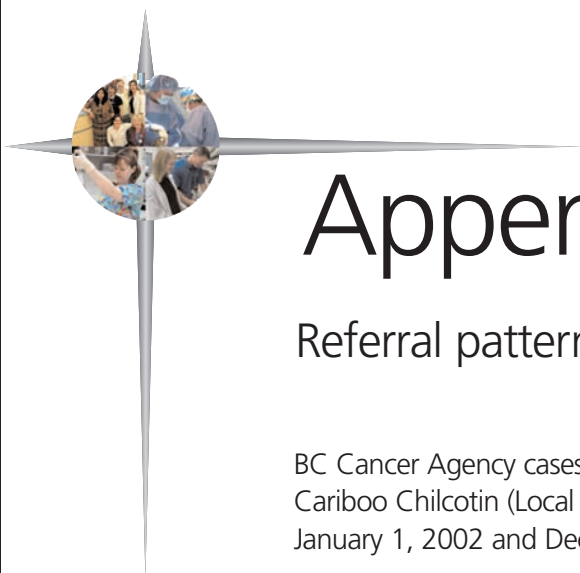
Location	Public Meeting(s)	Focus Group	Comment Forms	Total
Burns Lake	21	3	2	26
Dawson Creek	30	11	3	44
Fort Nelson	14	5	1	20
Fort St. John	36	5	4	45
Hazelton	43	0	3	46
Kitimat	24	11	2	37
Mackenzie	62	8	2	72
Masset	10	4	1	15
McBride	17	5	0	22
Prince George	205	40	38	283
Prince Rupert	35	17	9	61
Queen Charlotte City	7	3	2	12
Quesnel	46	17	2	65
Smithers ¹	51	16	16	83
Terrace	21	9	3	33
Valemount	6	2	0	8
Vanderhoof	14	3	1	18
Other locations	0	0	14	14
Total	642	159	103	904

Submissions from communities not visited by consultation

Location	Submissions	Location	Submissions
Cluculz Lake	1	Nakazdli	4
Fort St. James	1	Stewart	2
Hudson's Hope	1	Tatlayoko Lake	1
Kamloops	1	Unknown	1
Kitkatla	1		
Lax Kw'Alaams	1	Total	14

¹Other written submissions also included

²Public meeting included 4 participants from Houston



Appendix II

Referral patterns from the South-Central Interior

BC Cancer Agency cases diagnosed in 100 Mile House, North Thompson and Cariboo Chilcotin (Local Health Areas) and admitted to a BCCA centre between January 1, 2002 and December 31, 2004 (**by Local Health Area**)

LOCAL HEALTH AREA	Cancer Centre	2002	2003	2004	Total
100 Mile House	FV	2	4	6	12
	SI	17	45	41	103
	VA	12	19	15	46
	VI	1	1	0	2
North Thompson	FV	0	1	0	1
	SI	8	16	17	41
	VA	2	1	2	5
	VI	1	1	0	2
Cariboo Chilcotin	FV	5	4	3	12
	SI	25	50	51	126
	VA	19	8	18	45
	VI	0	0	1	1
Total		92	150	154	396

BC Cancer Agency cases diagnosed in 100 Mile House, North Thompson and Cariboo Chilcotin (Local Health Areas) and admitted to a BCCA centre between January 1, 2002 and December 31, 2004 (**by Cancer Centre**)

CANCER CENTRE	2002	2003	2004	Total
FV	7	9	9	25
SI	50	112	109	271
VA	33	27	35	95
VI	2	2	1	5
Total	92	150	154	396

FV—Fraser Valley, located in Surrey

SI—Centre for the Southern Interior, located in Kelowna

VA—Vancouver Centre

VI—Vancouver Island, located in Victoria

Appendix III

Letter from the Canadian Cancer Society



**Canadian
Cancer
Society**

BRITISH COLUMBIA AND YUKON

565 West 10th Avenue, Vancouver, BC V5Z 4J4
Telephone 604 872 4400 Fax 604 879 4533
www.cancer.ca
BOARD CHAIR Mike Mahony
CHIEF EXECUTIVE OFFICER Barbara Kaminsky

May 5, 2006

Dr. Charles Jago and Mr. Jeff Burghardt
Co-Chairs
Northern BC Cancer Consultation
c/o Withinsight Services
3140 The Middle Road
Nelson, BC V1L 6M3

Dear Dr. Jago and Mr. Burghardt:

The Canadian Cancer Society's BC and Yukon is pleased to submit our response to the Premier's Consultation for Improved Cancer Care in Northern BC.

We are committed to working with government and other stakeholders to ensure a systematic cancer control strategy is in place in every region of British Columbia. In a recent communication with the Premier, I was pleased to set out our prioritized list of cancer issues that we want the provincial government to take action on over the next year or two.

Within this list, we identified the need to improve cancer care in Northern BC by establishing a cancer treatment centre and providing travel and accommodation subsidies to patients attending the centre. We are prepared to consider funding construction of a lodge in the North (similar to those we already have in Vancouver, Victoria and Kelowna) assuming appropriate cost sharing of operational expenses from the Provincial Health Services Authority who currently provide grants for all our lodges.

I look forward to further discussions on this important initiative.

Sincerely,


Barbara Kaminsky
Chief Executive Officer

c.c. Pam Aikman
Linda DuBick
Cathy Adair
Kate Smallwood

Special thanks to the following individuals who assisted in the consultation process and in the production of this report:



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