CancerCare
MANITOBA

COMMUNITY HEALTH ASSESSMENT

2005

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ACKNOWLEDGEMENTS

CancerCare Manitoba (CCMB) is proud to release its first Community Health Assessment (CHA). This assessment builds on the work performed in 1998/99 in producing the Cancer Projections Report and the Cancer Capacity Planning Study.

As with many initiatives, the process can be as educational and rewarding as the outcome, and I believe this is the case for our first CHA. It is an ongoing challenge to look at the cancer patient and their family and the services and programs that are critical to their care from a population health perspective. The information systems we have are not always designed to support this lens and the pressures of patient care provide staff with little opportunity to look at cancer services from the population health perspective. Despite these challenges, we have attempted to look at the services provided to cancer patients and their families from the perspective of access to the full range of services across the cancer control spectrum. This viewpoint will inform our strategic plan, our information requirements, and the scope and nature of our relationships with our Regional Health Authority and community partners.

CCMB's first CHA is the result of a significant effort by many people, all of whom have busy and over-committed work requirements. They all gave freely of their time to this new process within CCMB, and I am grateful for their professionalism and commitment to explore cancer from the perspective of the Manitoba population.

The members of the steering committee are named in the methodology section, and each and every one of them must be given credit for the full and final product. Each contributed from their professional, organizational and personal perspective, and the document is richer because of it.

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Linda Venus
Provincial Director Cancer Control and Program Planning
CancerCare Manitoba
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EXECUTIVE SUMMARY

CancerCare Manitoba (CCMB) is the provincial healthcare organization charged by an act of the legislature to manage cancer and complex hematological disorders for Manitobans. The organization has made significant strides in providing the construct necessary to provide exceptional, patient-centred care. Expanded facilities, innovative and enhanced program offerings, commitment to research and extensive partnerships have positioned CCMB for the future.

These strides are significant; however, so is the need for continuous improvement in the constant pursuit of excellence. This Community Health Assessment (CHA) serves as an important tool in measuring the pulse of CCMB and the community it serves. This document will act as a guide in understanding the current state of services, the projected future demand for services, and the challenges associated with moving forward to ensure that we continue to meet the needs of cancer patients and their families.

The CHA also provides an opportunity to expand our partnership base, as well as to understand and expand existing relationships, by communicating that cancer is a disease whose demands impact the health care system throughout Manitoba. In recognizing the need for patient-centred vision in healthcare, CCMB acknowledges the importance of partnerships to provide the best care possible that is both financially sustainable and of best benefit to the patient.

The CHA provides an internal environmental analysis, statistical insight into population demographics in recognizing the provincial mandate of CCMB, and statistical insight into the disease itself, concluded by an external environmental analysis including partner and patient feedback. We are particularly grateful to the patients and healthcare partners who so willingly shared their views and experiences with us through interviews and focus groups.

Who We Are and What We Do

CCMB provides a broad range of cancer control and cancer care services spanning the cancer continuum. "Cancer control" has been defined as all activities that reduce the burden of cancer in the population, including prevention, detection, treatment, rehabilitation and palliation. The organization is housed in two Winnipeg facilities and throughout a network of fourteen Community Cancer Program (CCP) sites. The internal structure of the organization follows vertical departmental boundaries but integrates horizontally through the Disease Site Groups (DSGs) and process teams to promote interdisciplinary care and a seamless patient experience. In addition to ambulatory medical care, other cancer-related patient services include:

- Hematology Laboratory responsible for blood drawing and testing;
- Nursing responsible for direct patient care, including care, teaching, support and coordination;
- Volunteer Services responsible for making the patient experience as pleasant as possible;
- Patient Representative responsible for acting as a liaison between patients and their service providers;
- Medical Physics responsible for a wide range of services, including device manufacturing, service support, radiation safety, improved imaging capability and radiation treatment planning;
- Pharmacy provides full range of clinical pharmacy services as well as provincial leadership in oncology pharmaceutical challenges;
- Radiation Therapy responsible for providing patients with radiation services; and
- Psychosocial Oncology responsible for patient and family education and support.

The organization also has a strong basis in cancer control and program planning that involve the departments of cancer screening, as well as epidemiology and the cancer registry. These programs provide the foundation of early detection and population-based research. CCMB is also strongly grounded in basic research, housing the Manitoba Institute of Cell Biology, which brings together knowledge gleaned both through research and in a clinical setting. Virtually all CCMB departments engage in research. The Clinical Investigations Office, for example, is dedicated to increasing scientific knowledge and improving patient care to reduce the impact of cancer. Many CCMB departments are recognized as centres of excellence in their specific disciplines.

CCMB partnerships have been formed to acknowledge that the needs of cancer patients impact the entire healthcare system and that care as close to home as possible is desired by Manitobans with cancer. Fourteen Community Cancer Program sites, as well as the Winnipeg Regional Health Authority Community Oncology Programs and the Urban Primary Care Oncology Network, are significant partners, linking community care and cancer specialists.

The Community

In order to best serve the provincial demand for cancer-related services, it is necessary to understand the population, specifically population risk factors. Cancer is a disease associated with aging, which is of concern in Manitoba and the rest of Canada as our populations become older. It is projected that by the year 2025, Manitoba's population over the age of 65 will have grown by 47 per cent. This growth will present distinct challenges as it will also bring with it an increased number of cancer cases.

Risk factors go beyond age alone and encompass a variety of lifestyle choices, which present the opportunity for primary prevention. Health issues such as obesity, inactivity, tobacco use, exposure to ultraviolet rays, alcohol consumption, limited access to primary health care, and sexual health have all been linked to cancer. The Government of Manitoba has introduced legislation that will directly impact the rate of smoking, as well as limiting exposure to second-hand smoke. This is a significant piece of legislation that directly addresses a major cancer risk factor. However, there is considerable room for additional primary prevention activities in reducing lifestyle risk factors. Increasing obesity rates and corresponding inactivity rates illustrate the need for prevention activities to curb the trend and reduce the burden of disease on the healthcare system. The Government of Manitoba is currently conducting community meetings to determine how obesity can be prevented in young people.

Although cancer is a disease directly associated with several risk factors, much is still unknown about its development; therefore, it is not yet a disease that is fully preventable. Prevention combined with early detection has been shown to reduce incidence and improve outcomes. The Manitoba Breast Screening Program and the Manitoba Cervical Cancer Screening Program have been developed in response to the recognition that early detection of these cancers leads to better outcome and decreased mortality. CCMB is also in the process of developing models for consideration of a colorectal cancer screening program in compliance with recommendations made by a national task force.

The Manitoba Breast Screening Program has, to date, achieved fifty per cent population penetration. This is a significant achievement but falls below the target of seventy per cent penetration that is required for the full impact on breast cancer mortality rates. In order to achieve the goal of seventy per cent of the eligible population being screened, there is demonstrated need for increased capacity, particularly as the population ages, resulting in increasing numbers of women who will qualify for screening service.

The Manitoba Cervical Cancer Screening Program has established close partnerships with primary health care providers. The Program has established a provincial registry to track the use of Pap tests, while encouraging providers to screen the eligible population of 18-69 year olds. It includes a fail-safe feature to ensure that abnormal results are followed up by the woman and her physician. The partnerships with primary care physicians are critical to achieve this goal and encourage appropriate screening. CCMB, and specifically the screening programs, may benefit from further educating the public as to the benefits of screening and its importance to their continued health.

The demographic analysis illustrates opportunities for CCMB in partnership with Manitoba Health and Regional Health Authorities (RHAs) to engage in prevention and early detection activities. Impacting lifestyle risk factors through primary prevention activities is important, not only to decrease the incidence of cancer in the population, but also the co-morbidities associated with obesity, inactivity and tobacco use. Partnerships in primary prevention will be of substantial provincial health benefit. There is also room for improvement in the use of screening activities in the population. Increased education of the public, and their primary care providers is important in eliminating the barriers to screening, and reaching the target goals of each of the established screening programs. Finally, CCMB is exploring the development of a colorectal screening program, which would be important for detecting colorectal cancer in the population at earlier stages so as to decrease the associated mortality. CCMB faces opportunities for growth beyond treatment services, to promote and provide appropriate screening services, and to contribute to primary prevention activities.

Cancer in the Community

Cancer is a disease of the aged: more than three-quarters of cases diagnosed occur in the population aged 65 and over. The disease also accounts for one-third of deaths that occur before the average expected life span of 75 years. In Manitoba, there are four cancer diagnoses (prostate, breast, lung and colorectal malignancies) that account for more than half of the number of new cases each year.

In order to assess the provincial experience of incidence and mortality, provincial and national comparisons were undertaken. This investigation revealed that the levels of cancer incidence and mortality in Manitoba are consistent with the Canadian experience. Although this is comforting in that it indicates Manitoba is not experiencing unacceptable differences, there is still an obvious need for improvement in reducing cancer incidence and mortality, as there will be until the disease can be prevented and cured.

In further examining variation, the incidence and mortality of the most common cancers were evaluated by RHA. This information illustrated variation in incidence rates across the province. Possible explanations for the variability in cancer rates include differences in underlying risk factors and random variation, but further investigation may be necessary. This additional exploration would provide CCMB with greater insight as to if a problem exists, and how it can be best addressed.

Understanding the current and future needs of the population is paramount to the success of CCMB in providing excellent patient-centred care. In order to predict future demand for services, two factors were taken into account - projected cancer incidence and cancer survivorship. The increasing age of the population presents distinct challenges in that it predicts an increasing cancer burden. At the same time, due to improvements in cancer treatments and increasing efforts in early detection, a greater number of patients are surviving. A greater prevalence of cancer in the population indicates a greater demand for follow-up cancer services, including rehabilitation, home care and psychosocial care. Meeting the demands of the future will require CCMB to be creative in the provision of services in order to best service the population, as well as improving cohesion with services provided by RHAs.

System Responsiveness to Manitoba Cancer Patients and their Families

The environment external to CCMB is critical to understanding the opportunities and challenges associated with access to care for cancer patients in Manitoba. In order to provide the most accurate picture possible, key informant interviews with RHAs, a focus session with primary care providers, and focus group sessions with patients and families were conducted. Accessibility to services is fundamental to understanding how well CCMB is meeting the needs of the patients they are serving. Therefore the focus of these groups was to understand the perceptions surrounding access to cancer services and the perception of CCMB.

CCMB offers access to surgical, medical and radiation oncologists within its two facilities in Winnipeg. These facilities also host the radiation services for the province. Radiation services will be offered in Brandon within the next several years. CCMB has also expanded its scope to incorporate a community-based structure for the provision of chemotherapy services. Fourteen satellite CCPs are now in existence, with two more coming on line in the near future.

Accessibility to these services is most often measured through patient waiting time. The radiation therapy program has dramatically reduced their median wait time for radiation therapy to 1.1 weeks in the most recent quarter, down from 6-7 weeks in 1998. The program has recognized that waiting time is a measure of accessibility and quality service, and, accordingly, has taken steps to reduce patient waits. However, there are numerous wait time points in a patient's experience, including time to surgery, to diagnostic testing, to receipt of test results, to first visit with an oncologist, and to chemotherapy. There are currently no data readily available to facilitate the reporting and monitoring of wait times for these services. CCMB must look to provide this capability in the future in order to have the data necessary to understand patient accessibility and to make changes as necessary.

CCMB also provides a number of services that compliment medical care and treatment - access to clinical trials through the Clinical Investigations Office, psychosocial oncology, nutrition, speech and language pathology, and information services.

In order to evaluate these services and understand the gaps in the patient care experience, key informant interviews with partner RHA's were conducted. These interviews revealed that although the relationship between the organizations was considered to be strong, there is room for improvement in several areas. The RHAs revealed that access to programs in their home regions was acceptable in relation to palliative and home-care programs. At the same time, the RHAs indicated a needs for greater capability built around psychosocial needs, nutritional and rehabilitative need as well as greater provision of treatment information. It was of specific note that patient-centred care requires the patient to be fully informed so they can make decisions that are in their best interest. This is an area where CCMB can have immediate impact in providing greater information to primary care physicians to inform themselves, as well as in the provision of more easily accessible information for patients.

Greater partnerships with RHAs are essential given the projected increase of cancer in the province. Forums such as the key informant interviews are important as a measure of how well CCMB is meeting the needs of the patients across the province. These forums also provide RHAs with the opportunity to identify areas in which CCMB can improve, and where the relationship between the organizations can be strengthened. This format identified some immediately actionable items that would improve patient care, as well as some long-term goals that can be achieved through collaboration.

The importance of primary care physicians is paramount to the detection and follow-up care of patients with cancer. The focus group session with the physician group identified the importance of involving the primary care physician throughout the cancer treatment process in order to provide the patient with seamless, high-quality care. The physicians recommended an improved scheduling system and greater involvement in the treatment team. CCMB initiated the Urban Primary Care Oncology Network in order to identify the issues facing primary care physicians in relation to cancer care and attempt to resolve them. This initiative will provide a structure for provision of cancer services through partnership with primary care.

The external environmental analysis also included eleven focus groups of patients, both current and former, as well as families of patients. The feedback from these groups was very positive in tone. Patients were quick to recognize the importance of CCMB in providing the services they required on their treatment path. The Community Cancer Programs Network was noted as important in allowing patients to receive their treatment closer to their homes, thus relieving the financial and physical burden of travel. Patients also were able to articulate areas that they felt required improvement. Patients suggested improved diagnostic services, better-quality information prior to treatment, and greater follow-up care.

The comments recorded in the focus group sessions indicate that patients require services that extend beyond the specific treatment of their cancer. In recognizing the demand for expanding the services provided on both ends of the cancer trajectory, CCMB must investigate how these patient needs can be met. Although there has been movement by the organization through partnerships with DSGs to create guidelines for follow-up care, these efforts are not yet standard or available to the primary care population. However, movements in this direction are certainly supported by patient response. CCMB must also look at how to provide patients with better access to information, noted within both the patient and RHA forums as necessary for appropriate patient care. This is certainly an opportunity that may require the reallocation of resources to more effectively distribute the available information.

In realizing the importance of patient feedback in providing patient-centred care, CCMB is embarking on a province-wide patient satisfaction survey. This survey looks to provide a greater sample of participants in aiming to better understand patients' needs in planning for the future of the organization.

The CHA process has identified areas of both strength and weakness, while highlighting opportunities for organizational improvement. CCMB will benefit from the strategic foundation that has been laid in the creation of this document. In order for improvements to be made to the system, the state of the system must first be measured. This assessment serves as the baseline upon which organizational achievements and success will be gauged.

1

WHO WE ARE AND WHAT WE DO

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1.0 CANCERCARE MANITOBA – WHO WE ARE AND WHAT WE DO

CancerCare Manitoba (CCMB) is dedicated to the care and treatment of cancer and blood disorders on behalf of the people of Manitoba. Prevention, early detection, education and research are key strategies. We strive to enhance the quality of life and to improve the control of cancer for all Manitobans.

Like all cancer agencies, CCMB faces unprecedented challenges. Cancer continues to increase relentlessly by two to three per cent per year. Thanks to many advances, more people survive cancer and enjoy productive lives, but requiring ongoing care. By 2020, the number of people living with cancer will have doubled. Since budgets and resources are unlikely to keep pace with these requirements, finding innovative methods to meet the needs of our patients and their families will be essential.

During the past year we have identified critical areas that need our attention, and have begun work on a comprehensive Manitoba Cancer Plan in order to fuse our efforts in the fight against cancer. Working with our community partners, some of whom were actively engaged in our Community Health Assessment (CHA), will enable us to mobilize our efforts and work cooperatively to energize the community and encourage greater interaction and involvement.

CCMB continues to follow the guiding principles articulated in our mission statement that focus our efforts on those who matter most - our patients and their families. We are also active on the provincial and national stage in addressing the anticipated increase in the burden of cancer on Canadians and the Canadian health care system. The organization has joined with other provincial counterparts, Health Canada, and Provincial and Territorial governments to form the Canadian Strategy for Cancer Control. This group has developed six priorities for action - clinical practice guidelines, rebalancing focus, human resources, primary prevention, research, and standards. A Council has been created to facilitate the implementation of the Canadian Strategy for Cancer Control on a national basis.

CCMB is also a member of the Canadian Association of Provincial Cancer Agencies (CAPCA), which is an interprovincial organization representing cancer agencies and programs that are responsible for reducing the burden of cancer on Canadians. CAPCA facilitates collaboration and supports agencies and programs through effective leadership, communication and advocacy for cancer control. CAPCA focuses primarily on challenges faced by provincial cancer agencies in the delivery of services, and has identified six strategic priorities for action - human resources, information technology, technology assessment, interprovincial standards, communication/education, and research.

1.1 Mandate of CancerCare Manitoba

CCMB is charged by an act of the legislature of Manitoba with responsibility for cancer prevention, detection, care, research and education for the people of Manitoba. CCMB is dedicated to excellence in cancer care. In so doing CCMB strives to prevent, endeavours to cure, and is committed to enhancing the quality of life for people living with cancer and blood disorders.

CCMB, initially known as the Manitoba Cancer Relief and Research Institute, was founded in 1930 through the provisions of the Cancer Relief Act. The mandate of the Institute was to oversee cancer-related issues in Manitoba, a mandate that serves as a foundation for the current work of CCMB.

In the past 75 years, CCMB has made significant strides in providing the construct to fulfill its mission and position the organization for the future direction of cancer care in the province. These achievements, from renovations of the facilities and buildings, through to new and expanding programs, will allow CCMB to face both current and future challenges in best serving the needs of cancer patients and their families. The complexities of the future provision of cancer care and cancer-control activities are great. The population of Manitoba is aging, and in combination with increased rates of cancer risk factors, Manitoba's health care system will face increasing demand for cancer services in the future. Success in early detection and treatment of cancer has been demonstrated in recent years. Therefore the increasing number of cancer survivors also needs to be taken into consideration as to the support and services they require in providing them the tools to lead healthy and productive lives.

1.2 CancerCare Manitoba Services

CCMB provides a broad range of cancer control and cancer care services across the province and throughout the cancer continuum, including surveillance, screening and early detection, diagnosis, treatment, rehabilitation, follow-up and supports to survivorship, palliation, and bereavement.

1.2.1 Facilities and Medical Services

CCMB provides diagnostic, treatment, rehabilitation and support for those living with cancer and their families. CCMB operates in two Winnipeg locations, supports a network of Community Cancer Programs (CCPs) throughout the province, and provides program leadership to the Winnipeg Regional Health Authority (WRHA) oncology program.

Pediatric oncology, surgical oncology, hematology, lab services, bone marrow transplant and CCMB administration is housed solely in the newly renovated 675 McDermot location. Radiation Therapy services will be consolidated at the McDermot site in March 2005. Medical assessment and treatment planning, nursing care, chemotherapy, follow-up care, pharmaceutical services, pain and symptom management , treatment of benign blood disorders, psychosocial oncology and supportive care are delivered at the two Winnipeg sites, 675 McDermot and the St Boniface Unit (located in "O" block of Saint Boniface General Hospital).

CCMB's Community Cancer Programs (known as CCPs), established in collaboration with the rural and northern Regional Health Authorities (RHAs), allow most cancer patients the opportunity to receive systemic chemotherapy and follow-up care closer to home. This network of 14 CCPs recognizes the geographic challenges of living with cancer in rural Manitoba, and affords most patients the opportunity to receive treatment at a CCP located in or near their home communities.

CCMB has also established relationships with the WRHA in providing program leadership to the WRHA Oncology Program and working closely with the WRHA Palliative Care Sub Program.

Disease Site Groups

CCMB has a wide range of medical specialties and disciplines to provide cancer care services. Multidisciplinary teams are organized into 15 Disease Site Groups (DSGs) by malignancy type - brain, breast, gastrointestinal, genitourinary, gynecologic oncology, head and neck, hematology, leukemia, lymphoproliferative disorders/BMT, pediatric, sarcoma, skin, symptom management, thoracic and thyroid. These DSG teams are composed of nurses, physicians, therapists, technologists, pharmacists, counsellors, support staff, and volunteers from across the continuum of services. The team representatives are from across the continuum of services such as surgery, pathology, radiation therapy, medical oncology, respiratory and basic science, thereby recognizing the multimodal and multidisciplinary nature of cancer care. The work of each DSG focuses on clinical investigation, evidence-based practice, and cultivating the partnerships necessary to provide multimodal, multidisciplinary patient-centred care.

The Hematology Laboratory

The mandate of the Hematology Laboratory is to provide support to patient care, and to the clinical research activities of CCMB, by providing appropriate laboratory services in a safe and effective manner.

The laboratory technical staff consists of medical laboratory technologists and laboratory technicians. All staff are fully trained in blood drawing techniques and will ensure that the patient's blood drawing experience is as positive as possible. The staff are also able to perform analyses on blood products including complete blood counts (CBCs). External facilities including the Heath Sciences Centre, the Cadham Provincial Laboratory and Canadian Blood Services provide the analysis for other laboratory services.

Nursing

Patients attending CCMB are assigned a primary nurse who coordinates the care of the patient and his or her family. The primary nurse provides assessment, education, symptom control, and emotional support to patients and families in the clinic and over the telephone. Primary nurses play a vital role in linking patients and their families to other services within the CCMB community.

Nurses provide patient care in the treatment areas at both of the main CCMB clinics in Winnipeg. This includes skin and wound care, administration of chemotherapy and other supportive systemic therapy, apheresis, central venous device care, and insertion of peripherally inserted central devices. Nurses also assist with procedures such as bone marrow aspirations and biopsies, and provide patient care in the operating and recovery room to patients undergoing high-dose radiation therapy, brachytherapy and other procedures.

Patient care is supported by other team members including laboratory technologists, communication clerks, unit assistants and nursing assistants.

Day/Evening Hospital

CCMB has provided leadership in the development of expanded hours for systemic therapy. This program (the Day/Evening Hospital) delivers systemic therapy seven days a week, and includes extended hours on weekdays. The expanded hours provide for longer treatments traditionally done within hospitals and provides for more flexibility for patients.

Volunteer Services

At CCMB, volunteers team up with staff to work toward the common goal of providing excellent patient care. Volunteer Services is responsible for volunteer recruitment, interviewing, screening, orientation, training, placement, recognition and evaluation. Each year more than 350 volunteers donate time to the Manitoba Screening Programs, CCMB's Breast Cancer Centre of Hope, and the two main CCMB clinics.

Volunteers serve in a variety of roles aimed at making patient visits a little easier and supporting clinic activity. Volunteers also work behind the scenes, providing clerical support and assisting staff to make the system more efficient. Volunteer Services ensures that community involvement is an important part of the cancer care strategy.

Patient Representative

The Patient Representative acts as a liaison between patients, their families and CCMB staff. This confidential service strives to address concerns, answer inquiries and act on suggestions in a respectful, compassionate and timely manner. The Patient Representative is located at the 675 McDermot location, and the St. Boniface site by appointment.

The Patient Representative is part of the quality and risk management framework, providing feedback to CCMB by identifying areas of concern. This means of feedback allows for the design of new processes, or modification of existing processes. The Patient Representative is also responsible for receiving and reporting staff commendations to both the staff member involved and their immediate supervisor. Commendations that are received are also acknowledged through publication in the CCMB monthly staff newsletter.

Medical Physics

The Division of Medical Physics encompasses five departments - Medical Devices, Nuclear Electronics, Radiation Protection, Imaging Physics, and Radiotherapy Physics that cover all aspects of cancer control, including that prevention, early detection, treatment, education, and basic and applied research.

Operating within a matrix structure, Medical Physics staff work in multi-disciplinary teams, in concert with other services within CCMB as well as with external stakeholders, including the WRHA, the RHAs, and the University of Manitoba. The departments collaborate in order to provide critical services in the support of the provincial Radiation Therapy Program, Diagnostic Imaging Program, Radiation Protection Program, and the Radiosurgical Program. Research and teaching (at both graduate and undergraduate levels) is carried out in all areas in collaboration with the University of Manitoba (Faculties of Science, Engineering and Medicine), CCMB's School of Radiation Therapy, and the National Research Council's Institute for Bio-Diagnostics.

- The Medical Devices Service is an ISO 9001 certified design and manufacturing department specializing in fabricating clinical devices required by the Radiation Oncology and Diagnostic Imaging programs.

They also provide customized clinical and physics testing equipment, not commercially available, for the clinical and research programs of CCMB, the WRHA and external clients, and assist with mechanical repairs of equipment throughout the CCMB facility.

- The Nuclear Electronics department services and maintains linear accelerators, CTs and gamma cameras throughout Winnipeg and provides electronic service and support for the mammography, chemotherapy and bio-medical requirements of CCMB.

- The Radiation Protection department oversees radiation protection responsibilities that fall under provincial jurisdiction, specifically in making the use of ionizing and non-ionizing radiation treatment machines safe for all involved. They travel to all corners of the province to ensure that x-ray producing equipment meets safety standards, are first responders to radiological emergencies, and are responsible for ensuring that the linear accelerators and gamma knife equipment and associated processes meet the requirements to maintain the necessary federal licensing.

- The Imaging Physics department works with radiologists, physicians and radiation technologists to ensure that medical imaging throughout the province is of the highest possible quality. Working with service engineers, they accept and commission new pieces of equipment and design optimal imaging studies to meet specific needs.

- Radiotherapy Physics supervises, supports and carries out a variety of tasks to ensure that radiotherapy patients receive well-planned radiation treatment on machines that are operating safely, accurately and reliably. They develop new tools and techniques to improve the current standard of care and will advise radiation oncologists as to the optimal approach to treat particular conditions.

Pharmacy

The CCMB Pharmacy Team is committed to managing and coordinating the pharmacy activities of the two treatment sites of CCMB and in the 14 CCPs located throughout the province. The Pharmacy department has been a leader in adopting the organizational values of patient/family-centred care as well as striving for excellence. Pharmacists fulfill their traditional roles of dispensing in the pharmacy as well as their clinical roles in disease site clinics. In recognizing patient needs, the pharmacists are also available for medication counselling and teaching services. The department provides expertise and leadership in oncology pharmacy issues.

This leadership was recently demonstrated in identifying the potential for the OpTx clinical management system to improve patient care and organizational health. The Team saw the possibility of the system in capturing province-wide oncology drug ordering as a tool to report drug utilization, standardize drug regimens, increase patient safety, and develop reports on the cost and billing of drugs. The potential use of the information is now being realized as all pharmacy drug dispensing and dose recording are captured in the clinical management system. The leadership that the pharmacy team demonstrated in linking patient and organizational health is important as the burden of cancer grows and the development and release of new and costly medications increases. This organizational culture, which strives toward providing the best possible and sustainable care to patients, must be recognized and supported at every level.

Radiation Therapy

The Radiation Therapy Program is responsible for pre-treatment and treatment activities for patients undergoing radiation therapy, as well as education of student radiation therapists. The Program endeavours to support a multidisciplinary team approach to the effective delivery and ongoing improvement of all aspects of the radiation therapy process. Recognizing and respecting the diverse professional skills within the team, as well as promoting research and continuing education, Program staff work closely with radiation oncologists, nurses, physicists, and technical and other support staff in order to improve quality of care. Direct service delivery staff includes radiation therapists, mould room technicians, communication clerks, and unit assistants who plan and carry out complex courses of treatment while providing ongoing patient education and emotional support throughout the radiation therapy experience. Service areas include Pre-treatment (mould room, simulation, treatment planning), Treatment (linear accelerators and other treatment units, as well as brachytherapy), Support (patient bookings, transport, data management), and the School of Radiation Therapy.

The School of Radiation Therapy, located at the CCMB 675 McDermot site, graduates an average of six students per year after having completed a twenty-eight month program. School staff includes a program manager, a deputy program coordinator, and course instructors. The School works closely with many CCMB departments that provide instruction in specific areas of expertise, such as Epidemiology and Cancer Registry and Radiation Oncology. Students graduating from the program are certified through the Canadian Association of Medical Radiation Technologists (CAMRT) national certification exam. The School is accredited by the Canadian Medical Association/CAMRT Conjoint Committee and regularly receives the highest level of accreditation available.

1.2.2 Support Services

In recognition of the emotional stress of a cancer diagnosis on patients and their families, a number of support services are offered. CCMB's Patient and Family Support Service (PFSS) emphasizes holistic services dedicated to addressing the psychological, rehabilitative, social, emotional, spiritual and information needs of people living with cancer and their family/support networks. Services span the continuum of care, from diagnosis through treatment to survivorship, palliation, and bereavement. PFSS is an interdisciplinary, integrated department that consists of six distinct but related programs.

Psychosocial Oncology: includes social workers, psychiatrists, psychologists, and other mental health professionals who address the psychological, social, emotional and spiritual needs of people living with cancer and their family/significant others. A range of programs is provided including individual, couple, family and group counselling and psychotherapy.

Nutrition Services: provides professional dietician counselling and support as many cancer patients are at high risk of malnutrition. Registered dieticians specializing in the challenges of the cancer patient are available. The dietician works with patients to replete or preserve their nutritional status before, during or after treatment, manage food related discomfort due to cancer and the treatment, and to improve strength, well being and quality of life.

Rehabilitation Services: aimed at maintaining or improving function, comfort and independence are available directed or through referral. CCMB has secured the services of speech and language pathology, and the service is available on site and in the clinics as required. Other rehabilitation services are available to cancer patients through regional health authorities.

Patient and Family Resource Center: provides comprehensive cancer information at both locations as well as supporting the information resource needs of some rural centres.

The Guardian Angel Caring Room: located at 675 McDermot, assists Manitobans living with the appearance-related issues associated with cancer treatment. The Look Good Feel Better program is coordinated from this site, and provides wigs and head coverings at other cancer sites in Manitoba.

CancerCare Manitoba Breast Cancer Center of Hope: provides comprehensive information and support to breast cancer patients. Services include a nurse educator, a lending library, prosthesis and bra bank, peer support to all Manitoba women with a breast cancer diagnosis.

1.2.3 Cancer Control and Program Planning

Cancer Screening

CCMB operates two screening programs. The Manitoba Breast Screening Program (established in 1995) provides mammography and clinical breast examinations for women 50 to 69 years of age. The program has fixed sites in Winnipeg, Brandon, Morden/Winkler (Boundary Trails) and Thompson, and two mobile units that provide screening services throughout the province. The mobile units, which began operations in 1998, travel to more than 90 Manitoba communities on a two-year cycle to improve access to breast screening for women in rural and Northern Manitoba as well as the inner city of Winnipeg.

The Manitoba Cervical Cancer Screening Program was established in January 2000 with a mandate to ensure that Manitoba women receive organized, high-quality cervical cancer screening services. To increase the number of women having Pap tests, program resources are directed toward improving public knowledge about the importance of Pap tests, screening frequency, and recommendations for follow-up of abnormal findings. Professional education initiatives support health care providers in understanding methods to improve Pap test quality and utilization of resources to improve Pap test participation in their practice. Through the central collection of screening test results, the program supports cytology laboratory quality assurance activities and enables notification to health care providers if recommended follow-up has not occurred. In addition, the registry supports evaluation of screening activities, outcomes and program effectiveness.

Epidemiology and Cancer Registry

The Department of Epidemiology and Cancer Registry at CCMB contributes directly to the development and evaluation of the cancer control strategy activities in Manitoba. The Manitoba Cancer Registry has been in existence since 1937, and is legally mandated by the Public Health Act to collect information on all cancer cases in Manitoba. The registry has been certified by the North American Association of Central Cancer Registries (NAACCR), in recognizing the quality, accuracy and completeness of the registry.

The Department's strength is in its exceptional data quality, which allows for linkage of the cancer registry with supporting administrative databases. This ability to link patients across databases allows for a more complete analysis of the patient experience in relation to their care and outcomes. The Department provides an epidemiological basis for cancer control activities in the Province of Manitoba, as well as through external collaborative projects with national and international agencies to further population-based cancer research.

1.2.4 Research

Many programs and services at CCMB are actively involved, or are dedicated to, research pursuits. For example, the Manitoba Institute of Cell Biology (MICB) was founded in 1969 jointly by CCMB (under its former name, the Manitoba Cancer Treatment and Research Foundation) and the University of Manitoba. The Institute is associated with the Faculty of Medicine and the Health Sciences Centre and is located on the 5th, 6th and 7th floors of the CCMB at 675 McDermot Avenue in Winnipeg. It is dedicated to basic and translational research in biology and its relation to health, with a primary emphasis on cancer and related diseases. Scientists study such challenging problems as the molecular origins of cancer, the role of signal transduction pathways in regulating cell proliferation, cell death, gene expression and platelet function, development of markers of risk of developing invasive breast cancer, neuronal growth and differentiation during development, programmed cell death and the biochemical action of cancer chemotherapeutics. Although not a degree-granting institution, the Institute plays a major role in training scientists, whether graduate or postgraduate students, medical trainees or investigators who come from around the world to work with CCMB and MICB staff. Degrees are granted through the Faculty of Medicine, Departments of Human Anatomy and Cell Science, Biochemistry and Medical Genetics, Immunology, Pharmacology, Physiology, and Medical Microbiology.

Another key component to research done at CCMB is clinical research conducted through the Clinical Investigations Office (CIO). The DSGs set standards of care via clinical research. CIO facilitates clinical trails under the direction of the DSGs. Ninety per cent of clinical oncology research in the Province of Manitoba is conducted and carried out by the CIO. The vision of the CIO is that 100 per cent of all patients referred to CCMB are screened for eligibility to participate in a research study. In the short term, the CIO is striving to increase the number of clinical trials available, the number of patients screened, and the number of patients entered on a research study.

Patients entered on a clinical trial are treated and followed at CCMB's two sites and at the Victoria General Hospital Community Oncology site. Some rural patients can also be treated and monitored at Community Cancer Programs Network sites. The number of trials that are available to patients is based on the direction provided by the DSGs at CCMB, which decide collectively what research will be done, who will conduct it, and site locations.

1.3 Community Oncology Sites

Chemotherapy treatment services are offered in four community hospitals within Winnipeg - the Victoria General Hospital, Seven Oaks General Hospital, Grace General Hospital, and the Concordia Hospital. The WRHA Oncology Program Team provides program management to the community oncology sites, the Breast Health Centre, and the inpatient services required for the Bone Marrow Transplant program. Three members of the CCMB Senior Management Team are cross-appointed to the WRHA, forming the WRHA Oncology Program leadership.

1.4 Community Cancer Program Sites

Recognizing the need to provide quality cancer care to all Manitobans in or near their home communities, CCMB developed an Outreach program in 1978. Initially developed as a pilot project, five rural sites (Brandon, Dauphin, Flin Flon, The Pas and Thompson) provided chemotherapy treatment to women with breast cancer. Due to the great success of the project, the Outreach program, now known as the Community Cancer Programs Network (CCPN), has evolved and today includes 14 Community Cancer Program (CCP) sites including Brandon, Dauphin, Flin Flon, Gimli, Hamiota (satellite), Boundary Trails, Neepawa, Portage, Russell (smaller satellite), Selkirk, Steinbach, Swan River, The Pas, and Thompson. Recently the Province of Manitoba approved the creation of two new CCPs, one in Pinawa and one in Deloraine.

The 2001 Cancer Capacity Planning Study found that 92.3 per cent of all new malignancies in Manitoba are referred to CCMB and the community oncology sites. The importance of the CCPN in providing care is evident in that 30 per cent of patients who received chemotherapy were able to do so at a CCP. Another 35 per cent of clients were seen at community oncology sites, with the remaining 35 per cent being seen at the two CCMB home sites. These statistics illustrate the success of the CCPN in providing care as close to home as possible.

Operating as outpatient departments within acute care hospitals, the CCPs offer a range of cancer chemotherapy and follow-up care for most cancer diagnoses, and eliminate the need for patients to travel to Winnipeg for this portion of their cancer care. The CCPs operate under a shared-care model (CCP staff and direct service costs are the responsibility of the regional health authority) with the specialist oncologists retaining the overall responsibility for the patients' treatment plans. Together, the oncologists and CCMB oncology staff work in concert with the family physicians, surgeons, registered nurses and pharmacists at the local CCPs, which deliver the same care the patient would have received at CCMB, or at a Winnipeg community oncology site, had the patient opted to remain in Winnipeg for their chemotherapy and follow-up care.

To ensure quality cancer care is provided at the CCPs, the CCPN provides support to all fourteen CCPs. Support includes CCP staff initial orientation and education, ongoing CCP staff education, clinical support, medical direction, information management, and ongoing collaboration. The CCPN promotes interaction among the CCPs and CCMB through ongoing teleconferences, an annual provincial educational conference for CCP staff, and annual site visits. Through the CCPN, CCMB is able to ensure the delivery of quality decentralized oncology services to a standard consistent with its provincial mandate. Continued quality improvement, safe patient care, communication and program partnerships are supported through regular contact, annual site visits, and strong working relationships with all current CCPs.

1.5 Information Infrastructure

CCMB has developed and been involved in the facilitation of a broad information infrastructure. Partnerships with the Manitoba Telehealth Network have been critical to the development and expansion of Teleoncology. As well, CCMB has implemented an electronic patient record that enables care providers to share patient information in a timely manner.

The CCPN is responsible for managing CCMB's use of videoconferencing via the MBTelehealth Network. Teleoncology is the term used at CCMB when referring to videoconferencing in the oncology setting. This new and exciting technology is used at CCMB for clinical care (patient assessments and consultations), educational events (e.g., clinicians participating in clinical rounds held both nationally and internationally), as well as a weekly link to the St. Boniface Unit of CCMB to televise Rounds to CCMB staff working from that site. Administrative events such as job interviews and meetings are also conducted via Teleoncology. This technology has afforded CCMB new ways of improving access to care, and breaking down the geographical barriers to care.

CCMB is also responsible for the operation of the Manitoba Cancer Care Network (MCCN), an electronic patient record that enables CCMB, the community oncology programs and CCP sites to share patient information in a timely manner. This electronic patient record ensures that all oncology care providers have access to pertinent information and affords a format for communication between oncology caregivers.

1.6 Urban Primary Care Oncology Network

Recognizing the need to establish stronger linkages with the Winnipeg primary care community, CCMB developed a proposal and received funding from the federal Primary Health Care Transition Fund (PHCTF) in June 2003. This funding has allowed CCMB to establish the Urban Primary Care Oncology Network (UPCON).

UPCON currently benefits Manitobans by creating links with twelve medical clinics and community health centres in Winnipeg. These links help participating family doctors, other primary health care professionals and cancer care specialists to communicate about patients more easily, and ensure that people with cancer experience better coordination of their care between their different care providers. Lead physicians and nurses from each clinic receive in-depth training in cancer and palliative care, as well as education to enable them to advise their patients and colleagues about navigating the cancer and palliative care systems.

Linkages include access to the electronic CCMB patient chart for the participating primary health care clinic staff, as well as enhanced cancer-related education for the family physicians and primary health care staff who then serve as a resource to their colleagues. Enhanced partnerships between CCMB staff and these members of the Winnipeg primary health care community will result in better patient care.

1.7 CancerCare Manitoba Foundation

The CancerCare Manitoba Foundation supports the mission of CCMB by enhancing our efforts through sustained and unfaltering support in the form of community efforts and effective fundraising. Through their efforts, and the efforts and generosity of numerous Manitobans, millions of dollars are provided each year for ongoing support of cancer research and better care for Manitobans living with cancer. The efforts of the Foundation, and the generous support of individual Manitobans and corporations, provide funding for investments in infrastructure (buildings and equipment), the education of oncology professionals, enriched and supportive care for patients, and a full range of basic and applied research.

1.8 Health System Partners

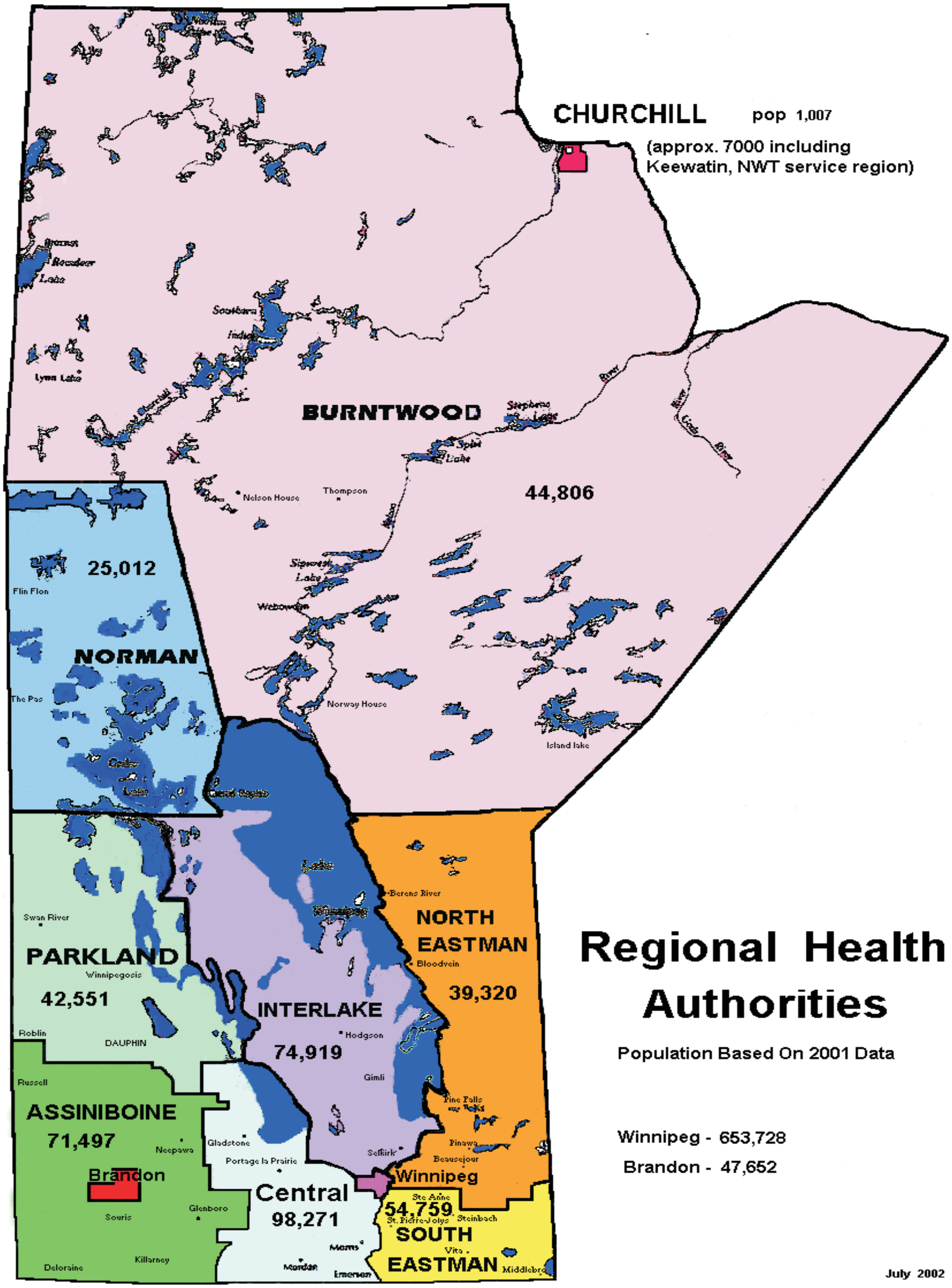
CancerCare Manitoba achieves is mission through partnership with the Manitoba health care system. These partnerships exist at every level, between boards and executives and between the full range of clinicians involved in the care of cancer patients. The majority of costs in support of the cancer patient are borne by the Regional Health Authorities (RHA) in Manitoba. They provide diagnostic, surgical, inpatient and palliative care. A map of the RHA`s in Manitoba shows their geographic boundaries and population sizes. Achieving the goals of cancer control from prevention to palliation, and more specifically those associated with the provision of high quality, accessible and equitable care will build on these partnerships.

1.9 Conclusion

CCMB has evolved from its more concentrated beginnings as a Winnipeg-based organization concerned with cancer treatment to an encompassing organization that is provincially active across the cancer-control spectrum. As the mission of the organization requires excellence, continuous change and improvement will be required in order to respond to the increasing burden of cancer in the population. The Community Health Assessment (CHA) serves as a tool to assess the current state of the system, and to identify priority areas for the most effective use of resources, and the highest quality of care to patients, as a centre of excellence for cancer care.

The challenges for our organization will be to take the information of this CHA and integrate the findings into upcoming strategic and operational planning processes. The analysis of the current situation forms the baseline against which the organization will be measured in the next cycle of the CHA in five years time.

Map of Manitoba



Regional Health Authorities

Population Based On 2001 Data

Winnipeg - 653,728

Brandon - 47,652

July 2002

2

PURPOSE OF COMMUNITY HEALTH ASSESSMENT

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2.0 PURPOSE OF COMMUNITY HEALTH ASSESSMENT

A Community Health Assessment (CHA) serves as a strategic, evidence-based process that identifies the strengths and needs of a community and the health systems that support them. This process enables evidence from a variety of sources, including consumers and partners, to establish health priorities, effectively building the foundation for collaborative action planning. The CHA was established as a tool to identify and improve community health status and quality of life.

The CHA serves as a guiding document to the establishment of organizational policies and priorities. Engaging in the process enables CancerCare Manitoba (CCMB) to establish baseline data describing the current state of the people of Manitoba and the organization of the healthcare system as it affects cancer patients. It is this baseline that serves as evidence to support the continuation of successful and beneficial programs, as well as the impetus for improvement of services where needed and the establishment of new services according to population, patient and health system needs. The CHA also serves as an important tool in creating accountability to the community CCMB serves, while remaining faithful to the original mandate of the organization and the priorities of our funding partner, Manitoba Health.

Each of Manitoba's Regional Health Authorities (RHAs) is required to complete a CHA to comply with *The Regional Health Authorities Act* of 1997. Although CCMB does not fall under this legislation, Manitoba Health has required CCMB to perform an assessment of the population's cancer services needs of the population. The information provided to Manitoba Health through the completion of this CHA is important in creating a foundation for maintaining, improving, developing and implementing strategies to create sustainable and integrated health services.

Manitoba Health released a document in 1996 entitled *A Planning Framework to Promote, Preserve and Protect the Health of Manitobans* that speaks to the role of each RHA and CCMB, as well as the role of the Minister of Health. This document states that the Minister of Health is responsible for determining and developing provincial strategies, determining core services, ensuring accountability for public spending, ensuring needed legislation, and approving RHA health plans. In return, the RHAs and CCMB are responsible for determining and developing regional strategies, assessing regional health status and needs, carrying out the community health assessment, managing the organization and delivery of health services, and developing and submitting health plans. This identification of roles and expectations illustrates the importance of the CHA in the provision of health care in the Province of Manitoba.

In addition to defining the roles of the RHAs and CCMB in preparing CHAs, Manitoba Health has identified the following purposes for their completion:

- To inform the Regional Health Authority RHA/CCMB Strategic Planning Process
- To inform RHA/CCMB communities and stakeholders
- To inform the Department of Health strategic planning and performance deliverable process
- To inform consultants and liaisons about the RHA/CCMB
- To inform evidence-based decision making (e.g., to enable the Department of Health to support RHA health plan requests, and the development and implementation of policies)

As the first CHA CCMB has undertaken, this document will serve as a guide illustrating the state of the current system, while revealing future opportunities. This document will be used as a critical planning tool for CCMB, Manitoba Health, as well as our partners, the RHAs, in order to continue the provision of cancer-related services to the population of Manitoba, especially cancer patients and their families.

3

METHODOLOGY

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3.0 METHODOLOGY

A Steering Committee was formed in January 2003 to oversee as well as guide the process of the CancerCare Manitoba (CCMB) Community Health Assessment (CHA). Under the direction of the Steering Committee, it was decided that this assessment would use the cancer control framework as a lens for viewing the population and service provision, and focus on issues of accessibility.

The CCMB Steering Committee was comprised of:

Vivian Bicknell – Community Cancer Programs Network, Administrative Director

Karen Fletcher – Director of Nursing

Marion Harrison – Director of Screening

Alason Lorimer – Patient Representative

Kathi Neal – Communications Co-ordinator

Patrick Saydak – Planning Associate, Provincial Director, Cancer Control and Program Planning

Dr. Jeff Sisler – Director of Primary Oncology

Kathy Suderman – Provincial Director, Radiation Therapy Program

Jill Taylor-Brown – Director Patient and Family Support Services

Dr. Donna Turner – Epidemiologist

Linda Venus – Provincial Director, Cancer Control and Program Planning

EPI Research Inc. was commissioned to work with the Steering Committee in April 2003 for the purpose of producing the Community Health Assessment CHA. The firm was responsible for reviewing appropriate data and information sources and arranging consultations in developing the framework for the CHA, and preparation of the CHA document. The Steering Committee met directly with EPI Research Inc. on six occasions, in addition to task specific sub-committee meetings.

In recognizing the multi-disciplinary nature of CCMB, the key partnerships with external stakeholders and the diversity of the patient population, the Steering

Committee acknowledged the need for EPI Research Inc. to conduct consultations. These consultations were conducted with physicians, Regional Health Authority (RHA) administration, cancer patients, family members of cancer patients, and recently bereaved friends and family of cancer patients. EPI Research Inc. developed the focus group questions and methodology and facilitated the focus groups. Interviews with key stakeholders and focus groups were conducted in May and June 2004.

The CHA is structured around two components:

1. **The review of existing and developing data sources to serve as the foundation for understanding the operational environment of CancerCare Manitoba.**

In identifying the relevant data sources, three provincial sources and three national sources of data and information were determined to be particularly relevant. These sources serve as the statistical basis of the CHA and include:

A. CancerCare Manitoba

- Manitoba Cancer Registry – provincially mandated to collect information on all individuals diagnosed with cancer; provides reports pertaining to cancer incidence, prevalence, projections and mortality
- Screening Programs – the breast and cervical screening programs report screening rates and population penetration
- Patient Representative – the Patient Representative Database captures patient feedback, providing data for quality audit and staff commendation
- Service Utilization – data are collected on patient utilization of radiation therapy and chemotherapy services and are reported for a variety of organization, administrative and facility planning purposes
- Waiting Times – Radiation Therapy collects and publishes information related to access to radiation therapy services, which is available to the public on the Manitoba Health website
- Patient Family Support Services (PFSS) – data are captured and reported pertaining to the use of PFSS
- Community Cancer Programs Network (CCPN) – data are collected by the CCPN including activity data and patient satisfaction surveys

B. Manitoba Health

- Manitoba Health collects information about the provision of all health care services in the province of Manitoba. Publications include regional and provincial health status indicators, as well as health determinants and population estimates.

C. Acumen Research 2003 Telephone Survey of Regional Health Authorities

- Eight of the eleven RHAs (excluding Winnipeg, Burntwood and Churchill) participated in a telephone survey pertaining to accessibility to a primary health care provider. CCMB obtained permission to access the data for the purpose of the CHA.

D. Statistics Canada

- 2001 Census data
- Canadian Community Health Survey (CCHS) data from Cycles 1.1 (2000-01) and 2.1 (2003)
- National Population Health Survey (NPHS) 1994/95, 1996/97 and 1998/99.

Although both the CCHS and NPHS are important sources of nationally comparable health status and determinants data, their methodologies must be taken into consideration. These surveys are conducted as a household survey for residents aged twelve and over; however it does not reach households located on a reserve, or residents of institutional settings including personal care homes. In order to statistically correct for this methodology, weighting by age group and gender is applied to most accurately reflect regional, provincial and national experiences.

E. Canadian Cancer Statistics, National Cancer Institute of Canada

- The National Cancer Institute of Canada reports information aggregated at both the provincial and national level. Publications centre on cancer incidence, prevalence, mortality and projection estimates. The reports that were used for this report included historical information up to 2001, and estimates for the years 2001-2004.

F. Peer Reviewed Journals

- Literature reviews were conducted in relation to the topics of cancer risk factors and service accessibility. Relevant resources are listed at the conclusion of each chapter.

2. Stakeholder Consultation

The Steering Committee, in conjunction with EPI Research Inc., identified the need for consultations with people who have been affected by cancer, the Urban Primary Care Oncology Network (UPCON) physicians, and RHA senior administrators. EPI Research Inc. developed and conducted all focus group sessions with each of the groups identified.

A. People who have been affected by cancer

- Patients with a recent cancer diagnosis
- Cancer patients who attended CCMB for treatment
- Cancer patients who did not attend CCMB for treatment
- Cancer survivors
- Recently bereaved family and friends of cancer patients

Eleven focus groups were conducted with individuals who had been affected by cancer. In recognizing the provincial mandate of CCMB, it was important that the focus groups be representative of the patient population. Therefore, of the eleven sessions, three were held in rural locations - Thompson, Neepawa and Beausejour. Of the remaining focus groups, all were held at CCMB, with the exception of one that was held at the Mount Carmel Clinic. This special urban site was chosen in an attempt to reach the patient population living in the inner city where cultural and other access issues may have limited contact with CCMB.

Potential focus group candidates were identified through collaboration between the Patient Representative, the Director of PFSS, and the Administrative Director of the CCPN. Prospective participants were selected based upon specific criteria, including date of diagnosis, as well as services used in selecting a representative sample. To solicit their participation in a focus group session, a CCMB staff member contacted individuals who qualified based upon the selection criteria. Those who agreed to participate received a letter of confirmation indicating the date and time of the selected focus group session, and received a phone call one day prior to the session to remind them of the focus group. Exceptions to the focus group sessions were made for two families of pediatric patients, who were unable to attend the scheduled sessions. One-on-one sessions were conducted with these two families.

Prior to the commencement of any of the focus sessions each participant was required to sign a statement of consent. A facilitator, in conjunction with an administrative assistant, conducted each focus group. A social worker was in attendance at all focus group sessions to provide support to focus group participants as necessary, and information was made available for participant follow-up support.

The focus group sessions were intended to receive participant response on a wide breadth of questions relating to the cancer trajectory. The focus group discussion tools used in the sessions for people affected by cancer are available in Appendix A.

B. Urban Primary Care Oncology Network physicians

Eleven family physicians participated in the focus group targeted to physician members of the UPCON. The participants discussed the family physician perspective in interacting with CCMB. Specifically, the hour-long session addressed obstacles in navigating and accessing CCMB services and information systems, as well as possible improvements in partnerships that would positively impact patient care. The discussion tools used in guiding the dialogue are available in Appendix B.

C. RHA Senior Administrators

In recognizing the importance of the partnerships with RHAs in providing patient care through the Community Cancer Programs, as well as the growing burden of cancer in the population and its corresponding care patterns, ten interviews were conducted representing ten of the eleven RHAs in Manitoba. Interviews were conducted over a three-week period in May 2004, and were limited to one and a half hours. These interviews covered issues corresponding to the continuum of cancer care (prevention, early detection, diagnosis, treatment, follow up, and palliative care) within the region. These discussions also focused on services currently available, as well as areas for improvement, concluding by defining the existing relationship between the RHA and CCMB. The discussion tools used to facilitate these interviews are available in Appendix C.

The ten RHA representatives interviewed for the purpose of the CHA were:

- Barbara Dreher, Executive Director of Clinical Services, NOR-MAN Regional Health Authority
- Judy Coleman, Acting Vice President of Programming and Services, North Eastman Health Authority
- Nadine Volanski, Program Manager OR and Chemotherapy and Dialysis; Dr. Walter Reynolds, physician, Margaret Paradis, chemotherapy nurse, Burntwood Regional Health Authority
- Pat Cockburn, Vice President of Communications and Long Term Care, Assiniboine Regional Health Authority
- Jan Currie, Vice President and Chief Nursing Officer, Winnipeg Regional Health Authority
- Dianne Mestdagh, District Director South East; Lorne Charbonneau, Vice President of Health Services, Interlake Regional Health Authority
- David Driedger, Facility Manager, Bethesda Hospital, South Eastman Health
- Jan-Marie Graham, Program Leader for Palliative Care and Mental Health, Regional Health Authority – Central Manitoba Inc.
- Kathy McPhail, Vice-President of Acute Care and Diagnostic Services, Brandon Regional Health Authority
- Pat Yaskiw, Director of Clinical Services, Swan River Health Facility

The discussion results of the focus group sessions form a platform upon which CCMB is able to evaluate its current services, as well as a forum for discussion of service improvements and expansion of partnerships in providing excellent patient care.

This report thus relies upon both qualitative and quantitative data sources in attempting to provide a picture that most accurately reflects both the current and future position of Manitoba, its population, and the health service needs of cancer patients.

4

THE COMMUNITY

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4.0 THE COMMUNITY

The provincial mandate of CancerCare Manitoba (CCMB) means that the "community" includes all residents of Manitoba. This chapter will explore the demographic characteristics of the population, risk factors associated with cancer, and health practices and knowledge among Manitoban residents. This chapter serves as an environmental analysis of the CCMB community, which incorporates all Manitobans.

KEY FINDINGS

This chapter defines the population and identifies both current and future health issues that will affect the provision of excellent cancer care. The key findings of this chapter are:

- The Manitoban population is aging, with the population over 65 expected to grow by 47 per cent by 2025.
- The Aboriginal population has a lower proportion of the population aged 65 and over than the cumulative provincial population; in addition, the Aboriginal population is the fastest growing ethnic segment of the province.
- Socio-economic, cultural and language barriers may prevent optimal cancer care. Strategies have been developed in some areas of CCMB, specifically Screening Programs, to address these issues. Such strategies may be more broadly applied throughout CCMB to provide patient care reflective of the needs of the population.
- Opportunities exist in primary prevention activities in relation to lifestyle choices. Areas of concern include obesity rates, inactivity rates, tobacco use, exposure to ultraviolet rays, alcohol consumption, access to primary health care, and sexual health.
- Smoking rates are still high among the population but are decreasing, especially among men. The introduction of a province-wide smoking ban may affect these rates, as well as the rates of exposure to second-hand smoke. Decreasing the rates of smoking in the province will directly reduce lung cancer incidence.

- Despite controlling for both lifestyle and environmental factors, heredity may influence the incidence of cancer. It is important to reduce risks as much as possible; however, much remains unknown about the development of cancer, and therefore it is a disease that cannot yet be fully prevented.

- CCMB provides population-based screening programs for breast and cervical cancer. In response to national recommendations, the organization is in the process of examining the possible models of a colorectal cancer screening program.

- The Manitoba Breast Cancer Screening Program has achieved screening of approximately fifty per cent of the target population. This volume is less than the target of seventy per cent. Reaching the target will require increased screening capacity.

- The Manitoba Cervical Cancer Screening Program has established a provincial registry to track Pap test use and monitor appropriate follow-up. The program works in partnership with primary health care providers in encouraging the use of Pap tests in the 18-69-year-old female population in compliance with cervical cancer screening guidelines.

- Primary care physicians serve as important partners in providing excellent cancer care to patients. Physicians are a critical component to the success of screening programs. Expanding partnerships and guidance as to appropriate cancer screening and cancer care is important, given the increasing prevalence of cancer in the population.

- Screening requires population participation, which requires the population to be educated, screening to be accessible, and regular reinforcement as to the importance of screening activities.

- Partnerships with external organizations, the Province of Manitoba, and Regional Health Authorities (RHAs) are essential to providing excellent cancer care to the population.

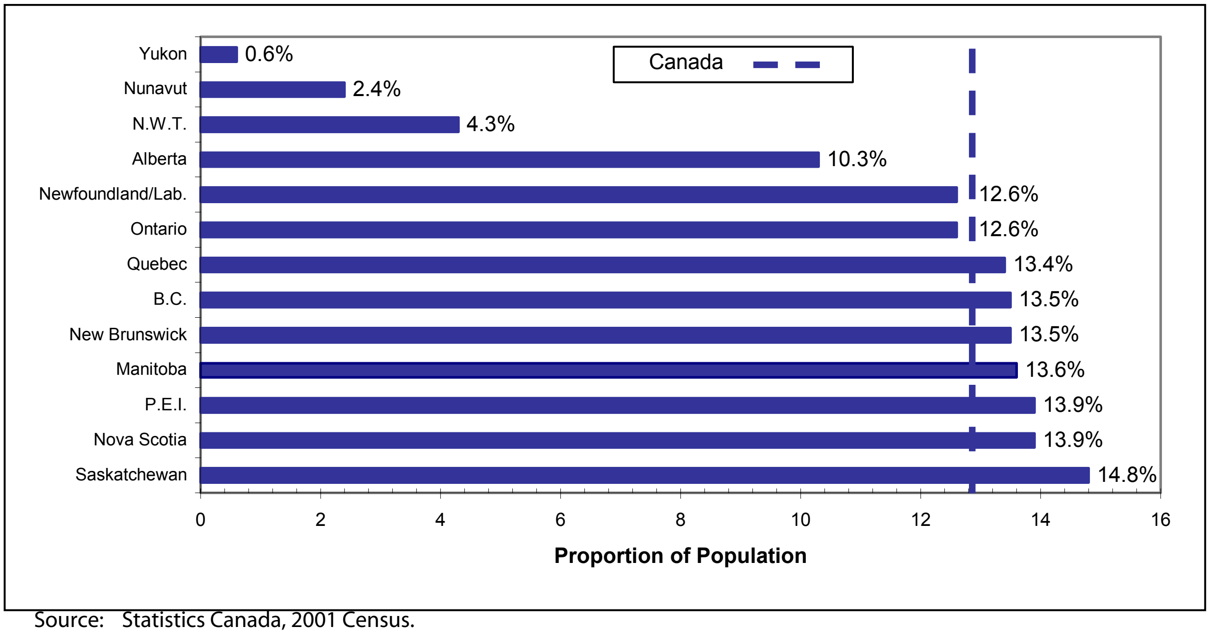
4.1 *Population Demographics*

4.1.1 Population Structure

Cancer is a disease of aging, as both incidence and prevalence is greatest among the oldest age groups. In Canada, those older than 60 years of age account for 75 per cent of new cancer cases in men, and 82 per cent in women[1]. In recognizing the correlation between cancer and age, it is important to understand the age structure of the province, as well as future aging trends.

As is displayed in Figure 4.1, 12.8 per cent of the Canadian population is over 65 years of age. At 13.6 per cent, Manitoba has a slightly higher proportion of the population above 65 years of age.

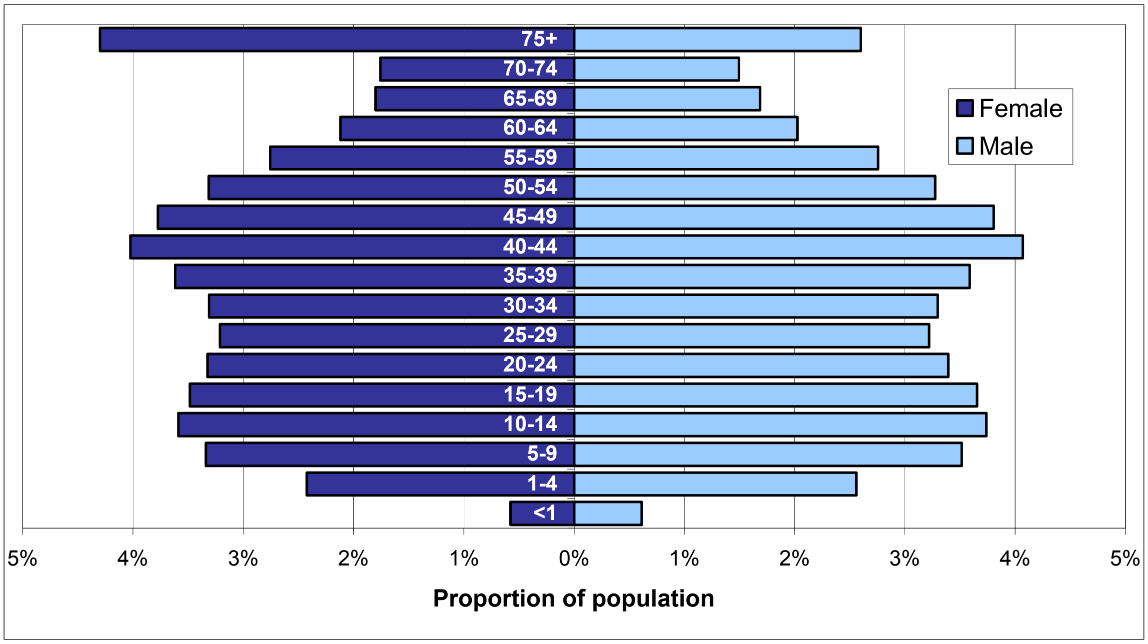
Figure 4.1 Proportion of population age 65 and older by province, 2001



Source: Statistics Canada, 2001 Census.

As of June 1, 2003, Manitoba's population was 1,159,784. The population pyramid shown in Figure 4.2 illustrates that fourteen percent of the population is over 65 years of age. The distribution of the population among the age groupings is considered "stationary", meaning a distribution that is approximately even among age groups, supported by a narrow base.

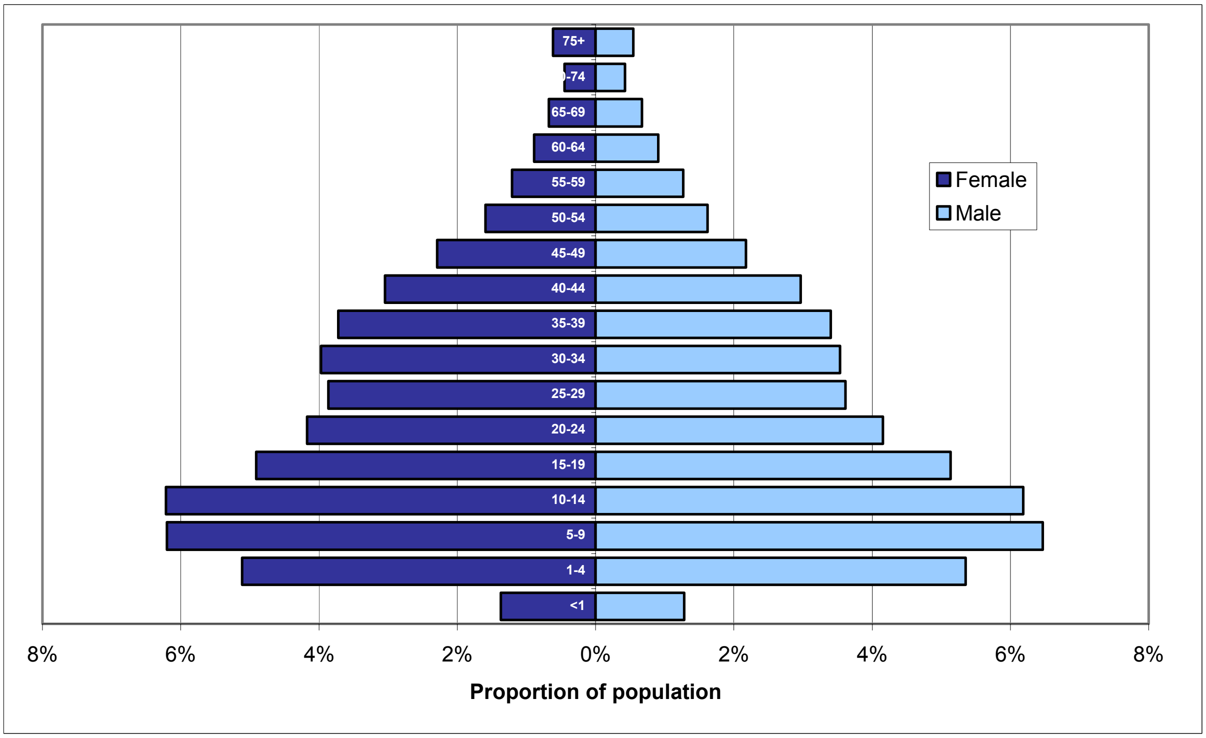
Figure 4.2 Manitoba population pyramid, 2003



Source: Manitoba Health, June 1, 2003 population estimates.

Approximately 6.5 per cent of Manitobans are of Aboriginal descent. Therefore, it is also necessary to examine the Aboriginal population pyramid in the province to best understand this population's needs. The Aboriginal population has an age structure that is distinctly different from the province-wide structure. As Figure 4.3 demonstrates, the population pyramid is "expansive", indicating a high proportion of children, rapid population growth, and a relatively low proportion in the older age brackets.

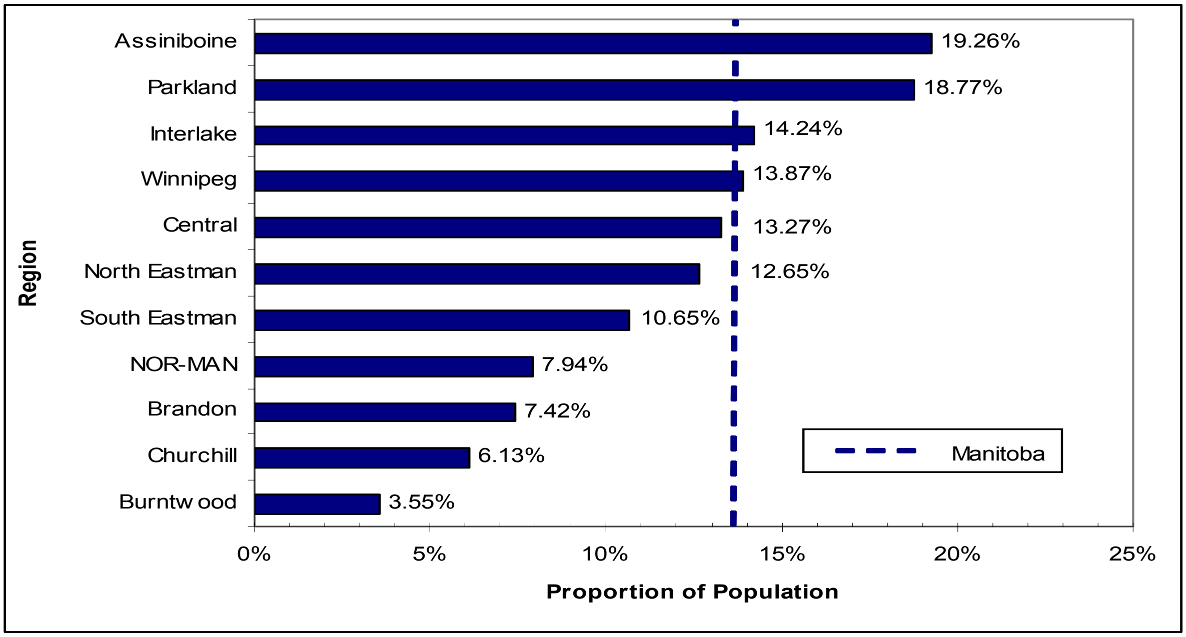
Figure 4.3 Manitoba First Nations population pyramid, 2003



Source: Manitoba Health, June 1, 2003 population estimates.

In recognizing the provincial mandate of CCMB, and in planning the provision of cancer care, it is necessary to understand the age structures within RHAs. As Figure 4.4 illustrates, there are noticeable differences between RHA age distributions. These differences may in part reflect the size and distribution of the Aboriginal population in each region of the province. While RHAs in northern Manitoba have younger populations, those regions in the south have more aged populations.

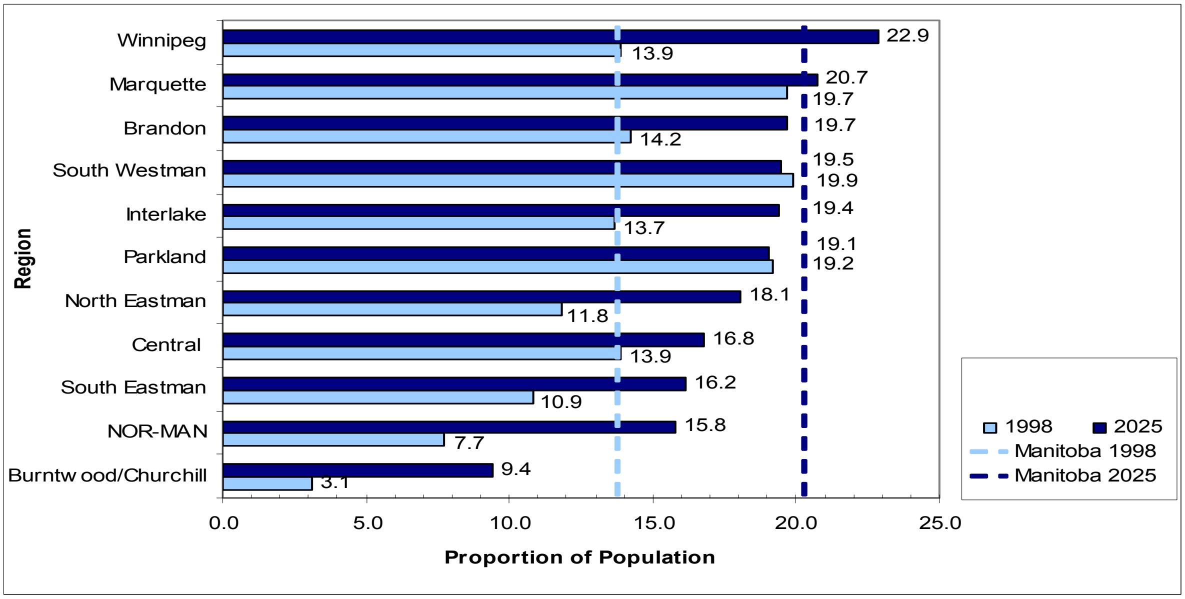
Figure 4.4 Proportion of population age 65 and older by RHA, 2003



Source: Manitoba Health, June 1, 2003 population estimates.

In order to form a complete understanding of region-specific age influences, and therefore potential demand for cancer services, trends in aging must be analyzed. In 1999, the Manitoba Bureau of Statistics released population age projections by region for the year 2025. These projections estimate a 47 per cent population growth will occur in those aged 65 and over between 1999 and 2025. This projection coupled with an estimated decrease in the youngest age groups means that the population aged 65 and over may account for 20 per cent of the provincial population by 2025. Figure 4.5 demonstrates the population change for adults aged 65 and over between 1999 and 2025 by RHA. An aging population coupled with RHA-specific growth present clear challenges but potential opportunities in providing cancer care in the future.

Figure 4.5 Projected increase in regional populations aged 65+



Source: Manitoba Bureau of Statistics, 1999.
Note: Marquette and South Westman were amalgamated to Assiniboine Region in 2003.

Understanding population age structures and the resulting anticipated increase in cancer incidence is important in projecting the need for cancer services.

4.1.2 Socio-Economic Indicators

Some research has suggested a relationship between socio-economic status (SES) and diseases such as cancer. SES includes the combined effects of income, poverty status, education and occupation. Ideally it is measured with a composite index, but often in practice only one or two of these factors may be used to indicate a person's SES.

One area requiring consideration is the potential role of SES in cancer survival. Although some studies of SES and cancer survival in Canada[2] have been inconclusive, studies in the United States, Australia, United Kingdom, Sweden and Finland have found statistically significant differences in survival based on cancer patients' SES. Of particular interest are the studies in which Canada is compared to other countries, especially the United States since it is often assumed that patients from these two countries should have similar experiences. A number of studies have examined cancer survival rates by SES in different American and Canadian cities. Of particular interest, a comparison of Winnipeg and Des Moines, Iowa, showed that cancer survival rates for women with breast cancer were significantly higher in Winnipeg.[3] Although cancer survival rates differed between Canada and the United States, there was no significant difference between high and low-income areas within Canada.[4] This finding was supported by researchers in Ontario who did find differences in cancer incidence and mortality by SES, but no differences in length of survival.[5]

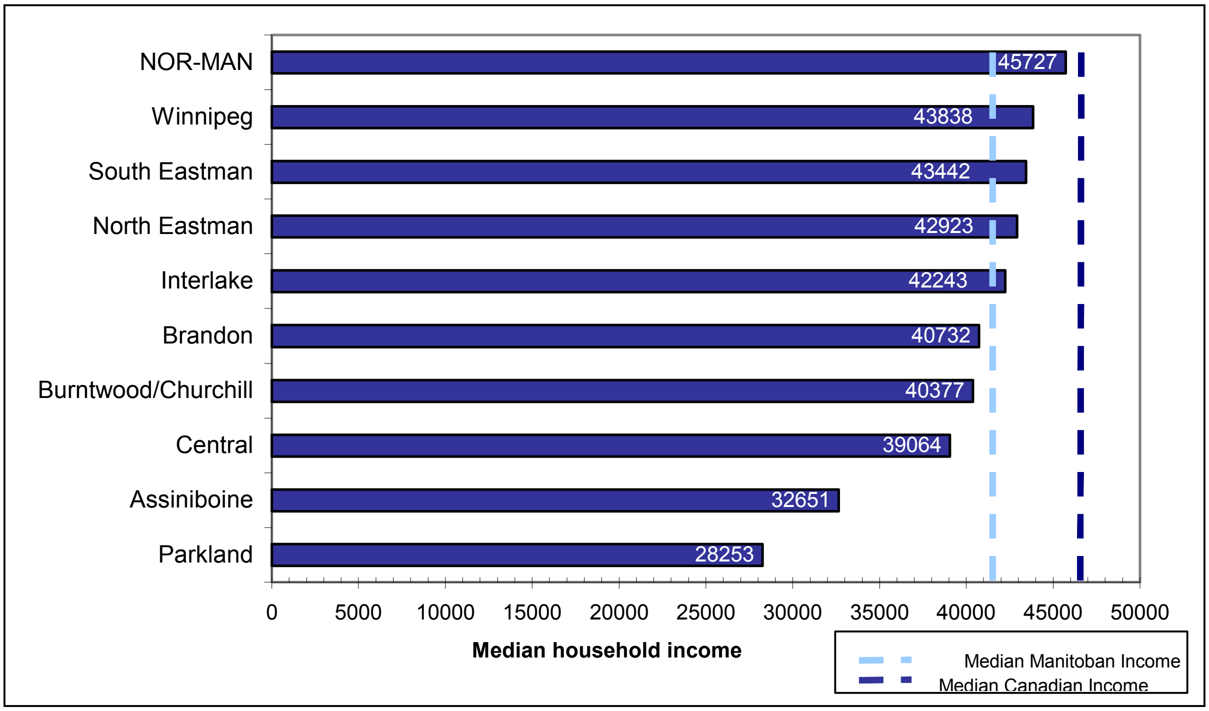
However, contradictory findings have been published in which a link between SES and cancer survival is suggested. A study conducted in Ontario found statistically significant correlation between community income and survival from specific cancers, namely head and neck, cervical, uterine, breast, prostate, bladder and esophageal cancers.[6] [7] Other studies have shown a correlation between SES and screening, in which individuals with higher SES were more likely to be screened for cancer.[8] As a result, those with higher SES may have their cancers detected at an earlier stage, which may improve their chance of survival.

The existing publications on this subject are contradictory and therefore inconclusive as to the effect of SES on cancer survival. Thus CCMB will continue to monitor associations between SES and cancer survival in published data to determine the impact of this factor to ensure that all patients will be well served, regardless of SES.

4.1.2.1 Income

Although there has been conflicting information published in relation to SES and cancer survival, it is recognized that particular socio-economic factors such as education, income and unemployment may be issues in the provision of cancer care. Figure 4.6 illustrates the median household income by RHA, as well as both the provincial and national median incomes. A median income is the point at which half of the population earns less than that amount, and half earns more than that amount. CCMB recognizes the financial challenges of having cancer, including travel costs, time away from work, and costs of childcare and accommodations when away from home. In order to ensure all patients can access treatment, a patient's financial status must be taken into account.

Figure 4.6 Median household income

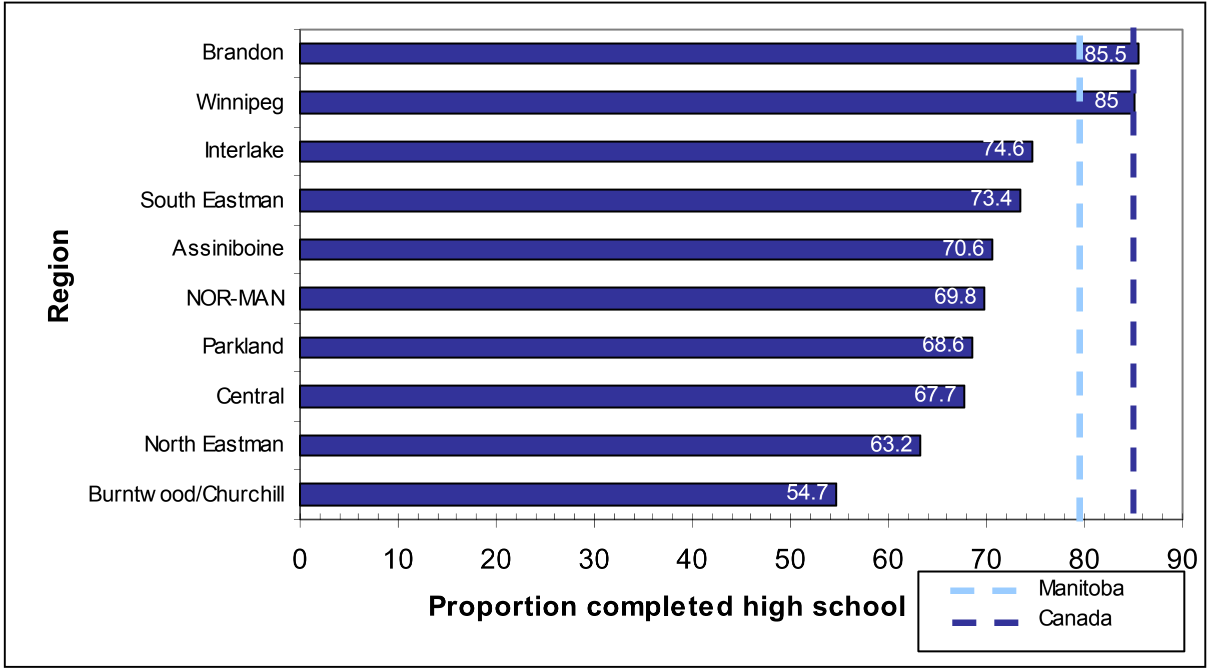


Source: Statistics Canada, 2001 Census.

4.1.2.2 Education

The Manitoban population has achieved high school completion rates of 79.2 per cent. This rate is lower than the Canadian average of 85.3 per cent. Figure 4.7 illustrates the substantial range in high school completion rates across the province.

Figure 4.7 High school completion rates among 25-29 year olds



Source: Statistics Canada, 2001 Census.

Although Manitoba is still below the national average in high school completion rates, there are improvements in the population's educational achievements. Table 4.1 demonstrates that a higher proportion of the population aged 20-34 have graduated high school compared to those in the 35-44 age group, with both graduating at higher rates than the population aged 45-64. Thus it is clear that Manitobans are achieving higher educational completion rates over time. CCMB must recognize that although education levels are increasing, the majority of cancer patients are aged 60 and over, where high school completion rates are lower. In providing patient-centred care, it is important to understand the educational levels of the patient population in targeting information, screening and patient management tools.

Table 4.1 Proportion of population with a high school certificate, 2001.

AGE GROUP	MANITOBA		
	Total	Male	Female
20-34	77.5%	74.9%	80.0%
35-44	74.4%	71.7%	76.9%
45-64	65.7%	65.2%	66.2%

Source: Statistics Canada, 2001 Census.

4.1.2.3 Employment

At 67.3 per cent, Manitoba has a higher labour force participation rate than the national rate of 66.4 per cent. Men are more likely than women to participate in the labour force. At the same time, women have a lower unemployment rate than men.

Table 4.2 Labour force indicators by sex, 2001

	MANITOBA			CANADA		
Labour Force Indicators	Total	Male	Female	Total	Male	Female
Participation rate	67.3	73.6	61.4	66.4	72.7	60.5
Employment rate	63.3	69.0	57.9	61.5	67.2	56.1
Unemployment rate	6.1	6.3	5.7	7.4	7.6	7.2

Source: Statistics Canada, 2001 Census.

The education and health care sectors employ the largest proportion of Manitobans. The province employs a greater proportion of workers in agriculture than the national rate.

Table 4.3 Employment by industry, 2001

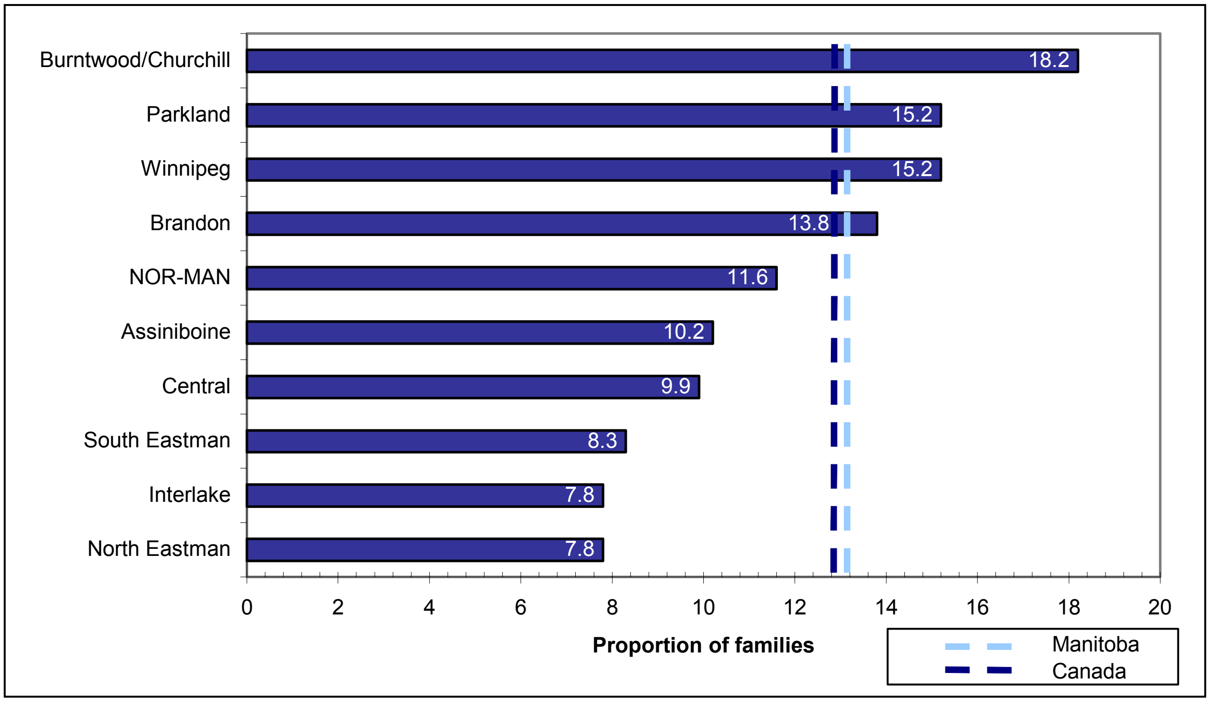
	MANITOBA	CANADA
Agriculture and other resource-based industries	8.4%	5.5%
Manufacturing and construction industries	16.7%	19.6%
Wholesale and retail trade	14.6%	15.7%
Finance and real estate	5.0%	5.8%
Health and education	19.8%	16.3%
Business services	15.2%	17.9%
Other services	20.2%	19.3%

Source: Statistics Canada, 2001 Census.

4.1.2.4 Poverty

The Low Income Cut-Off (LICO) represents levels of income where people spend disproportionate amounts of money on food, shelter and clothing. LICOs are based on family and community size, and cut-offs are updated to account for changes in the Consumer Price Index. The proportion of families at or below the LICO differs across the province. Figure 4.8 shows the variation by RHA. The provision of health care, specifically cancer care, must take into account the economic and resulting lifestyle and environmental factors of the population.

Figure 4.8 Incidence of low income families, 2001



Source: Statistics Canada, 2001 Census.

4.1.3 Culture

Communication is essential in providing excellent patient care. In order to do so, it is important to be aware of the languages that are understood by the population. Although the majority of the Manitoban population has a first language of English (74.7 per cent), or French (4.0 per cent), a significant proportion (21 per cent) has other primary languages. This must be considered in providing information, screening and treatment services.

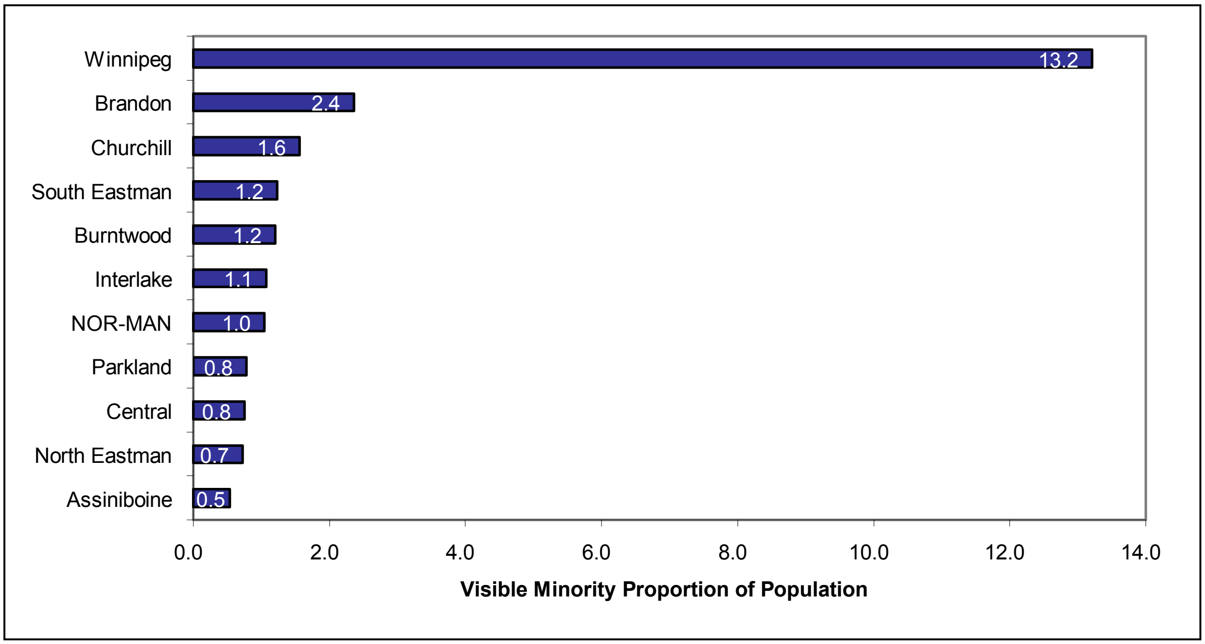
Table 4.4 Language characteristics of residents, 2001

LANGUAGE FIRST LEARNED AND STILL UNDERSTOOD	MANITOBA	CANADA
English Only	74.7%	58.5%
French only	4.0%	22.6%
Both English and French	0.2%	0.38%
Other languages	21.0%	18.25%

Source: Statistics Canada, 2001 Community Profiles.

As is shown in Figure 4.9, Winnipeg has a distinctly greater proportion of visible minorities than any other RHA. Acknowledging this difference may be beneficial to CCMB in the planning and provision of services, and in concentrating their cultural communication development in areas where it will have the greatest impact. Tools can then be developed for minority populations living in any region.

Figure 4.9 Visible minority population, 2001



Source: Statistics Canada, 2001 Census.

4.2 *Population Risk Factors*

> ***"At least 50% of cancers can be prevented through healthy living and policies that protect the public."*[9]**

Risk factors associated with cancer can be grouped broadly into three categories: lifestyle, environment and heredity.

4.2.1 Lifestyle

Lifestyle risk factors refer to factors that are part of daily living. These factors can be broken down into six categories:

- **Nutrition and physical activity**
- **Tobacco use**
- **Exposure to UVA and UVB rays**
- **Alcohol consumption**
- **Access to regular health care provider**
- **Sexual Health**

Each of these factors may lead to an increase in the risk of cancer, while in concert the risk is multiplied.

4.2.1.1 Nutrition and physical activity

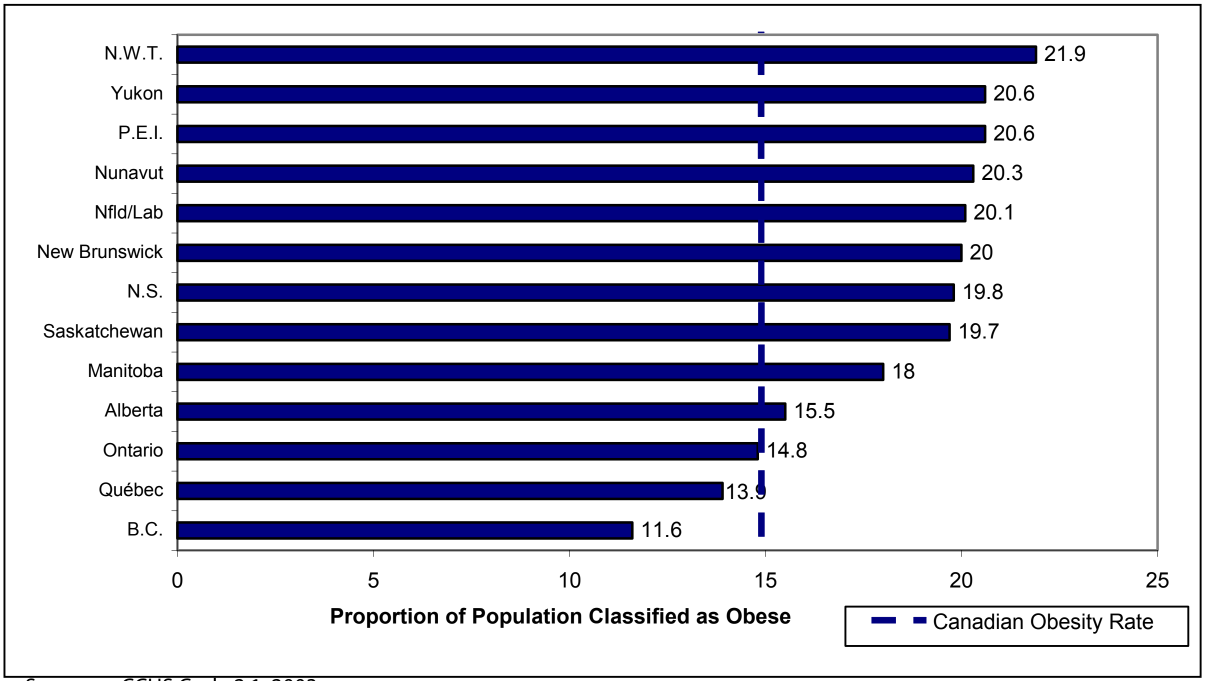
Nutrition is a lifestyle choice that affects the risks of developing cancer. Closely related to appropriate diet and nutrition, maintaining an appropriate body weight significantly reduces the risk of cancer. Obesity as been linked with a fifty per cent greater risk of developing cancer, specifically cancers with higher mortality rates such as uterine, gallbladder, kidney, stomach, colon and breast cancer. A healthy lifestyle and body weight can be achieved through appropriate caloric intake and physical activity.

> *"Overall, excess body mass accounted for 7.7% of all cancers in Canada - 9.7% in men and 5.9% in women. [There is] further evidence that obesity increases the risk of overall cancer, non-Hodgkin's lymphoma, leukemia, multiple myeloma, and cancers of the kidney, colon, rectum, breast (in postmenopausal women), pancreas, ovary, and prostate."*[10]

The measurement of body weight using the Body Mass Index (BMI) classification system identifies health risks associated with body mass. Those classified as a normal weight - calculated as a BMI between 18.5 and 24.9 - are considered to be at the least health risk. Individuals who are underweight - with a BMI less than 18.5 - and those who are overweight, with a BMI between 25.0 and 29.9 - are at increased health risk. Obesity has been classified into three levels, those being BMI between 30 and 34.9, BMI between 35 and 39.9, and a BMI over 40. As would be expected, the associated health risks increase with obesity class from high health risk to extremely high health risk.

At 18 per cent, the Manitoban obesity rate is higher than the national average of 14.9 per cent. Manitoba is still in line with many other provinces, but this level of obesity is a significant health risk in the population.

Figure 4.10 Rates of obesity (BMI > 30.0) by province and territory, 2003



Source: CCHS Cycle 2.1, 2003

In addition to the 18 per cent of Manitobans classified as obese, another 35 per cent are overweight. As Table 4.5 illustrates, males (62.1 per cent) are more likely than females (44.2 per cent) to be either overweight or obese.

Table 4.5 **Proportion of Manitoba population aged 18+ by Body Mass Index**

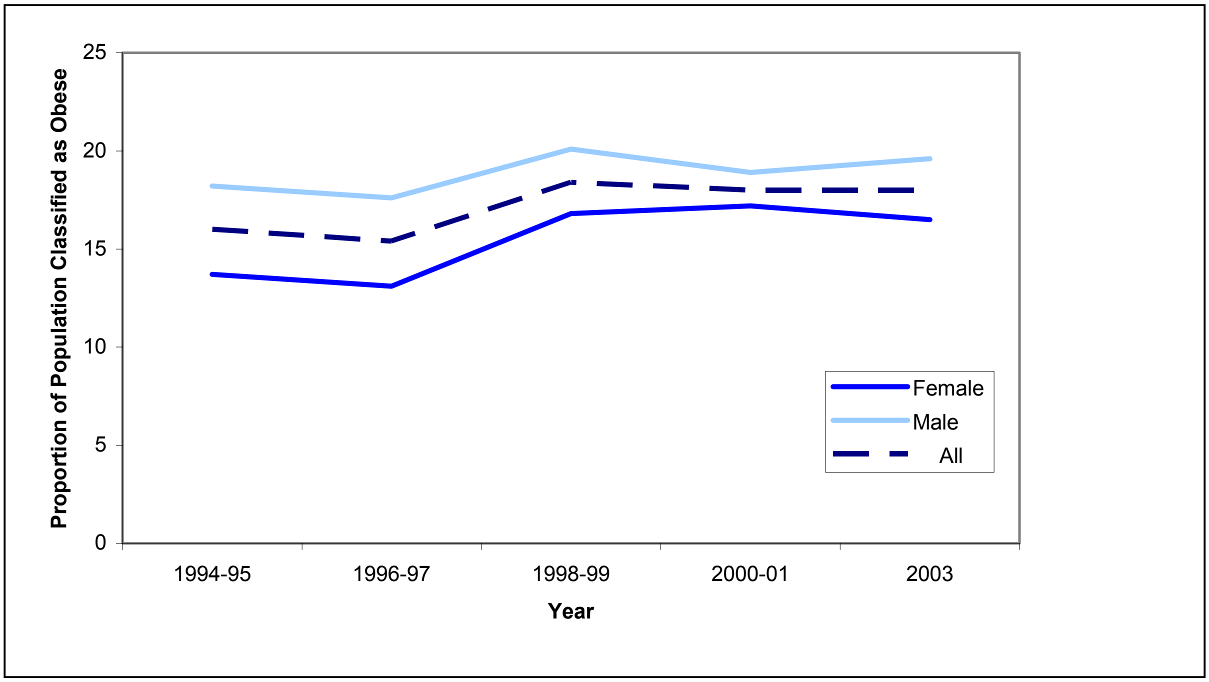
	BOTH SEXES	MALES	FEMALES
Underweight - BMI under 18.5	2.1	1.0	3.1
Acceptable weight – BMI 18.5-24.9	41.4	35.6	47.0
Overweight – BMI 25.0-29.9	35.0	42.5	27.7
Obese - BMI 30.0 or higher	18.0	19.6	16.5

Source: CCHS Cycle 2.1, 2003.

Note: Pregnant women are excluded.

In examining obesity trends over time in the Manitoban population, it is of concern that trends are on the increase. While female rates have decreased slightly since 2001, they are still much higher than in 1994. An increasingly obese population brings with it increasing demands on the health care system, including CCMB.

Figure 4.11 Proportion of Manitobans who are obese (BMI > 30.0) by year and sex, 1994-95 to 2003

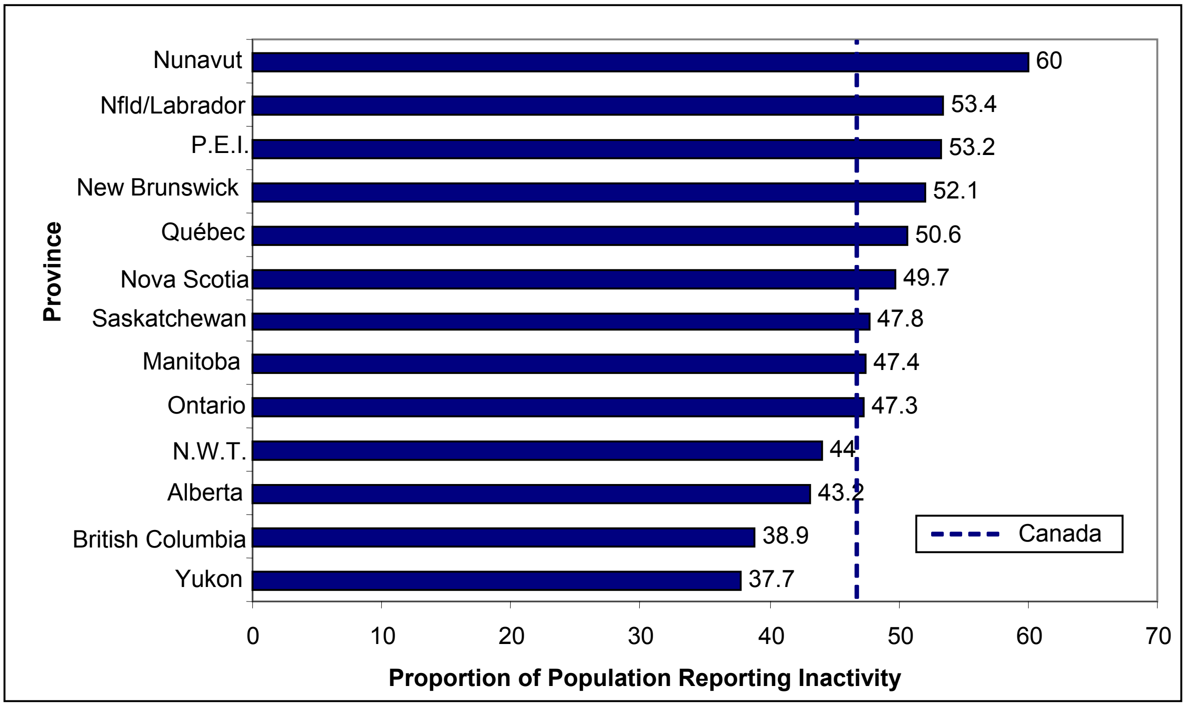


Source: 1994-1999 – National Population Health Survey, cross sectional data.
2000-2001, 2003 – Canadian Community Health Survey, Cycle 1.1 and 2.1

> *"It has been estimated that 12-14% of colon cancer could be attributed to lack of frequent involvement in vigorous physical activity."*[11]

Achieving and maintaining a healthy body weight requires both proper nutrition and physical activity. Incorporating activity is an important component of a healthy lifestyle. According to the Canadian Community Health Survey (CCHS) conducted in 2003, 47.4 per cent of the provincial population over the age of twelve is physically inactive (Figure 4.12).

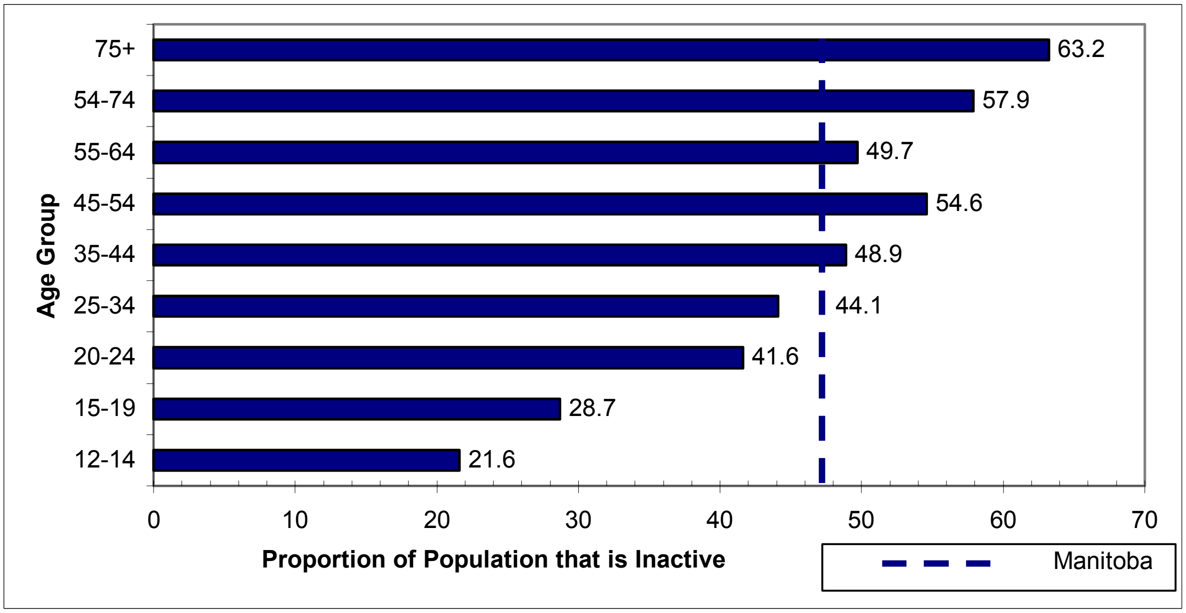
Figure 4.12 Physical inactivity among residents age 12+, by province and territory, 2003



Source: CCHS Cycle 2.1, 2003

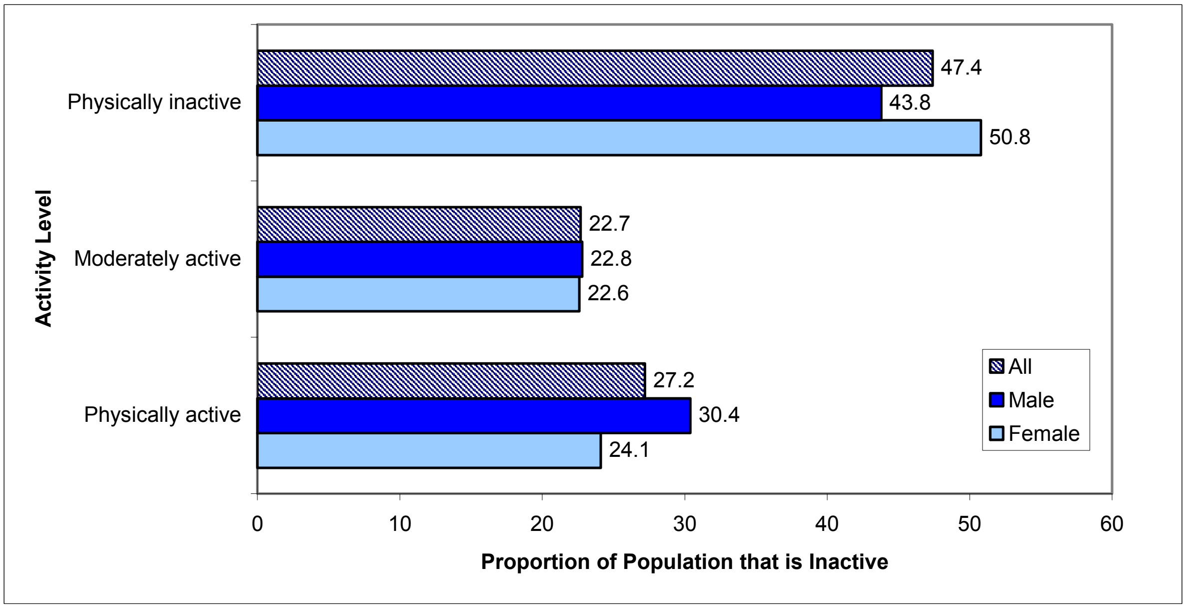
As Figure 4.13 illustrates, as the population ages it is increasingly less likely to be engaged in physical activity. As cancer may take many years to develop, lower levels of physical activity in all age groups, not just the oldest age groups when cancer is most likely diagnosed, are a concern. It is also a concern that Manitoban women are least likely to be active. Some movement toward moderative activity among the inactive populations will be an important primary prevention initiative.

Figure 4.13 Physical inactivity among Manitoba residents, by age group, 2003



Source: CCHS Cycle 2.1, 2003

Figure 4.14 Physical activity levels among provincial residents age 12+ by sex, 2003



Source: CCHS Cycle 2.1, 2003

Historically the rates of physical activity have changed very little over time. Data from 1994 through 2003 show a decrease in overall rates of physical inactivity from 51.1 per cent of the population to 47.4 per cent. This decrease is slight but should not be trivialized, as a substantial increase in activity is necessary to improve the overall health status of the population.

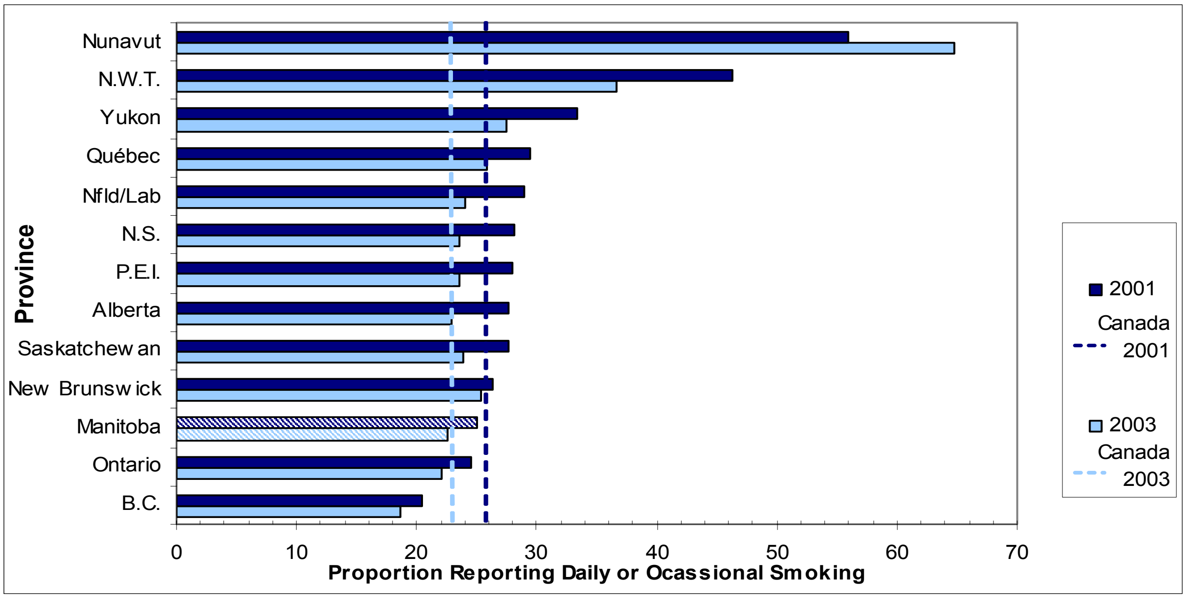
Nutrition and physical activity are risk factors in the development of cancer, and as such are of importance to CCMB. Increasing rates of obesity in the province, in concert with decreasing rates of physical activity, are of concern. In recognizing the importance of these two factors in the development of cancer, primary prevention activities targeted at improving rates of physical activity and decreasing obesity are of interest to CCMB.

4.2.1.2. Tobacco

Tobacco use is associated with lung, cervical, kidney, pancreatic and stomach cancer. The Canadian Cancer Society's 2004 Cancer Statistics Report illustrates the rapid increase in both incidence and mortality of lung cancer among women, following the trend of increasing tobacco use among women. Although lung cancer incidence and mortality among women is still lower than among men, sex-specific rates are trending in opposite directions. While tobacco consumption among men is on the decline, rates among women remain steady.

In 2003, 22.6 per cent of Manitobans (age 12 and older) reported that they were current smokers, defined as either daily or occasionally. This is noticeably lower than the 2001 rate of 25 per cent, and is slightly lower than the Canadian rate of 22.9 per cent. However, it should be noted that 17.9 per cent of the population smokes daily, with 4.7 per cent report smoking occasionally.

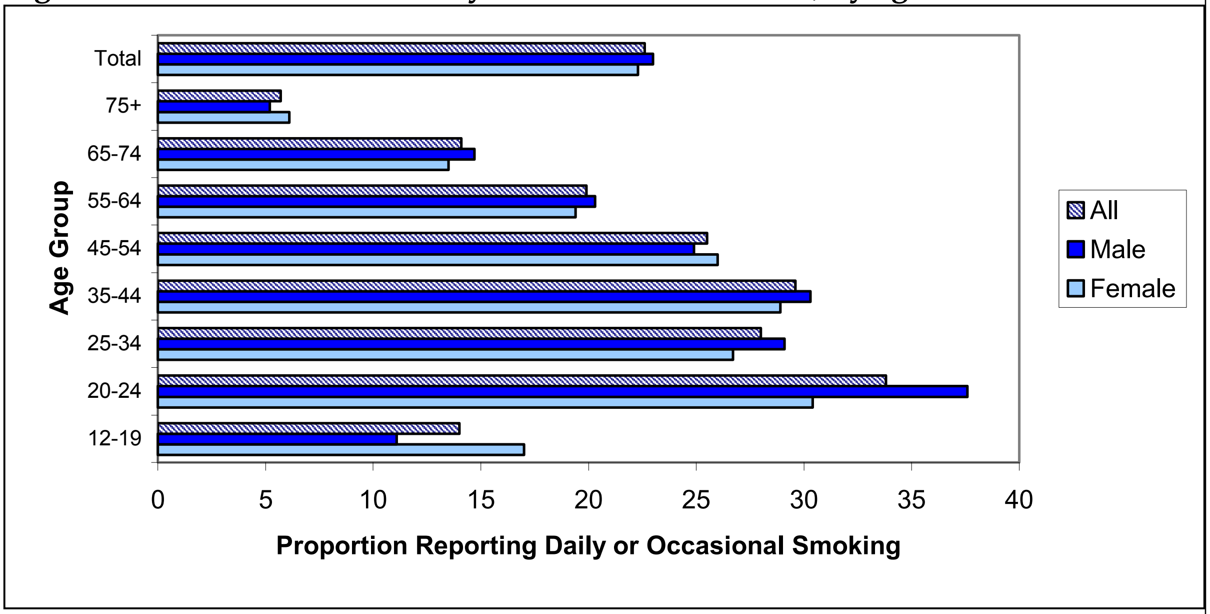
Figure 4.15 Rates of current daily or occasional smokers, by province



Source: CCHS Cycle 1.1 (2000-01) and Cycle 2.1 (2003)

Looking closer at Manitoba's situation, 23 per cent of men are current smokers, as are 22.3 per cent of women. Although this rate represents a 4.7 per cent decrease in smoking since 2001 for men, women's smoking rate remains unchanged. As is shown in Figure 4.16, smoking is most prevalent among 20-24 year olds. This is of particular interest in targeting information and resources to reduce smoking in the population.

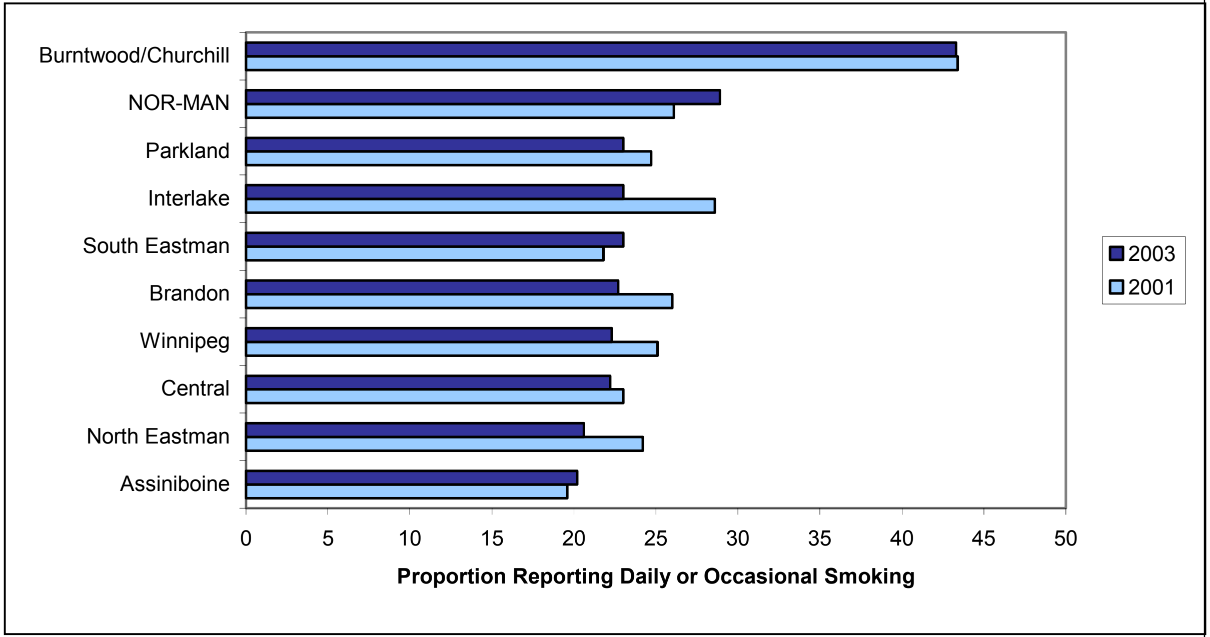
Figure 4.16 Rates of current daily or occasional smokers, by age in Manitoba



Source: CCHS Cycle 2.1, 2003

It is recognized that smoking rates vary across the province. Figure 4.17 illustrates the variation in smoking rates by RHA. It is noted that these rates have improved in all but four of Manitoba's RHAs.

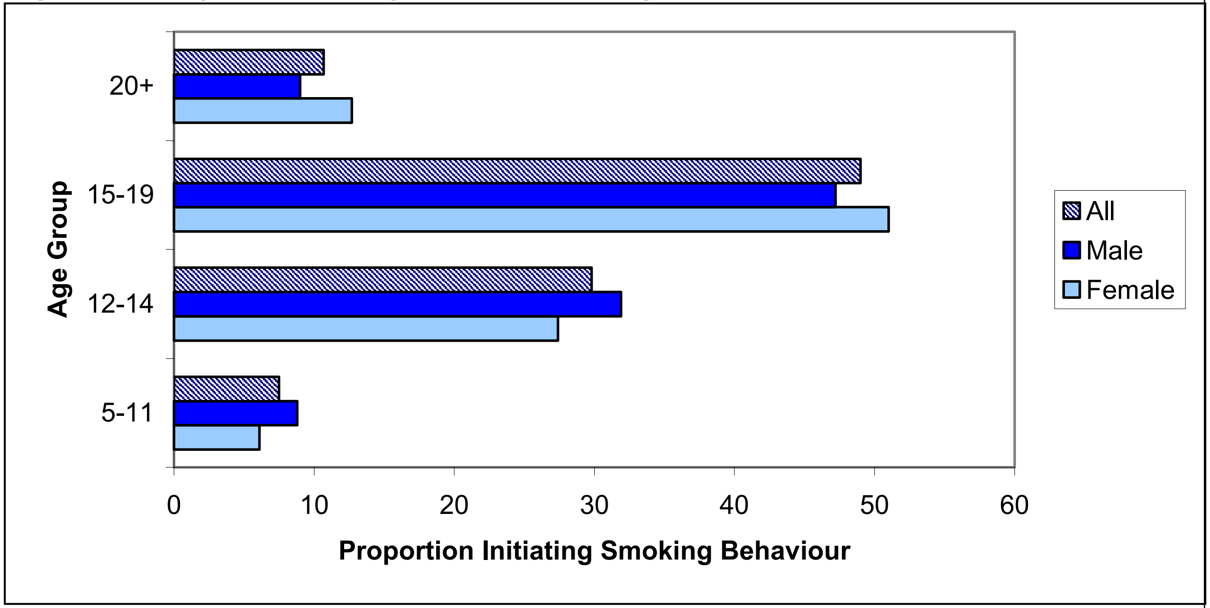
Figure 4.17 Rates of current daily or occasional smokers, by RHA



Source: CCHS Cycle 1.1 (2000-01) and Cycle 2.1 (2003).

In order to be effective in soliciting smoking cessation and preventing smoking initiation, it is important to understand when the population begins smoking. As is shown in Figure 4.18, more than one half of smokers began smoking between the ages of 15 and 19. Recognizing the age groups where smoking begins allows for targeting of resources to where they will have the greatest impact.

Figure 4.18 Age of smoking initiation among current and former smokers, 2003



Source: CCHS, Cycle 2.1, 2003

It is recognized that Manitoba is achieving an overall decrease in the smoking population. In October 2004, the Province of Manitoba implemented a province-wide smoking ban in public places. The effect of the ban on smoking rates in the province will be of specific interest to CCMB. Although cancer is a disease of relatively slow development, decreases in smoking and tobacco use will have a dramatic impact on the incidence of lung cancer and other tobacco associated malignancies in the future.

4.2.1.3. Exposure to UVA and UVB rays

> *"Skin cancer rates are increasing. The number of cases of skin cancer in Canada has increased by two-thirds since 1990. Anyone born today has a 1 in 7 chance of developing skin cancer in their lifetime."*[12]

Exposure to UVA and UVB rays is a risk factor in the development of skin cancer. The Canadian Cancer Society estimates that limiting ultraviolet ray exposure can prevent 90 per cent of skin cancers. Sun exposure is only one form of ultraviolet rays; intensive exposure through the use of sunlamps and tanning booths also increases the risk of developing skin cancer.[13] Several European studies have established an association between the use of tanning beds and the increase risk for melanoma.[14] The association is particularly strong for those who are young with fairer skin tone and regularly use sun tanning beds. One British study estimated that in the United Kingdom 100 people die every year from melanoma as a result of sunbed use.[15] Based on this scientific evidence, the use of protective lotions and limiting ultraviolet ray exposure are lifestyle choices that can considerably reduce the risk of developing skin cancer.

4.2.1.4. Alcohol consumption

> *"….Women who drink more than two beers, wines, or shots of liquor daily raise their risk of invasive breast cancer 30 to 40 per cent."*[16]

Some recent publications have associated alcohol consumption with health benefits; however, these benefits are only realized with moderate intake. Excessive alcohol consumption is a risk factor for a number of health complications including cancer. Controlled intake is important in reducing the risk of cancer.

Consuming five or more alcoholic products twelve or more times a year is defined by the CCHS as heavy drinking. According to this definition, one in five Manitobans who consume alcohol are heavy drinkers. Men are much more likely to be considered heavy drinkers (30.4 per cent) than are women (12.7 per cent).

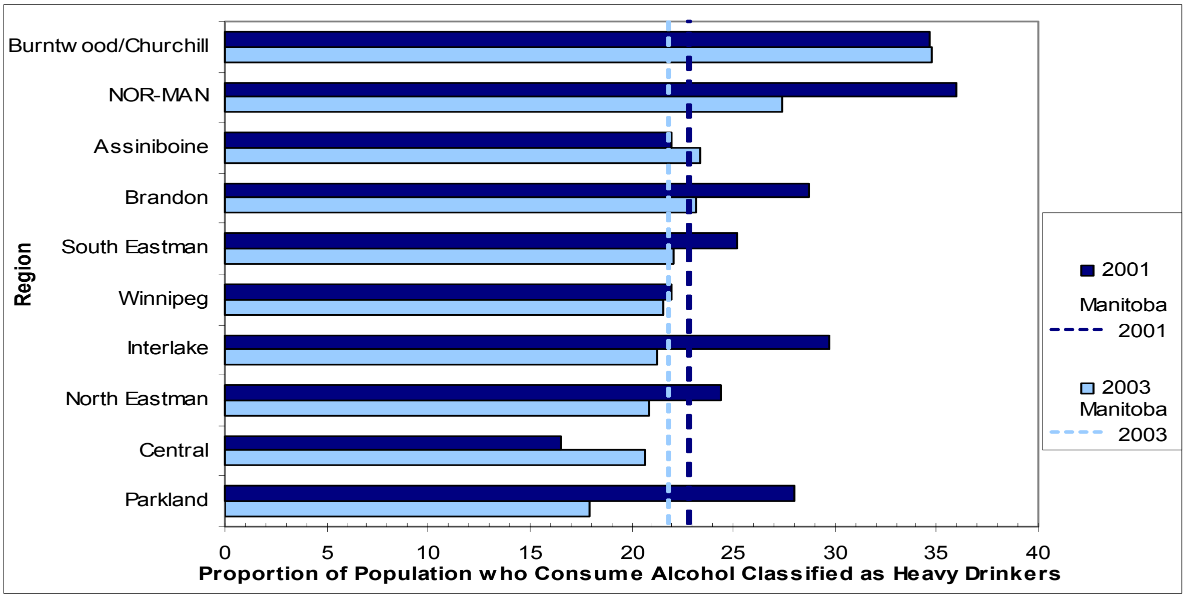
Table 4.6 **Consumption of alcohol by current drinkers in previous 12 months**

	Never 5 or more drinks on one occasion	5 or more drinks on one occasion, less than twelve times a year	5 or more drinks on one occasion, twelve or more times a year
Total	48.7	27.7	21.9
Male	38.8	29.2	30.4
Female	59.4	26.1	12.7

Source: CCHS 2003, Cycle 2.1
Note: Includes current drinkers age 12 and older.
Note: May not add up to 100% due to omission of current drinkers who did not respond.

In understanding the regional experience, Figure 4.19 illustrates that eight RHAs have had a decrease in the population classifying their drinking as heavy. Provincially the rates of heavy drinking has dropped a full percentage point from 22.9 per cent to 21.9 per cent in the two-year time period from 2001 to 2003.

Figure 4.19 Changes in rates of heavy drinking by region, 2001-2003



Source: CCHS Cycle 1.1 (2000-01) and Cycle 2.1 (2003).
Note: In 2001 Assiniboine was still Marquette and South Westman. 2001 Assiniboine rate is an average of the 2001 rate of those two regions.

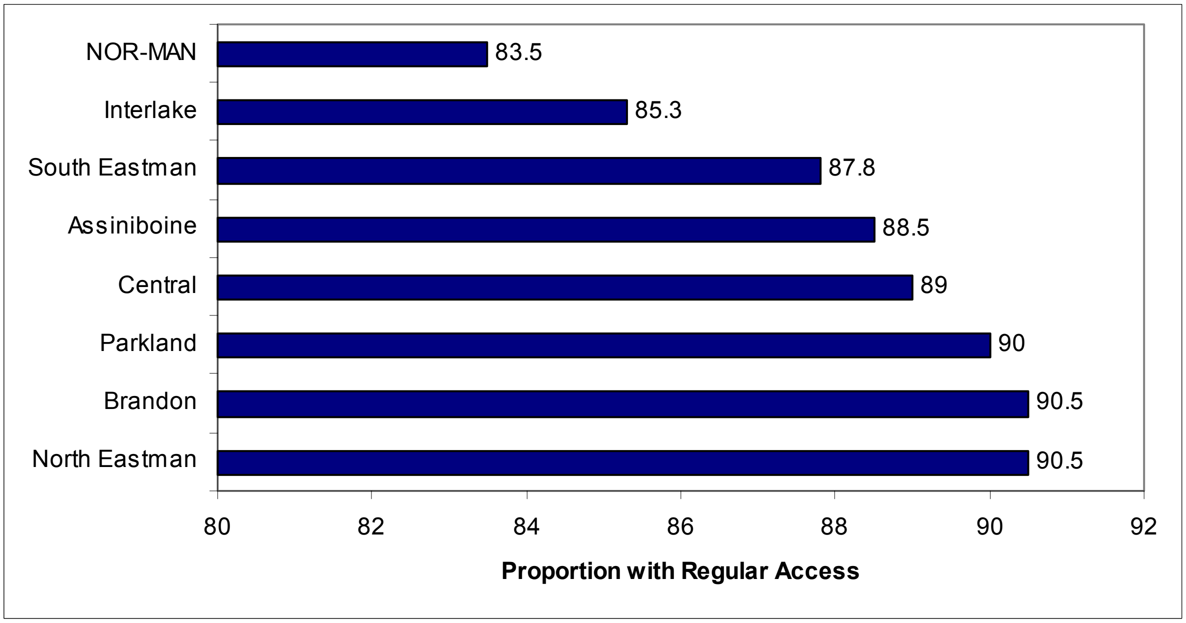
4.2.1.5. Regular health care provider

Positive health outcomes are strongly associated with patients having regular contact with their primary health care provider. Research has supported the role of the family physician in patient participation in screening programs for breast, colorectal and cervical cancer. This has been attributed to family physicians' ability to provide clear information and motivation to their patients. Given that population screening for breast, colorectal and cervical cancer leads to decreased mortality, regular access to family physicians is important in the early detection and treatment of cancer.

The continuity of primary care has also been shown to make a difference in the quality of life for cancer patients in the terminal phase of their illness. Palliative care patients often prefer to die at home rather than in a hospital setting, and research has indicated that terminal cancer patients who had regular contact with a family physician were more likely to die outside of a hospital.[17] Regular contact with family physicians also results in fewer visits to Emergency Departments for cancer patients who are palliative.[18]

In 2003, eight RHAs commissioned a telephone survey of regional residents, which included questions about access to a regular health care provider. In the participating regions, 88.1 per cent of survey respondents indicated that they did have a regular health care provider. Within the province, responses ranged from a low of 83.5 per cent of NOR-MAN respondents to a high of 90.5 per cent of Brandon and North Eastman respondents (see Figure 4.20).

Figure 4.20 Proportion of residents with regular access to health care provider, 2003



Source: Acumen Research 2003 Telephone Survey

As is illustrated above, improvements could be made to increase the access to regular health care service. CCMB recognizes the importance of partnerships between primary health care providers and cancer screening and treatment providers in delivering appropriate cancer-related services.

4.2.1.6 Sexual health

Cervical cancer and its cytologic precursors (changes in cells) occur among women who are sexually active. There are several risk factors relating to sexual behaviour that have been identified in association with an increased risk of cervical cancer. These include early onset of intercourse, sexually transmitted infection, HIV infection, and a greater number of lifetime sexual partners (and partners with a greater number of partners). Infection with high-risk strains of human papilloma virus (HPV), generally acquired sexually, is the most important risk factor for cervical cancer.[19]

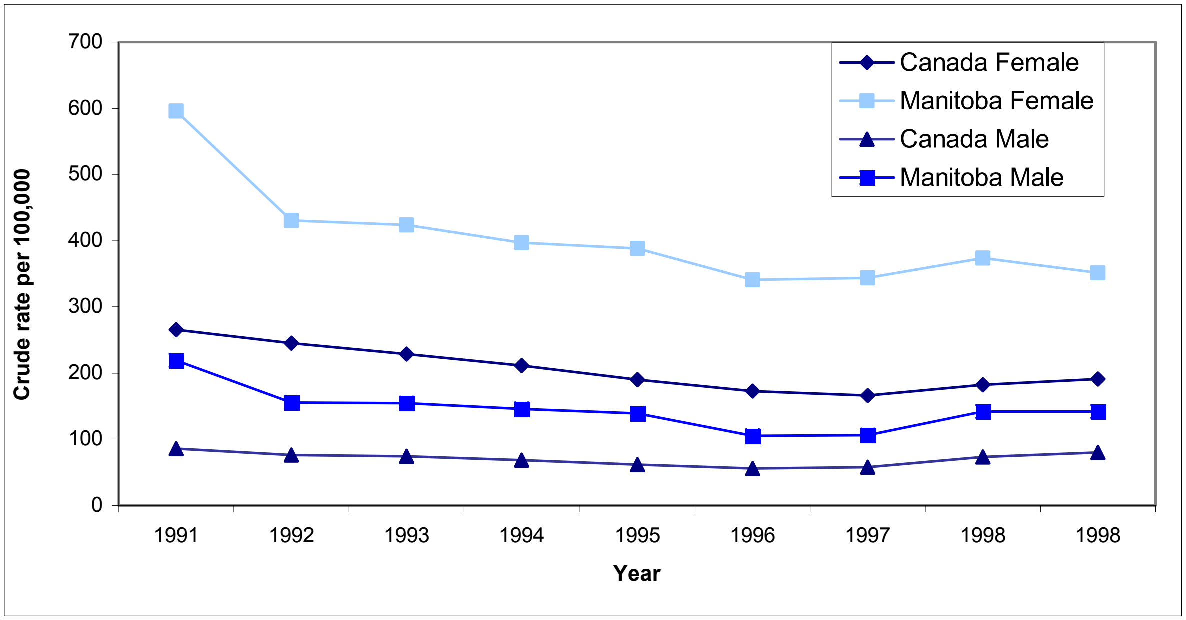
In Canada, it is estimated that the prevalence of all types of HPV (cancer and non-cancer causing) in different groups of Canadian women ranges from 20 to 33 per cent.[20] Cancer-causing types of HPV specifically have a prevalence range between 11 and 25 per cent but have been found to be as high as 49 per cent among a high-risk group of HIV-infected women.[21]

Between January 1 and December 31, 2003, 111 newly diagnosed cases of HIV were reported in Manitoba (71 men and 40 women), bringing the total number of cases to 1,097 since 1985. Overall, women represent 21 per cent of all HIV cases reported since 1985 (eight per cent between 1985 and 1994 compared to 31 per cent between 1995 and December 2003). The majority of all new cases, both men and women, were between the ages of 20 and 39 years.

Of the 40 women testing HIV positive in 2003, the predominant modes of transmission, after excluding those with no identified risk (n=6, or 15%), were sex with men who are at an increased risk of HIV (16/34 cases, or 47%) and having lived in an HIV-endemic country (11/34 cases, or 32%).

Of specific concern to sexual health are the reported rates of Chlamydia infection, which have been consistently higher among women than men. However, as Figure 4.21 illustrates, reported rates of Chlamydia among Manitobans are also very high, four times as high as the Canadian rates.

Figure 4.21 Reported genital Chlamydia cases, Canada and Manitoba, 1991-1999



Source: Division of STD Prevention and Control, Bureau of HIV/AIDS, STD

Although elimination of lifestyle risk factors is important in cancer control, cancer is a disease where a multitude of factors may lead to its development. Leading a healthy lifestyle reduces, but does not eliminate, the possibility of developing cancer. Other environmental and inherited factors also contribute to cancer incidence.

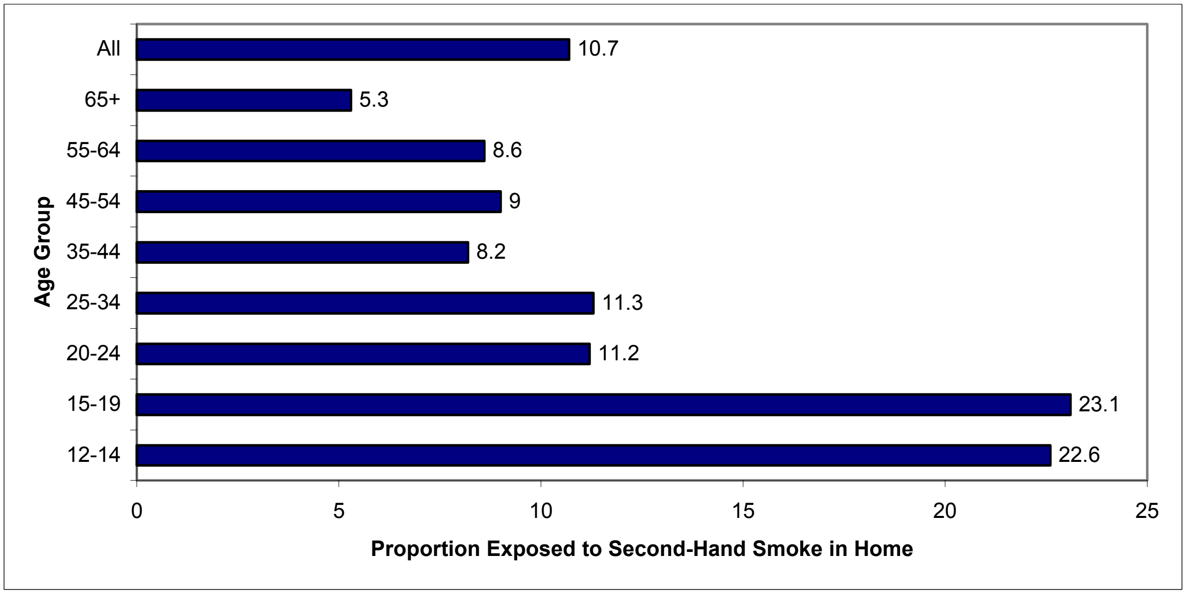
4.2.2 Environment

> *"More than 45,000 people will die prematurely this year in Canada due to tobacco use – at least 1,000 of them will be non-smokers."*[22]

The risk of developing cancer may be increased through environmental exposure to cancer-causing agents (carcinogens). In recent years it has been established that specific chemicals are, or contain, carcinogens. Based on current evidence, the Canadian Cancer Society estimates that up to five per cent of cancers can be directly linked to environmental contaminants. The Canadian Environmental Protection Act provides for strict controls of many substances deemed to be toxic, including pesticides, asbestos and air pollutants.

The harmful effects of second-hand smoke on non-smokers have also been shown in numerous studies internationally. While there is some dispute with respect to the impact of second-hand smoke, the majority of studies have shown that second-hand smoke is both harmful and deadly. In a 1993 report, the US Environmental Protection Agency estimated that cigarette smoke kills 53,000 non-smokers each year in the United States.[23] In Canada, it is estimated that second-hand smoke kills between 1,000 and 7,800 non-smokers each year.[24] According to the 2003 CCHS, 10.7 per cent of non-smoking Manitobans (age 12 and older) reported that at least one person smokes inside their home every day or almost every day. In recognizing that the CCHS does not capture the experiences of those under the age of 12 or people living on reserves, the rates of second-hand smoke exposure in the household may be even greater. As can be inferred from the information presented in Figure 4.22, most second-hand smoke exposure in the home occurs in situations where the exposed is a minor.

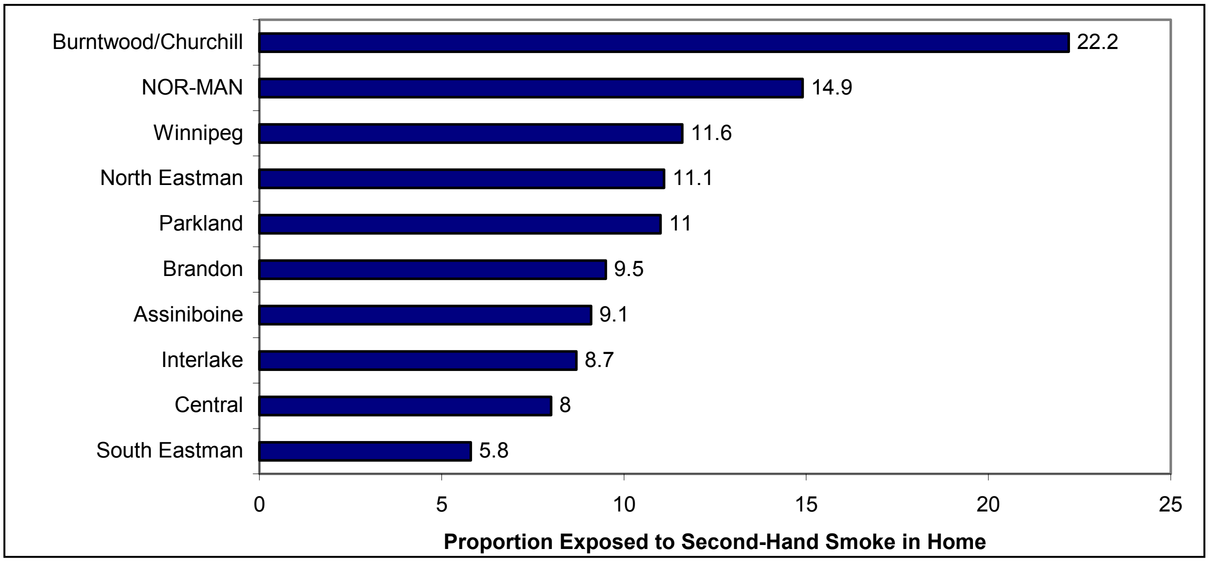
Figure 4.22 Proportion of non-smokers who were exposed to second-hand smoke in the home, 2003



Source: 2003 Canadian Community Health Survey

Figure 4.23 displays the exposure to second-hand smoke in the home by RHA. Clearly, there is considerable variation between the RHAs in second-hand smoke exposure.

Figure 4.23 Proportion of non-smokers exposed to second-hand smoke in the home, by region, 2003



Source: 2003 Canadian Community Health Survey

Although exposure to second-hand smoke in the home is an important measure of the prevalence of second-hand smoke exposure, it is by no means comprehensive. Exposure to second-hand smoke can occur in the workplace, in transportation, and in public arenas such as restaurants as bars. With the Province of Manitoba's smoking ban in public spaces, second-hand smoke exposure will be reduced in areas outside the home. However, as is illustrated by the above tables, exposure in the home is of critical concern.

4.2.3 Heredity

A small number of cancers, including melanoma and malignancies of the breast, ovary and colon, tend to occur more often in some families than in the rest of the population.[25] Current scientific evidence suggests that a relatively small proportion of people with these cancers have inherited genetic predisposition for these malignancies. However, for the vast majority of cases, it is not clear if the pattern of cancer in families is due to heredity or factors common to the family's environment. Since hereditary factors cannot be eliminated, reducing lifestyle and environmental risk factors is of particular importance for individuals with a family history of cancer.

4.3 Preventive Health Knowledge and Practice in the Population.

4.3.1 Screening for Cancer

> *"The impact of screening using existing evidence-based strategies for breast, cervical and colorectal cancers can result in about a five per cent reduction in overall cancer mortality."*[26]

Primary prevention activities such as lifestyle choices may prevent the development of cancer. However, cancer cannot always be prevented, so in recognizing the potential benefits of early detection, CCMB offers provincial screening programs for breast and cervical cancer. Screening by primary care providers is available for colorectal and prostate disease, although the use of tests for screening for prostate disease remains somewhat controversial.

Screening detects disease early in people who are asymptomatic for disease. The US National Cancer Institute estimates that between 3 per cent and 35 per cent of deaths due to cancer could be avoided through early screening. In addition to the potential benefit of avoided deaths, screening may reduce cancer morbidity (illness and disability) within the population. Early detection has a direct impact on treatment options and survival rates. Generally speaking, treatment for earlier stage cancers is less aggressive than for more advanced cancers. It should be noted that studies indicate that the reduction in cancer morbidity and mortality due to screening depends significantly on the organization and population penetration of a screening program.[27]

A successful organized cancer screening program incorporates several elements:

- identification of the target population to improve screening participation rates through education and recruitment;
- implementation of information systems to support quality control, recruitment, and promotion;
- monitoring and follow-up of abnormal results; and
- on-going program evaluation and quality assurance.

4.3.1.1 Breast cancer

Mammography screening with or without clinical breast examination has been shown in randomized trials to reduce mortality associated with breast cancer. Manitoba has approximately 800 new cases of breast cancer diagnosed each year. In 2001, 765 new cases of invasive disease and 103 cases of in situ disease were diagnosed. When seventy per cent of the target population is screened every two years, screening program for breast cancer is able to achieve mortality reductions through early detection. The Manitoba Breast Screening Program (MBSP) has, to date, achieved a rate of screening of approximately fifty per cent of the target population.

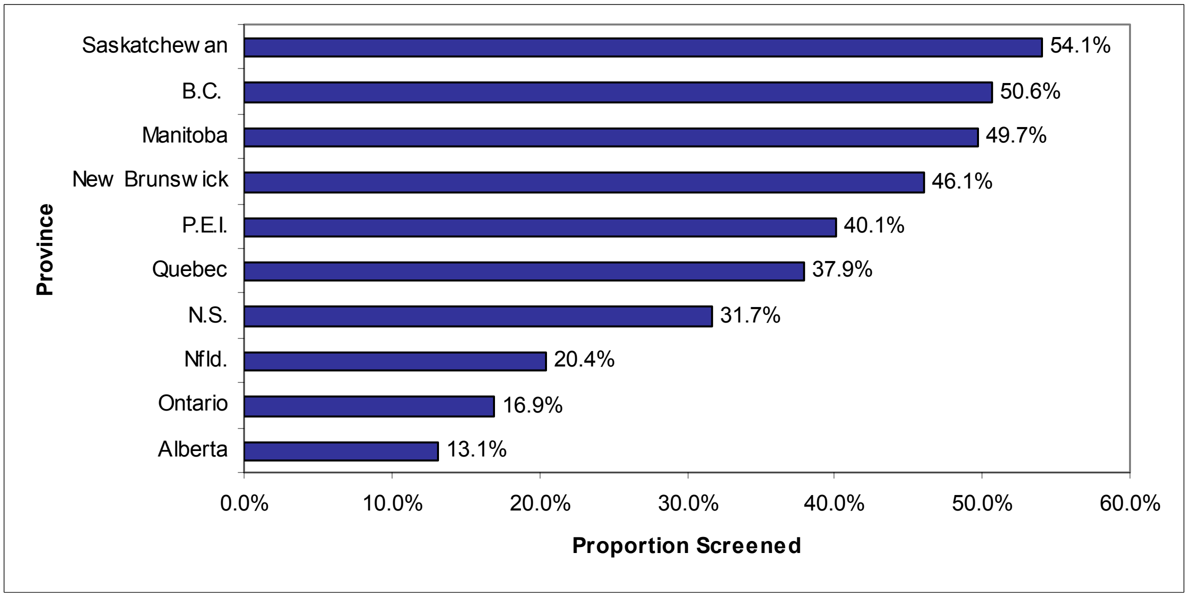
What is involved in Screening?

The MBSP is a population-based provincial breast screening program that offers bilateral mammograms and clinical breast examination to Manitoba women 50 to 69 years of age every two years. Women outside of this age group are advised to discuss their need for screening with their physician and make an informed decision based on the risks and benefits. The Program began operation in 1995 and provides screening through four fixed sites in Winnipeg, Brandon, Thompson, and Boundary Trails Health Centre which is located between the communities of Morden and Winkler. In addition, two mobile units travel to 80 different rural, and northern sites, as well as providing service to eight inner-city sites in Winnipeg.

Participation in Breast Cancer Screening

In recognizing the need for seventy per cent population screening to affect mortality, the MBSP has identified this target as the program goal. The MBSP has achieved a population penetration of 49 per cent in the period April 2001 to March 2003. While this rate shows room for improvement, Manitoba achieves a rate among the top three provinces nationally. No province has been able to achieve screening rates above 55 per cent. Health Canada has recognized that a lack of capacity may be the limiting factor in reaching seventy percent of the eligible population.

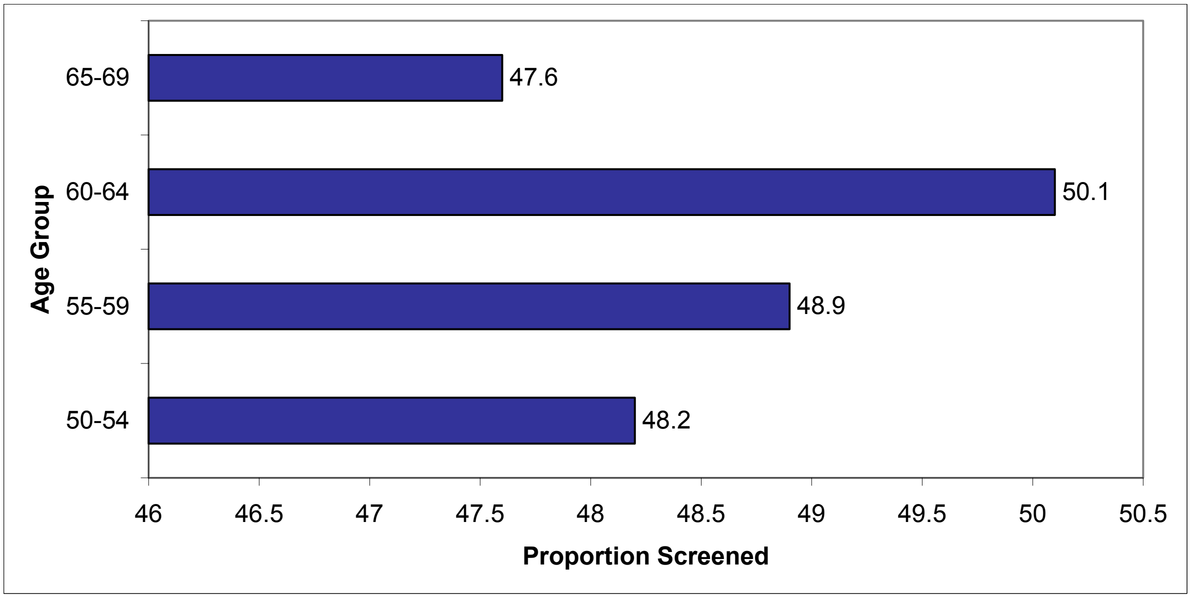
Figure 4.24 Proportion of women aged 50-69 who participated in provincial breast cancer screening programs in 1999 and 2000



Source: Health Canada, Organized Breast Cancer Screening Programs in Canada, 1999 and 2000 Report.

Although the target age group for screening is women aged 50-69, there is variation in the program's use across age groups. Women between the ages of 60 and 64 are most likely to receive screening services as illustrated in Figure 4.25.

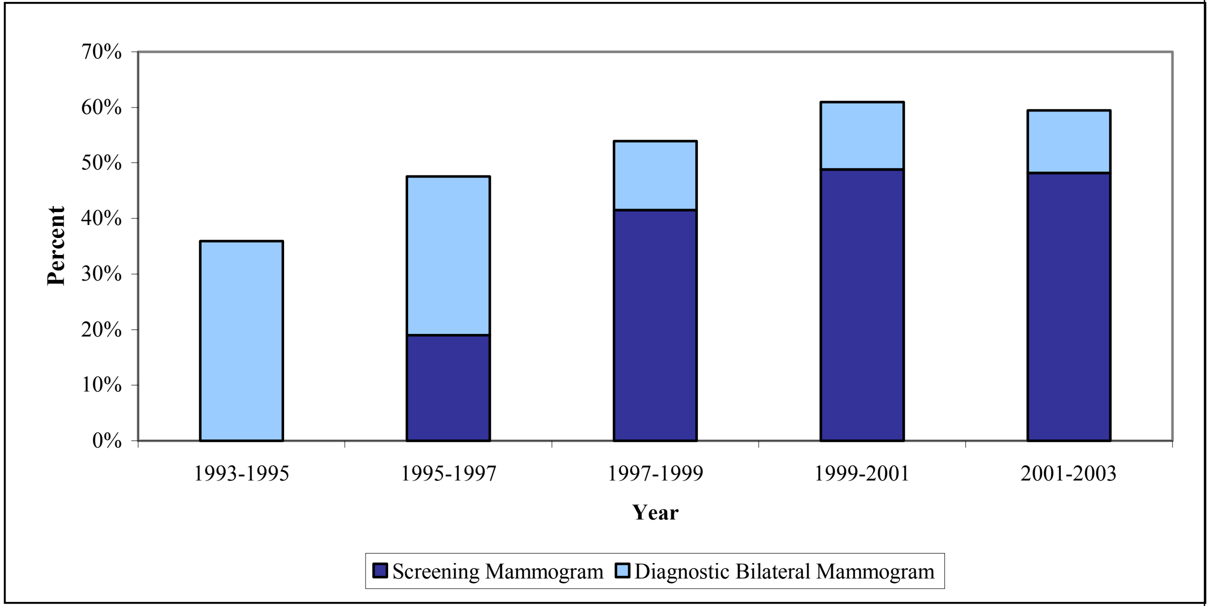
Figure 4.25 **Mammography screening rates by age group, April 2001-March 2003**



Source: Manitoba Breast Screening Program.
Note: Diagnostic mammography is not included.

As Figure 4.26 demonstrates the introduction of the provincial breast screening program has dramatically increased the use of mammography for screening purposes. Diagnostic mammography rates have remained relatively stable between 11 and 12%.

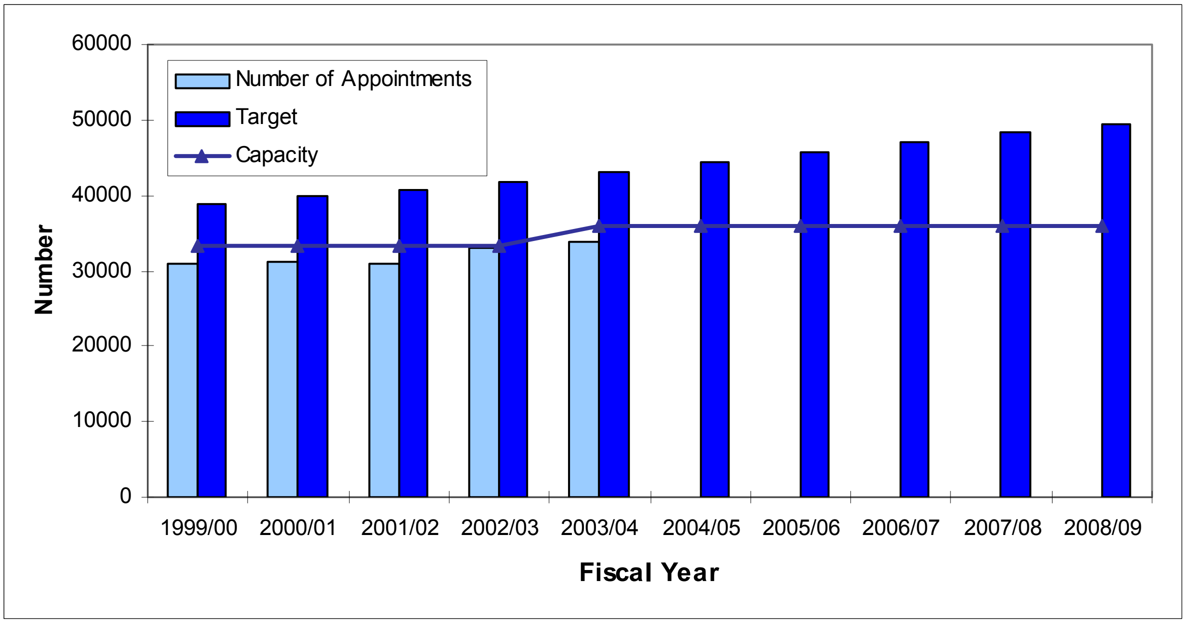
Figure 4.26 **Proportion of Manitoba women having a bilateral mammogram by 2-year time periods**



Source: Manitoba Breast Screening Program.

As illustrated in Figure 4.27, the screening program must increase their current capacity in order to reach their target of screening seventy per cent of the eligible population.

Figure 4.27 **Number of scheduled mammogram appointments, target population and program capacity, 1999/00 to 2008/09**



Source: Manitoba Breast Screening Program.

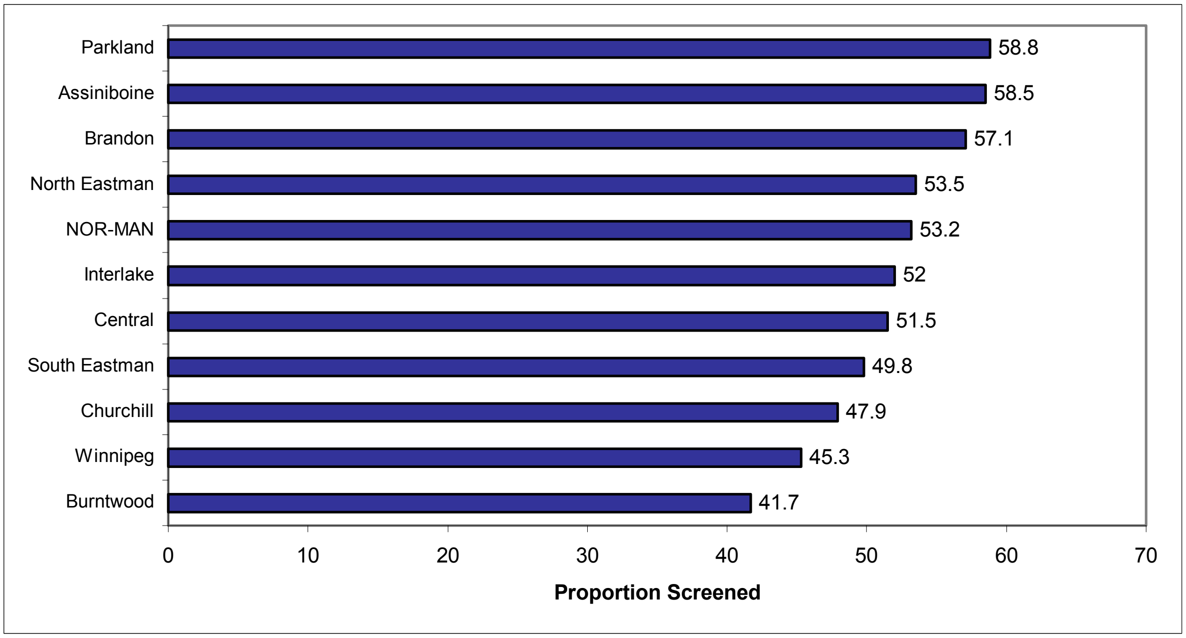
Capacity planning must take into account the screening program use and demand across RHAs. Allocating resources to those areas where demand exceeds capacity is essential to providing the service to the population. Re-alignment of capacity may be a program consideration, but will not be the sole answer to the projected need for a capacity increase of 8,000 women per year.

Breast Screening Accessibility Issues

Distance barriers

The MBSP has mobile units to provide screening services away from the fixed mammography sites. The mobile units have reduced travel barriers for the majority of Manitoba women who can now access screening services within 30 minutes of travel time. Although there is variation by RHA, rural women (55%) are on average, more likely to be screened than women living in Winnipeg (46%) (Figure 4.28).

Figure 4.28 Mammography screening rates, April 2001-March 2003



Source: Manitoba Breast Screening Program.
Note: Diagnostic mammography is not included.

Provincially the MBSP has made great strides in providing accessible care to the eligible screening population. The program strives to reach isolated women by transporting screening equipment to remote communities. Three of the mobile sites are accessed by winter roads and therefore are dependent on suitable weather conditions during the coldest weeks of the year. Two of the mobile sites are accessible only by rail. Despite these gains in accessing the most remote communities, there are still more than 200 Aboriginal women living in areas where the screening program is not able to be present.

Language and cultural barriers

The MBSP recognized that language and cultural barriers are limitations to reaching the eligible screening population. In response to this, the program has translated program pamphlets and questionnaires into 15 languages. As well, a video that demonstrates what can be expected in the breast screening appointment has been translated into six languages. The program plans to expand the available translations in the coming year.

The MBSP also works to reduce cultural barriers in the Aboriginal community by partnering with Aboriginal health workers to promote, educate, and arrange appointments on behalf of the program at mobile sites in Aboriginal communities. Such partnerships are crucial in improving the use of screening programs in the Aboriginal population.

In addressing the cultural issues in inner-city communities, local committees provide advice and work to improve screening rates. This work has prompted MBSP to establish mobile sites at centres that are convenient and where women in the community feel at ease, such as locations at the Indian and Métis Friendship Centre.

A pilot program in one cultural community - the Indo-Canadian community in Winnipeg - successfully reached women who had little information about breast screening, who had not historically participated in the program, and whose language barriers may have prevented them from participating. The program hired a respected community leader to recruit community support persons and to bring the information to women in their own language. Evaluation of the project revealed that women felt it was important to receive information in their own language as most of the women had little education, and many had little context in understanding the concept of a breast exam. The program discovered the importance of contacting women in their own language as well as arranging group screening visits with a trusted liaison to act as interpreter and educator. The MBSP has applied for funding to expand the multicultural outreach into the Chinese, Filipino, Portuguese, Spanish, and Vietnamese communities.

4.3.1.2 Cervical cancer

Screening with the use of the Pap test has significantly reduced the incidence and mortality of cervical cancer in the last 30 years. The Pap test can, in the majority of women, successfully detect abnormal cell changes on the cervix before they become cancerous or, if they are cancerous, when the disease is at a stage when treatment can be effective. However despite the demonstrated usefulness of Pap tests, a large proportion of Manitoban women are not tested on a regular basis. Research has shown that, of a group of women diagnosed with cervical cancer, almost one-half were never screened, or had not been screened in the previous five years.[28]

Manitoba had sixty-three women diagnosed with cervical cancer in 2001. The Manitoba Cervical Cancer Screening Program (MCCSP) established that in 2002, only 43 per cent of women between the ages of 18 and 69 had a Pap test.

What is involved in screening?

The MCCSP was established in January 2000 to ensure that Manitoba women receive high-quality cervical cancer screening services. Pap tests are available from a woman's regular health care provider including family physicians, nurse practitioner, gynecologist, midwife or community sponsored clinic. The MCCSP recommends that any woman who has ever had sex receive a Pap test on a regular basis. Women require a Pap test once a year for three years, at which point if the results are normal, screening frequency can be extended to once every two years. Women who have had a total hysterectomy for reasons other than cervical cancer should consult their physician regarding the need for a Pap test or vault smear. At the age of 70, in consultation with her physician, a woman may stop having Pap tests.

Participation in cervical cancer screening

The MCCSP organizes, implements and monitors an effective screening program to ensure that a uniform standard of screening is provided. Components of an organized cervical screening program include population-based recruitment, quality management and evaluation components, supported by computerized information systems. The MCCSP works within current health service provision offering public and professional education and operating a registry of cervical cancer screening results.

To increase participation rates in Manitoba, program resources are directed toward improving public knowledge about the importance of Pap tests, suggested screening frequency, and recommendations for follow-up of abnormal findings. Professional education initiatives support health care providers in understanding methods to improve Pap test quality and utilization of program developed resources available to improve Pap test participation in their practice. Partnerships with regional health authorities have been developed to increase Pap test utilization province-wide in identifying reasons for non-participation and determining strategies to target under-screened women.

In order to monitor the MCCSP program, a computerized registry was introduced in April 27, 2001, following an amendment to the Public Health Act. Through the central collection of screening test results, the registry supports laboratory quality assurance activities, enables notification to health care providers when recommended follow-up has not occurred, provides women with copies of their reports upon request, and facilitates evaluation of screening activities, outcomes and program effectiveness.

MCCSP statistics for participation by age group demonstrates that 43 per cent of women 18 to 69 years of age had at least one Pap test in 2002 (Table 4.7).

Table 4.7 Participation[1] in cervical cancer screening by age group, 2002

AGE GROUP	POPULATION[2,3]	PARTICIPATION (%)[4]
18-19	15,838	5,771 (36.4)
20-29	75,311	38,739 (51.4)
30-39	82,665	38,764 (46.9)
40-49	89,550	37,225 (41.6)
50-59	68,115	26,886 (39.5)
60-69	45,294	14,437 (31.9)
Total	376,773	161,822 (42.9)

Source: Manitoba Cervical Cancer Screening Program, 2002-03 Statistical Report.
Notes: 1. Participation is the number of women who had at least one Pap test in 2002 divided by the total number of women in the age group as of June 1, 2002.
2, Source: Manitoba Health Population Report, June 1, 2002.
Population is not corrected for hysterectomy.
Includes women who had a satisfactory or an unsatisfactory Pap test result.

Table 4.8 shows participation by age group and RHA in 2002. Participation rates ranged from a low of 26.6 per cent in NOR-MAN to a high of 46.3 per cent in Brandon. The overall participation rate for RHAs was 38.8 per cent. Discrepancies in Table 4.8 from Table 4.7 are due to missing postal code information for 10 per cent of women, preventing their assignment to an RHA.

Table 4.8. Participation[1] by age group and Regional Health Authority[2], 2002

Age Group	Winnipeg	Brandon	North Eastman	South Eastman	Interlake	Central	Assiniboine	Parkland	Nor-man	Burntwood	Churchill	Total
18-19												
screened	2,556	299	181	203	357	372	332	171	129	325	7	4,932
population[3,4]	8,435	698	544	845	1,032	1,585	956	554	388	787	14	15,838
participation	30.30	42.84	33.27	24.02	34.59	23.47	34.73	30.87	33.25	41.30	50.00	31.14
20-29												
screened	20,582	2,018	966	1,531	1,824	2,469	1,592	1,003	616	1,586	47	34,234
population	44,965	3,586	2,010	3,646	3,882	6,009	3,608	2,363	1,702	3,449	91	75,311
participation	45.77	56.27	48.06	41.99	46.99	41.09	44.12	42.45	36.19	45.98	51.65	45.46
30-39												
screened	21,559	1,655	1,127	1,531	2,199	2,410	1,556	848	508	1,256	30	34,679
population	49,499	3,431	2,651	3,989	5,069	6,410	3,960	2,448	1,771	3,355	82	82,665
participation	43.55	48.24	42.51	38.38	43.38	37.60	39.29	34.64	28.68	37.44	36.59	41.95
40-49												
screened	21,349	1,634	1,206	1,390	2,265	2,303	1,784	867	379	754	26	33,957
population	53,288	3,749	3,066	4,011	5,910	7,088	5,063	2,891	1,826	2,575	83	89,550
participation	40.06	43.58	39.33	34.65	38.32	32.49	35.24	29.99	20.76	29.28	31.33	37.92
50-59												
screened	16,005	1,124	922	907	1,699	1,584	1,314	739	292	425	9	25,020
population	40,836	2,712	2,393	2,843	4,734	5,008	4,152	2,501	1,258	1,636	42	68,115
participation	39.19	41.45	38.53	31.90	35.89	31.63	31.65	29.55	23.21	25.98	21.43	36.73
60-69												
screened	8,270	699	570	464	1,023	877	877	469	105	113	2	13,469
population	25,539	1,859	2,393	1,858	3,429	3,537	3,326	1,855	686	781	31	45,294
participation	32.38	37.60	23.82	24.97	29.83	24.80	26.37	25.28	15.31	14.47	6.45	29.74
All												
screened	90,321	7,429	4,972	6,026	9,367	10,015	7,455	4,097	2,029	4,459	121	146,291
population	222,562	16,035	13,057	17,192	24,056	29,637	21,065	12,612	7,631	12,583	343	376,773
participation	40.58	46.33	38.08	35.05	38.94	33.79	35.39	32.48	26.59	35.44	35.28	38.83

Notes:

1) Participation is the number of women who had at least one Pap test in 2002 divided by the population in the age group and RHA as of June 1, 2002.
2) Women for whom a RHA could not be determined (~10% of women screened in 2002) were not included.
3) Source: Manitoba Health Population Report, June 1, 2002.
4) Population is not corrected for hysterectomy.

Table 4.9 shows the two-year participation rate by age group for women with at least one satisfactory Pap test taken between January 1, 2002 and December 31, 2003. Overall, 63% of women 18 to 69 years of age had at least one satisfactory Pap test over a two-year period. Highest participation is again evident in the 20-29 age group at 72.5% with a steady decline in participation to 49.2% in the 60-69 age group.

Table 4.9. 2-year participation[1] by age group, 2002-2003

AGE GROUP	POPULATION[2,3]	PARTICIPATION (%)[4]
18-19	15,838	8,505 (53.7)
20-29	75,311	54,645 (72.5)
30-39	82,665	55,726 (67.4)
40-49	89,550	56,036 (62.5)
50-59	68,115	40,373 (59.3)
60-69	45,294	22,278 (49.2)
Total	376,773	237,562 (63.1)

Source: Manitoba Cervical Cancer Screening Program, 2003 Statistical Report (unpublished).
Notes:
1) Participation is the number of women who had at least one satisfactory Pap test in 2002-2003 divided by the total number of women in the age group as of June 1, 2002.
2) Source: Manitoba Health Population Report, June 1, 2002.
3) Population is not corrected for hysterectomy.
4) Includes women who had a satisfactory Pap test result. Unsatisfactory Pap test results not represented.

Cervical screening accessibility issues

MCCSP has supported a variety of initiatives throughout the province to increase Pap test participation. The program direction has been to improve access to Pap test screening to reach underscreened populations. In 2002/03 the MCCSP provided funding to the Interlake RHA for a project to raise the awareness of the importance of screening and to find creative ways to remove the barriers that women experience. Barriers identified by women in the Interlake included lack of awareness about screening, lack of physician services, transportation problems relating to distance, and the need to rely on others for assistance, as well as literacy and communication problems. A significant recommendation from this project was to advocate for transfer of the procedures to nurses in enhancing their role in community health services, specifically to take responsibility for Pap tests and to provide education simultaneously.

In 2002-2003, MCCSP provided NOR-MAN RHA funds for a Cervical Screening Project. The RHA, the Community Nurse Resource Centre (CNRC) and Public Health selected the communities of Cormorant and Sherridon for their project because of the low screening rates and limited access to clinical services. The first phase of the project included extensive consultations with community stakeholders to provide education sessions that would increase awareness about the importance of cervical screening and advertise upcoming clinics. The second stage of the project was the delivery of six well women clinics offering Pap test screening services by registered nurses, under the direction of the primary care physician associated with the CNRC. The project was considered a success in both communities, despite many challenges in service provision.

> To increase cervical cancer screening in women living in Winnipeg, the MCCSP partnered with seven inner-city clinics to provide a one-day, drop-in Pap test clinic in 2003. Seventy-five per cent of the 112 women having Pap tests that day had not had one within the previous three years. Sixty-eight per cent of the women reported having a regular physician and 76 per cent of these women reported seeing a physician within the last year. Two significant findings from this clinic day initiative indicate that under-screened women were reached, and that although women have access to physician services, they are not always having Pap tests. The MCCSP extended this initiative to 17 clinics in 2004. Preliminary findings demonstrate that of the 505 women who attended one of the 17 clinics, 54 per cent had not had a Pap test in the previous three years.

Similar results were found by North Eastman RHA in clinics held in Whitemouth, Black River and Hollow Water in 2003. Almost one half of the women had not had a Pap test in the previous two years. The majority of the women also indicated they had seen a doctor within the last year, although no Pap test had been conducted within the preceding three years.

Through these various initiatives the MCCSP has been able to demonstrate the need for cervical screening services and where some of the gaps occur. In addition, by working collaboratively with a variety of stakeholders, strategies to improve services can be identified and implemented.

4.3.1.3 Colorectal cancer

A Colorectal Cancer Screening Program Advisory Committee was established by CCMB in 2003 to develop options and recommendations for the organization and implementation of a colorectal cancer screening program in Manitoba in response to national committee recommendations and CAPCA policy position. The committee is in the process of investigating program options, costs and benefits for review by CCMB's Executive and Manitoba Health.

What is involved in screening?

The Canadian Task Force on Preventive Health Care recommends that for asymptomatic people at normal risk "there is good evidence to include annual or biennial fecal occult blood testing and fair evidence to include flexible sigmoidoscopy in the periodic health examination of asymptomatic people over 50 years of age. "

The National Committee on Colorectal Cancer Screening (2002) recommends the following:

- Screening should be offered to a target population of adults 50 to 74 years of age using unrehydrated Hemoccult or an equivalent as the entry test.
- Individuals should be screened at least every two years, recognizing that annual screening would have slight improvement in mortality reduction over biennial screening, but would require increased resources.
- Positive tests should be followed by colonoscopy, with options of barium enema and flexible sigmoidoscopy where appropriate.

It is a CCMB priority to determine if and how a colorectal screening program would be delivered on a population basis.

4.3.1.4 Prostate cancer

Prostate cancer accounted for 760 newly diagnosed cancers in 2001. Currently there is no recommended screening method that can be used as a stand-alone method of detection. However, the Prostate Specific Antigen (PSA) test may be used in conjunction with other indications to monitor prostate disease symptoms.

What is involved in screening?

CCMB recommends that men aged 50 and older discuss PSA testing with their physicians. However, CCMB recognizes that while the use of the PSA test is generally accepted as an important part of diagnosis and follow-up of prostate cancer, its use as a population-based screening tool in asymptomatic (healthy) men is controversial. PSA is not specific to the identification of cancer, and may falsely capture benign enlargements of the prostate gland. There is also insufficient evidence that screening for prostate cancer using the PSA test will reduce mortality rates. It appears that many older men have clinically unimportant prostate cancer that is slow growing and unlikely to result in death.

Neither the Canadian Task Force on the Periodic Health Examination nor the US Preventive Services Task Force recommends the PSA test as a routine screening test. CCMB will continue to monitor developments in prostate cancer screening in order to best serve the patient population.

4.3.2 Physician Knowledge and Attitudes Toward Cancer Screening

Family physicians are recognized as a critical component in the success of cancer screening programs, however their role in the provision of cancer care goes beyond screening functions. In the 2001-2004 Strategic Plan, CCMB recognized the need to increase the utilization of family physicians in addressing the projected demand for cancer care services.

In addressing the role of family physician in the cancer care system in Manitoba, CCMB held a Community Oncology Team Planning Workshop in April 2002.[29] Participants at the workshop concluded that while the family physician has a crucial role to play across the cancer spectrum, particularly in early detection and prevention interventions, their role lacks clarity resulting in under utilization of family physicians as partners in cancer care. Hesitation on the part of the family physician in taking on a greater role in cancer care was identified as a combination of the lack of clearly defined roles and existing workload pressures.

Workshop participants agreed that the role of the family physician in cancer care can be expanded. It was recognized that not all physicians may be interested or able to take an increased role in cancer care. A better strategy was to identify a group of interested family physicians to take increased referrals of cancer patients. A number of suggested areas where family physicians could take on increased responsibilities included cancer prevention strategies, patient-centred navigation through multiple treatments, and acting as an information and supportive resource.

Participants were also in agreement that family physicians require an increased knowledge base, skill and understanding to play a more effective role in cancer care. Suggestions included increased feedback to individual family physicians around screening rates, and a review of evidence on prevention strategies and cancer screening guidelines.

A recent Manitoba Centre for Health Policy (MCHP) report supported the physician sentiment expressed in the planning workshop.[30] MCHP conducted a study to find out how family physicians were performing based on a select number of indicators. The quality of care provided by family physicians was assessed based on a number of disease prevention/health promotion and acute and chronic disease management indicators. The disease prevention/health promotion indicators included cervical cancer screening, cholesterol screening and blood sugar screening.

For cervical cancer screening, researchers calculated the percentage of female patients aged 18 to 60 who had at least one Pap test in the last three years, the most conservative guidelines recommendation. The results show that cervical cancer screening rates were significantly lower in rural areas compared to Winnipeg and Brandon. The Winnipeg and Brandon rates were a combined 71 per cent and the rural rate was 60 per cent.

Given the varying and significant differences in quality of care results, a number of strategies need to be employed to address reduced accessibility to cancer screening, particularly for rural patients. The report's authors suggested that family physicians need to be actively engaged in the quality improvement process, that a culture of quality improvement be established through changes in physician remuneration, enhanced information technology infrastructure, and creation of an electronic health record, and that the Manitoba College of Physicians and Surgeons and the Continuing Medical Education Department play a role in enhancing the knowledge base of family physicians.[31]

The MCHP report on family physicians is consistent with other publicly available data. For example, one survey of family physicians revealed that most physicians were aware of the basic facts about prostate cancer, but there were significant knowledge limitations to the risk factors associated with prostate cancer. [32] While most family physicians correctly identified "father or brother with prostate cancer" as a risk factor, fewer respondents selected African ancestry and diets high in fat as risk factors.[33] Most physicians agreed that they needed more information about screening effectiveness, risk factors, preventive strategies and post-diagnosis care.

The great uncertainty around the effectiveness of PSA testing was illustrated in the survey by the majority of family physicians who do not discuss the PSA; most physicians only offer the PSA test if it is requested.[34] This response falls short of the recommended approach around prostate cancer screening, which calls for men to be made aware of the benefits and risks of prostate cancer screening so that they can make an informed choice. CCMB and Manitoba Health recognized this lack of patient/physician dialogue on prostate cancer screening and initiated a Prostate Cancer Awareness Media Campaign in April 2002 that encouraged men over 50 years of age to discuss options around prostate care with their physicians. CCMB has also addressed such concerns by providing family physicians with information on the advantages and disadvantages of PSA testing. This tool is expected to be used in combination with the upcoming production of a PSA brochure, to be released in January 2005, in addressing physicians' needs for greater information.

Although prostate cancer is the example discussed above, it is recognized that greater information needs to be provided to family physicians for all screening programs. Developing partnerships with physicians has also been an important strategic and operational initiative. The introduction of the Urban Primary Care

Oncology Network serves as a pilot project in creating greater partnerships between CCMB and family physicians to address patients' needs. CCMB recognizes the need for greater partnerships and a collaborative approach to cancer care to best serve patients, and particularly given the implications of an aging population.

4.3.3 Public Knowledge and Attitudes Toward Cancer Screening

The public's attitude to cancer screening is shaped by four critical factors - knowledge about cancer, accessibility to screening services, reinforcement of screening necessity, and disease-specific fear.

The first challenge is how much the patient knows about cancer. Deciding to pursue cancer screening will be largely determined by the amount of knowledge a patient has about the existence of cancer, the risk factors associated with cancer, the mortality and morbidity associated with cancer, the availability of screening tests that can reduce the risk, and recommendations regarding whether people should be screened and how often. Limited education and limited exposure to health information will impact knowledge of cancer negatively and result in lower screening rates. This finding was confirmed in an Alberta study in 2000 that found women with a university degree or some post-secondary education had a Pap test more recently than those without post-secondary education.

Accessibility to screening services can be an impediment even if people are knowledgeable about cancer and want to be screened. Access to a regular source of primary care is a challenge to Manitobans as the province has a shortage of family physicians and lacks adequate primary care resources particularly in rural and northern Manitoba. The 2003 Canadian Community Health Survey found that 9.7 per cent of Manitobans have not looked for a family doctor and 6.2 per cent of Manitobans cannot find a family doctor; both figures are above the national average. Access to screening is also challenged by the need to travel to be screened, taking time from work, and long waiting times to be screened.

In Manitoba, extended and more convenient hours for screening and the use of mobile mammography units have greatly assisted in improving access and breast cancer screening rates. This is particularly true in rural and northern areas of the province. CCMB has recognized that the most effective utilization of resources in providing screening to remote communities is to have mobile units travel to larger northern communities and have women who live in smaller remote communities travel in a group to the mobile site. This approach to providing screening services has reduced the issue of accessibility in rural, remote communities.

Reinforcement of the importance of regular screening is also critical to cancer-screening utilization. While the eligible population may be adequately informed and motivated to be screened, many still forget to get screened on a regular basis, particularly if there are long recommended intervals between screening tests.

The MBSP has recognized the importance of sending reminder letters to patients to encourage participation in upcoming breast screening tests and support regular screening activities.

Research has shown that fears of cancer and fears about knowing whether one has cancer also influence motivation to receive screening services.[35] Attitudes toward screening are also affected by the visibility and public knowledge of specific cancers. For example, the rate of colorectal cancer screening is lower than the rate of breast cancer screening, despite evidence showing that regular screening for colorectal cancer can reduce mortality significantly. The reasons for this difference relate to the lack of available information about colorectal screening and the perception of colorectal cancer as a disease that afflicts males. It is also recognized that physicians have an important role in providing an adequate amount of information about screening so that patients can make an informed decision. The nature of the screening test for colorectal cancer, the Fecal Occult Blood Test (FOBT) is also culturally viewed as distasteful, inconvenient, embarrassing and uncomfortable. As a result, an organized screening program may be necessary to encourage increased screening, as well as improve access and follow-up care for colorectal cancer.[36]

4.3.4 Cancer Prevention Activities in the Community

Outside of cancer screening programs, a number of cancer prevention initiatives are being carried out in Manitoba. Some of these initiatives are provincial, while others are more locally focused. CCMB, the RHAs, Manitoba Health and interested stakeholders are all involved in cancer prevention activities.

Several good examples of cancer prevention activities involve breast cancer specifically. The CCMB Breast Cancer Centre of Hope carries out a number of cancer prevention activities for CCMB. The Centre has conducted presentations emphasizing the importance of minimizing modifiable risk factors for breast cancer. Also, a breast health train-the-trainer package was developed in 2002 for public health nurses. In addition, the CCMB Breast Cancer Centre of Hope recently worked with the WRHA Lifelong Wellness program to develop a breast health educational program for the Healthy Start program. CCMB anticipates that some of the experiences derived from the development of breast cancer prevention programs will assist in other cancer prevention initiatives.

4.3.4.1 Tobacco control

In January 2002, the Minister of Health for Manitoba introduced a comprehensive, multi-year Provincial Tobacco Control Strategy addressing the four nationally identified tobacco control goals:

- Prevention: helping to prevent children and youth from starting to use tobacco and reduce their access to tobacco

- Protection: reducing exposure to second-hand smoke and protect the health of non-smokers

- Cessation: promoting tobacco use cessation among all users and help smokers quit

- Denormalization: influencing public attitudes toward smoking so that it is no longer seen as an acceptable behaviour

As part of the provincial strategy, a number of specific measures have been introduced targeting youth:

- The establishment of a Youth Advisory Committee to provide advice to government to ensure tobacco-control strategies are effective and relevant to young people.

- Expansion of teen cessation programs in Manitoba, including the Not On Tobacco (NOT) Program and the Quit for Life Program.

- Development of mass media campaigns targeting youth.

- Introduction of legislation to ban smoking in enclosed public spaces and indoor workplaces effective October 1, 2004. (Manitoba became the first provincial jurisdiction to introduce such legislation.)

- Enforcement of the Sales to Minors Program to ensure retailers are not selling tobacco to minors.

- Support of community smoking prevention initiatives by the Manitoba Tobacco Reduction Alliance (MANTRA), a group composed of not-for-profit groups, health care organizations, professional associations, RHAs and CCMB dedicated to providing leadership in reducing tobacco use in Manitoba.

- Establishment of a Smoker's Help Line - a new province-wide service is now available in Manitoba to help smokers quit smoking. A toll-free number is available, enabling Manitobans to speak with trained cessation counsellors.

- Development of the Tobacco Learning Resource Initiative: a source of teacher friendly learning resources.

While the work within this provincial strategy has just started, there are encouraging indications that Manitobans are benefiting. The Canadian Tobacco Use Monitoring Survey (CTUMS) indicates that smoking among Manitobans 15 years of age and older has dropped from 26 per cent in 2001 to 21 per cent in 2003.

4.3.4.2 Legislation to address cancer risk factors

The most visible piece of legislation that addresses cancer risk factors is the *Non-Smokers Health Protection Amendment Act*, which created a province- wide smoking ban as of October 1, 2004. In addition to the smoking ban, this provincial act prohibits the display, advertising and promotion of tobacco products in any place where children are allowed.

The Manitoba Workplace Safety and Health Act, in recognizing environmental impacts of chemical exposure, regulates exposure to those chemicals that have been linked to cancer and other health diseases.

Under the *Public Health Act*, the X Ray Safety Regulation, CCMB is charged with the responsibility of ensuring x-ray machines in Manitoba are emitting safe levels of radiation. The Diseases and Dead Bodies Regulation, which mandates the reporting of malignancies to the Manitoba Cancer Registry for surveillance purposes, was recently amended to permit Pap smear results to be entered into a registry operated by the Cervical Cancer Screening Program.

4.3.4.3 Regional Health Authorities

Perhaps of greatest strategic importance to the provision of excellent cancer services are the partnerships that have been established with RHAs. Together, CCMB and the RHAs have implemented cancer prevention activities to provide cancer-related education. Like CCMB, the RHAs have developed partnerships with the Alliance for Chronic Disease Prevention to develop broad-based, local strategies to reduce the incidence of chronic diseases such as cancer.

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5

CANCER IN THE COMMUNITY

CancerCare
MANITOBA

5.0 CANCER IN THE COMMUNITY

> *"During their lifetime, 38% of Canadian women and 43% of men will develop cancer, and, 1 out of every 4 Canadians will die of cancer."*[1]

Key Findings

Cancer is a significant health concern for Manitobans, with an average of 5,299 new cases of cancer diagnosed each year. This report has focused on reporting invasive cancers except for non-melanoma skin cancers, to conform with national standards in order to facilitate interprovincial comparisons. Invasive cancers have the ability to metastasize, and are operationally defined in terms of codes specified in the International Classification of Diseases versions 9 and 10, as ICD9 140-208 (excluding 173) or ICD10 C00-C97 (excluding C44).

- Cancer is a disease that is more common in older age groups, with almost three-quarters of all new cases diagnosed in people aged 65 years or older. It is also responsible for more than one-third of deaths occurring before the expected average lifespan of 75 years.

- The most common types of cancer diagnosed in Manitobans over the past 20 years are prostate cancer, lung cancer, breast cancer and colorectal cancer. Combined, these malignancies account for more than half of the new cancer diagnoses occurring in Manitoba each year.

- The rate of diagnosis of new cancers ("incidence"), the rate of cancer deaths ("mortality") and the rate of survival following diagnosis of cancer in Manitoba are similar to the national experience.

- As expected, there is variation between the RHAs in the province in incidence rates. A proportion of this deviation may be attributed to differences in underlying risk factors, differential use of screening and diagnostic services, and as random variation. Further investigation is necessary to understand the relative influence of these explanatory factors, in order to identify how the population can be best served.

- Projected increases in cancer incidence, in combination with survivorship, will create new challenges in the provision of cancer care and related health services.

- In order to ensure accessibility, partnerships with RHAs need to be strengthened in order to best serve patients and survivors in terms patient-centred care.

5.1 Cancer Morbidity

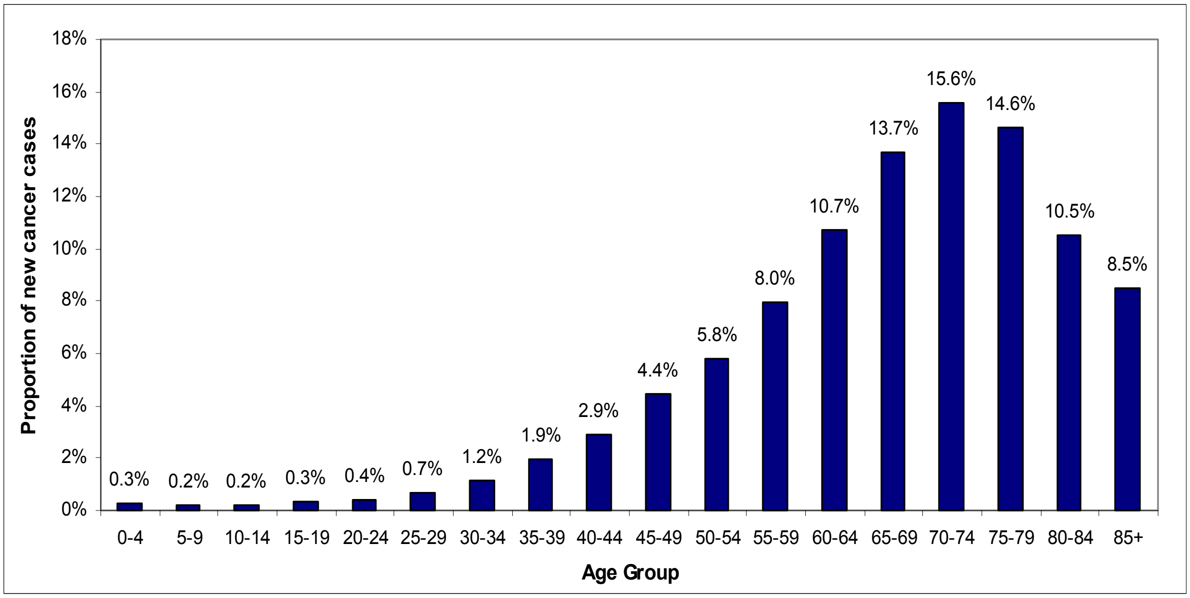
Cancer morbidity is measured through incidence (number of new cases) and prevalence (number of existing cases) in a population. Comparisons between provinces and regions and trends over time are presented in the following section. The data presented in this section were extracted from the Manitoba Cancer Registry and national cancer statistics resources, which aggregate information from provincial data sources.

5.1.1 Cancer Incidence

Between 1992 and 2001, men accounted for 52.4 per cent of invasive cancer diagnoses (27,746 cases) with women accounting for the remaining 47.6 per cent (25,246 cases) of diagnoses in Manitoba. These numbers correspond to an average of 5,299 people who are newly diagnosed with invasive cancer each year. These data reflect the focus of this report on invasive cancer, in fitting with national standards however there are pre-malignant diseases called in situ cancers. The impact of in situ disease is significant, in combination with the inclusion of non-melanoma skin cancers; the total of all invasive, in situ, and skin cancers (ICD-9 codes 140-208 and 230-239) diagnosed in Manitoba between 1992 and 2001 was 41,469 cases in men and 41,825 in women.

As discussed in Chapter 4, cancer is more common in the older population. In the ten-year period examined (1992-2001), almost three-quarters (73.7%) of new cases of invasive cancer were diagnosed among those aged 65 and older. Figure 5.1 illustrates the age distribution of invasive cancer incidence diagnosed between 1992-2001.

Figure 5.1. Proportion of new invasive cancer cases by age group, 1992-2001



Source: CancerCare Manitoba

Tables 5.1 and 5.2 list the most commonly diagnosed cancers among residents of Manitoba, and show both crude and age standardized rates. The crude rate represents the experience of the population as a simple proportion (number of cases divided by the number of people in the population), which is not comparable interprovincially or nationally due to differences in the ages of the populations. Standardized rates control for differences in age structures in populations, and are used to compare rates either over time or between locations. In recognizing that cancer is a disease of aging, standardization is important in that it eliminates the effects of the age in the populations being compared.

Three types of cancer account for at least 50 per cent of new cases of invasive cancer in each sex - prostate, lung and colorectal for men (58.4%), and breast, lung and colorectal for women (54.5%).

The most commonly diagnosed invasive cancer in Manitoba is prostate cancer, with an average of 787 new cases per year. This is followed by lung cancer (averaging 769 new cases per year), invasive female breast cancer (724 new cases per year) and colorectal cancer (715 new cases per year).

Although cases of lung cancer diagnoses among Manitoba women have increased over the ten-year period examined, breast cancer is diagnosed more than twice as often.

Table 5.1. Most commonly diagnosed cancers in Manitoba males, 1992-2001

ICD-9 Code	Cancer Site	Number and Proportion of cases	Crude rate per 100,000	Standardized rate per 100,000
INVASIVE				
185	Prostate	7867 – 28.4%	139.2	158.8
162	Lung	4532 – 16.3%	80.2	90.5
153, 154	Colorectal	3803 – 13.7%	67.3	76.2
188	Bladder	1355 – 4.9%	24.0	27.8
200, 202	Lymphoma (other)	1233 – 4.4%	21.8	24.1
189.0	Kidney	912 – 3.3%	16.1	17.7
204-208	Leukemia	781 – 2.8%	13.8	15.3
151	Stomach	771 – 2.8%	13.6	15.7
172	Skin (melanoma)	633 – 2.3%	11.2	12.0
157	Pancreas	602 – 2.2%	10.7	12.1
OTHER				
173	Skin (other)	9957	176.2	199.4

Source: CancerCare Manitoba, standardized rates are adjusted using the 1996 Manitoban population provided by Manitoba Health

Table 5.2. Most commonly diagnosed cancers in Manitoba females, 1992-2001

ICD-9 Code	Cancer Site	Number and Proportion of cases	Crude rate per 100,000	Standardized rate per 100,000
INVASIVE				
174	Breast	7238 – 28.7%	124.9	116.4
162	Lung	3160 – 12.5%	54.5	50.0
153, 154	Colorectal	3351 – 13.3%	57.8	51.1
182	Body of the uterus	1537 – 6.1%	26.5	24.7
200, 202	Lymphoma (other)	1116 – 4.4%	19.3	17.6
183	Ovary	1035 – 4.1%	17.9	16.8
204-208	Leukemia	648 – 2.6%	11.2	10.2
157	Pancreas	642 – 2.5%	11.1	9.6
172	Skin (melanoma)	581 – 2.3%	10.0	9.6
180	Cervix, uteri	572 – 2.3%	9.9	9.7
OTHER				
173	Skin (other)	8237	143.7	129.6
233.1	Cervix (in situ)	4090	70.6	71.9

Source: CancerCare Manitoba, standardized rates are adjusted using the 1996 Manitoban population provided by Manitoba Health

Disease outcomes are specific to the cancer site, and therefore differ by diagnosis. Based on the ratio of deaths to new cases, the National Cancer Institute of Canada classifies cancers into three groups: those with very good prognosis, those with fairly good prognosis and those with poor prognosis (see Table 5.3). Of particular interest, the most common malignancies diagnosed in women and men (breast and prostate cancer, respectively) have very good prognosis; colorectal cancer has a fairly good prognosis and lung cancer has a poor prognosis. This tells us that (a) the most frequent cancers are not necessarily the most frequent causes of death from cancer, and (b) some cancers have higher survival rates which means that these people may have additional needs in the future related to their survivorship (these can be physical, emotional and financial). These concepts related to survivorship will be discussed more fully later in this chapter.

> *"[In Canada], breast cancer and prostate cancer remain the most frequent cancers; lung cancer remains the most frequent cause of death from cancer."*[2]

Table 5.3. Invasive cancer site by prognosis.

Very Good Prognosis	Fairly Good Prognosis	Poor Prognosis
Female Breast	Male breast	Lung
Prostate	Colorectal	Leukemia
Melanoma	Non-Hodgkin's lymphoma	Pancreas
Body of the uterus	Female bladder	Stomach
Cervix	Kidney	Ovary
Thyroid	Oral	Brain
Hodgkin's disease	Larynx	Multiple myeloma
Testis		Esophagus
Male bladder		

Source: National Cancer Institute of Canada, Canadian Cancer Statistics 2004.

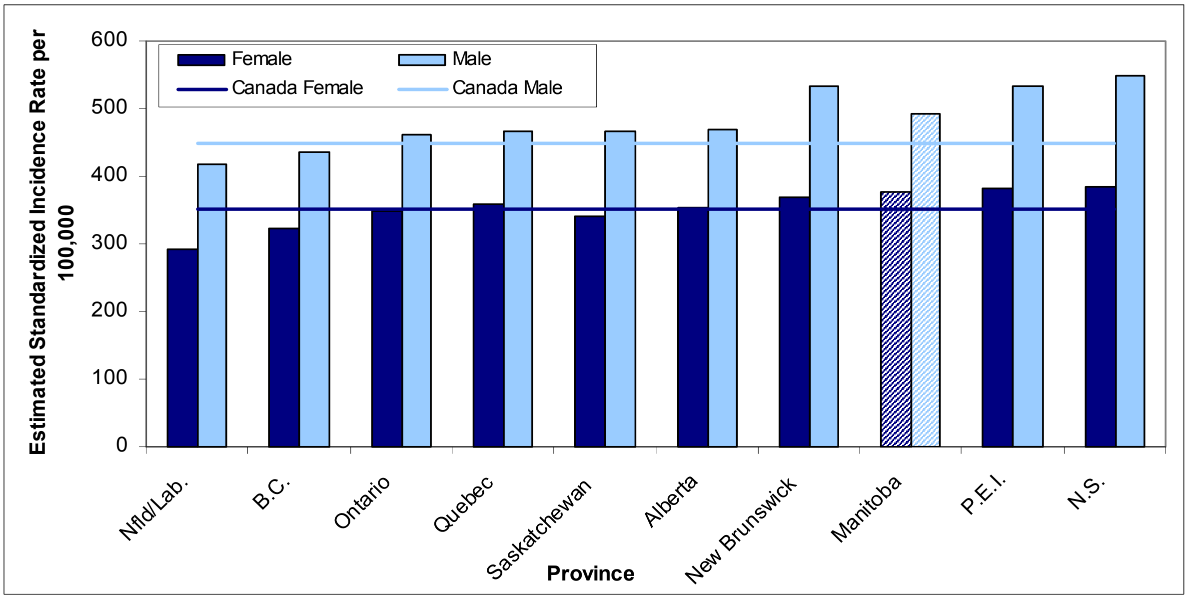
5.1.1.1 Provincial comparisons

Provincial comparisons are based on the National Cancer Institute of Canada's estimated number of new cases for 2004. The provincial information is standardized to the 1991 Canadian population and presented as whole numbers. The standardized rates allow for comparisons over time and between locations in accounting for different age structures within the compared populations. Provincial cancer incidence comparison graphs are presented for:

- All invasive cancers (ICD-9 codes 140-208, excl. 173)
- Prostate cancer
- Female breast cancer
- Lung cancer
- Colorectal cancer

The National Cancer Institute of Canada estimates that in 2004 there will be 5,700 new cases of invasive cancer diagnosed (2,900 among men and 2,800 among women). Although Manitoba's rate is third in incidence for men and fourth in women in comparison to the other provinces, the differences are not statistically significant.

Figure 5.2. Estimated age-standardized estimated rates of invasive cancer by province, 2004



Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
Note: Territory numbers are included in Canadian total but not reported separately due to small numbers.

Figures 5.3 to 5.6 illustrate provincial comparisons for the selected cancer sites identified on previous page. Highlights of the national comparison data include:

- For prostate cancer (Figure 5.3), it is estimated that in 2004 there will be 750 new cases among Manitoba men for a standardized rate of 125 cases per 100,000.
- With 810 new cases in Manitoba, breast cancer rates in 2004 are expected to be the second highest in the country (behind Quebec) at 112 new cases per 100,000 women (see Figure 5.4).
- There are expected to be a total of 830 new cases of lung cancer diagnosed among Manitobans in 2004 (430 among men and 400 among women) (see Figure 5.5).

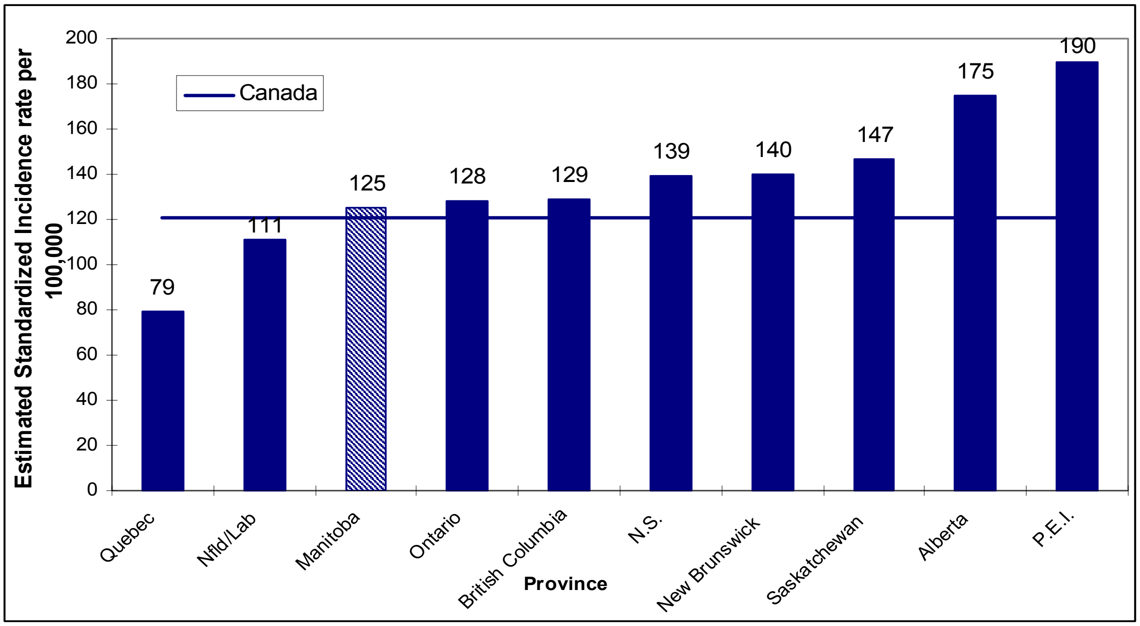
- Manitoba women are tied with Quebec with the highest expected lung cancer rate in Canada of 55 new cases per 100,000 women (see Figure 5.5). The rate among Manitoban men of 70 per 100,000 is just below the Canadian average of 72 per 100,000.

- Manitoba men are expected to have the fourth highest rate of colorectal cancer in 2004 with 400 new cases (for a standardized rate of 65 per 100,000) (see Figure 5.6).

- Manitoba women will be diagnosed with colorectal cancer at a rate comparable to the Canadian average (43 new cases per 100,000 compared to 41 per 100,000 for Canada).

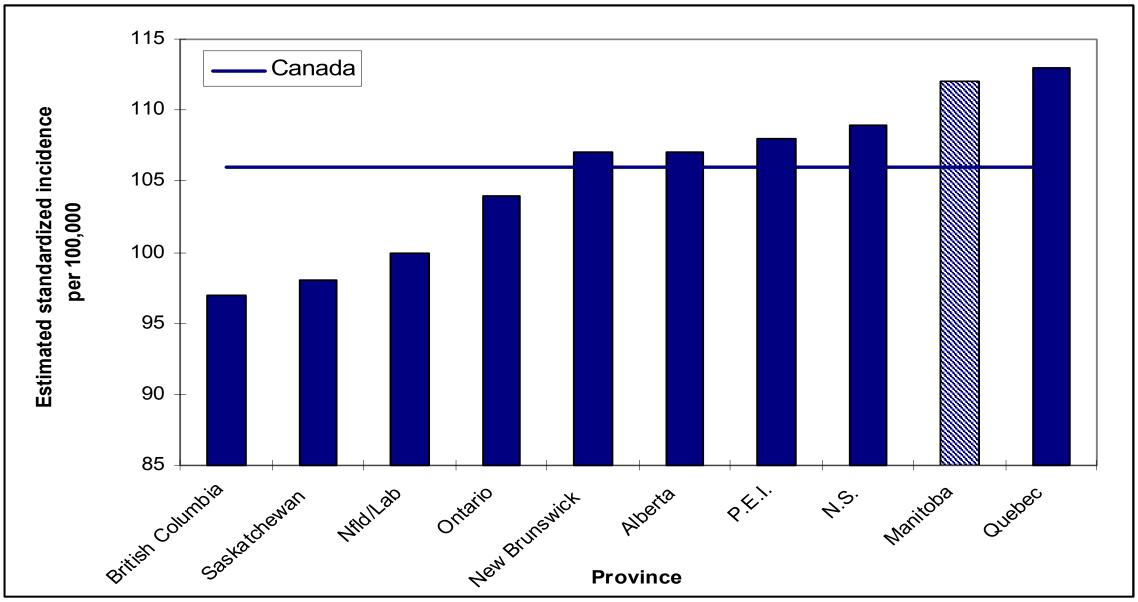
Although Manitoba's rates may appear to be somewhat different from the national average, the most recent data available on these common cancers from Health Canada's Cancer Surveillance OnLine website indicate that Manitoba's cancer incidence experience does not generally differ significantly from that observed for the country as a whole.

Figure 5.3. Estimated age-standardized incidence rates of prostate cancer by province, 2004



Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
Note: Territory numbers are included in Canadian total but not reported separately due to small numbers.

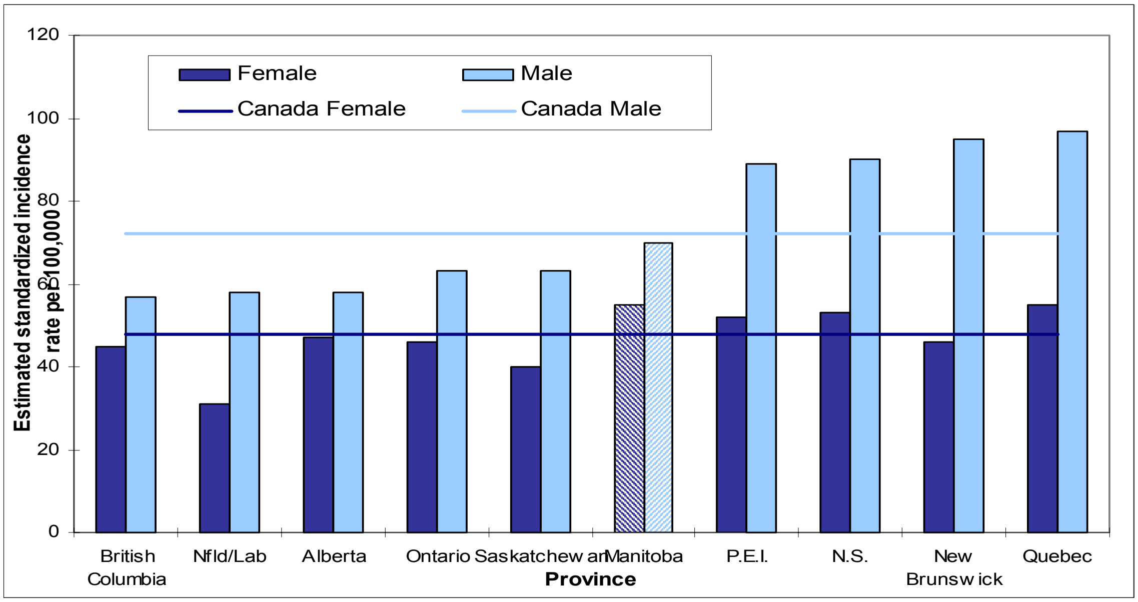
Figure 5.4. Estimated age-standardized incidence rates of female breast cancer by province, 2004



Source: National Cancer Institute of Canada, Canadian, Cancer Statistics, 2004.

Note: Territory numbers are included in Canadian total but not reported separately due to small numbers.

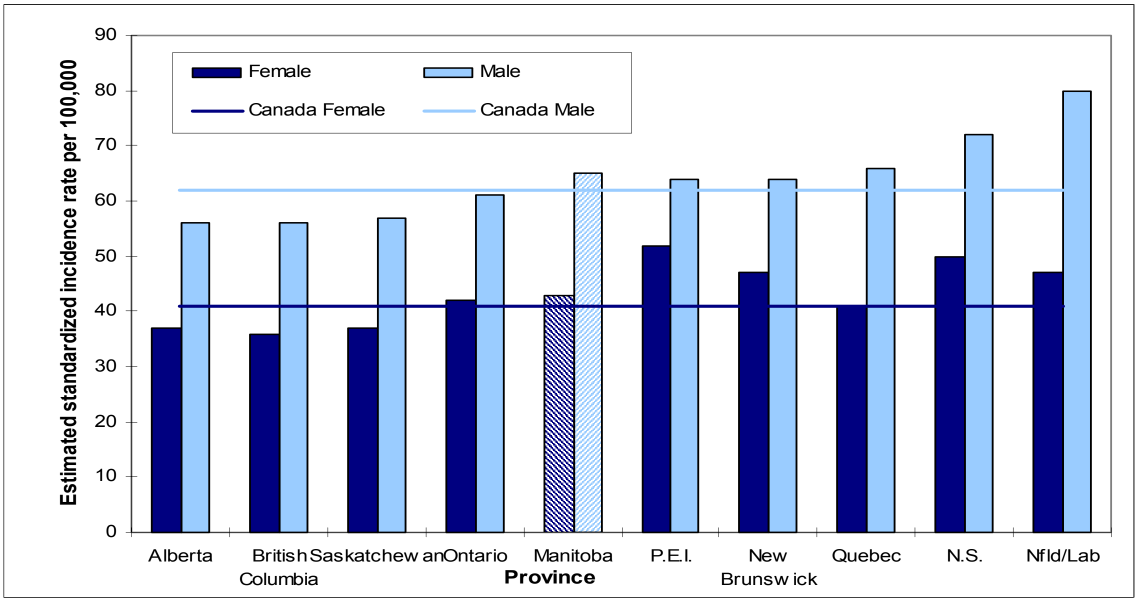
Figure 5.5. Estimated age-standardized incidence rates of lung cancer by province, 2004



Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.

Note: Territory numbers are included in Canadian total but not reported separately due to small numbers.

Figure 5.6. Estimated age-standardized incidence rates of colorectal cancer by province, 2004



Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
Note: Territory numbers are included in Canadian total but not reported separately due to small numbers.

5.1.1.2 Comparisons by Regional Health Authorities[a]

In analyzing cancer incidence by Regional Health Authorities (RHAs), it was apparent that prostate cancer was the leading cancer diagnosis among men while breast cancer was the leading cancer diagnosis among women. It is evident that there is variation between the regions in rates of overall invasive cancer diagnoses, as well as in specific cancer sites. In recognizing the population distribution and differing age structures by RHA, age standardization was used in the following graphs to make the data comparable across locations. Figures 5.7 and 5.8 illustrate the age standardized cancer incidence rates by RHA (standardized to the 1996 Manitoba population) for men and women.

In every region, standardized incidence rates of invasive cancer are lower among women than men. For both men and women the lowest average annual incidence rates of invasive cancer are in Burntwood RHA.

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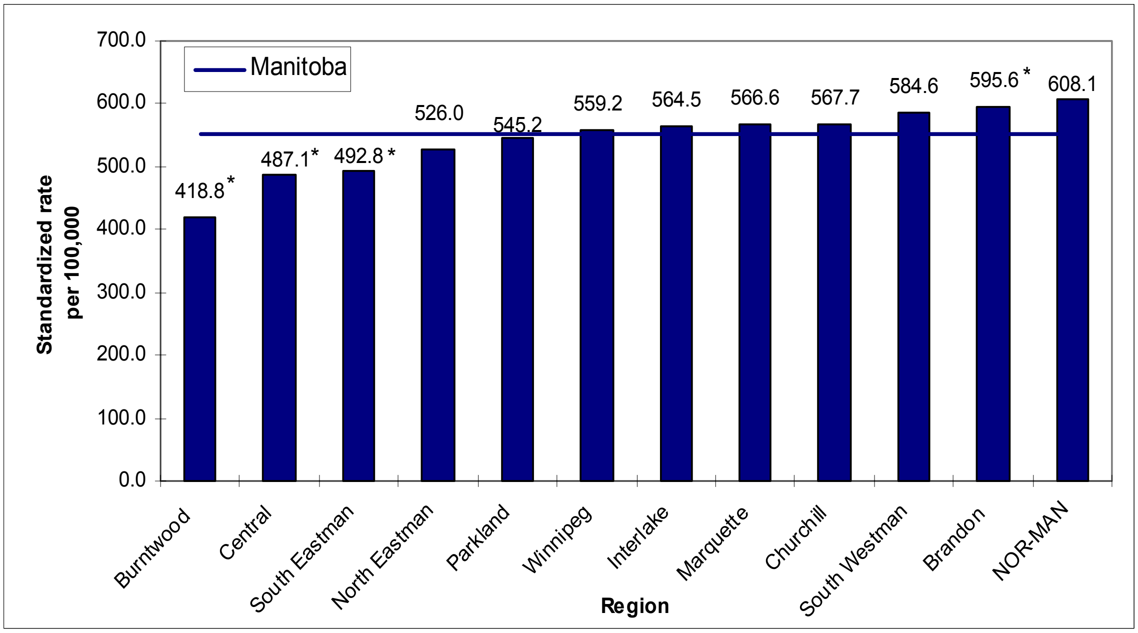
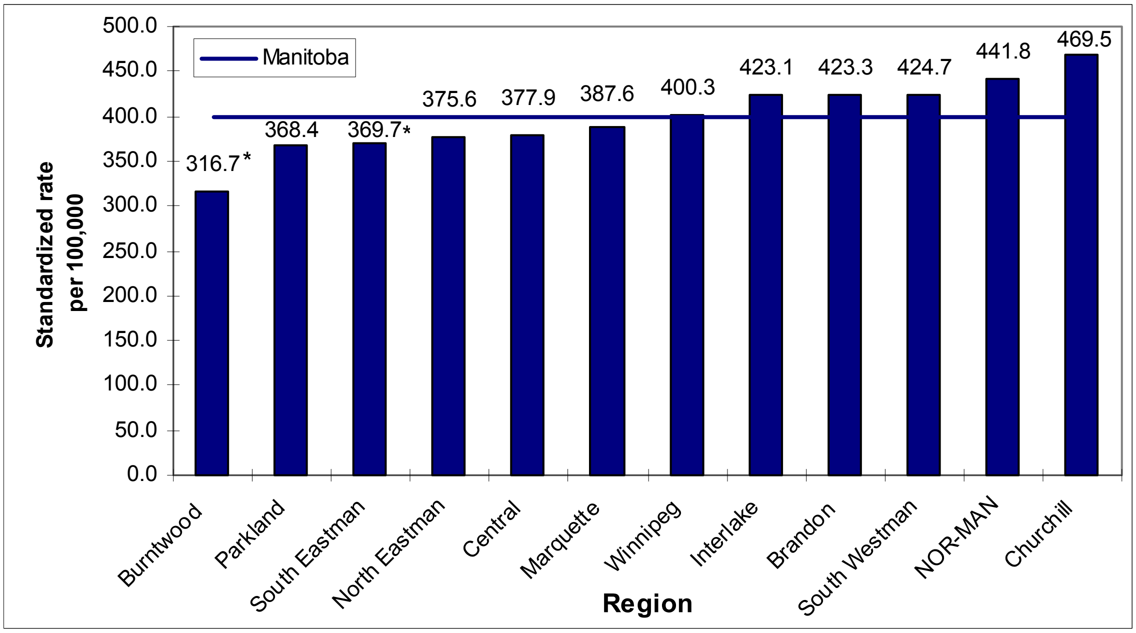
[a] Regional comparisons include the regions of "Marquette" and "South Westman". These regions were amalgamated on June 30, 2002 to form Assiniboine Regional Health Authority.

Figure 5.7. Age-standardized invasive cancer incidence rates by RHA, males 1992-2001



Source: CancerCare Manitoba
*Statistically different from provincial rate.

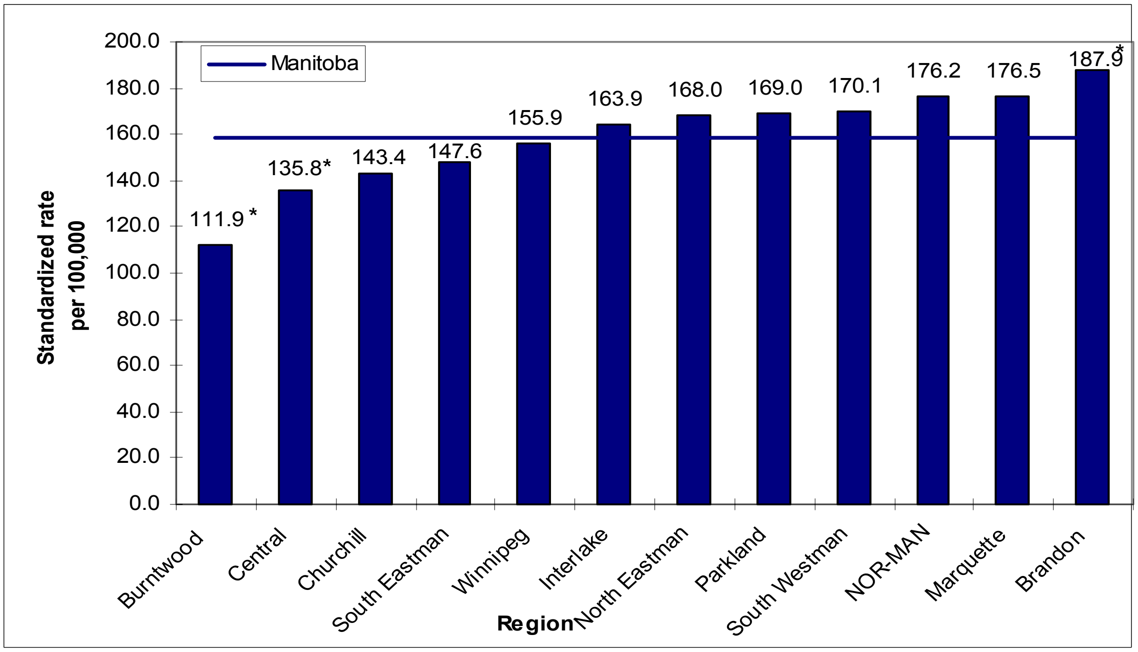
Figure 5.8. Age-standardized invasive cancer incidence rates by RHA, females, 1992-2001



Source: CancerCare Manitoba
*Statistically different from provincial rate.

Standardized rates of prostate cancer range across the province from an average annual rate of 111.9 new cases per 100,000 men in Burntwood to a high of 187.9 new cases per 100,000 men in Brandon (see Figure 5.9).

Figure 5.9. Age-standardized prostate cancer incidence rates by RHA, 1992-2001

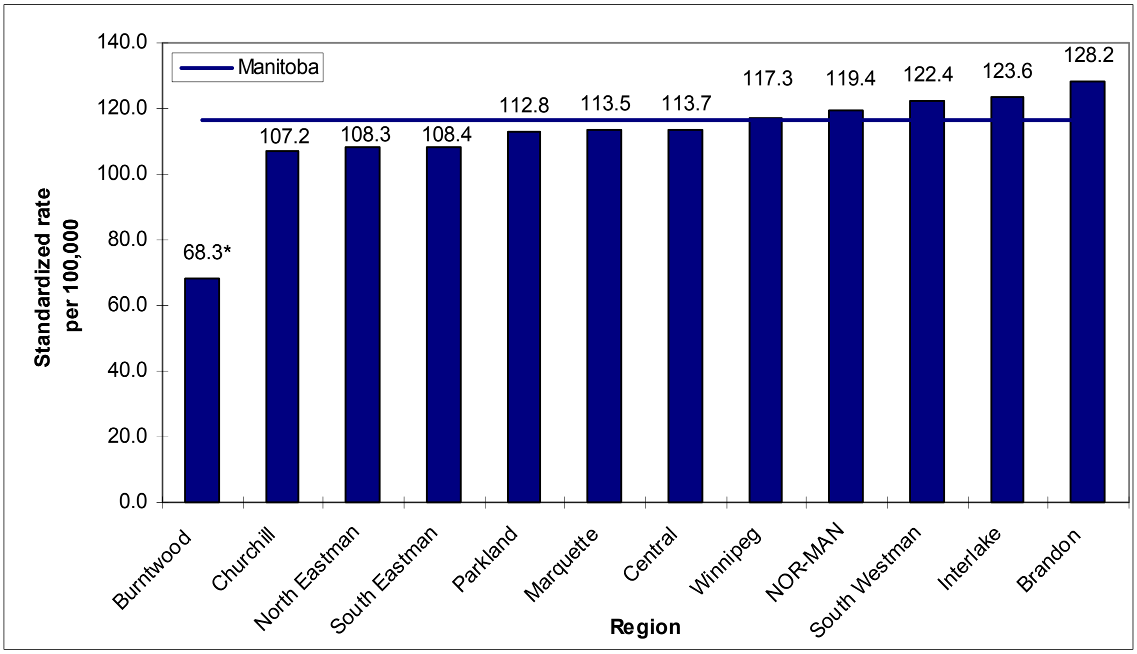


Source:	CancerCare Manitoba.
NOTE:	Churchill excluded due to small numbers.

*Statistically different from provincial rate.

Like prostate cancer, rates of invasive female breast cancer are lowest in Burntwood with an average annual rate of 68.3 new cases per 100,000 women and highest in Brandon at 128.2 new cases per 100,000 women (see Figure 5.10).

Figure 5.10. Age-standardized invasive female breast cancer incidence rates by RHA by region, 1992-2001

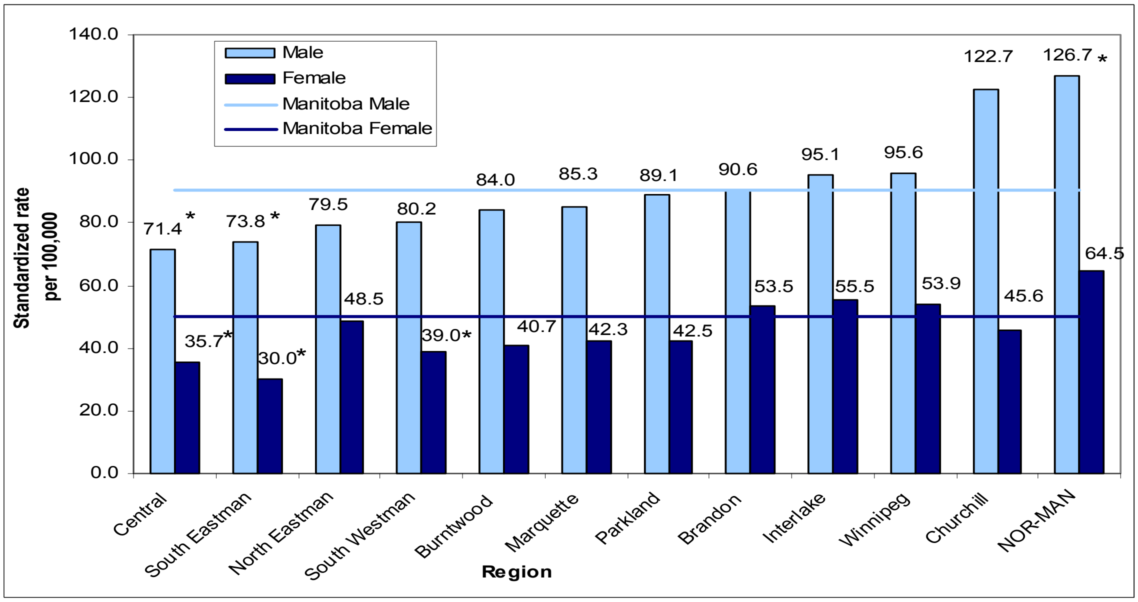


Source: CancerCare Manitoba
*Statistically different from provincial rate.

The highest rate of lung cancer among men is in NOR-MAN with an average annual standardized incidence rate of 126.7 new cases per 100,000 men (see Figure 5.11). As illustrated in the previous chapter, this region also has the second highest rate of smokers in the province (following Burntwood/Churchill). Among Manitoba women, the highest incidence rate of lung cancer is also found in NOR-MAN (64.5 new cases per 100,000 women).

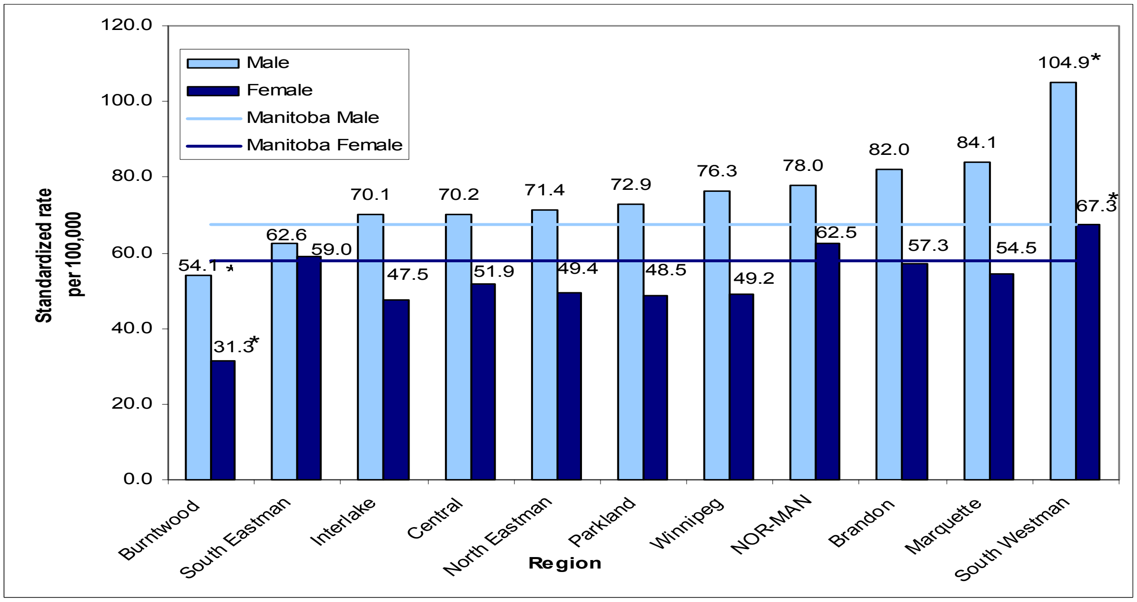
For colorectal cancer (see Figure 5.12), the highest rates among both men and women are found in South Westman (104.9 per 100,000 men and 67.3 per 100,000 women) and the lowest are found in Burntwood (54.1 per 100,000 men and 31.3 per 100,000 women.

Figure 5.11. Age-standardized incidence rates of lung cancer by region, 1992-2001



Source: CancerCare Manitoba.
*Statistically different from provincial rate

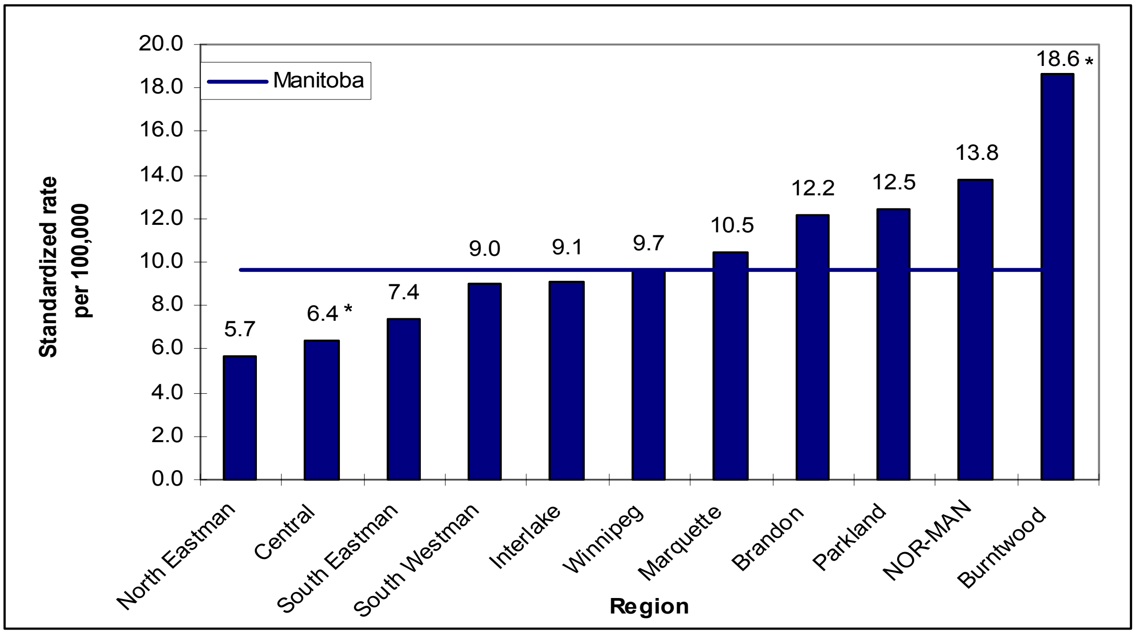
Figure 5.12. Age-standardized incidence rates of colorectal cancer by region, 1992-2001



Source: CancerCare Manitoba.
NOTE: Churchill excluded due to small numbers.
*Statistically different from provincial rate

As Figure 5.13 illustrates, although Burntwood RHA has the lowest rates of invasive cancers generally (as well as specific cancers such as prostate and breast) among both males and females in the province, this is not the case for invasive cervical cancer. Between 1992 and 2001, the average annual age-standardized incidence rate of invasive cervical cancer in Burntwood RHA was 18.6 cases per 100,000 females. This is almost double the provincial rate of 9.9 per 100,000. Burntwood RHA also had the lowest cervical cancer screening rates in the province (see Chapter 4) between April 2000 and March 2003. NOR-MAN and Parkland also have low screening rates compared to the rest of the province, and they have the second and third highest rates of invasive cervical cancer.

Figure 5.13. Standardized incidence rates of invasive cervical cancer by region, 1992-2001



Source: CancerCare Manitoba.
NOTE: Churchill excluded due to small numbers.
*Statistically different from provincial rate.

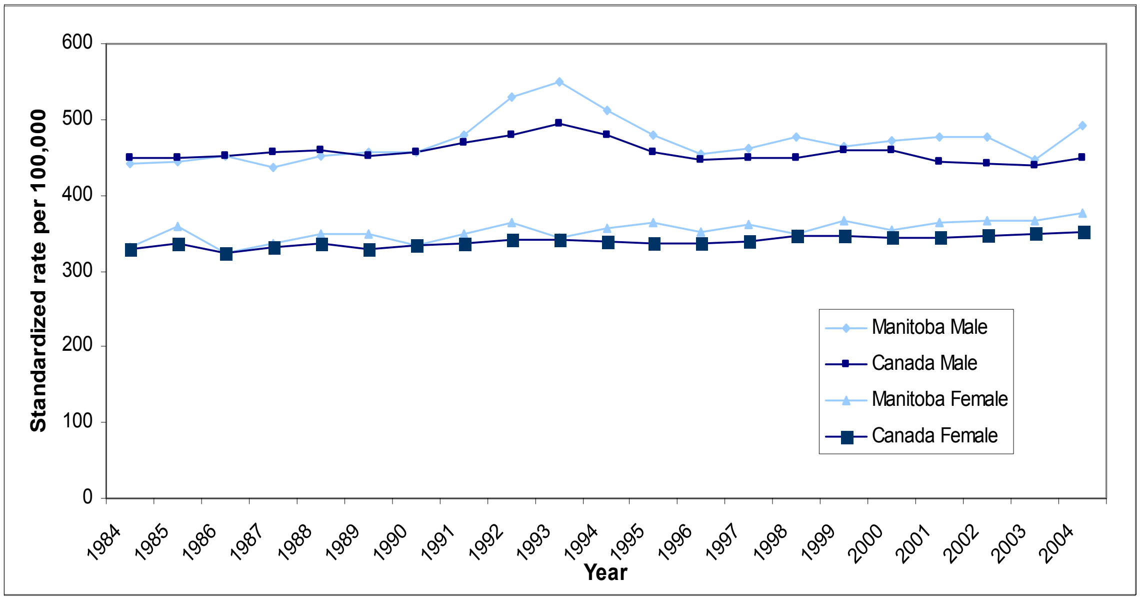
5.1.1.3 Time trends in cancer incidence

The time trend data presented in this section are based on actual data provided from the Manitoba Cancer Registry to Statistics Canada for the years 1984-2000 and projections for the years 2001-2004 reported by the National Cancer Institute of Canada. The information presented in this section is standardized to the Canadian 1991 population.

As Figure 5.14 illustrates, incidence rates of invasive cancer have increased among both Manitoba men and women in the twenty-one year time period examined. Among Manitoba men, rates have increased from 441.5 new cases per 100,000 in 1984 to 470.7 per 100,000 in 2000, and are estimated to be 492 per

100,000 in 2004. Cancer rates among Manitoba women have increased from 330.7 new cases per 100,000 women in 1984 to 355.2 per 100,000 in 2000, and are estimated to be 377 per 100,000 in 2004. Manitoba's cancer rates are very similar to those of the country as a whole, indicating that Canada is also experiencing growth in cancer incidence.

Figure 5.14. Age-standardized invasive cancer incidence rates Manitoba and Canada, 1984-2004



Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004).

Provincial time trends in cancer incidence are presented for the following specific sites:

- Prostate cancer (Figure 5.15)
- Female breast cancer (Figure 5.16)
- Lung cancer (Figure 5.17)
- Colorectal cancer (Figure 5.18)

Highlights of the time trend analysis include:

- Prostate cancer rates have been consistently higher among Manitoban men than Canadian men, but recent provincial rates are similar to the national rates.

- In both Manitoba and Canada, rates of prostate cancer increased steadily between 1984 and 1993, but then decreased until 1996 at which point rates began to climb again, although not as dramatically as in the early 1990s.

- The peak in prostate cancer incidence in the early 1990s is attributed to the introduction of the prostate-specific antigen (PSA) test and the resulting increase in detection of previously clinically inapparent tumours.

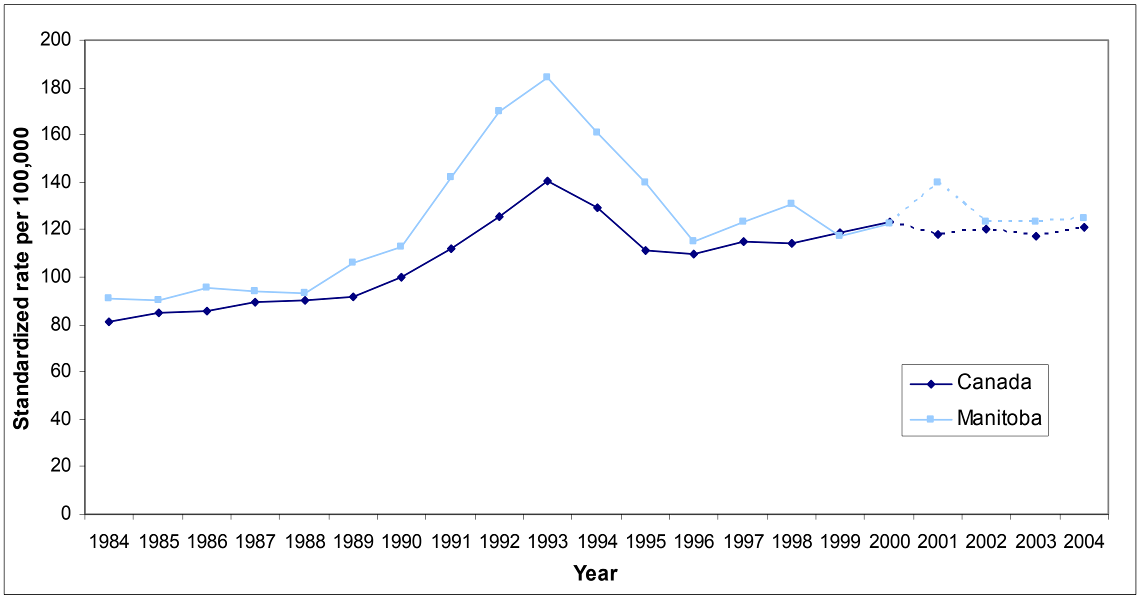
- Since 1988, breast cancer rates have been higher among Manitoban women than Canadian women but there is little difference in the patterns observed between the province and the country as a whole. Rates among both Manitoba and Canadian women appear to have increased steadily until the last few years, when rates appear to be levelling off.

- While rates of lung cancer are still higher among Manitoba men than Manitoba women, the difference in rates has decreased considerably. Rates among men are declining while the opposite is true for females.

- Rates of lung cancer among Manitoba women have historically tended to be somewhat higher than rates among Canadian women, but rates are very comparable in the most recent time frame.

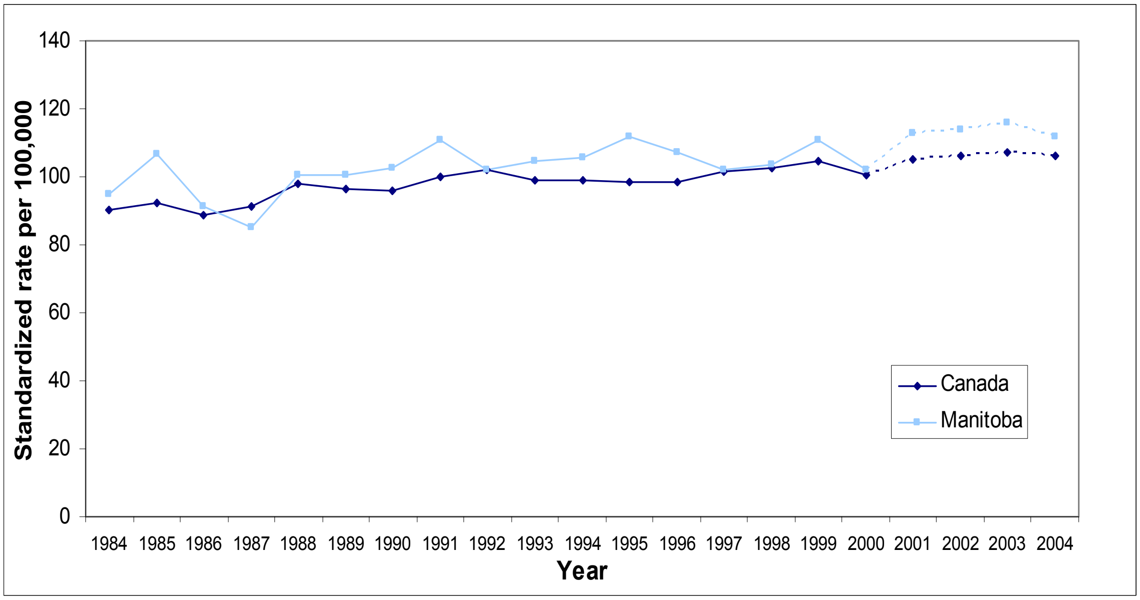
- Although there has been some variation in rates over the years, incidence rates of colorectal cancer among Manitoba men are expected to be the same in 2004 as they were in 1984. Rates among women, however, have decreased slightly.

Figure 5.15. Age-standardized prostate cancer incidence rates Manitoba and Canada, 1984-2004



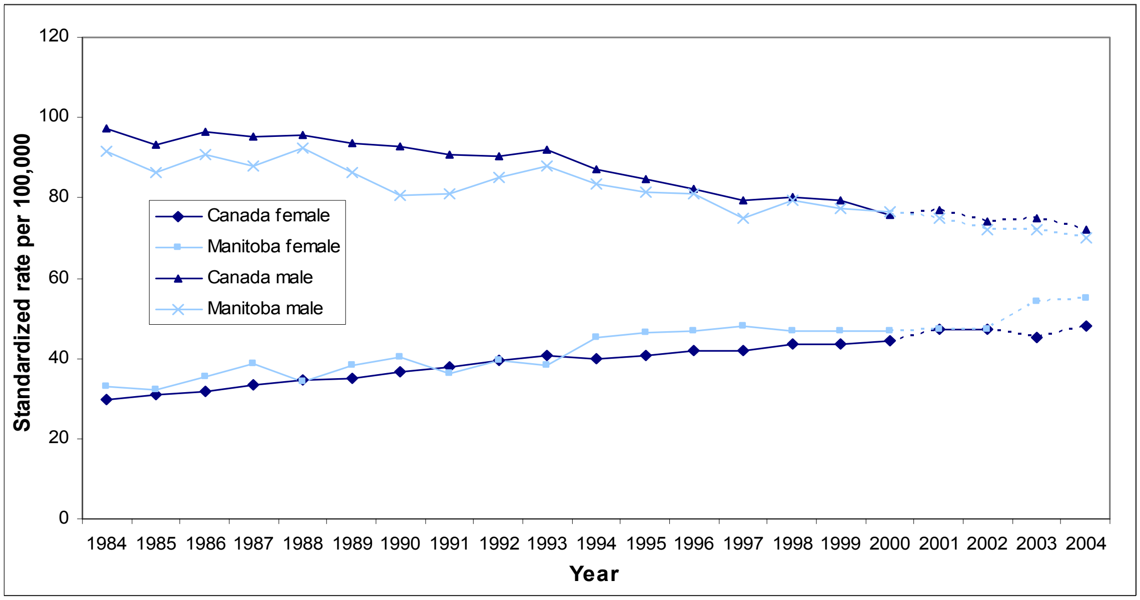
Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004).

Figure 5.16. Age-standardized female breast cancer incidence rates Manitoba and Canada, 1984-2004



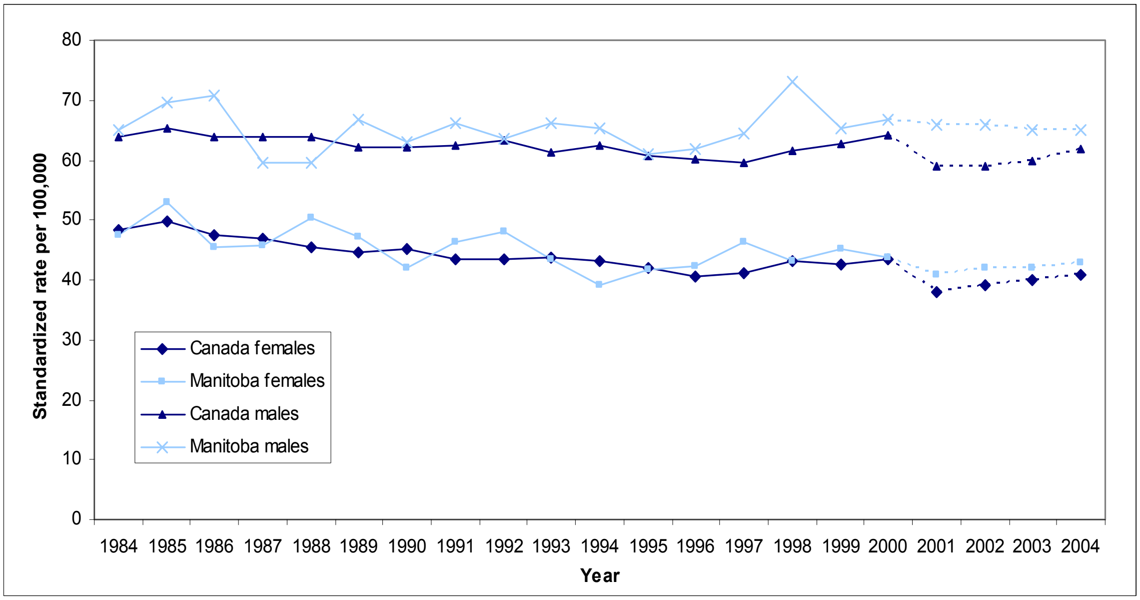
Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004).

Figure 5.17. Age-standardized lung cancer incidence rates in Manitoba and Canada, 1984-2004



Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004

Figure 5.18 Age-standardized colorectal cancer incidence rates in Manitoba and Canada, 1984-2004



Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004).
Estimated combined M/F rates not available.

5.1.2 Cancer Prevalence

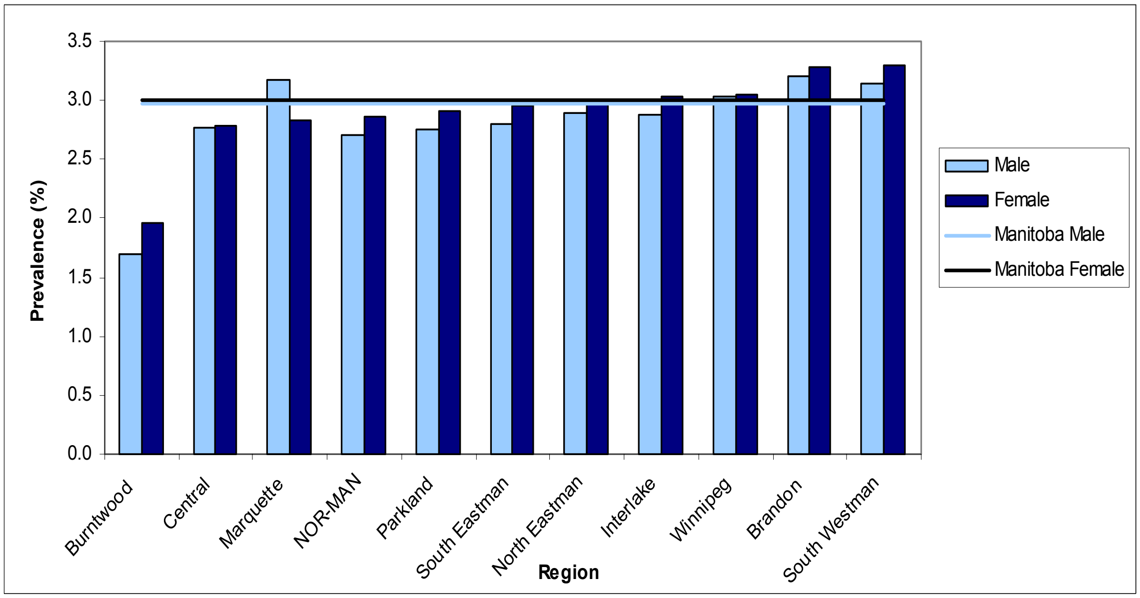
> *"A large number of Canadians live with the effects of cancer and have continuing need for cancer care resources and support services."* [3]

Prevalence is an important measure as it can provide an indication of the burden posed by cancer at the personal level and at the health care system level. People who have been diagnosed with cancer may experience physical, emotional, spiritual and financial challenges. After physical recovery, there is in many cases, the continuing need for rehabilitative and supportive care services. Cancer survivors may also have a cancer recurrence or develop cancer at a new site, which will result in increased demand for health services.

Prevalence refers to the number of people at a specific point in time who are alive and at sometime have had a diagnosis of cancer. In Canada it is estimated that the overall prevalence rate is 2.4 per cent among men and 2.6 per cent among women.[4] Within Manitoba, the (crude) prevalence of invasive cancer in 2000 was 3.4 per cent for women and 2.7 per cent for men.[5]

Figure 5.19 presents the invasive cancer prevalence rates for Manitoban RHAs. As with incidence rates, the lowest invasive cancer prevalence rates among both males and females are in Burntwood (1.0% and 0.7% respectively). South Westman has the highest crude prevalence rates among both males (4.0%) and females (4.7%). The experience in South Westman is reflective of the provincial experience in that the prevalence rates are higher among women than men.

Figure 5.19. Invasive cancer prevalence rates, 2000



Source: CancerCare Manitoba
NOTE: South Westman and Marquette amalgamated to Assiniboine in 2003.

According to National Cancer Institute of Canada estimates[4], prostate cancer is the most prevalent cancer among Canadian men at 0.7 per cent of the male population and breast cancer is the most prevalent among Canadian women at 1.0 per cent of the female population. Manitoba has a prevalence rate for prostate cancer of 1.1 per cent, and a female prevalence rate of breast cancer of 1.4 per cent among women.

5.1.3 Cancer Incidence and Prevalence Projections

Projections[6] of cancer incidence and prevalence indicate that by 2025 approximately five per cent of Manitobans will be living with cancer. Numbers of newly diagnosed cases are expected to increase between 45 and 54 per cent and the number of people living with cancer will increase by 75 to 84 per cent to between 58,000 and 61,000 Manitobans.

The work by Kliewer et al. indicated that because of the aging population, cancer cases will be primarily concentrated in the population aged 65 and older. It is projected that by 2025, 25 per cent of residents aged 80 and older will have been diagnosed with cancer.

Table 5.4 illustrates that rates of prostate cancer are expected to increase the most among specific cancer sites, and colorectal will increase the least.

Table 5.4. Per cent change in cancer incidence and prevalence by site, low and high population growth models, Manitoba, 1998-2025

SITE	INCIDENCE RANGE	PREVALENCE RANGE
Lung	83.2% to 92.2%	106.4% to 116.5%
Colorectal	26.1% to 32.9%	52.1% to 58.9%
Breast	59.0% to 68.3%	86.7% to 95.4%
Prostate	128.4% to 141.9%	174.4% to 187.2%
Total (invasive)	45.2% to 53.7%	74.6% to 83.6%

Source: Kliewer, Erich V., Wajda, A., Blanchard, J.F. (2001). The Increasing Cancer Burden: Manitoba Cancer Projections 1999-2025, page 19.

5.2 Cancer Mortality

5.2.1 Cancer Mortality Rates

According to vital statistics data analyzed by Manitoba Health, between 1984 and 1998[b], there were 43,488 deaths from cancer. This means that on average, there are about 2,900 deaths per year due to cancer. Males accounted for 54.2 per cent of deaths (or 23,551) and females accounted for 45.8 per cent (19,937). Between 1984 and 1998, the number of deaths due to cancer was second only to deaths due to disease of the circulatory system and accounted for 26 per cent of all deaths in Manitoba (see Figure 5.20).

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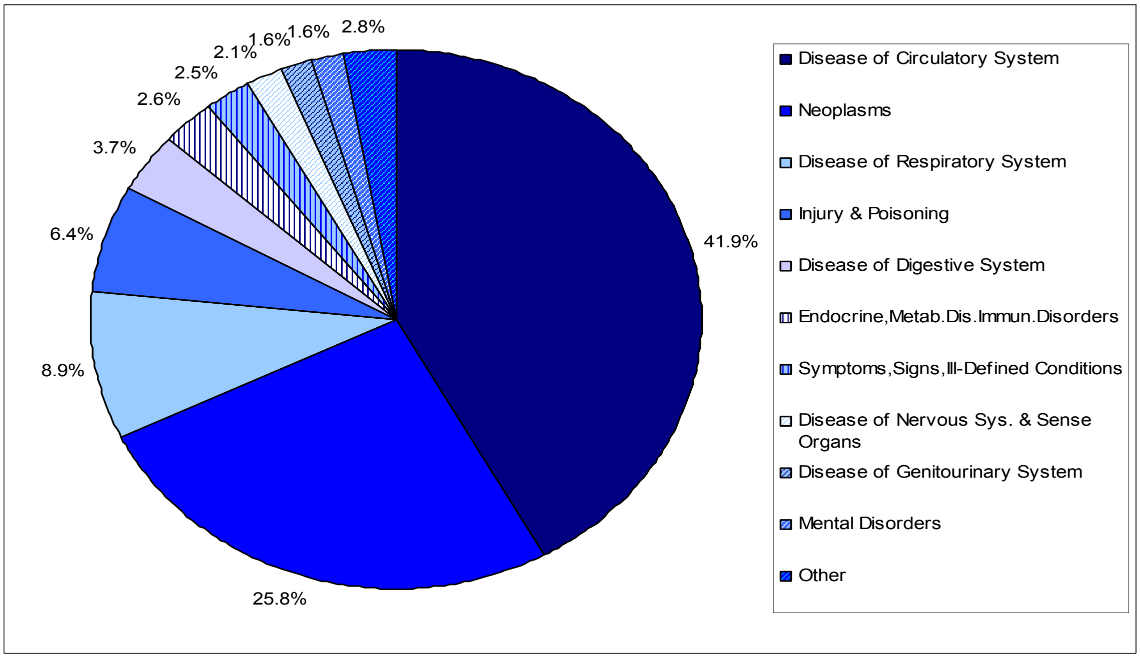
[b] Coding changes occurring for death data preclude proportionate mortality analysis by disease category for more recent years.

Figure 5.20. Proportion of deaths by ICD-9 classification, 1984-1998



Source: Data: Manitoba Health Decision Support Services, Analysis: EPI Research & Data Management.

Among specific causes of death, lung cancer is the second leading cause of death among Manitoba men and the third leading cause among Manitoba women.

Lung cancer accounts for the largest proportion of deaths due to cancer at 23.6 per cent of all cancer deaths that occurred between 1984 and 1998. Lung cancer accounted for 29.3 per cent of male cancer deaths and 17.0 per cent of female cancer deaths. Breast cancer accounted for 17.7 per cent of female cancer deaths, prostate cancer 12.7 per cent of male cancer deaths, and colorectal cancer 11.4 per cent of all cancer deaths.

5.2.1.1 Provincial mortality comparisons

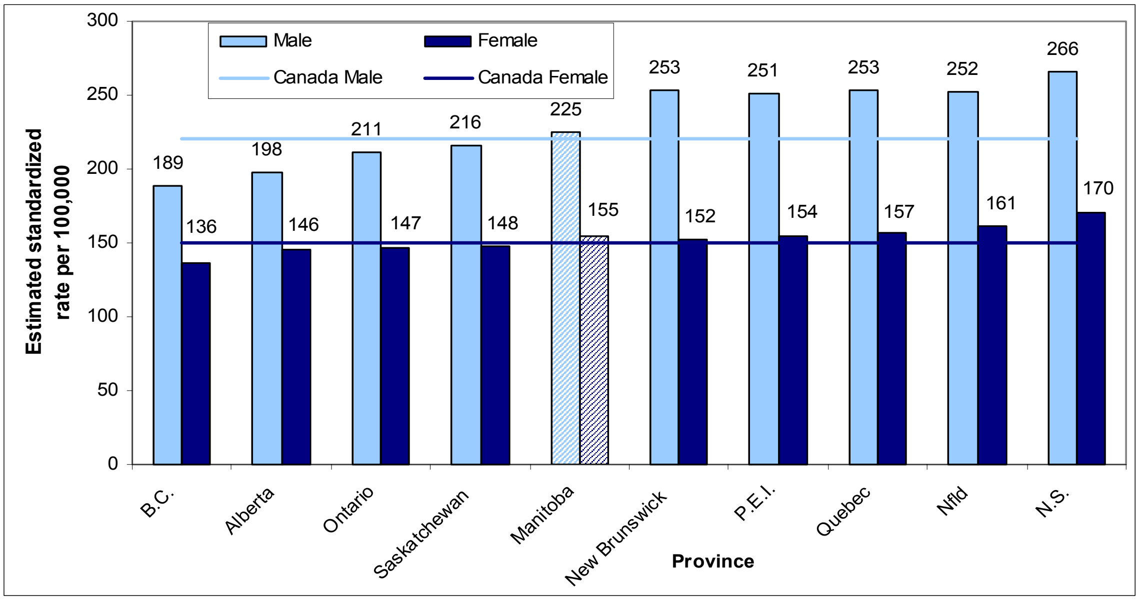
Provincial mortality comparisons are based on the National Cancer Institute of Canada's estimated number of new cases for 2004. The provincial data are age standardized to the 1991 Canadian population. Standardized rates control for differences in age structures in populations, and are used to compare rates either over time or between locations. Provincial cancer mortality comparison graphs are presented for:

- All invasive cancers (Figure 5.21)
- Prostate cancer (Figure 5.22)

- Female breast cancer (Figure 5.23)
- Lung cancer (Figure 5.24)
- Colorectal cancer (Figure 5.25)

The National Cancer Institute of Canada estimates that in 2004 there will be 2,650 deaths due to cancer in Manitoba (1,400 among men and 1,250 among women). Based on these estimates, Manitoban men will have the fifth lowest standardized cancer mortality rate in Canada and Manitoban women will have the fourth highest (see Figure 5.21). However, data from Health Canada's Cancer Surveillance OnLine system indicate that Manitoba's cancer mortality rates are statistically similar to that observed for Canada as whole, signifying that Manitoba's cancer experience is comparable to the national experience.

Figure 5.21. Estimated age-standardized invasive cancer mortality rates by province, 2004



Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
NOTE: Territory numbers are included in Canadian total but not reported separately due to small numbers.

Highlights of the national comparative data include:

- Estimates for 2004 predict 170 deaths due to prostate cancer in Manitoba for a standardized rate of 27 cases per 100,000. This is the third lowest rate (as was incidence) in Canada behind Quebec and British Columbia, but the pattern of prostate cancer mortality in Manitoba is similar to the national experience.

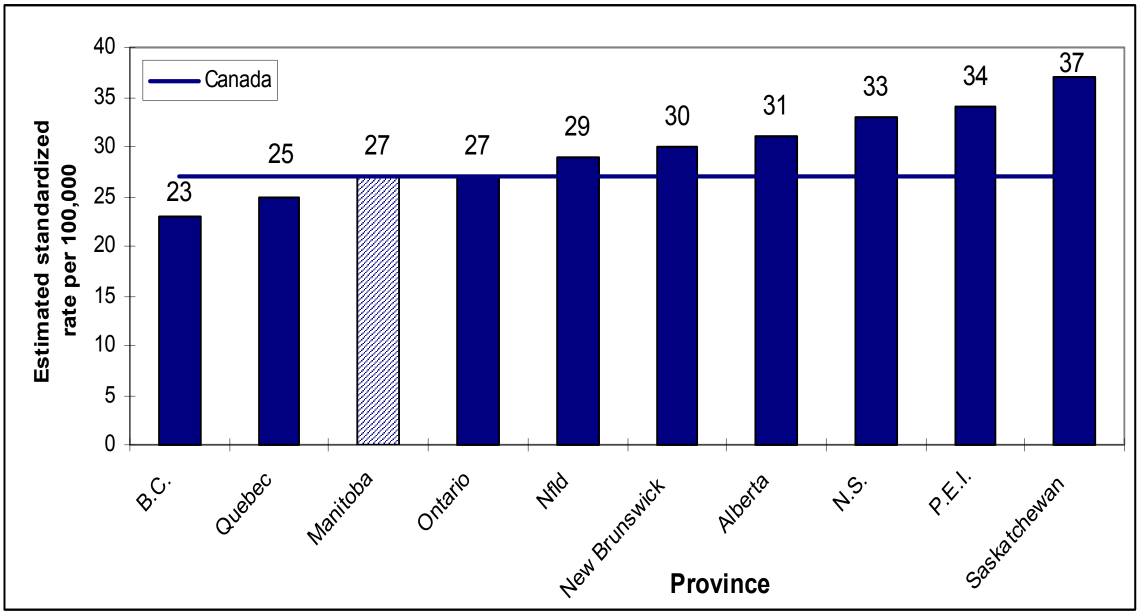
- With 200 deaths in Manitoba, breast cancer mortality rates in 2004 are expected to be the fourth highest in the country at 26 deaths per 100,000 women, but are very similar to the national rate at 24 per 100,000 women.

- There are expected to be a total of 690 deaths due to lung cancer among Manitobans in 2004 (370 among men and 320 among women).

- Manitoba females are expected to have the third highest lung cancer mortality rates in Canada at 43 deaths per 100,000 women, which is similar to the national rate of 40 deaths per 100,000 women. The rate among Manitoban men of 60 per 100,000 is slightly below the Canadian average of 65 per 100,000.

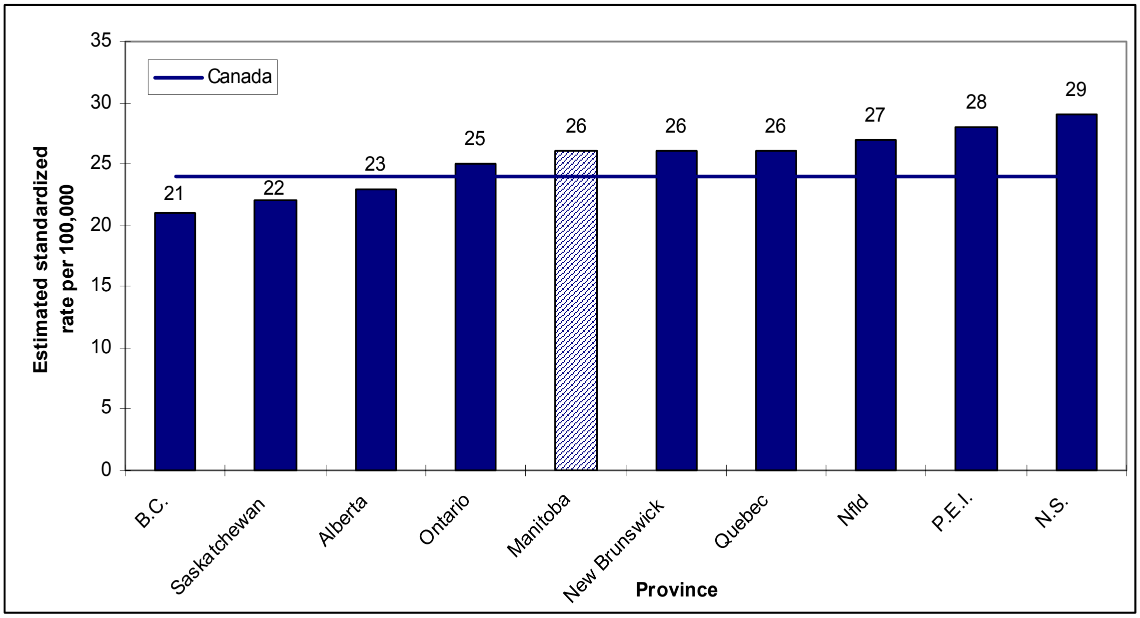
- Colorectal cancer mortality rates are comparable to the national average for both Manitoba women (18 deaths per 100,000) and Manitoba men (30 per 100,000); the Canadian averages are 17 and 27 per 100,000 respectively.

Figure 5.22. Estimated age-standardized prostate cancer mortality rates by province, 2004



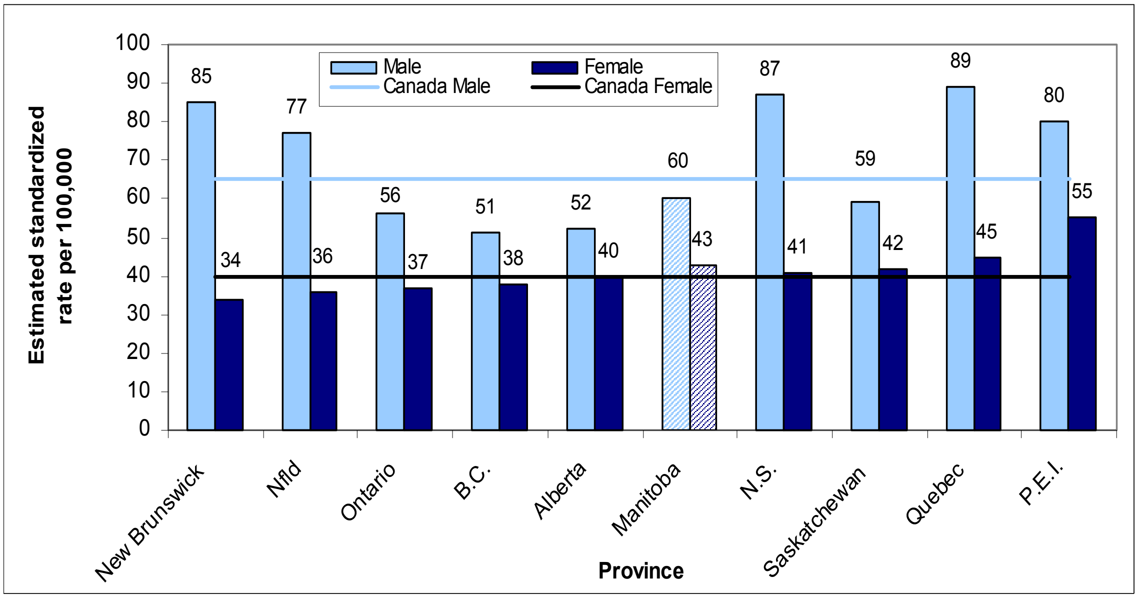
Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
NOTE: Territory numbers are included in Canadian total but not reported separately due to small numbers.

Figure 5.23. Estimated age-standardized breast cancer mortality rates by province, 2004



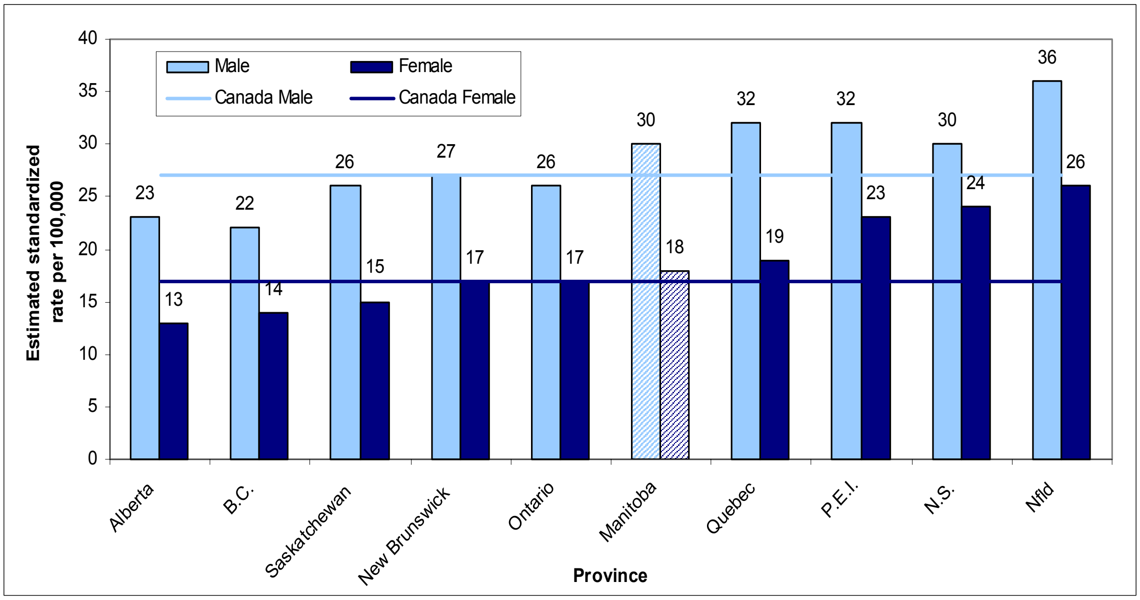
Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
NOTE: Territory numbers are included in Canadian total but not reported separately due to small numbers.

Figure 5.24. Estimated age-standardized lung cancer mortality rates by province, 2004



Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
NOTE: Territory numbers are included in Canadian total but not reported separately due to small numbers.

Figure 5.25. Estimated age-standardized colorectal cancer mortality rates by province, 2004



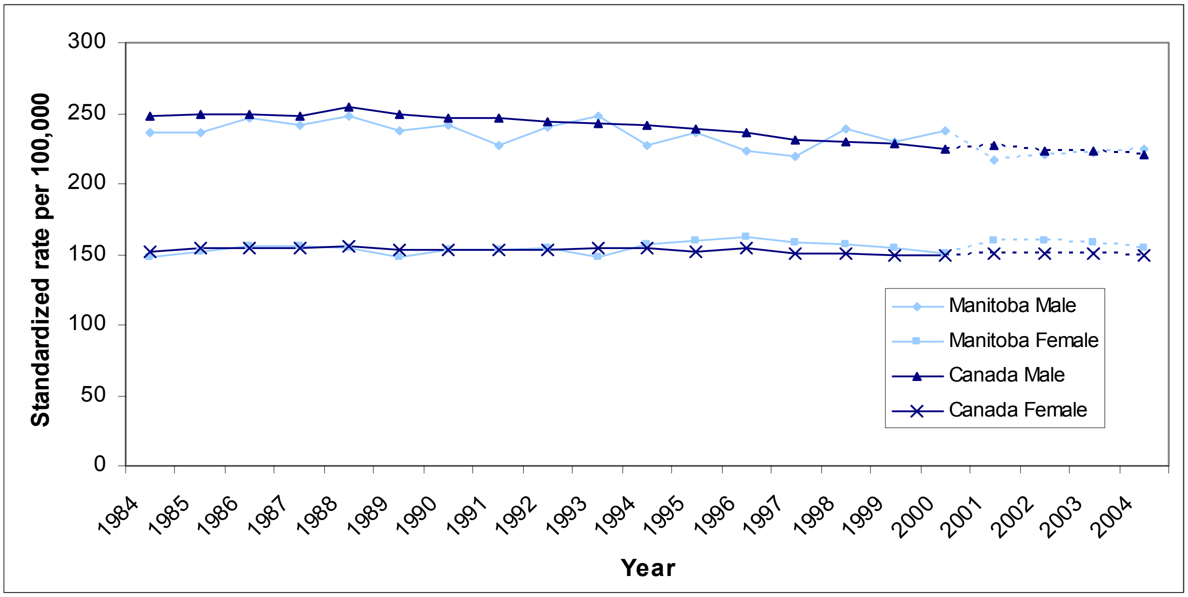
Source: National Cancer Institute of Canada, Canadian Cancer Statistics, 2004.
NOTE: Territory numbers are included in Canadian total but not reported separately due to small numbers.

5.2.2 Time Trends in Cancer Mortality

The time trend data presented in this section are based on data provided to Statistics Canada from the Manitoba Cancer Registry for the years 1984-2000. Estimates are used for the years 2001-2004 (provided by the National Cancer Institute of Canada). All data presented in this section are standardized to the Canadian 1991 population.

As Figure 5.26 illustrates, cancer mortality rates have decreased among both Canadian and Manitoba men, and have stayed fairly constant for Canadian and Manitoban women. Among Manitoban men death rates have remained stable for most of the past two decades, at 236.7 deaths per 100,000 in 1984 and 237.9 per 100,000 in 2000, with a decrease to an estimated rate of 225 deaths per 100,000 expected in 2004. These rates are consistent with the national average. Mortality rates among Manitoban women have also remained fairly stable over time, at 148.7 new cases per 100,000 women in 1984 and 150.3 per 100,000 in 2000, with an estimated rate of 155 deaths per 100,000 expected in 2004. In short, Manitoba's cancer mortality experience is comparable to the national experience.

Figure 5.26. Age-standardized invasive cancer mortality rates, Manitoba and Canada, 1984-2004



Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (NATIONAL CANCER INSTITUTE OF CANADA, Canadian Cancer Statistics, 2004).

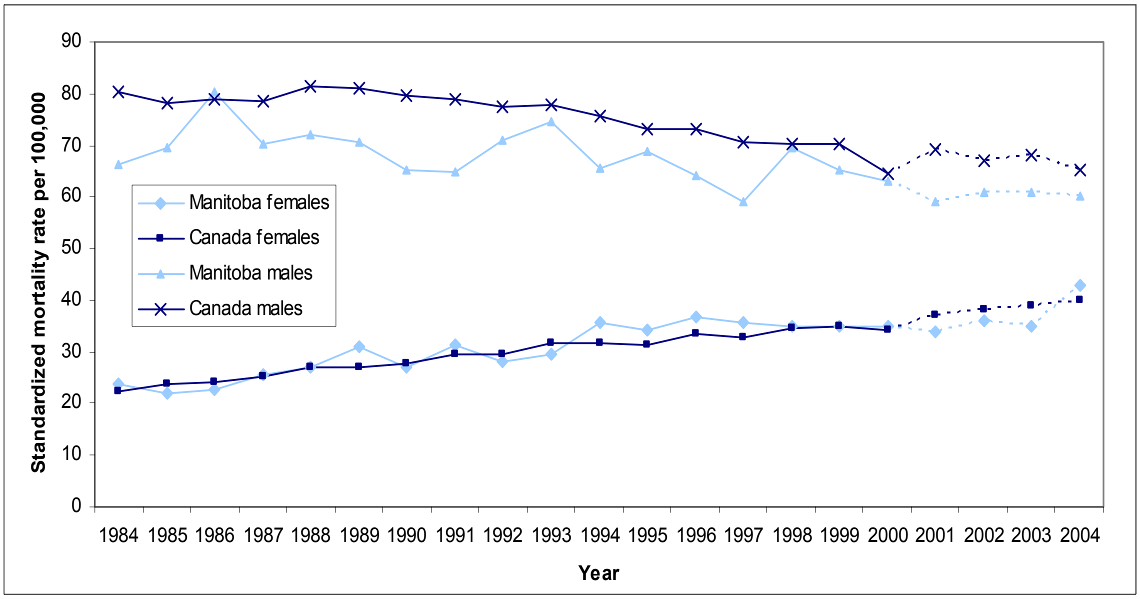
Provincial time trends in cancer mortality are presented for the following specific sites:

- Lung cancer (Figure 5.27)
- Prostate cancer (Figure 5.28)
- Female breast cancer (Figure 5.29)
- Colorectal cancer (Figure 5.30)

Highlights of the time trend analysis include:

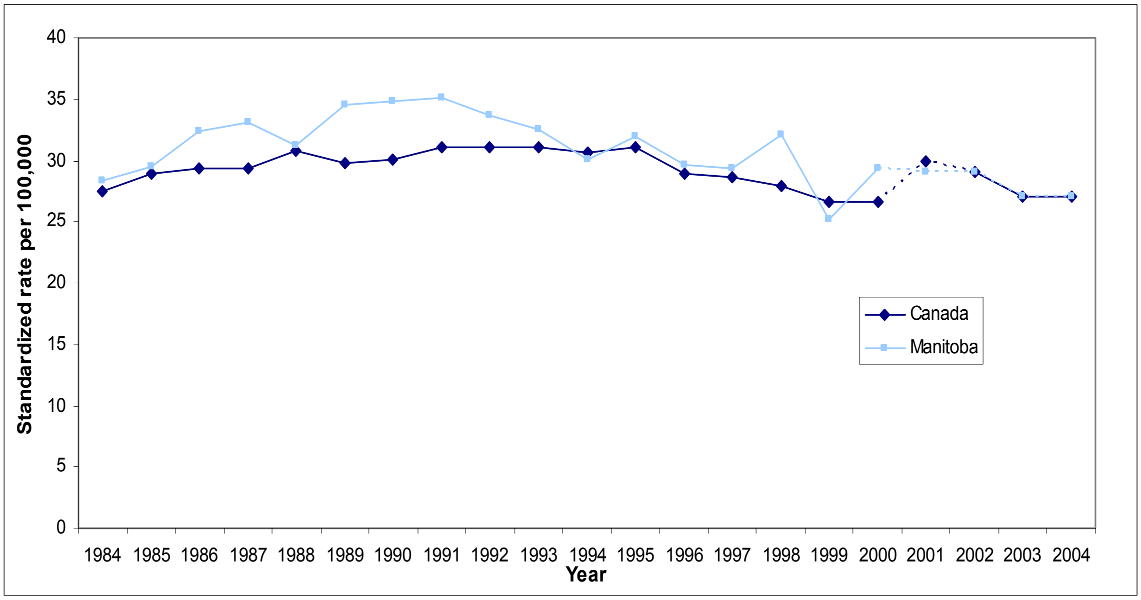
- As with lung cancer incidence, lung cancer mortality rates are higher among males than females. However, the difference has decreased quite dramatically.
- Lung cancer rates among Manitoba men are declining while the opposite is true for females.
- Prostate cancer mortality rates are generally declining from their highest point in the late 1980s and early 1990s. This is a positive trend given the increase in prostate cancer incidence (and indicates very good prognosis for prostate cancer).
- Manitoba prostate cancer mortality rates are similar to those observed for the country as a whole.
- Manitoba's breast cancer mortality rates have generally been comparable to the national rates. Mortality rates in 2004 are expected to be similar to the national rates, with 26 deaths per 100,000 Manitoban women compared to 24 deaths per 100,000 Canadian women.
- Colorectal cancer mortality has been declining gradually for both men and women.

Figure 5.27. Age-standardized lung cancer mortality rates, Manitoba and Canada, 1984-2004



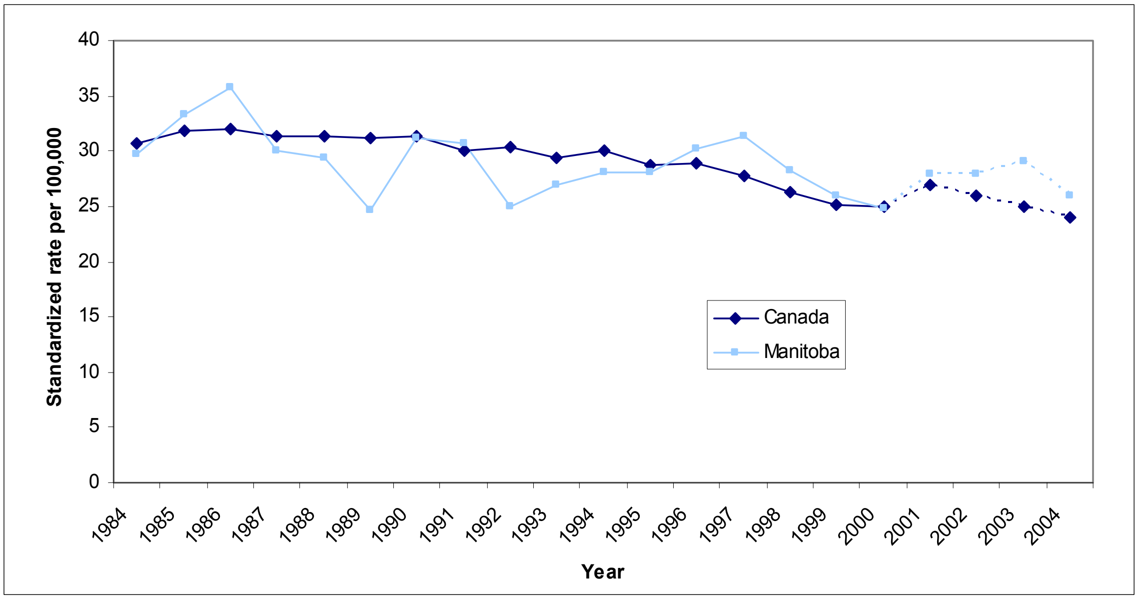
Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004).

Figure 5.28. Age-standardized prostate cancer mortality rates, Manitoba and Canada, 1984-2004



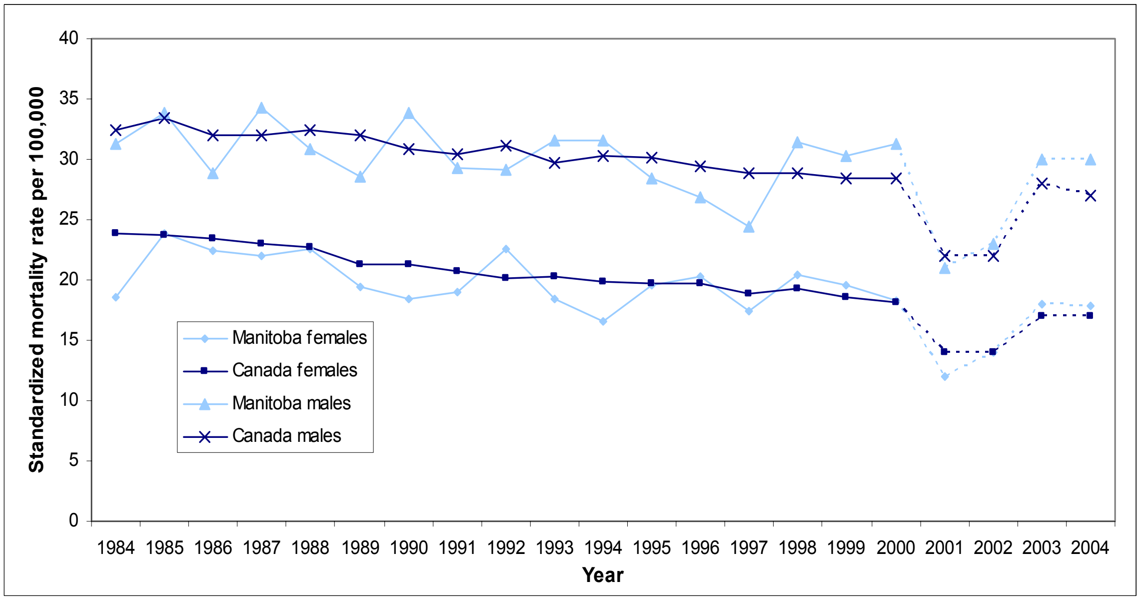
Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004).

Figure 5.29. Age-standardized breast cancer mortality rates, Manitoba and Canada, 1984-2004



Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004).

Figure 5.30. Age-standardized colorectal cancer mortality rates, Manitoba and Canada, 1984-2004



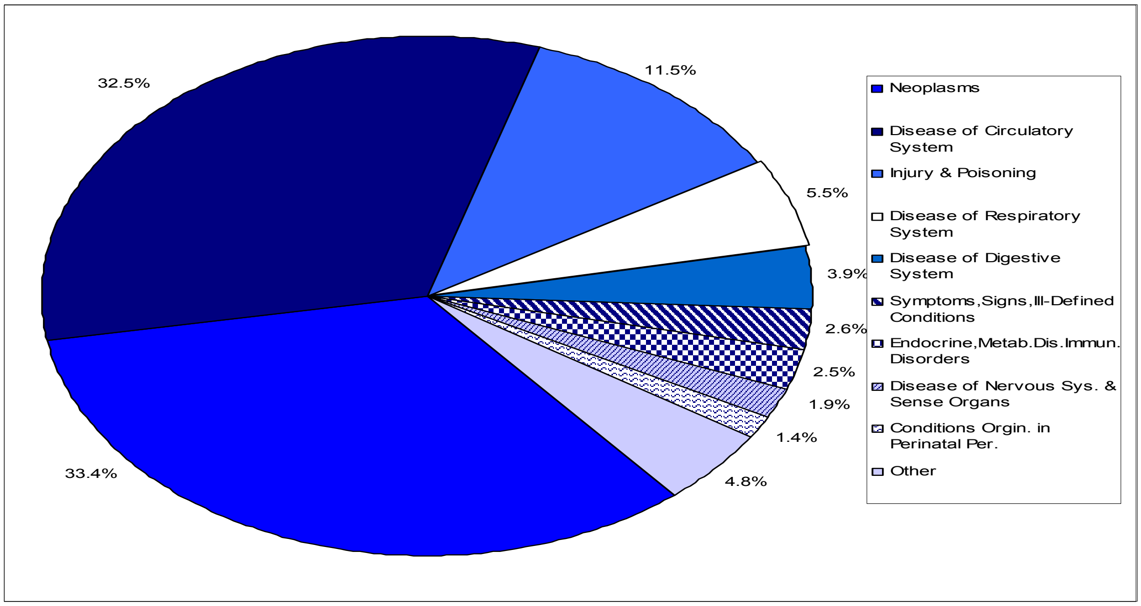
Source: 1984-2000: Health Statistics Division, Statistics Canada.
NOTE: 2001-2004 rates are estimated (National Cancer Institute of Canada, Canadian Cancer Statistics, 2004)

5.2.3 Premature Deaths Due to Cancer

> *"Cancer is the leading cause of premature death in Canada."*[7]

Between 1984 and 1998[c], there were 76, 313 premature deaths accounting for 1,362,364 potential years of life lost[d] (PYLL) among Manitoba residents. As Figure 5.31 illustrates, cancer was responsible for one-third of all premature deaths in Manitoba, accounting for just slightly more premature deaths than Diseases of the Circulatory System (which is the leading cause of all deaths).

Figure 5.31. Proportion of premature deaths by ICD-9 disease classification, 1984-1998



Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research & Data Management.
NOTE: "Other" includes all classes that accounted for less than 1,000 deaths each.

Females accounted for 28,985 (or about 38%) of all premature deaths while males accounted for the remaining 62 per cent of premature deaths. Figures 5.32 and 5.33 illustrate the distribution of premature deaths from various diseases for males and females separately. Cancer is the leading cause of premature death among females, accounting for almost 40 per cent of deaths, and is the second leading cause among males, accounting for approximately 30 per cent of premature deaths.

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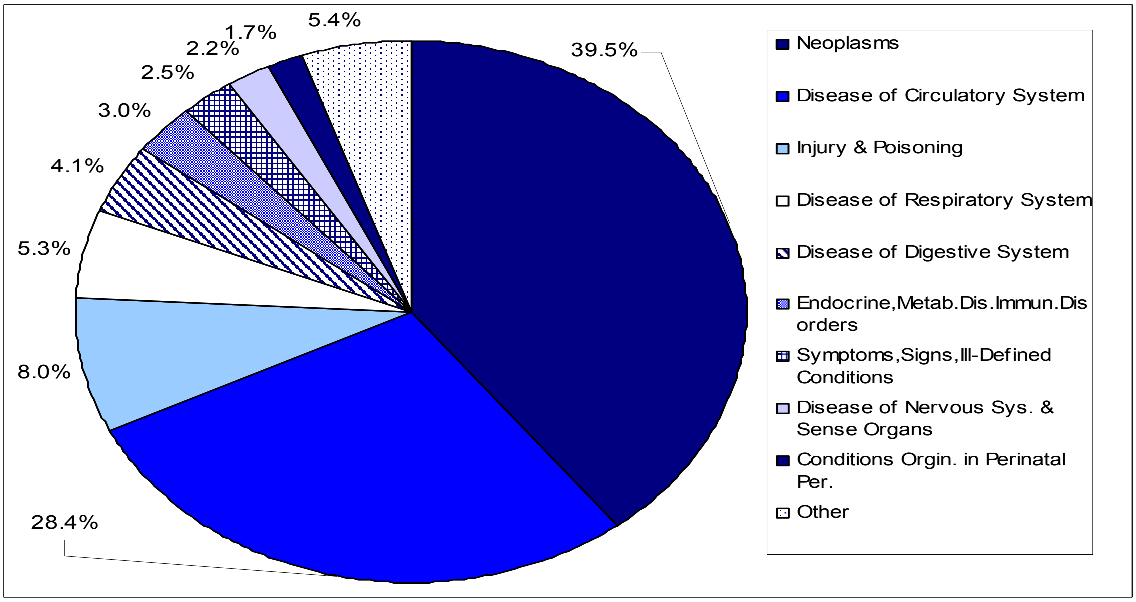
[c] Coding changes occurring for death data preclude proportionate mortality analysis by disease category for more recent years.

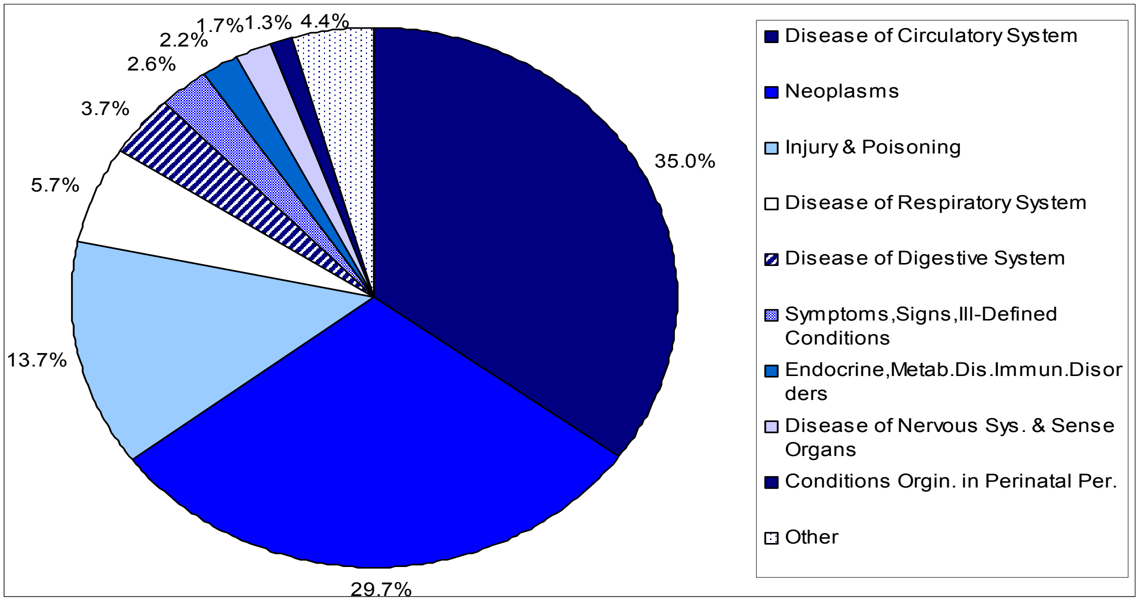
[d] Potential Years of Life Lost is calculated using the formula (75 – (age of death for all deaths that occurred at an age younger than 75))

Figure 5.32. Proportion of female premature deaths by top ten ICD-9 disease classification, 1984-1998



Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research & Data Management.

Figure 5.33. Proportion of male premature deaths by top ten ICD-9 disease classification, 1984-1998



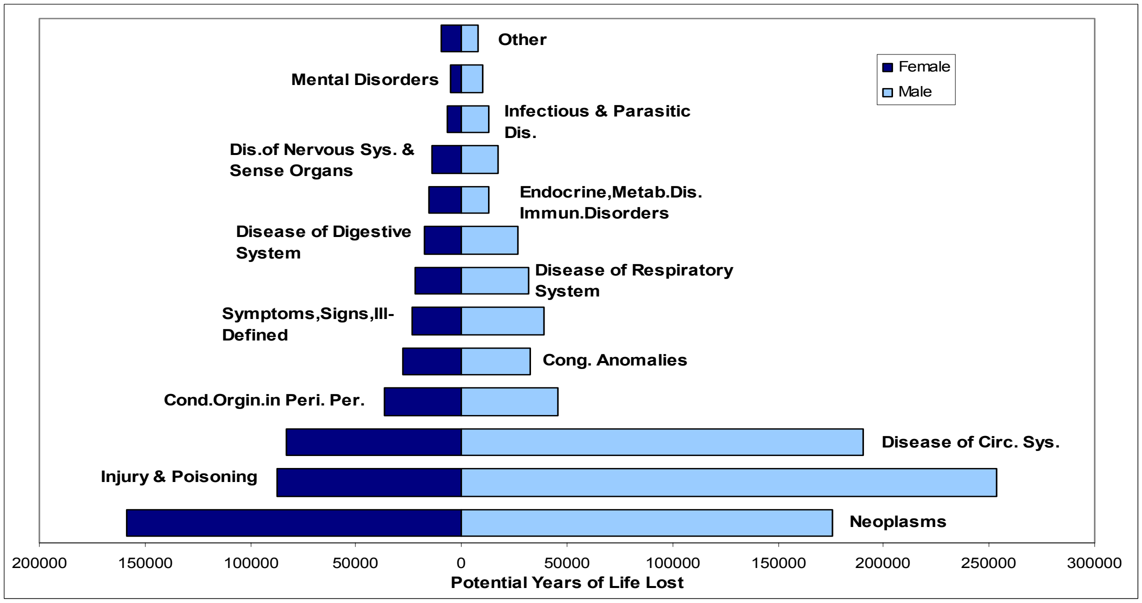
Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research & Data Management.

PYLL is a measure that takes into account both the number of premature deaths and the relative youth of each person at death. A review of the classifications of death by PYLL, indicates that cancer and injuries are the leading causes of PYLL each accounting for 24.6 per cent of PYLL. Although the classification of diseases of the circulatory system was the leading cause of death and second leading cause of premature death, it is the third leading cause of PYLL at 20 per cent.

This implies that cancer (and injuries) results in deaths at earlier ages than do diseases of the circulatory system.

Figure 5.34 illustrates the rank order of the 12 leading classifications of death in Manitoba between 1984 and 1998 as represented by PYLL. This illustrates that cancer was the leading cause of PYLL among women and the third leading cause among men.

Figure 5.34. Potential years of life lost, 1984-1998, by ICD-9 Classification



Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research & Data Management.

Lung cancer, breast cancer and colorectal cancer are among the top ten leading causes of PYLL among Manitobans between 1984 and 1998 (see Table 5.5). Lung cancer is the fourth leading cause of PYLL overall, accounting for 78,365 PYLL. Among females specifically (see Table 5.6), breast cancer is the second leading cause of PYLL (36,464 PYLL) and lung cancer is the fourth leading cause. Among males lung cancer is the fourth leading cause of PYLL (see Table 5.7) with 50,082 PYLL.

Table 5.5. Top ten leading causes of PYLL, 1984-1998, all Manitobans

CAUSE OF DEATH	TOTAL PYLL	PROPORTION OF PYLL - ALL CAUSES
Ischemic heart disease	166,761	12.2%
Motor vehicle traffic accidents	100,053	7.3%
Suicide	89,935	6.6%
Lung cancer	78,365	5.8%
Cerebrovascular diseases	43,399	3.2%

Other ill-defined and unknown causes	38,853	2.9%
Breast cancer	36,734	2.7%
Colorectal cancer	30,894	2.3%
Cirrhosis and other liver diseases	25,136	1.8%
Pneumonia and influenza	23,944	1.8%

Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research & Data Management.

Table 5.6. Top ten leading causes of PYLL, 1984-1998, Manitoba females

CAUSE OF DEATH	TOTAL PYLL	PROPORTION OF PYLL - ALL CAUSES
Ischemic heart disease	39,665	7.9%
Breast cancer	36,464	7.2%
Motor vehicle traffic accidents	28,671	5.7%
Lung cancer	28,283	5.6%
Cerebrovascular diseases	19,895	3.9%
Suicide	18,366	3.6%
Other ill-defined and unknown	13,761	2.7%
Colorectal cancer	13,183	2.6%
Short gestation/low birthweight	10,274	2.0%
Pneumonia and influenza	10,166	2.0%

Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research & Data Management.

Table 5.7. Top ten leading causes of PYLL, 1984-1998, Manitoba males

CAUSE OF DEATH	TOTAL PYLL	PROPORTION OF PYLL - ALL CAUSES
Ischemic heart disease	127,096	14.8%
Suicide	71,569	8.3%
Motor vehicle traffic accidents	71,382	8.3%
Lung cancer	50,082	5.8%
Other ill-defined and unknown	25,092	2.9%
Cerebrovascular diseases	23,504	2.7%
Accidental drowning	17,877	2.1%
Colorectal cancer	17,711	2.1%
Cirrhosis and other liver diseases	15,196	1.8%
Homicide/Assault	13,923	1.6%

Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research Data Management.

Analysis of PYLL due to specific types of cancer (Table 5.8) illustrates that lung cancer was responsible for 78,365 PYLL, almost one-quarter of PYLL due to cancer. Among men, the top three leading causes of cancer-specific PYLL were lung, colorectal and leukemia, accounting for 44.2 per cent of PYLL due to cancer. The three leading cancer-specific PYLL for women were breast, lung and colorectal, accounting for almost half of the PYLL due to cancer. Of note, PYLL for lung cancer overall is twice as high as for the next leading cause of PYLL.

Although mortality rates due to prostate cancer are slightly higher than for breast cancer, PYLL due to breast cancer is approximately five times higher than for prostate cancer. This reflects that women with breast cancer are being diagnosed and dying at an earlier age than men with prostate cancer, who tend to be diagnosed at a later age.

Table 5.8. Potential years of life lost due to cancer, Manitoba 1984-1998

	TOTAL		FEMALE		MALE	
Cancer Site	Years	Proportion	Years	Proportion	Years	Proportion
Lung	78,365	23.4%	28283	17.8%	50082	28.5%
Breast (female)	36,464	11.0%	36464	22.9%	---	---
Colorectal	30,894	9.2%	13183	8.3%	17711	10.1%
Leukemias	16,218	4.8%	6370	4.0%	9848	5.6%
Non-Hodgkin's Lymphoma	15,420	4.6%	6,572	4.1%	8,848	5.0%
Brain	14,523	4.3%	5,345	3.4%	9,178	5.2%
Pancreas	13,756	4.1%	6,050	3.8%	7,706	4.4%
Stomach	10,743	3.2%	3,600	2.3%	7,143	4.1%
Ovary	9,084	2.7%	9,059	5.7%	25	0.0%
Kidney	8,517	2.5%	2,808	1.8%	5,709	3.2%
Prostate	7,111	2.1%	---	---	7,111	4.0%
Oesophagus	6,131	1.8%	1,140	0.7%	4,991	2.8%
Cervix	6,027	1.8%	6,027	3.8%	---	---
Liver	5,232	1.6%	1,825	1.1%	3,407	1.9%
Skin	5,085	1.5%	2,310	1.5%	2,775	1.6%
Multiple myeloma	4,577	1.4%	1,714	1.1%	2,863	1.6%
Connective & other soft tissue	4,375	1.3%	2,062	1.3%	2,313	1.3%
Bladder	3,714	1.1%	807	0.5%	2,907	1.7%
Gallbladder	2,591	0.8%	1,460	0.9%	1,131	0.6%
Larynx	2,397	0.7%	326	0.2%	2,071	1.2%

Source: Data: Manitoba Health, Decision Support Services, Analysis: EPI Research & Data Management.
Note: Ranked in order of total PYLL for both sexes combined. Unspecified sites, “other & ill-defined” and “cancer of unspecified nature” are excluded.

5.3 Five-Year Survival Rates for Selected Cancers

The five-year relative cancer survival rate reflects the survival experience of people diagnosed with cancer in comparison to the survival experience of members of the general population (those without cancer) matched for age, sex, and geographic place of residence. Relative survival is the most widely used method for analyzing the survival of cancer patients in population-based studies. Relative survival rates are expressed as a percentage - a percentage close to one indicates that the cancer cases have a mortality experience similar to that of the general population, which means that the diagnosis of cancer had little impact on their chance of surviving five years after their diagnosis.

The relative survival rate is influenced by two distinct factors - (1) the severity or stage of the cancer at the time of diagnosis, and (2) the effectiveness of cancer treatment after diagnosis. While the data to distinguish between the relative contribution of one factor over another are not available, it is noteworthy that both factors have a positive impact on survival. For example, an improvement in screening would result in cancers being detected at an earlier stage when the cancer is more localized and when treatment is thought to be more effective, resulting in greater survival rates.

The most recently available five-year survival rate data are from Canadian Cancer Statistics (2002) and are based on the experience of individuals diagnosed in 1992.

- Five-year survival rates for lung cancer are considerably lower than that for other cancers. Manitobans diagnosed with lung cancer in 1992 were only 15 per cent as likely as the general population to be alive in 1997. This was comparable with the national experience (14% for men, 17% for women).
- Manitoban men diagnosed with prostate cancer in 1992 were 85 per cent as likely as the general population of men to be alive in 1997. This figure is comparable to the national average five-year relative survival rate of 87 per cent.
- Manitoban women diagnosed with breast cancer in 1992 were 79 per cent as likely as the general population of women to be alive in 1997. This did not differ significantly from the national average five-year relative survival rate of 82 per cent.
- Manitoban men diagnosed with colorectal cancer in 1992 were 53 per cent as likely as the general population to be alive in 1997, which was similar to the national experience of 56 per cent. Manitoba women diagnosed with

colorectal cancer had a 60 per cent relative survival, consistent with the national relative survival rate of 59 per cent.

5.4 Survivorship

> *"Increased demand and the complexity of survivors' health needs must be considered in the planning and development of interdisciplinary health services."*[8]

Long-term survival rates still remain low for many forms of cancer. It must also be recognized that even after someone is declared cancer-free, the chance of recurrence years later still remains. However, the growing interest in what is called "cancer survivorship" arises from the fact that more people will be living with a diagnosis of cancer in their past.

Many cancer survivors experience long-term psychosocial distress, sexual dysfunction issues, fertility problems, and as require continued monitoring for cancer recurrence. The majority of cancer survivors today are over the age of 65, an age at which people are also more likely to have other pre-existing chronic conditions such as heart problems, diabetes and arthritis, making it difficult to assess the financial costs of the services associated with cancer survivorship.

In 2000, there were approximately 771,000 Canadian cancer survivors who had been diagnosed with cancer at some point in the last 15 years.[9] This number represents 2.5 per cent of Canada's population. In the United States, recent trends suggest that almost two-thirds of people diagnosed with cancer now live at least five years, an increase from a five-year survival rate of 59 per cent in the late 1980s and early 1990s.[10]

Childhood cancers have seen particularly notable improvements in cancer survival rates. Mortality rates of childhood cancer have been reduced by 50 per cent since the early 1950s. The 2004 Canadian Cancer Statistics Report noted that:

> *"Although essentially no one survived childhood Leukemia 40 years ago, currently, approximately 80% of Canadian children and teenagers with acute lymphoblastic Leukemia are alive five years after diagnosis."*[11]

The growth of cancer incidence and prevalence is shifting the way in which the health care system responds to this increasing patient population. It has been recognized that the challenges faced by a growing population of cancer survivors must be addressed through a comprehensive strategy. Health Canada, Provincial Ministries of Health, Provincial Cancer Agencies and cancer survivors worked to formulate a Canadian Strategy on Cancer Control in 2001.

The vision of the Strategy is:

- Within the short term (1-5 years), morbidity and mortality rates will be reduced through improved application of screening, diagnostic and treatment strategies.

- Increased access to supportive and palliative care will improve quality of life.

- In the longer term (10 years and beyond), preventive strategies will achieve reduction in incidence rates.

- In the medium (5-10 years) and long term, research will progressively improve the outcomes of all cancer control strategies.

- The relentlessly increasing economic and personal burden of cancer will be alleviated as decreasing incidence and morbidity reduce direct and indirect costs to individuals and society.

While these goals have implications for the entire population, several speak specifically to the quality of life for cancer survivors.

In Manitoba, the RHA key informants interviews with RHA administrators revealed that there is variation in support services for long-term cancer survivors. However, across the province there appears to be good access to spiritual care, home care and palliative care across all RHAs for cancer patients.

In terms of programming gaps, most RHAs do not have many resources for cancer specific psychosocial professionals including social workers, psychologists and psychiatrists. They are also only available in major centres within the region. Similarly, access to registered dieticians is limited to regional centres with only a small amount of dedicated cancer staffing resources. Access to rehabilitation services also appears to be limited. Of particular concern for cancer patients is that several RHAs offer rehabilitation services on an inpatient basis only.

RHAs could improve in addressing the challenges of cancer patients experiencing a recurrence of their disease. It appears that it is up to family physicians and specialists involved in the person's care to address disease recurrence. RHAs did note that those who are re-accessing the health care system after cancer care appear to have difficulties in appropriate access and are relying on their oncologist in Winnipeg to access the cancer care system for recurrent disease.

In the United States, the National Cancer Institute (NCI) estimates that there are now more than 9.6 million cancer survivors, a number that is expected to rise as the population ages. This growing pool of survivors in the US has led to recommendations that more money needs to be spent studying the long-term health effects of treatment used for cancer, ways to prevent second cancers from arising years after treatment is finished, and programs that address the psychological burdens of returning to work and regular life.

In the US, the Centers for Disease Control and Prevention (CDC), along with the Lance Armstrong Foundation, released a plan[12] in May 2004 setting out for the first time national public health strategies for cancer survivors. The Plan calls for the following strategies to address cancer survivor needs:

- Develop a comprehensive database on cancer survivorship.
- Develop and maintain patient navigation systems that can facilitate high-quality care for cancer survivors.
- Establish and disseminate clinical practice guidelines for each stage of cancer survivorship.
- Develop and disseminate public education programs that allow cancer survivors to make informed decisions.
- Conduct ongoing evaluation of all activities to determine their impacts and outcomes, and ensure quality improvement of services.
- Conduct research on preventive interventions to evaluate their impact on cancer survivorship issues.
- Educate policy- and decision-makers about the role and value of providing long-term follow-up care, addressing quality-of-life issues and legal needs, and ensuring access to clinical trials and ancillary services for cancer survivors.
- Provide survivors with advocacy skills.
- Educate decision-makers about barriers related to health care for cancer survivors.
- Establish and disseminate guidelines that support quality and timely service provision to cancer survivors.

The report reflects a significant shift in thinking by the CDC. The CDC has previously published similar guidelines on arthritis, heart disease and stroke, but for cancer, the agency has typically focused on prevention and early detection.

> *"It is increasingly clear to us that the life-long consequences of diseases like cancer are the principal sources of disease burden." Dr. James Marks, Director of the National Center for Chronic Disease Prevention and Health Promotion, CDC.*

Some major cancer centres in the US are increasing their focus on survivors. At the Dana-Farber Cancer Institute in Boston, a new clinic called the Perini Family Survivors' Center will open in 2004. The clinic will conduct research on the psychosocial needs and long-term health effects on adults who have had breast cancer, genitourinary cancers such as prostate cancer, and Hodgkin's disease.

The President's Cancer Panel this year will publish the results of its investigation into the challenges experienced by survivors and their families, and the National Academy of Science's Institute of Medicine was expected to issue a report on the policy implications of adult cancer survivorship in the year 2004.

A new magazine devoted exclusively to cancer survivors and their families, called *Heal*, was planned for release in the summer of 2004. The magazine, which is free and expected to have a circulation of 100,000 in the US, will feature articles dealing with survivors' post-treatment issues, from dealing with insurance, emerging side effects of drugs, fear of recurrence, fatigue, and even suggestions for holidays.

There does not appear to be a consensus yet regarding the kind of follow-up care and continued surveillance individuals with a history of cancer need. While health care providers increasingly recognize that many survivors face health complications that may arise years, even decades, after their cancer treatment ends, there is a lack of evidence on the best interventions to prevent or ameliorate these conditions or which patients may be most at risk for developing further health problems. For example, in a paper co-written by Julia H. Rowland, director of NCI's Office of Cancer Survivorship, it was concluded that:

> *"Long-term adverse outcomes are more prevalent, serious, and persistent than expected in survivors of both pediatric and adult cancer. In addition, there is very little known about the impact of cancer on the physical and mental health of family members and caretakers of people with cancer."*[13]

Estimating the costs of treating and monitoring this growing population is also difficult. Again using American references, the NCI estimates that in 2003, $64.2 billion was spent in direct medical costs for cancer treatment and an additional $16.3 billion was the cost of lost productivity due to illness; however, these figures do not reflect the other burdens of cancer on survivors or family members who may leave the work force to care for them.[14] The Canadian Cancer Statistics Report for 2004 focused on the economic impact of cancer in this country in terms of both direct and indirect costs. For cancer, the total direct costs for 1998, including hospitals treatment, physician services and drugs, was calculated at $2.5 billion. Within that $2.5 billion figure, hospital-based care consumed represented 74 per cent of the costs, with 14 per cent attributed to physician care. Total indirect costs, which estimates the value of life lost due to premature death and value of activity days lost due to disability, was estimated at $11.8 billion for cancer in 1998.

The economic burden of cancer has shifted over time. The total cost of cancer increased from $12.7 billion in 1986 to $13.9 billion in 1993 and to $14.2 billion in 1998. While the total costs have increased, the direct costs have gone from $2.8 billion in 1986 to $3.4 billion in 1993 and then declining to $2.5 billion. This decrease in direct costs and increase in indirect costs from 1993-1998 suggest that the costing data for direct costs may not have been completely captured, particularly those cancer care services offered in an outpatient setting. It may, however, suggest a trend in cancer care delivery in Canada where cancer care services are shifting from inpatient services to outpatient services delivered by provincial cancer agencies like CCMB. This shift in care, along with the growing population of cancer survivors, will continue to challenge CCMB and other cancer agencies in Canada to provide the needed accessibility to a range of support services cancer survivors will require to deal with their cancer experience.

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6

SYSTEM RESPONSIVENESS TO MANITOBA CANCER PATIENTS AND THEIR FAMILIES

CancerCare
MANITOBA

KEY FINDINGS

CancerCare Manitoba (CCMB) is responsible for meeting the needs of individuals diagnosed with cancer and blood disorders in the Province of Manitoba. Providing excellent patient-centred services requires a full understanding of the patient experience from early symptoms to palliation. In order to assess access to the full range of services needed by cancer patients, qualitative and quantitative data, including feedback from RHA administrative partners and patients and their families, was collected and analyzed.

The following highlights emerged:

- Patients identify the diagnostic phase as a very stressful part of their cancer experience.

- The Manitoba Breast Screening Program (MBSP) is working to meet national guidelines specific to time to diagnosis for women with abnormal screens. The program has implemented a direct referral process that has had a positive effect in reducing the time closer to national standards.

- More work needs to be done to examine and improve the time to diagnosis for all cancer patients.

- All of Manitoba's oncologists work in Winnipeg. Most have clinics at the two main CCMB sites, and four community oncologists are linked to the WRHA oncology program.

- Radiation services in Winnipeg will be consolidated at the McDermot site by the end of fiscal 2004/05. The provincial government has announced that CCMB and Brandon Regional Health Authority (RHA) will work together to open radiation facilities in Brandon within the decade.

- Radiation therapy median wait times have been reduced from 6-7 weeks in 1998/99 to 1.1 weeks in the most recent quarter.

- Manitobans have good access to chemotherapy at the two CCMB sites, as well as at the fourteen Community Cancer Programs (CCPs) and four community hospitals in Winnipeg; however the wait time has not been documented.

- Radiation therapy wait time and a well distributed chemotherapy infrastructure are inadequate measures of timely and appropriate access. More work is required to measure other critical time periods or waits in the cancer trajectory e.g. time to surgery; time to diagnostic test or diagnostic results, time to first visit with an oncologist etc.

- CCMB is the provincial centre for benign hematological disorders. Improved mechanisms of data capture are necessary to assess accessibility to these services.

- The Manitoba Prostate Centre was opened in October 2004. The Centre provides diagnostic and treatment services for men with prostate disease. The Centre's program model was designed in response to recommendations from Manitoba's prostate cancer patients.

- Use of clinical practice guidelines is often used as a measurement of quality care. Funding to support the development and implementation of clinical practice guidelines throughout the patient experience and for all cancer patients in Manitoba has been provided by CancerCare Manitoba Foundation`.

- The Clinical Investigations Office (CIO) enrolls eligible cancer patients in clinical trials. Expansion of the CIO is required to manage the existing patients enrolled in clinical trials, screen more cancer patients for possible participation in trials, and to increase the number of trials available to eligible cancer patients in Manitoba.

- The umbrella of Patient Family and Support Services (PFSS) encompasses psychosocial oncology, nutrition, speech and language pathology, and cancer information. These programs receive positive feedback, but some patients are not aware of their services.

- The key informant interviews held with RHA administrators revealed that palliative and home-care services in each of the regions were adequate to meet the palliative and home-care needs of cancer patients.

- The interviews revealed areas in which the partnerships between RHAs and CCMB could improve patient care, specifically developing a greater psychosocial capacity, increasing nutritional and rehabilitative services, and providing additional patient information to aid residents in their decision-making around treatment choices.

- The RHAs recognize the need to develop closer relationships with CCMB to address the future needs of their cancer patients.

- Feedback from patients and their families was very positive regarding the services that CCMB makes available. Patients voiced their support of the

Community Cancer Programs Network (CCPN) in allowing their chemotherapy treatments to occur in or near their home communities.

- Patients also identified CCMB services requiring improvement, including timely access to diagnostic services and follow-up care. The need for greater information, presented in a clear and concise fashion was noted, specifically in relation to treatment options and decision-making.

- CCMB recognizes that feedback of patients is essential in creating and maintaining a patient-centred system. CCMB is conducting a province-wide patient satisfaction survey to increase understanding of the patient experience.

The following sections explore access issues from a variety of perspectives. The exploration is limited by the data that are available.

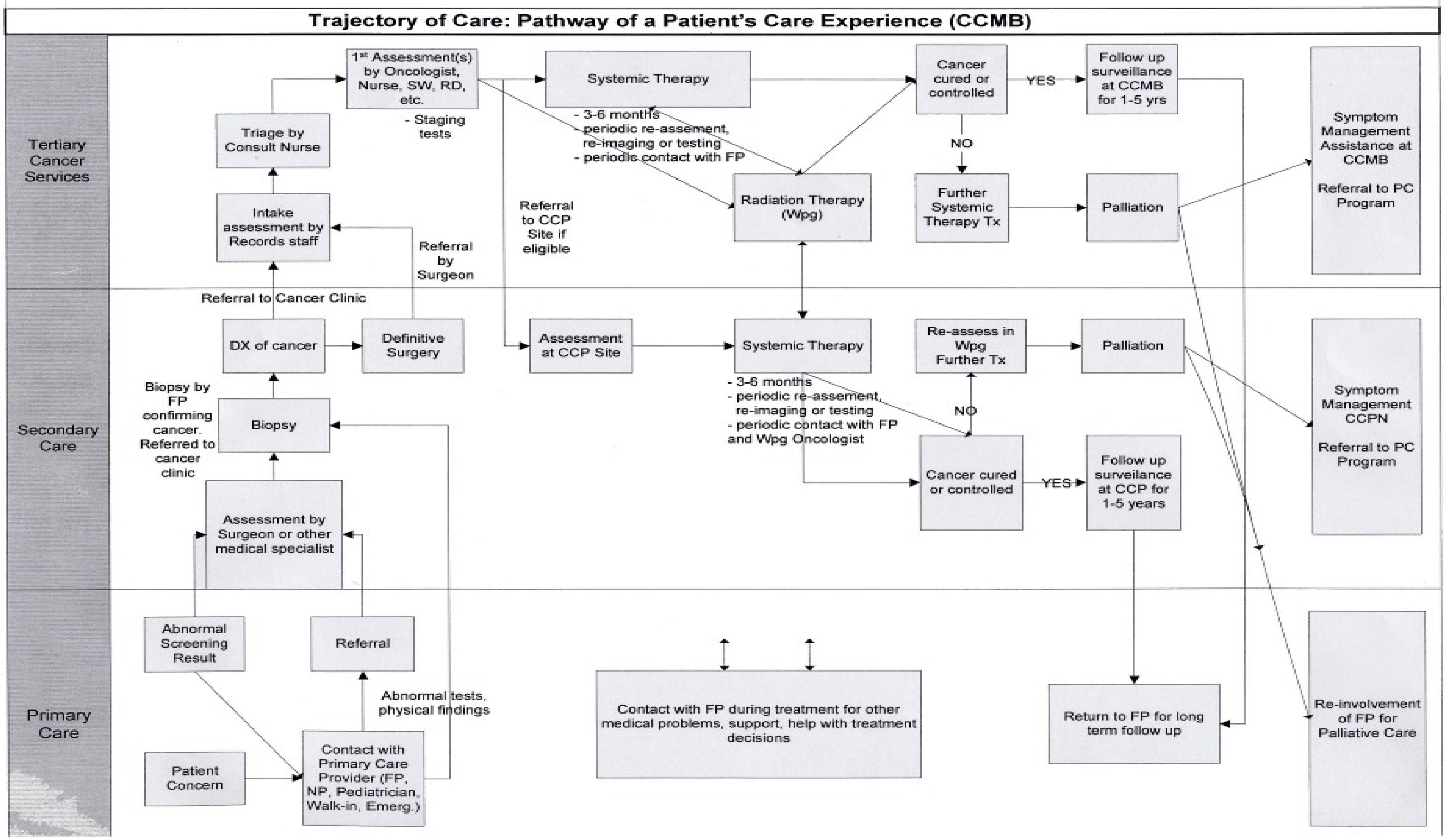
6.1 Diagnostics and Acute Care/Treatment

Waiting time for key medical procedures and diagnostics is an important challenge facing the health care system. It has long been an actionable priority at both the federal and provincial level. Its high political importance culminated at the First Ministers' Conference in September 2004 where federal, provincial and territorial governments agreed to a 10-Year Plan to reform the health care system. A key component of the agreement was a 10-Year Wait List Fund that will target cardiac care, orthopedics, diagnostics, cataracts and cancer care.

The principal challenge in making access to the care that patients require more timely is the complexity of the trajectory of care for cancer patients, in coordinating the services of family physicians and specialists, diagnostics, support services, ambulatory care, and acute care. The challenge facing CCMB is in the creation of a coordinated system that is patient centered, and in providing excellent cancer care services along the cancer treatment path.

Figure 6.1 illustrates the trajectory of care in a patient's cancer experience.

Figure 6.1. Pathway of a Cancer Patient's Experience



6.1.1 Diagnostic and Oncology Services

CCMB is responsible for the provision of many cancer services including screening, medical oncology, radiation oncology, surgical oncology and benign hematology specialties. Diagnostic and surgical services are provided by the RHAs in Manitoba. Therefore, the following discussion will focus on a variety of services that are provided in diagnosing and treating cancer and benign hematological disorders.

A diagnosis of cancer is often the conclusion of a series of diagnostic procedures. Most diagnostic services are provided by the RHAs, not CCMB. Therefore timely coordination of the tests and timely receipt of the results require coordination of multiple players. The following initiatives of the MBSP illustrate the challenges and opportunities.

6.1.1.1 Time from abnormal breast screen to diagnosis

Approximately 7 per cent of women screened at the MBSP will have an abnormal result that requires further diagnostic testing. Further diagnostic options include diagnostic mammography (magnification and cone compression), ultrasound, core or open biopsy and surgical consultation. The majority of women will require only diagnostic mammography for which waiting periods are considered to be acceptable. However, delays are often lengthy for women who require more than one test to establish a diagnosis. Waiting for these tests can cause significant anxiety for women and may worsen prognosis, depending upon the length of delay. [1, 2]

The MBSP closely monitors wait times and sets targets for diagnostic intervals based on national guidelines as illustrated in Table 6.1.[3] In response to observed delays in the follow-up period after an abnormal breast screening, the MBSP implemented a direct referral process in 2000. With the family physician's approval, the MBSP arranges for diagnostic follow-up procedures for women with an abnormal breast screening results directly rather than referring the woman first to her family physician. The program measured the impact of these changes by comparing times between three groups of women - women screened before the direct referral process began, women screened after the direct referral process began but who were not directly referred, and women who were directly referred. [4] This process significantly reduced the average waiting time from screening to diagnosis from 6 weeks to 4 weeks.

The MBSP results illustrated in Table 6.1 are for the year 2002/03. Although the MBSP has not yet achieved the national targets for acceptable diagnosis waiting times, it is important to understand the confounding environmental factors that serve as barriers to the realization of the national targets.

Table 6.1 Proportion of MBSP participants diagnosed within target time interval from abnormal screen to diagnosis by type of biopsy

Interval from screening to diagnosis	Target for diagnosis	MBSP result
No open biopsy	90% within 5 weeks	62% (n=2,220) within 5 weeks
Open biopsy	90% within 7 weeks	11% (n=108) within 7 weeks
Core biopsy	No target	46% (n=299) within 7 weeks

Source: Manitoba Breast Screening Program.

Delays are most often a function of access to the recommended diagnostic test required in addition to the number of tests required. For example, women requiring an open biopsy first must have a surgical consultation followed by a wait for available operating room time.

The average waiting time from an abnormal screening result to a final diagnosis for all women 50 to 69 years of age with an abnormal screening result in 2002/03 was 5.2 weeks (median 3.9 weeks). MBSP continues to work with RHAs and other partners to decrease the time to diagnosis for women attending the Program.

MBSP's work in capturing time to diagnosis for breast cancer patients demonstrates the utility of having this kind of information for understanding the patient's experience at this phase of the cancer experience. More work is required to understand and monitor the time to diagnosis for all cancers.

6.1.1.2 Access to surgical oncology

CCMB benefits from an established academic surgical oncology department. The department is recognized as a clinical service in the Section of General Surgery at the University of Manitoba. Five fellowship trained surgical oncologists conduct their clinical practice exclusively through CCMB clinics. The major areas of practice include breast, head and neck, sarcoma, and melanoma. Although surgical oncologists provide services through CCMB, they are not employees of the organization.

Wait times for access to a surgical oncologist or the operating room are not routinely collected by the WRHA or CCMB. These wait times are critical indicators of quality in relation to patient access and need to be documented and monitored.

A strategic plan for Surgical Oncology has been presented to CCMB, the University of Manitoba and Manitoba Health. Benefits of the Surgical Oncology program include:

- Access to multi-modality care plans derived from evidence-based multidisciplinary practice
- Improved outcomes through reduction of inappropriate variation in surgical cancer practice
- Increased access to subspecialty consultation in surgical oncology
- Improved patient information regarding cancer surgery and services
- Benefits from academic advances in surgical practice in oncology

Cancer surgery is provided by surgical oncologists and a vast array of other surgical specialists. Surgery is considered to be the primary treatment for many types of cancer. As Table 6.2 illustrates, almost 60 per cent of people diagnosed with an invasive cancer between 1999 and 2001 had surgery. It should be noted that this table indicates the region where the patient was residing at diagnosis, which is not necessarily reflective of where a patient received their surgical care.

Table 6.2. Use of surgery among cancer patients, 1999-2001

RHA OF DIAGNOSIS	CANCERS	% OF PATIENTS SEEN AT CCMB	% OF PATIENTS HAVING SURGERY
Winnipeg	Breast (ICD9 174)	80.5	93.1
	Prostate (ICD9 185)	52.1	55.0
	Colon (ICD9 153)	44.3	84.8
	Rectum (ICD9 154)	68.8	83.2
	Lung (ICD9 162)	67.7	27.7
	All Invasive (ICD9 140-208 excl 173)	64.9	58.3
Brandon	Breast (ICD9 174)	67.6	89.2
	Prostate (ICD9 185)	64.1	32.8
	Colon (ICD9 153)	42.7	82.4
	Rectum (ICD9 154)	65.7	91.4
	Lung (ICD9 162)	56.0	29.0
	All Invasive (ICD9 140-208 excl 173)	60.0	57.9
North (Churchill, Burntwood, NOR-MAN)	Breast (ICD9 174)	90.9	95.5
	Prostate (ICD9 185)	44.6	53.6
	Colon (ICD9 153)	69.1	85.7
	Rectum (ICD9 154)	70.0	90.0
	Lung (ICD9 162)	61.5	23.1
	All Invasive (ICD9 140-208 excl 173)	65.5	58.1
South (all other RHAs)	Breast (ICD9 174)	70.8	94.1
	Prostate (ICD9 185)	54.9	45.1
	Colon (ICD9 153)	51.0	86.6
	Rectum (ICD9 154)	61.7	84.4
	Lung (ICD9 162)	56.9	27.6
	All Invasive (ICD9 140-208 excl 173)	59.7	57.2

Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

In recognizing the provision of surgical services, CCMB has integrated surgical oncologists and other surgical specialists into the DSG structure. The DSG structure was developed as a tool to improve the coordination of care and the development of standards, and for the provision of indicators to be used in outcomes analysis. Participation in the DSG process renders surgeons full and equal partners in the planning, delivery and evaluation of provincial cancer care programs.[5]

6.1.1.3 Access to medical and radiation oncology

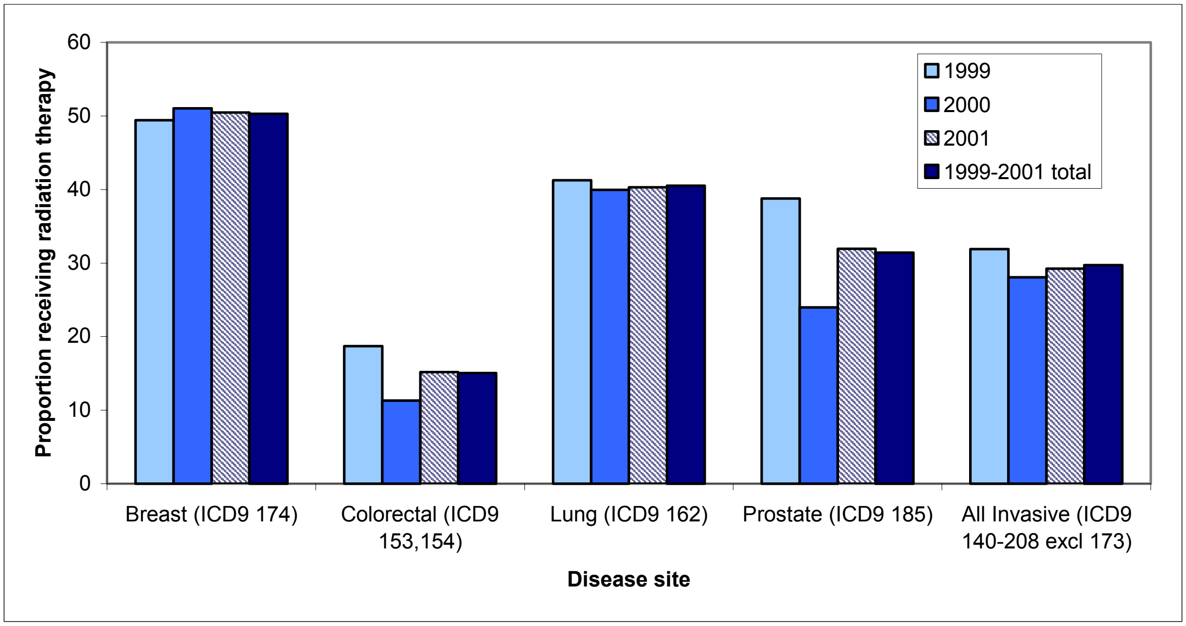
Timely access to the assessment, diagnostic and treatment planning skills of medical oncologists and radiation oncologists is critical to the provision of excellent patient care. CCMB does not have the capabilities at this time to measure, in a routine and timely manner, the accessibility of these services. A cross-sectional study has been designed to provide a snapshot of wait times and to assess the capacity of the computerized clinical management system to routinely provide this information. CCMB expects to establish a routine, timely reporting structure in the near future. Development of this capability is expected to require process re-engineering of data entry processes and continuous data quality auditing. CCMB will leverage the clinical management system to provide clinically relevant accessibility information. CCMB is working with other cancer agencies in Canada to establish inter-provincial and, therefore, comparable definitions and benchmarks upon which provincial waits can be measured in recognizing the national impetus to measure and report accessibility to cancer services.

6.1.1.4 Access to radiation therapy

Although radiation therapy is currently available at both of CCMB's two main program sites, by March 2005, radiation therapy services will be consolidated at the 675 McDermot site. The Government of Manitoba has announced expansion of the service in its commitment to introduce radiation therapy in Brandon before the end of the decade. CCMB and the Brandon RHA are working co-operatively to provide this critical and highly complex service to Western Manitoba residents in a manner that will ensure service that is both sustainable and of high quality.

Radiation therapy was provided for 29.7 per cent of the patient population diagnosed with invasive cancer between 1999 and 2001. The rates of radiation therapy differ by disease site in reflecting the benefits derived from the treatment based on disease site, stage and type (see Figure 6.2). For example, radiation therapy is more often appropriate for treating breast cancer than colorectal cancer and the data show that while approximately 50 per cent of women diagnosed with breast cancer underwent radiation therapy in the three-year time period, it was performed in only 15 per cent of patients diagnosed with colorectal cancer.

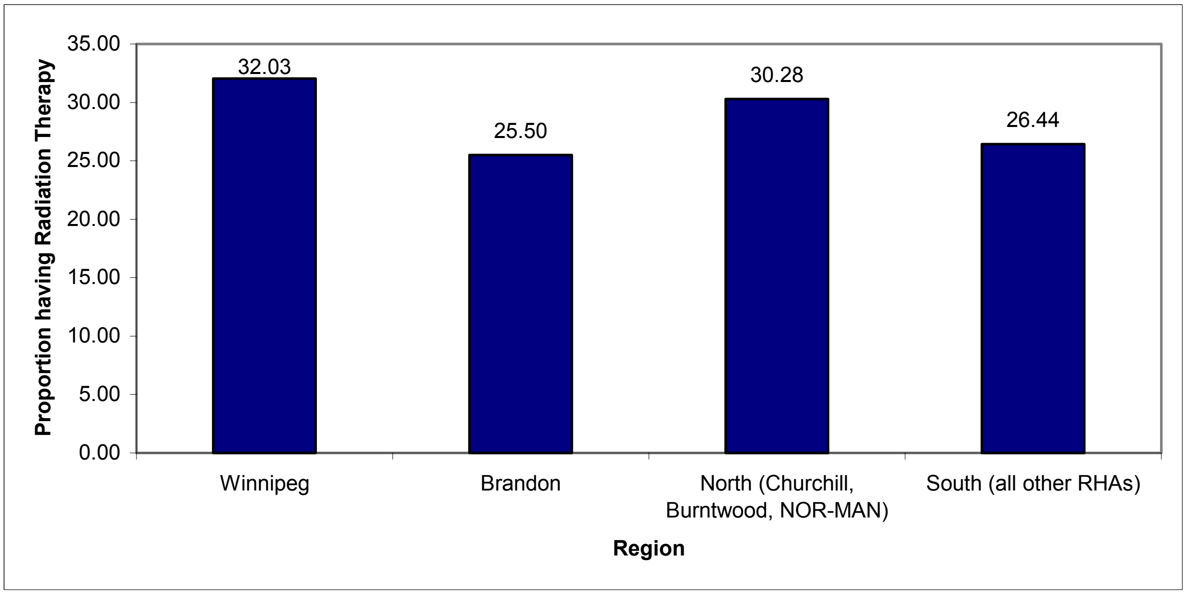
Figure 6.2. Proportion of patients who have radiation therapy by disease site, 1999-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.3 illustrates the proportion of cancer patients (diagnosed between 1999 and 2001) who received radiation therapy at CCMB by home region. A very slightly higher proportion of people who live in Winnipeg received radiation therapy compared to residents of the other regions. Some of the observed variation in radiation therapy use relates to the different mix of cancer types occurring in different regions, but some of the variation may be due to treatment decisions made based on how far a patient lives from Winnipeg, where all radiation therapy is currently provided. Geographical barriers to receiving radiation services are the underpinning of the expansion of radiation therapy to Brandon.

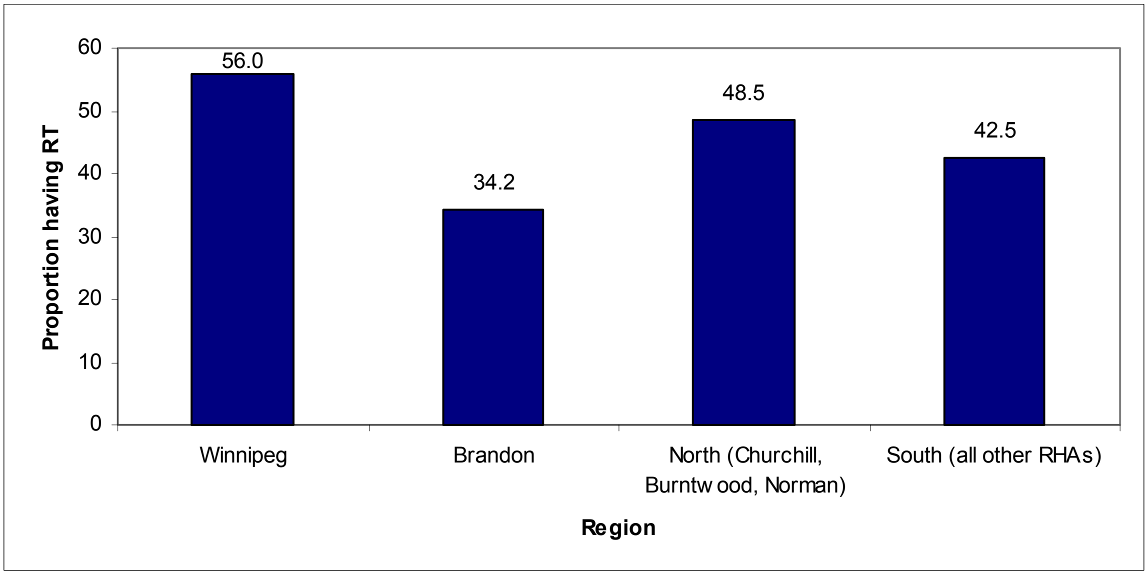
Figure 6.3. Radiation therapy by patient home region, 1999-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

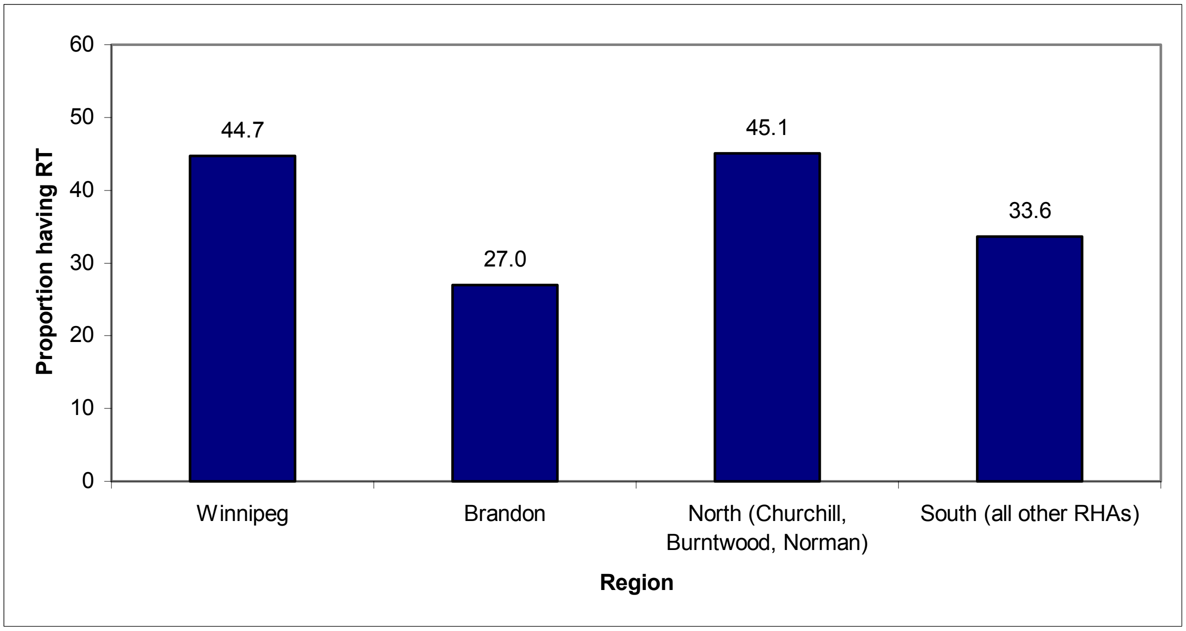
Figures 6.4 to 6.7 illustrate proportions of patients undergoing radiation therapy by both disease site and home region. While some differences are very likely due to geography, some of the variation will be due to the mix of types of cancers diagnosed in each region, as well as specific clinical indications for treatment such as stage at diagnosis.

Figure 6.4. Radiation therapy by breast cancer patient home region, 1999-2001



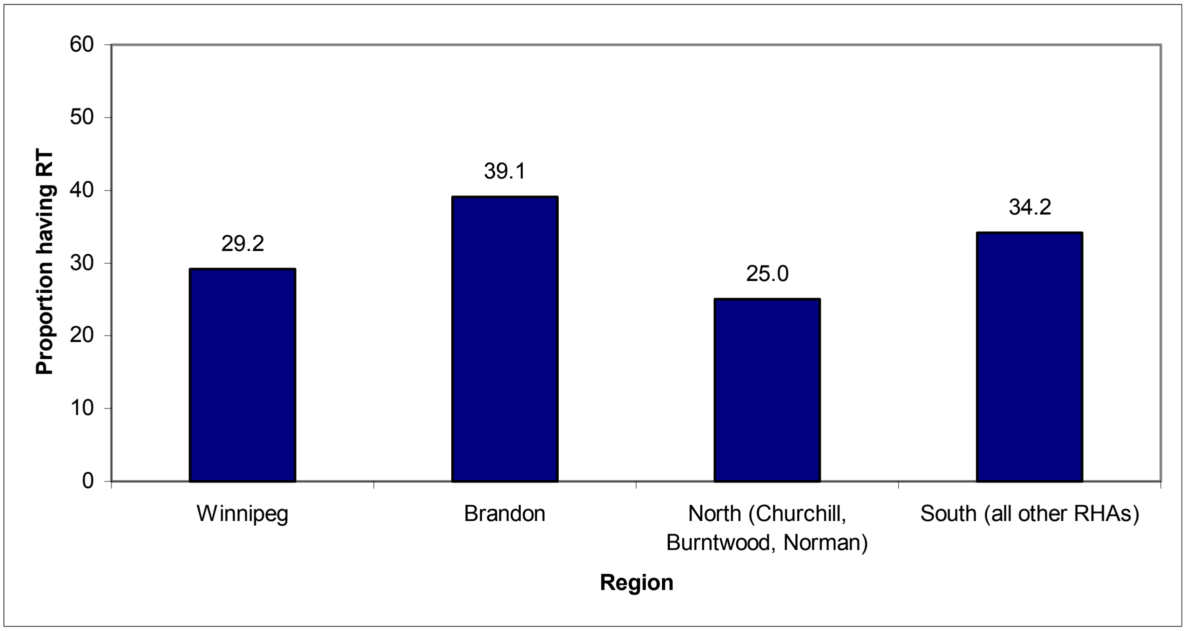
Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.5. Radiation therapy by lung cancer patient home region, 1999-2001



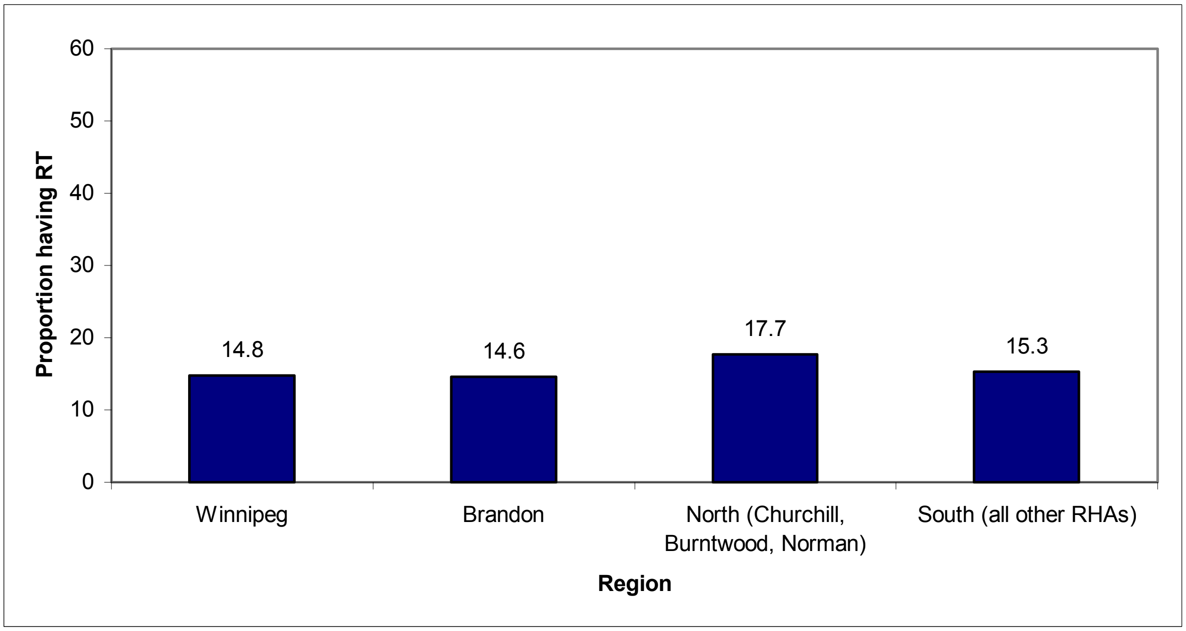
Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.6. Radiation therapy by prostate cancer patient home region, 1999-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.7. Radiation therapy by colorectal cancer patient home region, 1999-2001



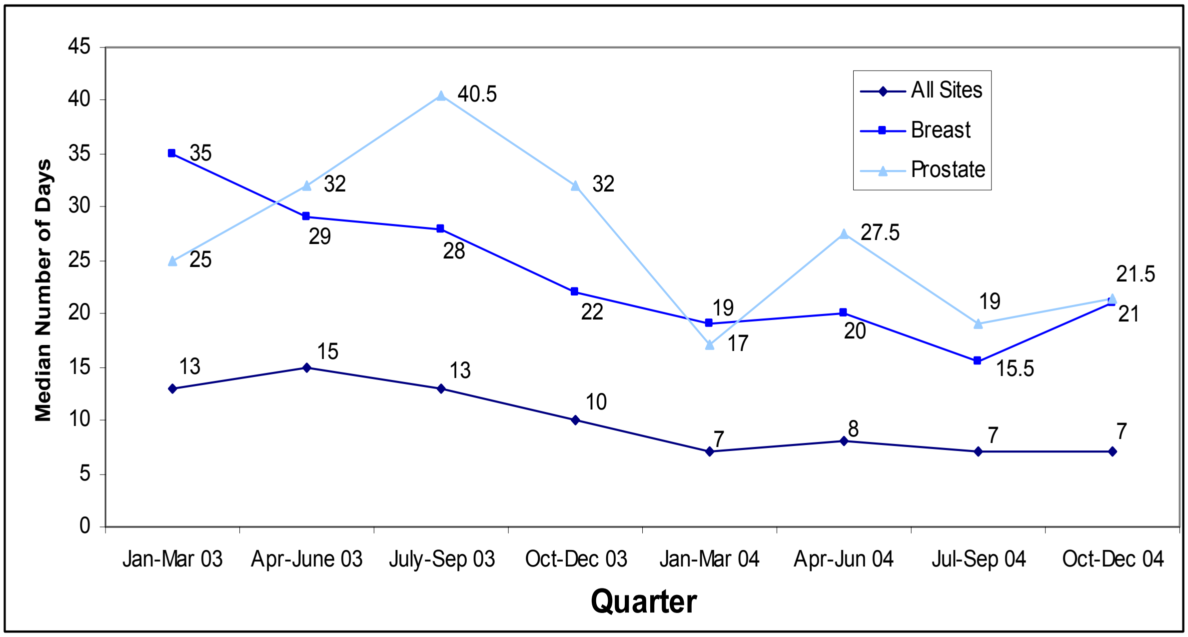
Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

CCMB has invested in reducing radiation therapy wait times. Specific strategies have been employed to address the challenge of providing appropriate care in a timely manner. Process improvements, increased enrollment in the School of Radiation Therapy in combination with improved retention of graduates, and the installation of new linear accelerators are strategies that have been employed in successfully reducing the waiting times for radiation therapy services in the province.

A full understanding of wait times for radiation therapy is a complex issue, and our current data systems do not allow for appropriate monitoring of these complex variables. We publicly report wait time on a routine basis using the Canadian Association of Radiation Oncologists (CARO) definition, which is the time from “ready to treat” to the initiation of treatment; this wait time has dropped dramatically as a result of the efforts noted above. However, we recognize that this does not provide the full picture. A number of activities need to be completed before the patient is ready for treatment, including referral to CCMB, visits with a radiation oncologist and completion of important diagnostic tests. Each event takes time, which may be measured as “waits” in a patient’s journey. In order to manage the cancer system, CCMB needs to be able to measure the full range of wait time intervals in order to monitor the health care system’s response to the cancer patient.

Patients that participated in the focus groups in May, 2004 had no complaints about the provision of radiation therapy services and the patient representative complaint database recorded only 12 complaints related to delay in starting radiotherapy treatment for the 2003-04 fiscal year. This is down in comparison to the 2002-03 year when there were 22 complaints in that category. Recent wait times for radiation therapy confirm the positive trend. In 1998, the median wait time to initiation of radiation therapy was approximately 6 to 7 weeks. In September 2004, this wait time was reduced to a median of 1.1 weeks. Despite improvements in radiation therapy delivery, CCMB recognizes that maintaining acceptable wait times requires ongoing commitment and vigilance.

Figure 6.8. Median radiation therapy wait times* (days), by quarter, 2003/2004



Source: CancerCare Manitoba

*Radiation therapy wait times are calculated according to the national standard (CARO) definition, time between "ready to treat" and initiation of radiation therapy.

6.1.1.5 Access to chemotherapy

Wait time to first chemotherapy treatment is as complex as the wait time described for radiation therapy. While anecdotal evidence suggests that once a patient is ready for treatment there is no wait, data are not routinely available to support this position. Again, the steps leading to a patient being deemed as "ready to treat" take time and the accumulation of these wait times must be monitored. The cumulative wait time includes many processes in the patient's journey, including surgical/pathological confirmation, visits with a medical oncologist, completion of additional diagnostic tests and receipt of diagnostic test information.

However, Manitoba is fortunate to have a well dispersed network of sites for chemotherapy care. Two sites (the MacCharles and St. Boniface Unit) are managed by CCMB, four sites are operated by the WRHA in four of Winnipeg's community hospitals, and rural and northern Manitoba has 14 sites located in acute care hospitals, managed by the RHA and supported by CCMB.

Recent improvements in the recruitment and retention of oncology nurses, the opening of the new CancerCare building at the MacCharles site, and the introduction of the Oncology Day/Evening Unit have significantly improved the convenience and choices available for chemotherapy.

The Oncology Day/Evening Hospital is an area of pride in the organization; it was developed to offer extended hours on weekdays and on weekends for patients with lengthy chemotherapy regimens. This program allows many chemotherapy patients to avoid the need to occupy a hospital bed or wait for treatment until a hospital bed is available.

Recent capital improvements at the Grace, Concordia and the Seven Oaks oncology units have also improved the cancer experience for chemotherapy patients served in Winnipeg. There are now plans to redevelop oncology space at the Victoria General Hospital.

6.1.1.6 Access to benign hematology services

CCMB is also the provincial centre for the assessment, diagnosis and treatment of benign hematology, a mandate that reflects the historical foundations of the centre. Although estimates suggest that benign hematology workload in the clinics comprises up to one-third of clinic activity, this workload is integrated with clinic and chemotherapy activity reports and cannot be routinely separated from standard workload reports. This issue has been identified as a critical area for investment in data systems that will monitor activity as well as timely and appropriate access to hematological expertise.

6.1.1.7 Access to the Manitoba Prostate Centre

The Manitoba Prostate Centre, which is housed in CCMB's 675 McDermot facility, opened in October 2004. The Centre has the established objectives of providing multidisciplinary, coordinated and timely access to diagnosis and treatment services for men with prostate disease. It is evolving as a provincial centre of excellence, providing leadership in research and clinical care throughout the province. The Centre provides sexual support, decision support, and counselling for all Manitoba men with prostate cancer. The model of care was developed in response to needs identified by prostate cancer patients.

6.1.2 Perception of CCMB by RHAs and Family Physicians

In the key informants' interviews with RHA administration, the relationship between RHAs and CCMB was described in general terms as very positive. RHAs were particularly pleased with the relationship they have with CCMB front-line staff. Annual CCP site visits by CCPN staff were cited as critical to maintaining open communication between the RHAs and CCMB. CCMB and the CCPN were also praised for providing timely information, data, education, and training support to the staff of the CCPs. Although communication among front-line staff was a source of commendation, communication between management of RHAs and CCMB was noted as an area where there was opportunity for improvement.

Information about family physicians' interactions with CCMB was acquired through a focus group conducted with physicians involved in CCMB's Urban Primary Care Oncology Network (UPCON) project. The physicians in attendance commended the project for its achievements in improving communication and accessibility to CCMB services. However, because the focus of the session was on the areas where CCMB could improve the partnership, the physicians identified opportunities for reducing the delay in sharing documentation of their patients' care and treatments provided at CCMB. This, was identified as very important in involving the family physician as a partner in patient care. The family physicians also expressed concerns about the challenges of getting their patients into CCMB when first referred to the organization, the time consumed in scheduling of appointments, and the lack of direct access to or contact with oncologists.

The UPCON physician group recognized the importance of maintaining the relationship between patients and primary care providers throughout their cancer treatment, acknowledging benefits to both patients and the primary care physician. Patients benefit from continuity of care and improved psychological support. The UPCON physicians recognized opportunities for expansion of their role as a more recognized part of the cancer treatment team. This expanded role was envisioned as an opportunity that would increase accessibility to CCMB clinics by freeing up oncologists to see new patients, as family physicians were attending to the primary care needs of the shared patients, not the oncologists.

The final recommendation of the UPCON group was to increase standardization. Specifically the physicians identified the need to define referral requirements, diagnosis guidelines, and the guidelines for follow-up care to enable family physicians sharing in the care to provide more consistent care.

The purpose of the UPCON partnership was to discover the potential benefits of collaboration between CCMB and primary care physicians. Although the establishment of UPCON itself is a significant step in providing more continuous patient-centred care, the physician group identified several areas for improvement. CCMB will continue to explore improvements to its partnerships with the primary care community.

6.1.3 Practices

6.1.3.1 Clinical practice guidelines

The routine implementation of clinical practice guidelines in medical practice is often used as one of the indicators of quality care. A number of DSG`s at CCMB have adopted guidelines developed in other jurisdictions However sustained and expanded use of guidelines requires ongoing review and monitoring, and the implementation of guidelines must be extended to all practitioners dealing with cancer patients including; the community cancer program sites, the family physicians participating in after-care and the community oncology sites of the WRHA. CCMB along with other Canadian cancer agencies, is committed to working to ensure that all cancer patients are receiving care based on the best evidence currently available, regardless of where they seek treatment.

CCMB has secured funds from CancerCare Manitoba Foundation to launch a clinical practice guidelines initiative. The guideline initiative will involve defining care expectations across the trajectory of cancer services, including referral, treatment and follow-up.

6.1.3.2. Clinical trials

CCMB recognizes the importance of clinical trials in patient treatment, and sees access to the clinical trials as an indicator of quality. The CIO is given the responsibility for facilitating and coordinating the enrollment of patients into clinical and non-clinical cancer research studies. The department is also responsible for expanding the clinical trials available, and improving enrollment. In recognizing this directive, CIO developed a vision that includes every cancer patient treated at CCMB or a CCP to be screened for participation in an appropriate clinical trial. Currently, there are 125 open and active research studies for both adults and children. More than 700 patients were enrolled in 2003, and some 2,800 patients continue to be followed.

In assessing the accessibility of clinical trials, a number of observations can be made. The number of trials available for a DSG depends on many factors, including CIO/CCMB's track record, sponsor interests, and the number of cancers diagnosed in Manitoba that would be available for a study. Although there are between fifty and sixty pediatric cancers diagnosed per year, CIO has fifty-six pediatric trials open for these patients, with some children being enrolled in more than one trial. This volume of trials is a success story and illustrates the potential availability and volume of trials CIO envisions for all CCMB patients.

Regrettably, investigational treatment trial protocols do pose impediments to accessibility for rural and northern patients. While some trials allow patients to be monitored and treated at CCPs, most studies require the patient to be treated in Winnipeg and limit patient travel distance to one hour from CCMB facilities. CIO is also limited in its access, as screening to determine eligibility for clinical trials must be conducted at the CCMB facilities in Winnipeg. Although CIO does not have statistics to indicate the breakdown of clinical trial patients by region, it would be reasonable to expect that there are proportionally fewer clinical trial participants from rural and northern Manitoba. Accessibility to CIO is limited in terms of capacity in that currently not all patients referred for a clinical trail are being screened for trial enrolment. This is an issue of concern to both CIO and CCMB, given the importance of clinical trials in advancing cancer care. CCMB continues to consider strategies to establish the capacity necessary to increase patient recruitment to clinical trials, as well as increasing the number of clinical trials available.

6.1.3.3. Patient safety

CCMB collects and monitors information related to patient safety in a variety of clinical areas. A formal internal occurrence reporting system is in place to report and review issues, both of a general nature (e.g., patient falls) as well as specifically for medication and radiation incidents. Critical incidents or occurrences are also immediately reported externally to Manitoba Health and the Chief Medical Examiner, as necessary, through the office of the CEO. The organization is currently reviewing the system to improve the ability to provide more detailed cumulative reports to administration and process teams.

6.2 Rehabilitation, Supportive Care and Palliative (R/S/P) Care

> *"It would mean a lot to me if someone could come and draw pictures with me when I have to be in the hospital." (Pediatric focus group participant)*

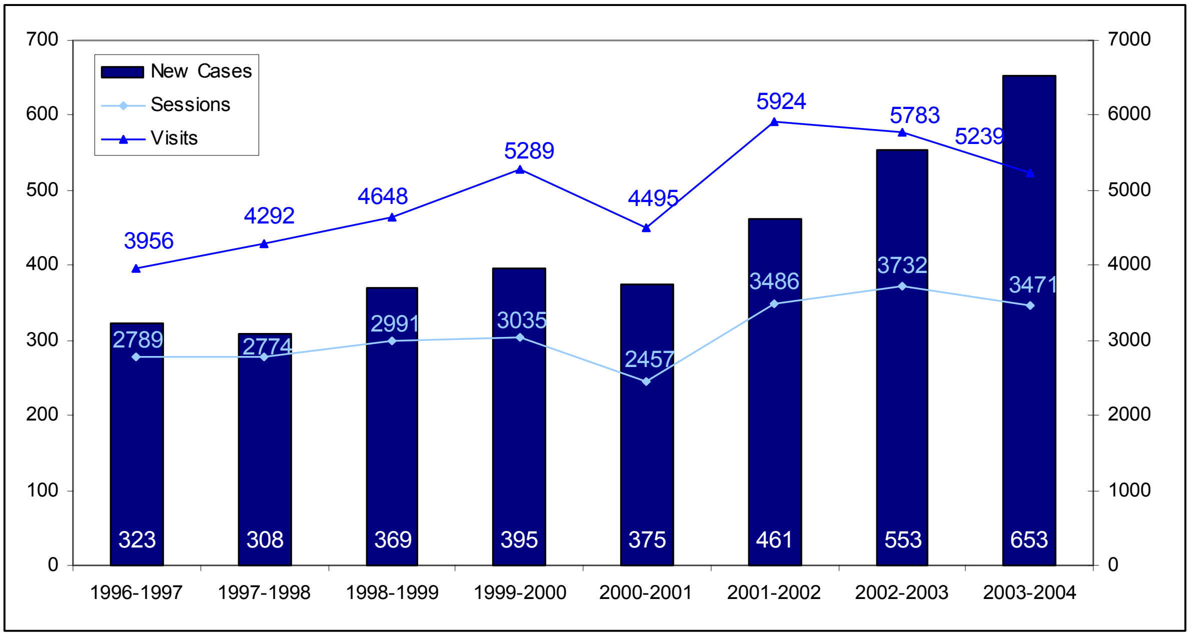
A diagnosis of cancer can be overwhelming for a patient, as well as a patient's family and support network. A cancer diagnosis can affect the patient and the family emotionally, socially and spiritually. Figure 6.10 illustrates the continuum of care and the associated supportive care and rehabilitation needs of patients who are diagnosed with cancer.

The psychological, rehabilitative, social, emotional, spiritual and information supports are organized within Patient and Family Support Services (PFSS). Services span the continuum of care, from diagnosis through treatment to survivorship, palliation and bereavement. PFSS is an interdisciplinary, integrated department that consists of six distinct but related programs - Psychosocial Oncology; Nutrition Services; Speech Language Pathology; CCMB Breast Cancer Centre of Hope; Patient and Family Information and Resource Centre; and the Guardian Angel Caring Room.

In 2003-04, 653 new cases were opened in Psychosocial Oncology. This number represents 5.5 per cent of the newly diagnosed cases seen at CCMB. The number of new cases that can be opened and the amount of support an individual client can receive is limited to the staff resources in the unit. The unit sees patients at any point along the continuum, including confirmation of diagnosis, treatment, and follow-up care. As the incidence and prevalence of cancer increases and the resources in the unit remains stable, access to appropriate care is insufficient. The increase in cases causes a reduction in clinical sessions available to the individual client (see Figure 6.9).

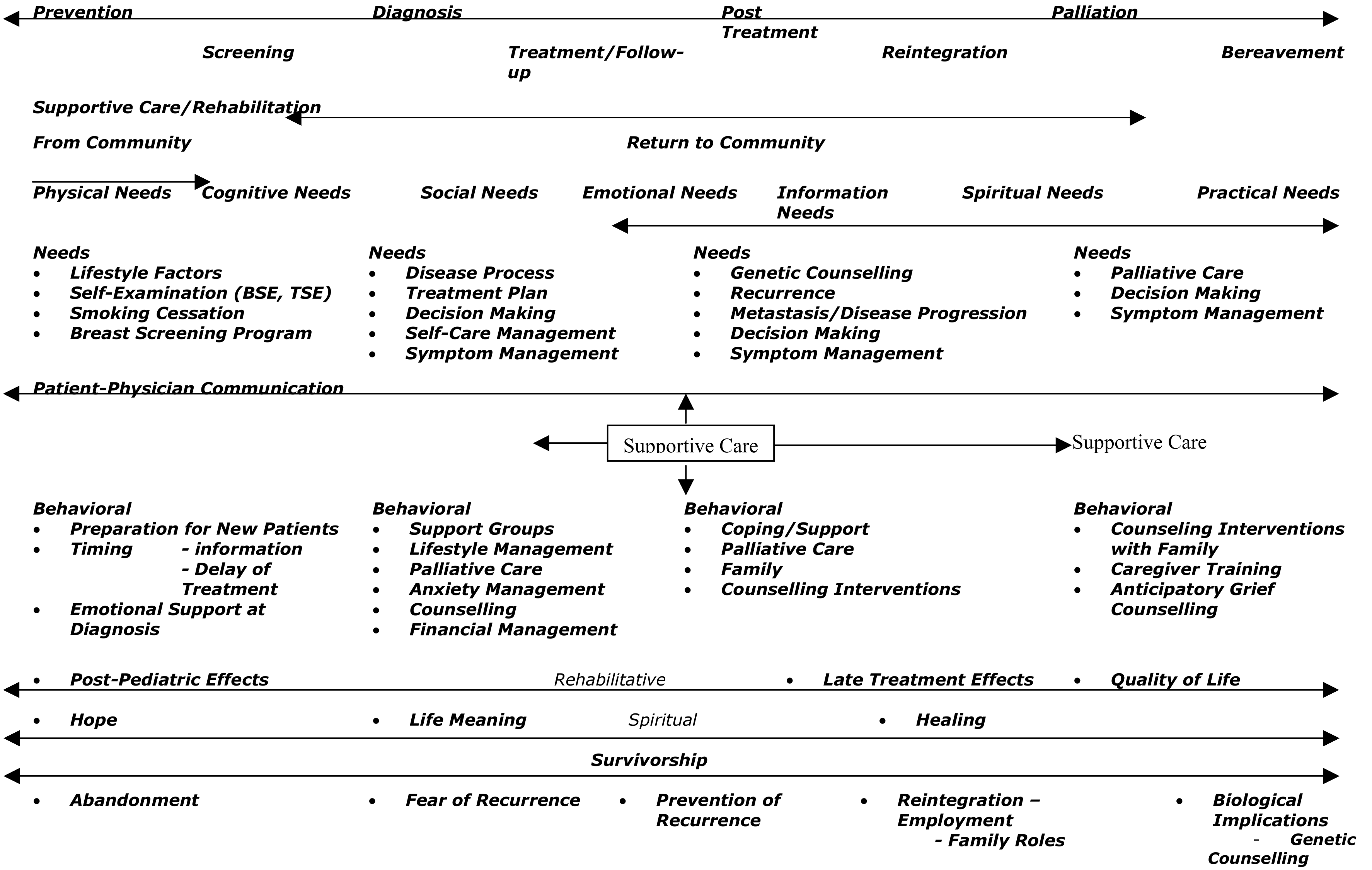
Research indicates that at least one-third of all people with cancer experience distress requiring psychosocial intervention; service to 5.5 per cent of newly diagnosed cases is clearly insufficient. Ways of improving access to psychosocial and other supportive care services are ongoing issues in Manitoba as in other parts of Canada. The PFSS unit utilizes group sessions, including participation through telehealth and support and mentoring to clinicians in Rural and Northern Manitoba, to increase access by patients.

Figure 6.9 Psychosocial Oncology, new cases seen by CCMB staff, 1996-97 to 2003-04



Source: CancerCare Manitoba, Patient and Family Support Services.

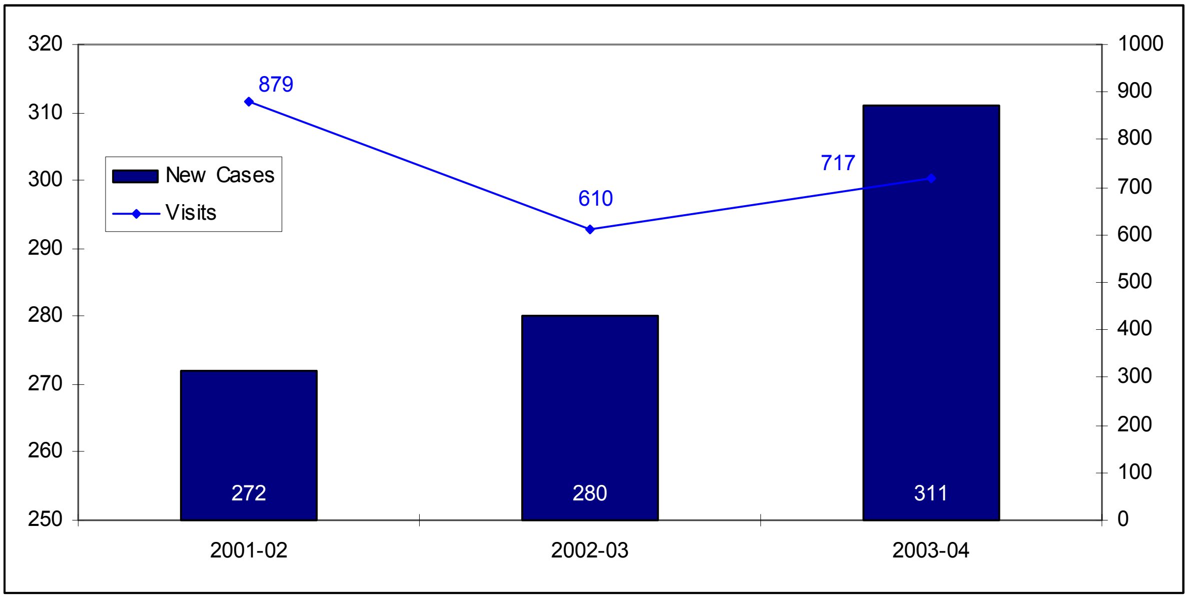
Figure 6.10. Continuum of Cancer Care
Supportive Care & Rehabilitation Needs
Behavioural Interventions



(Doll & Green 1998) Reproduced from Canadian Strategy for Cancer Control: Supportive Care/Cancer Rehabilitation Workgroup Final Report January 2001

PFSS provides specialized dietician support to assist in managing the nutritional needs and difficulties of patients. In 2003/04, 311 new referrals were opened, representing approximately 2.2 per cent of patients seen at CCMB in 2003. This level of access is inadequate given the nutritional support needs of cancer patients.

Figure 6.11. Nutrition services, number of new cases seen by CCMB staff, 2001-02 to 2003-04



Source: CancerCare Manitoba, Patient and Family Support Services.

Speech Language Pathology (SLP) services are available at CCMB. This service is a critical component of the care requirements of head and neck cancer patients. Occupational Therapy and Physiotherapy are available through referral to private therapists, WRHA Community Rehabilitation Services and hospital Rehabilitation Departments.

Psychosocial Oncology, Nutrition Services and SLP are available to rural patients through Manitoba Telehealth However, in many cases; R/S/P care services are not as comprehensive or specialized in the rural and northern regions of Manitoba as in to Winnipeg.

PFSS provides assistance to people by providing information about types of cancer and cancer treatments, helping them to understand the roles of various members of their health care team, and helping them to "navigate" the system. These services supplement the information provided by the primary nurse and

the oncologist, and are available through the Patient and Family Information and Resource Centre and the CCMB Breast Cancer Centre of Hope.
Pediatric Oncology offers social work services, a school teacher, child life therapists, physiotherapists, occupational therapists, access to a registered dietitian, a spiritual care worker, and a music therapist through Children's Hospital. These services are available to children with cancer and their families either on an inpatient or outpatient basis.

CCMB has developed specialized multi-disciplinary Pain and Symptom Management clinics at both the 675 McDermot site and the St Boniface Unit site.

CCMB also maintains close relationships with the Palliative Care programs within the WRHA as well as the palliative care programs in each of the RHAs. In recognizing the tight-knit nature of the partnerships, CCMB has several staff who work closely with the Pain and Symptom Management clinics, and the WRHA Home Care Service. This work has served as a model for the provision of seamless care between the three agencies, as the needs of patients change in the transition from active treatment to palliation.

Spiritual Care is provided by the host hospitals throughout Winnipeg and a number of the rural and northern RHAs, as well as through community programs. At this time, CCMB does not have supportive care services specifically directed toward the Aboriginal population. Starting in 2005, CCMB will undertake an internal and external scan of the accessibility and cultural appropriateness of services and programs for Aboriginal Manitobans across the cancer control spectrum.

Some CCPs have formalized the availability of psychosocial support and/or spiritual care. Three of the fourteen CCPs have secured some portion of an EFT to provide dedicated social work services for their CCP patients. Two CCPs have a spiritual care worker on staff from within their health care facility who is available to cancer patients and their families. In an attempt to address the shortage of psychosocial and/or spiritual care in all RHAs, all CCPs are assigned a psychosocial clinician from PFSS at CCMB who acts as a liaison/consultant to CCP staff around supportive care issues.

6.3 Location of Cancer Treatment

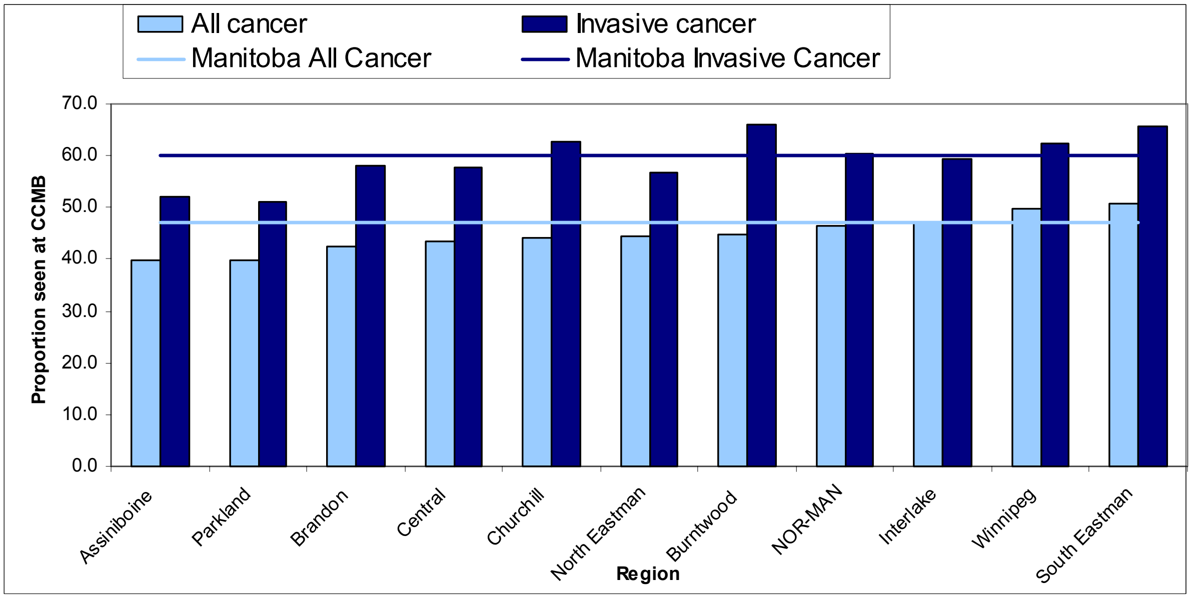
The ability to receive cancer treatment and follow-up care as close to home as possible is a significant factor impacting a patient's (and family's) quality of life. The requirement to receive treatment away from home can result in significant financial and emotional stressors. Although radiation therapy is available only in Winnipeg, chemotherapy, surgery and follow-up care can, in many cases, be provided in a patient's home region.

It is also recognized that four medical oncologists work within the WRHA but outside CCMB's main clinics. Therefore, the statistics provided in the following sections do not capture cases that are treated by these oncologists.

6.3.1 Proportion of Cancer Patients Treated at CCMB's Main Clinics

The time period 1992 through 2001 saw 47.1 per cent of patients diagnosed with cancer having contact with one of the two CCMB sites. For invasive cancers, this number rises to 60.2 per cent. It is recognized that contact with CCMB varies across health regions. While residents of Assiniboine and Parkland regions are least likely to attend CCMB, residents of Burntwood were most likely to visit the facility.

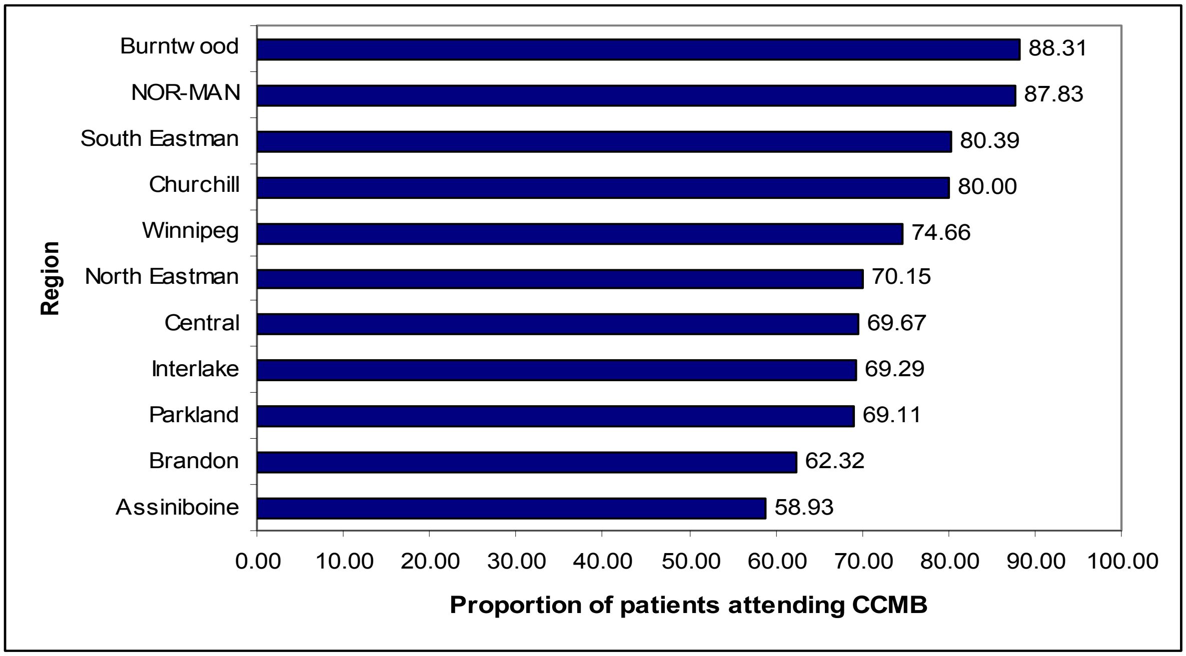
Figure 6.12. Proportion of Manitoba residents with cancer who attend CCMB's main clinics, 1992-2001 summary



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

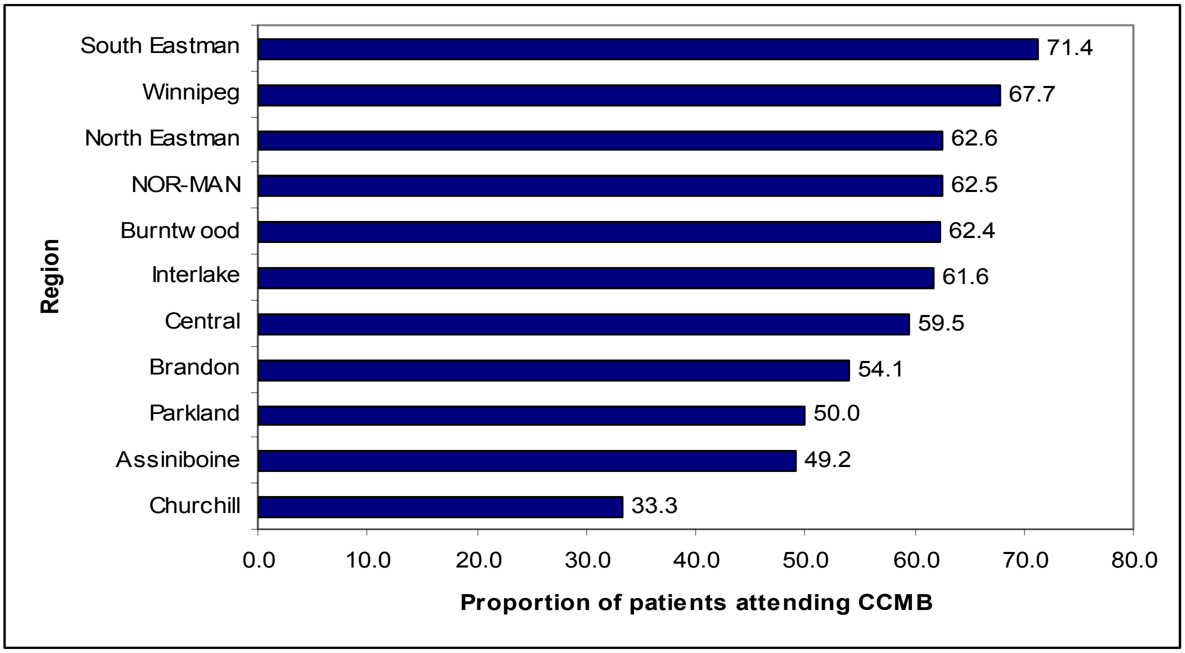
The proportion of patients seen at CCMB's main clinics also varies by disease site. Breast cancer patients are most likely to have contact with CCMB, with 72.2 per cent of those diagnosed between 1992 and 2001 being seen at the two facilities. Lung cancer patients were second with 63.6 per cent of patients seen. Colorectal patients, at 51.9 per cent, were only slightly more likely to be seen at CCMB than prostate patients, at 51.5 per cent.

Figure 6.13. Proportion of regional residents with invasive breast cancer who attend CCMB's main clinics, 1992-2001



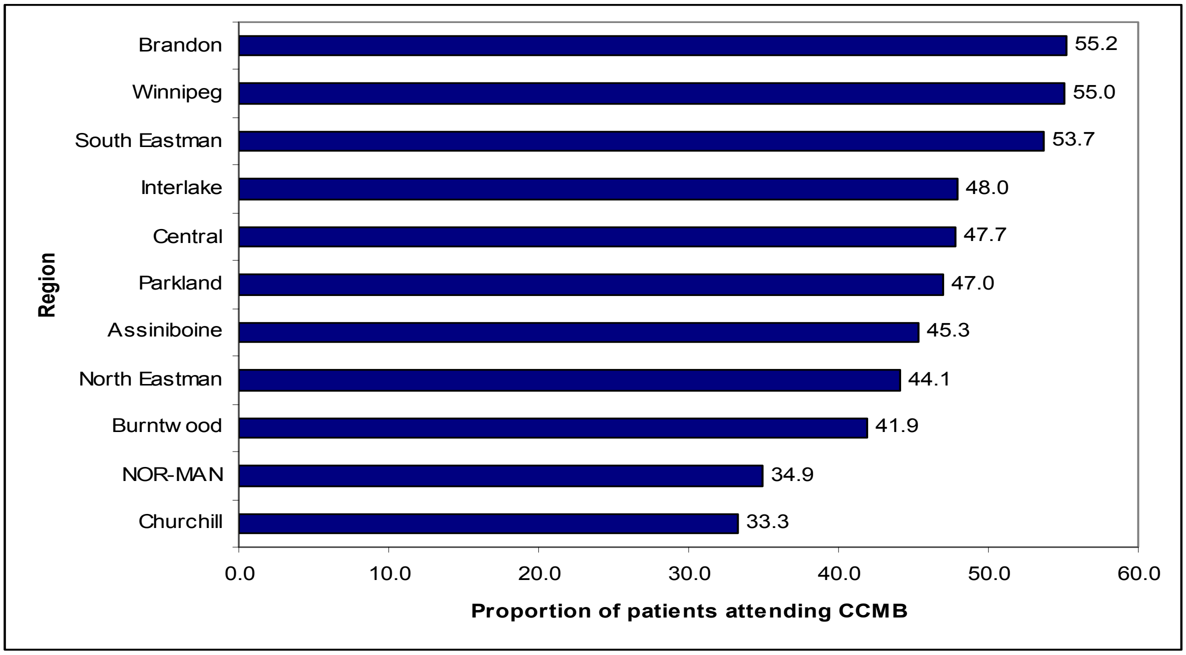
Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.14. Proportion of regional residents with lung cancer who attend CCMB's main clinics, 1992-2001



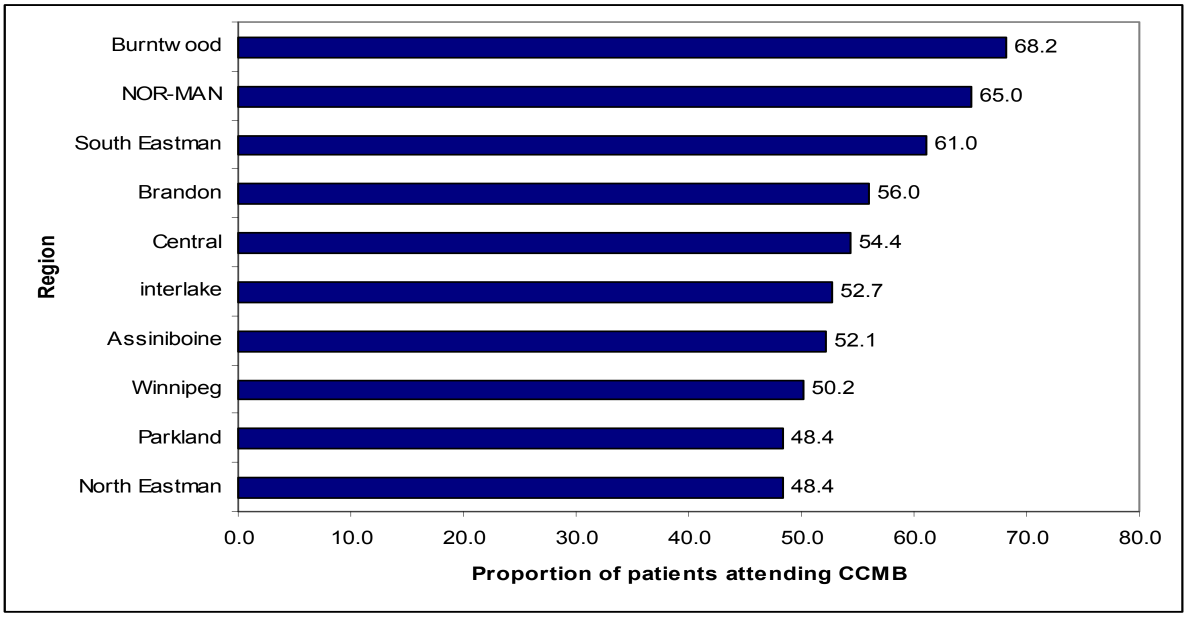
Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.15. Proportion of regional residents with prostate cancer who attend CCMB's main clinics, 1992-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

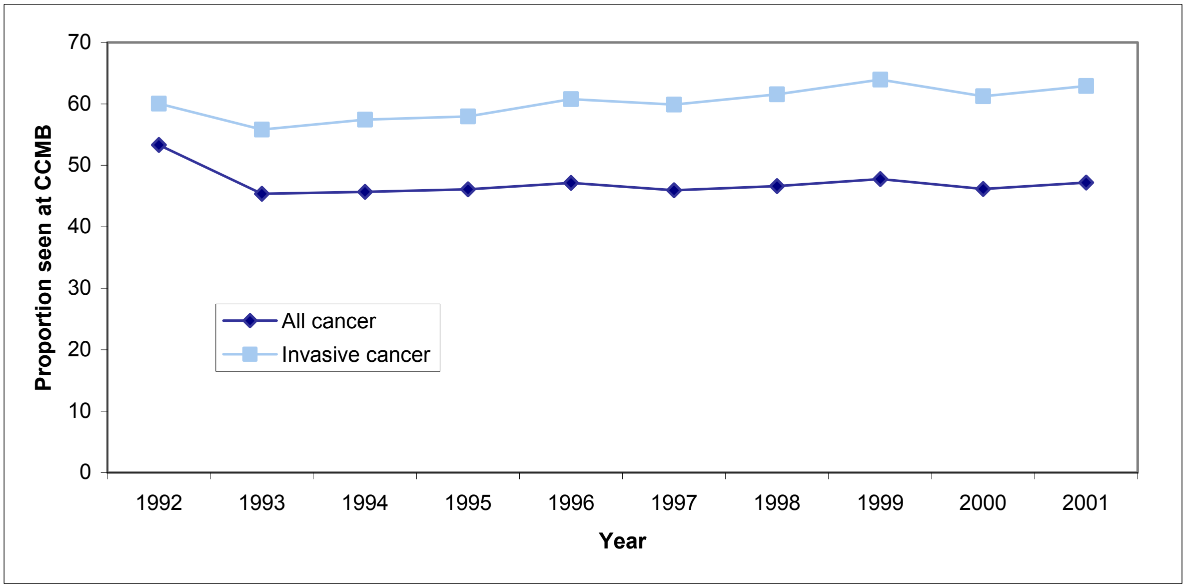
Figure 6.16. Proportion of regional residents with colorectal cancer who attend CCMB's main clinics, 1992-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

As Figure 6.17 illustrates, patients with invasive cancer are more likely to be seen at CCMB. The overall rate at which patients are seen at CCMB is remaining steady. This suggests that more patients with non-invasive disease are being treated outside the walls of CCMB's clinics.

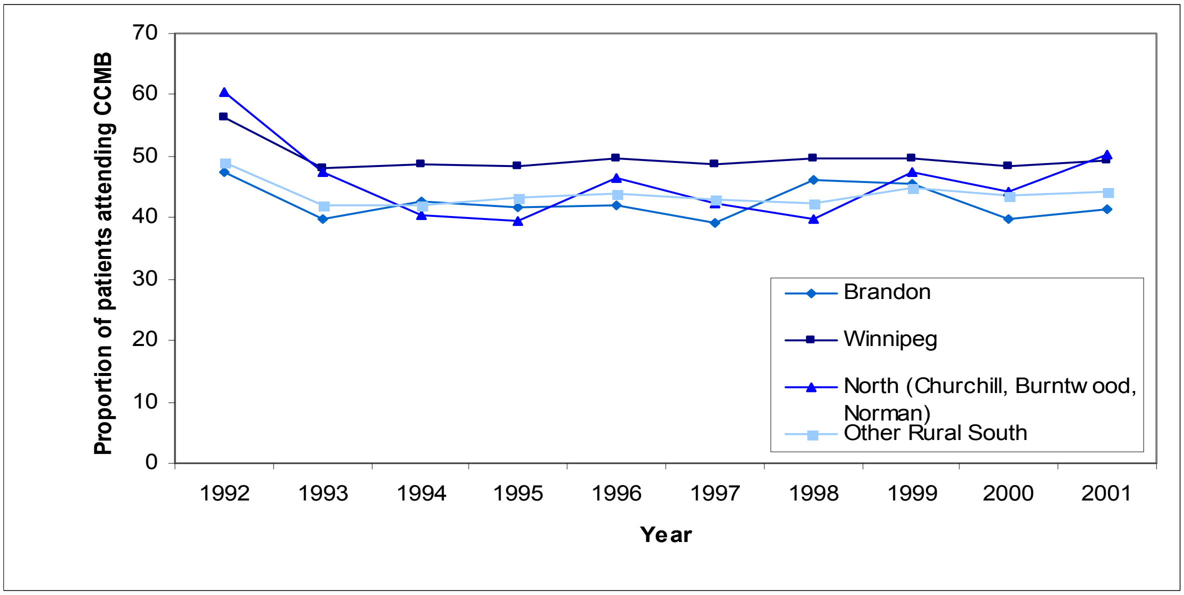
Figure 6.17. Time trend of proportion of Manitoba residents with cancer who attend CCMB, 1992-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

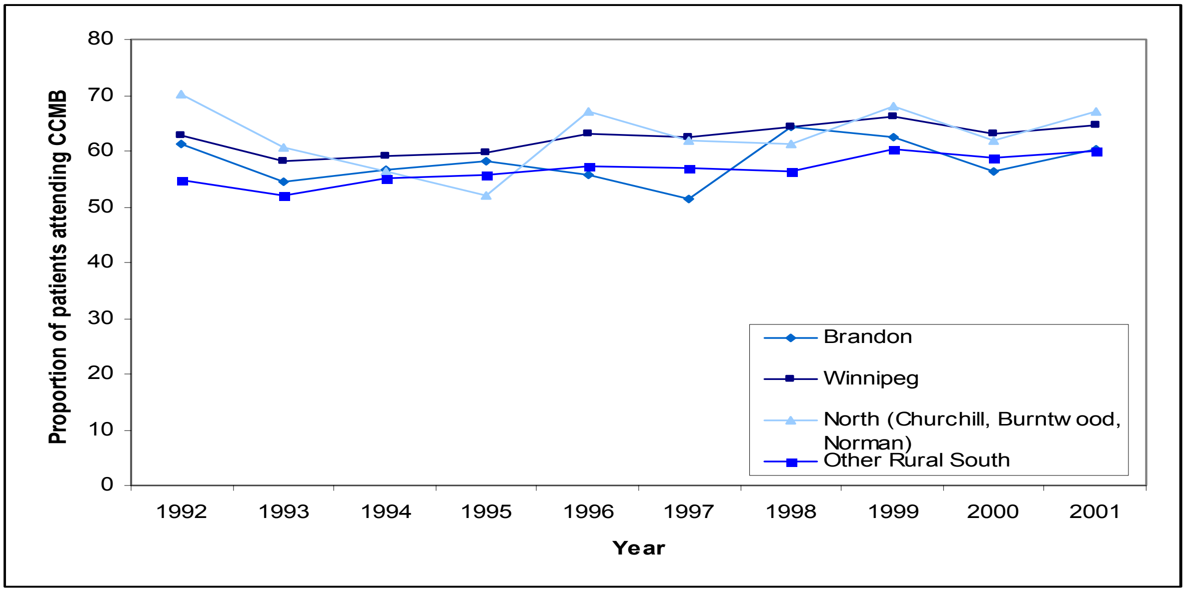
Figures 6.18 and 6.19 show patient attendance at CCMB by region. It should be recognized that due to the small populations of the rural and northern RHAs, variability will appear more pronounced.

Figure 6.18. Time trend of proportion of regional residents with all cancers who attend CCMB, 1992-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

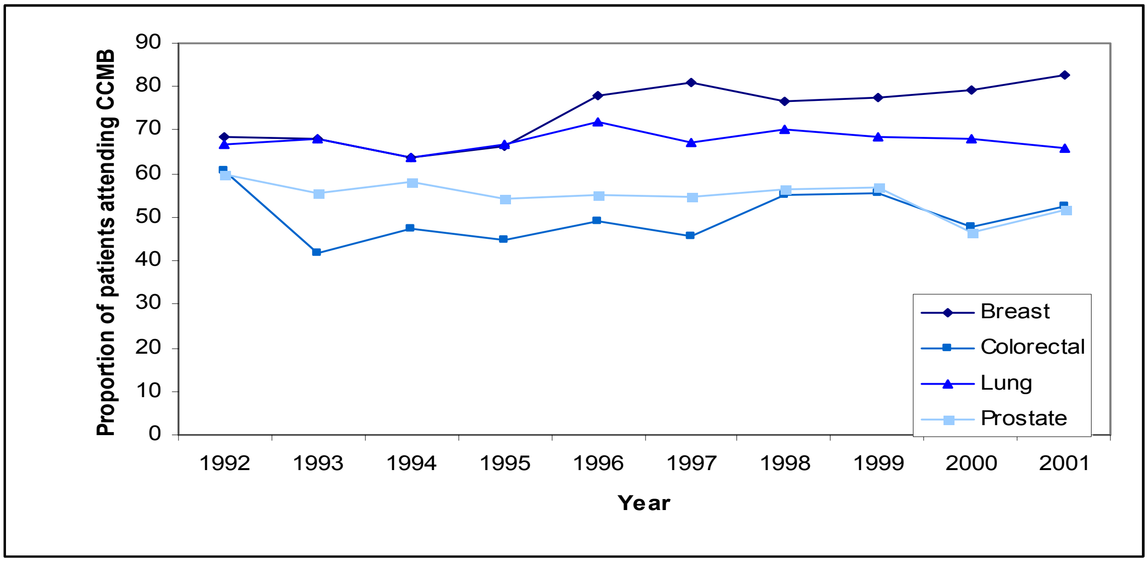
Figure 6.19. Time trend of proportion of regional residents with invasive cancer only who attend CCMB, 1992-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

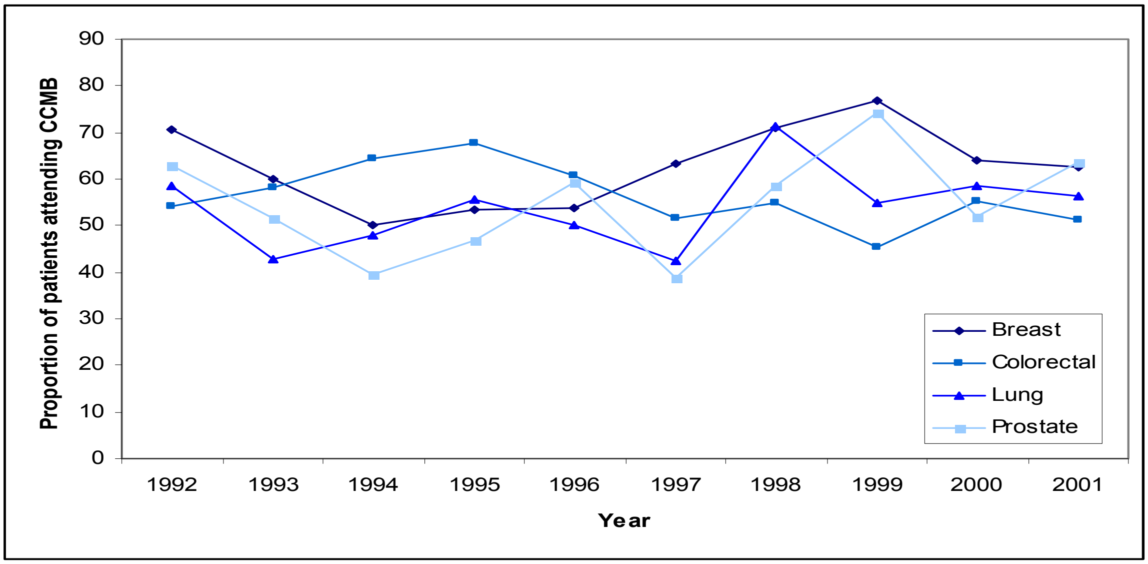
Figures 6.20 through 6.23 show cancer-specific rates of CCMB clinic attendance by region. Although subject to variability due to small sample size, some general conclusions may be drawn from these figures. Each of the graphs illustrates a high proportion of breast cancer cases attending CCMB. Additionally, cancer-specific CCMB contact rates are remaining steady or gradually increasing.

Figure 6.20. Proportion of Winnipeg residents with cancer who attend CCMB, 1992-2001



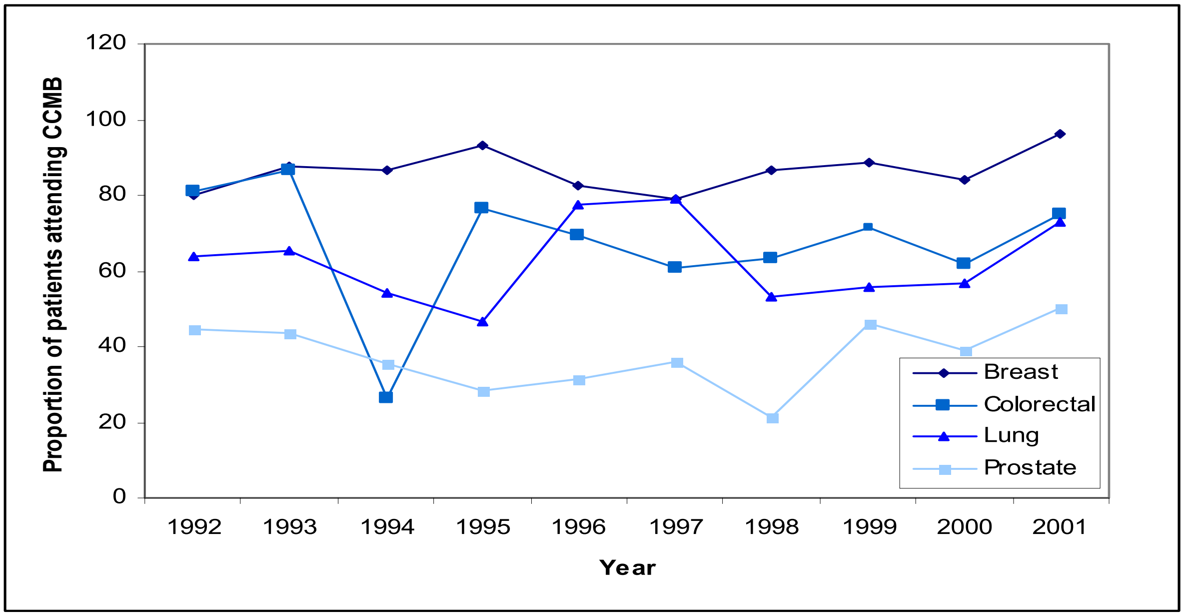
Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.21. Proportion of Brandon residents with cancer who attend CCMB, 1992-2001



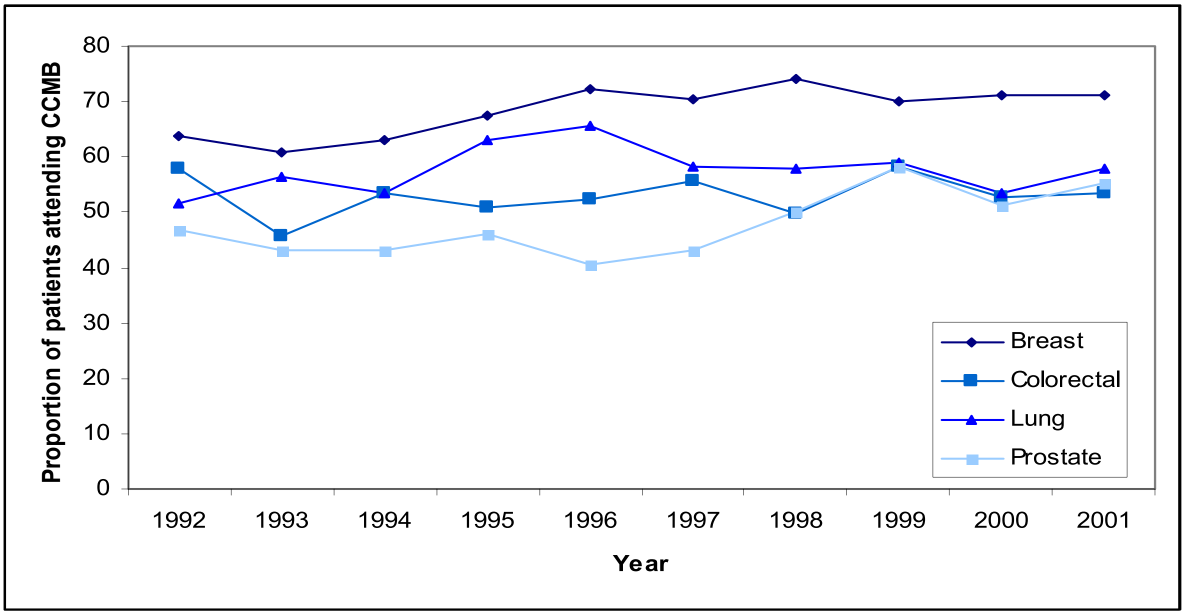
Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.22. Proportion of rural residents with cancer who attend CCMB, 1992-2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

Figure 6.23. Proportion of northern residents with cancer who attend CCMB, 1992-2001

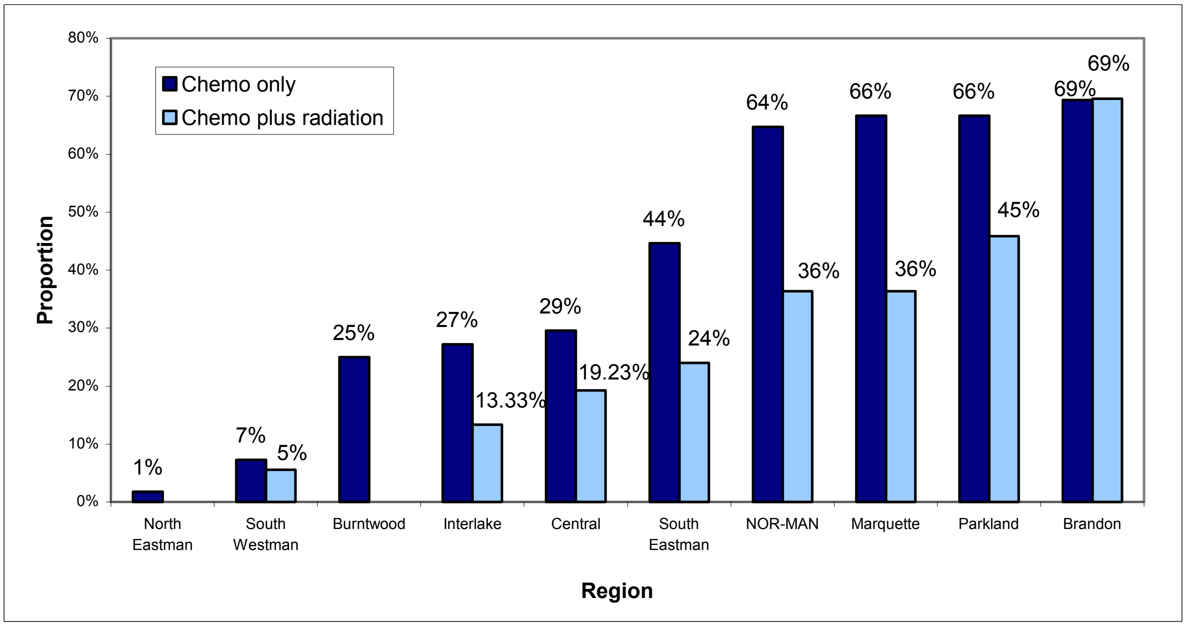


Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

6.3.2 Proportion of Cancer Patients Treated at Community Sites

As radiation therapy is available only in Winnipeg, it is interesting to examine how many patients who require both chemotherapy (which can, in most cases, be provided at the CCPs in the region) and radiation therapy choose to receive chemotherapy in their home region. Because patients have to travel to Winnipeg to receive radiation therapy, once could assume that they would be more likely to elect to undergo chemotherapy at the same location. Figure 6.24 illustrates that this theory does indeed appear to be supported. With the exception of Brandon, patients were less likely to undergo chemotherapy at their regions CCP if they had to travel to Winnipeg for radiation therapy. For example, while almost two-thirds (64.7%) of NOR-MAN region residents who require chemotherapy only opt to receive this in their home region, when they require both chemotherapy and radiation therapy, only 36.4 per cent stay in the region for the chemotherapy portion of the treatment. This suggests that if additional radiation services were provided (i.e., in Brandon) more patients would opt to receive their chemotherapy care where their radiation therapy is provided. Other theories for this pattern should be explored to ensure appropriate and timely access.

Figure 6.24. Proportion of patients requiring chemo receiving chemo in their home RHA, 2001



Source: CancerCare Manitoba, Epidemiology and Cancer Registry.

6.4 RHA Feedback

The support services available and the way in which they are provided vary across the RHAs. The RHAs identified well-developed palliative and home-care programs that provide the services required by cancer patients. Spiritual care services are also available within the health care system and in the community. The RHAs also acknowledge the existence of patient-driven support groups in many community settings, many of which are specific to cancer patients. However, the discussion focused most specifically on key areas surrounding patient care, including support services for cancer patients and survivors, access to the cancer system especially for recurrent disease, and palliative care.

In discussing the support services CCMB provides to RHAs, there was a clear acknowledgement of the assistance of CCMB. Specifically, the RHAs identified treatment services at the CCPs, peer and professional support, direction for treatment from CCMB oncologists and nursing staff, symptom management, information and library services, and the CCMB Navigator newsletter as services they had accessed.

There were a variety of program gaps identified in the discussions with the RHAs. The majority of RHAs lacked cancer-specific psychosocial supports. Where psychosocial support services are available, they are most often provided in only a few select centres within an RHA, which may pose accessibility issues for some patients. Discussions also identified that the capacities of nutritional and rehabilitation services may be strained by the specific needs of cancer patients. An increasing disease burden in the population may require expansion of these types of services for cancer survivors.

RHAs identified the need to partner with CCMB to improve the services available to patients, especially those with recurrent disease. It was identified that patients who are re-accessing services have difficulties in receiving appropriate care. RHAs described experiences in which patients went through more invasive treatment options to avoid the travel that would be required to receive radiation therapy. Although this requires more investigation, a patient-centered system must respect a patient's choice of treatment, which may included choose alternatives that keep them close to their support networks. However, providing appropriate information and decision tools may be a method of aiding RHAs in ensuring the provision of disease appropriate patient-centered care.

The majority of RHAs had well-developed palliative care programs led by a palliative care coordinator. It was of concern that there are very limited dedicated direct care resources for palliative care services. Current programs rely heavily on the volunteer sector to provide services. Stable, long-term funding would greatly improve the consistency of palliative programs.

CCMB's Community Health Assessment steering group felt that the discussions with the RHAs would be a useful way to collect information on the partnerships required to deliver cancer services, acknowledging system-wide ownership of cancer care. CCMB recognizes the importance of the services provided by RHAs for cancer patients and understands that RHAs are committed to providing care as close to home as possible, while maintaining access to high-quality services for their residents. The RHAs will need CCMB's assistance in projecting the future demands for such services.

6.5 Patient and Family Feedback

In May 2004, eleven focus groups and two one-to-one interviews were conducted by CCMB to get a more detailed assessment of the experiences of patients and families in the cancer care system in Manitoba.[a] A representative patient sample was chosen to participate, including those diagnosed with breast cancer, rural and northern patients and families, inner-city Winnipeg patients and families, patients who accessed CCMB's PFSS, patients who did not access PFSS, parents of children with cancer, and bereaved family members.

Participants were asked questions ranging from their knowledge of cancer before diagnosis, their experience at time of diagnosis and treatment, and their knowledge and use of support services.

While focus group participants had a diverse range of experiences with the cancer care system, a number of common themes emerged from the focus group sessions - access to cancer care, experience with cancer pre-diagnosis, the cancer experience, impressions of CCMB, cancer information, and impressions of the CCPN.

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[a] See Chapter 3 "Methodology" for a more detailed overview of the process and participants. Specific questions are provided in Appendix A.

6.5.1 Access to Cancer Care

As the focus group sessions revealed, cancer patients are generally quite satisfied with the level of accessibility for oncology services. Despite the public perceptions around long waits for radiation therapy, few focus group participants discussed wait times for radiation therapy and those who did expressed their impression that access to radiation therapy was very timely. There was also a similar level of satisfaction for chemotherapy services, though there were a few instances where focus group participants reported waiting for an extended period of time between their arrival at CCMB and the administration of their chemotherapy. Long waits for CT scans were also noted, illustrating bottlenecks in the care trajectory that are beyond the scope of services provided by CCMB.

Some rural patients who did not receive their chemotherapy at a CCP did note the stress and added burden of traveling to Winnipeg over an extended period of time for radiation therapy and chemotherapy services. These patients expressed the pressures of the amount of travel time for treatment, the costs associated with traveling, and the sacrifices family members had to make. Those sacrifices included providing transportation for the cancer patients, taking care of their basic needs and child care.

> *"Had to hire someone to take us [drive us to our treatments]. I hired someone privately but didn't know [there was] a service ... Kids took turns driving me in, they had to take time off work." (Rural focus group participant)*

Some concerns were also voiced about access to CCMB in the follow-up care phase. There were some focus group participants who felt 'ignored' by CCMB during their follow-up phase as oncologists frequently postponed or cancelled follow-up appointments.

The greatest worry regarding accessibility concerned the diagnosis of the disease by their family doctor and the wait times for diagnostics and lab results. As is described later on in this chapter, most focus group participants agreed that this was the most stressful period of the cancer experience due to the time it took for diagnosis and the uncertainty of how their diagnosis and treatment would proceed.

6.5.2 Experience with Cancer – Pre-Diagnosis

Prior to receiving a diagnosis of cancer, people's perceptions were generally formed by family and friends who had been diagnosed with cancer. Prior to their personal experience, they had minimal understanding of cancer or CCMB. Not surprisingly, people's pre-diagnosis perception of cancer was negative. Most people viewed cancer as a death sentence, having watched family and friends die of it.

6.5.3 The Cancer Experience

The most difficult part of the experience for many patients and families was the time between their initial recognition of symptoms to the time of the definitive cancer diagnosis. From the patient's point of view, diagnosis by the general practitioner is a long, fragmented process during which physicians seemed to have difficulty providing a timely diagnosis.

> *"I felt 'up' when I got the diagnosis and thought everything would move along but I kept getting bogged down. I kept thinking just one more barrier away from treatment." (Focus group participant)*

Many participants commented that the time to diagnosis was the most difficult time for them emotionally.

6.5.4 Impressions of CCMB

CCMB received a generally favourable response about the treatment, support services and information resources available. Social workers were praised for the emotional support provided to patients and their families. Many focus group participants identified the critical role played by social workers in helping patients deal with the psychological impact of cancer on themselves and their relationships with family members. Nurses were also praised for their professionalism, empathy and clarity. Patients described the role of the nurse as an information provider, an emotional support, and a navigator through the cancer system. The information resource centre at CCMB and at the CCMB Breast Cancer Centre of Hope were found to be extremely helpful.

> *"I used to think of CancerCare as a treatment centre, now I think of it as a resource centre." (Focus group participant)*

The only criticism of support services was that there was generally not enough communication about support services available to the patient either within CCMB or externally. Patients simply did not know enough about all the resources available to them, and as a result some did not reap the benefits of those services.

The focus group participants were also under-informed about the Patient Representative. Most participants thought that any concerns or difficulties they had about their care at CCMB could be handled by dealing with their oncologist or nurse. This finding reinforces the value the patients place on their primary nurse at CCMB, who is seen as a provider of knowledge and support.

6.5.5 Cancer Information

There were mixed reactions about the level of information provided to cancer patients. Some thought there was not enough information about what to expect when treated and what side effects may be experienced. Others found the information confusing, contradictory, and inconsistent depending on which health care professional they asked.

> *"I had not enough information and not the right kind." (Focus group participant)*

Others were quite satisfied with the amount of information received and sought out as much information as possible.

> *"The surgeon said not to read too much because you'll get scared. I was waiting because they were 3 hours late [for my surgery appointment]. So I went to the resource library and read and read." (Focus group participant)*

There seemed to be two distinct categories of patients - those who did not want a great deal of information and who relied on their physician for advice on how to proceed in their treatment, and those who actively sought information on their disease and the available treatment options from a variety of sources. A common complaint from both groups was that physicians often made assumptions about the level of information a patient wanted without asking the patient. This led to some negative feelings about the level of physician communication.

6.5.6 Impressions of Community Cancer Programs Network

The CCPN conducts a patient satisfaction survey on an ongoing basis. The survey is distributed to all new patients who receive treatment at one of the 14 CCPs, and asks patients a series of questions about their experience at the CCP. Survey responses are consistent with the focus group findings. Generally, patients report their care experience at the CCP was convenient and efficient. Patient responses have highlighted space limitations at CCPs where treatments are provided in a physical setting within the acute care hospital that has not grown to meet the demand for services in the local area. Many CCPs have expanded or are in the process of expanding their physical space, which will help address concerns about the lack of adequate treatment, private examination and meeting space at some CCPs.

Patients have reported that communication between CCP physicians and nurses regarding their care was excellent. Patients identified some instances when they would have appreciated additional information regarding community supports available to them locally, such as home care, counselling and support groups. As a whole, CCP patients are happy with the CCPs in meeting their physical and emotional needs related to their cancer care. Overall, patients who received care at a CCP report that their care was provided in a timely manner and their experience was very good. In addition, staff of the CCPs was reported to be excellent.

Three of the patient focus groups involved cancer patients from smaller communities in Manitoba - Thompson, Beausejour and Neepawa. Participants from these communities reported varied experiences regarding where they had received their treatment. Some had the option of cancer treatment at the CCP in their community, whereas some patients did not have that option, because not all chemotherapy treatments were available at their region's CCP. There was at least one focus group participant who had to pursue treatment in Winnipeg as their CCP did not have a chemotherapy nurse at the time.

Patients who needed radiation therapy or certain types of chemotherapy that were not available at their CCP had to have their treatment in Winnipeg. Thompson, Neepawa and Beausejour focus group participants were very positive about their experiences in Winnipeg for treatment and amount of information given. As discussed previously, the biggest drawback around receiving treatment in Winnipeg was the stress of travel and the associated inconveniences related to treatment far from home.

> *"I walked into CancerCare Manitoba (McDermot Location) and first thing I felt was hope." (Rural focus group participant)*

Those who received their treatment or follow-up care at the Thompson and Neepawa CCPs had differing experiences. While the Thompson CCP was given positive reviews, some patients were not as satisfied with the level of care received from their physician or the Thompson hospital. Cancer patients in Neepawa raised concerns with the physical limitations of the small CCP space in Neepawa and indicated a need to have a new space, given the lack of privacy and cramped conditions. The Neepawa focus group was, however, very pleased with the quality of care received and the communication between CCMB and the CCP. A new facility for the Neepawa hospital has now been approved by government.

> *"The CCP provides a much needed service to rural patients, to be closer to home when taking cancer treatments definitely makes the procedure more bearable. The staff was very well trained; efficient, concerned and always willing to help patients anyway they can. This program is very much appreciated." (CCPN Patient Satisfaction Survey Participant)*

The overall theme of the responses received by the CCPN in the form of written comments on the CCPN Patient Satisfaction Survey reflect significant satisfaction with the care received at the local CCPs, and an overall gratitude for the benefits realized from having this level of care provided closer to home.

CCMB is currently in the process of gathering further feedback from patients and families with the NRCPicker Group Canada's survey tool. This survey has been utilized in other provincial cancer agencies, and one of the goals is to eventually be able to compare CCMB's results with other jurisdictions. Feedback from the survey is expected in early 2005 and a team is in place to analyze and report on what is being done well, along with areas indicated as needing improvement. All patients in the province who received chemotherapy and/or radiation therapy in the last eight months were sent the survey. This type of survey will be carried out on a regular basis in the future as part of CCMB's ongoing quality improvement processes.

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7

APPENDICES

CancerCare
MANITOBA

1. Focus Group Questions for Cancer Survivors

- What were some of the challenges and quality of life implications of being diagnosed and treated for cancer?
- What are some of the major obstacles people had in accessing care?
- What types of CCMB services did survivors use and what is their impression (satisfaction) with these services?
- Are survivors aware of the full range of services offered by CCMB – particularly support services?
- What more can CCMB do for patients and families during treatment and survivors after treatment?

Agenda Item	Questions for Discussion
1. Arrive, Meet, Greet, Sign/Collecting Consent Forms	
2. Introductions (5 – 10 mins)	I will introduce myself, administrative support, and Fred and explain each role. Ice Breaker: Participants will be asked to briefly introduce themselves and talk about their cancer experience in brief if comfortable (i.e. when were you diagnosed? What kind of cancer are potential topics).
3. Discussion of Objectives (10 mins)	• Focus of our Community Health Assessment is Accessibility and how your quality of life was impacted by both having cancer and your access to cancer services. • To learn more about your experiences as a cancer patient (and as family members supporting the patient if appropriate) as you moved through the cancer care continuum from the point of your diagnosis, through treatment to follow up. • To learn more about what services or experiences worked very well for you and what were some barriers to services (what did not work well for you). • To learn more about your experiences as a cancer survivor and what your needs are now.
4. Discussion: Before you were diagnosed with cancer, what did you know about cancer? What did you know about	**What did you know about cancer?** *Other questions to help guide the discussion:* • *Did you know where to find information about cancer?* • *Did you know about breast cancer screening? How to access it, who should be screened etc.* • *What have been some barriers to accessing/receiving information about cancer, prevention and*

CCMB?(15 min)	*risk factors? (knowledge, location, language, culture etc.)* • *What have been some barriers to accessing screening services?*
5. Brief Presentation (5 mins)	• Illustration of continuum of care from Screening to Follow up. • Define/describe the services along the continuum of care.
6. Discussion: Thinking about the continuum of care, what was the most difficult or problematic time? (30 mins)	**What was the most difficult or problematic time for you?** *Other questions to help guide the discussion:* • *What were some of the obstacles or challenges you faced in living with breast cancer?* • *What were barriers to accessing/receiving services? (knowledge, location etc.)* • *What difficulties did you face in decision making process? (time to make decisions, too little/too much information, lack of knowledge, confusion, communication with health professionals etc)*
7. Discussion: What kinds of things helped you to cope with your cancer diagnosis? (30 mins)	**What kinds of things helped you to cope with your cancer diagnosis?** *Other questions to help guide the discussion:* • *What kinds of things did you rely on during your cancer diagnosis?* • *Did you feel you have enough of, or enough access to these things?* • *Where did you get most of your information about cancer services and treatment?* • *Who do you rely on for support right now?* • *What did your family or community do to help you? What did you need them to do?* • *Talk about accessibility to specific programs at CCMB during treatment .*
8. What kinds of things do cancer survivors need to help their overall quality of life? (10 mins)	Some of these issues may have come up in the previous discussions. *Other questions to help guide the discussion:* • *How did you feel once your active treatment was completed? (happy, sense of abandonment etc.)* • *Was there enough interaction between you and health care providers after your finished active treatment?* • *What more can CCMB do to help cancer survivors?*

	- *Talk more about supportive care services.*
9. Summary and Wrap-up of Discussion (10 mins)	
10.Conclusion	Thank you and explain how we will use this information

2. Focus Group Questions for Cancer Patients

- What are some of the challenges and quality of life implications of being diagnosed and treated for cancer?
- What are some of the major obstacles people have in accessing care at CCMB?
- What types of CCMB services have people used and what is their impression (satisfaction) with these services? **OR** Why did patients NOT use support services (depending on which focus group).
- Are patients aware of the full range of services offered by CCMB?
- What more can CCMB do for patients and families?

Agenda Item	Questions for Discussion
1. Arrive, Meet, Greet, Signing/Collecting Consent Forms	
2. Introductions (5 – 10 mins)	I will introduce myself, administrative support, and support staff and explain each role. Make sure indicate that I am not a cancer expert, cannot answer the questions. Ice Breaker: WE only have 2 hours together but just want a bit of information about you and the types of cancer you have. Participants will be asked to briefly introduce themselves and talk about their cancer experience in brief **if comfortable**. Maybe talk a bit about where you are in your treatment right now. (i.e. diagnosis, and stage at now)
3. Discussion of Objectives (10 mins)	• Focus of our Community Health Assessment is Accessibility and how your quality of life has been impacted by both having cancer and your access to cancer services. • To learn more about your experiences as a cancer patient (and as family members supporting the patient if appropriate) as you moved through the cancer care continuum from the point of your diagnosis, through treatment to follow up. • To learn more about what services or experiences worked very well for you and what were some barriers to services (what did not work well for you).
4. Discussion: Before you were diagnosed with cancer, what did you know about	**What did you know about cancer?**

cancer? What did you know about CCMB?(15 min)	
5. Brief Presentation (5 mins)	• Illustration of continuum of care from Diagnosis to Follow up. • Define/describe the services along the continuum of care.
6. Discussion: Thinking about the continuum of care, which part of the continuum was what was the most difficult or problematic time or had the most challenges? (30 mins)	**What was the most difficult or problematic time for you?** *Other questions to help guide the discussion:* • *Did you have what you needed to help you at the point of time they've identified?* • *What are some of the obstacles or challenges you face in living with cancer?* • *Issues around timelines?* • *Too much or too little information?* • *What have been some barriers to accessing/receiving services? (knowledge, location etc.)* • *Did you get enough information along the way, did you get enough support along the way? What did you need at different points.*
7. Discussion: What kinds of things helped you through this experience and continue to help you? (30 mins)	**Anything from CCMB that helped you through this experience?** *Other questions to help guide the discussion:* • *What kinds of things do you rely on in order to deal with your diagnosis?* • *Do you feel you have enough of, or enough access to these things?* • *Where do you get most of your information about cancer services and treatment?* • *Who do you rely on for support right now?* • *Talk about accessibility to specific programs at CCMB* • *Do you have a sense of what your families experience has been – do they feel supported, do they need more services.*
8. What kinds of things help your overall quality of life right now (specific to	Some of these issues may have come up in the previous discussions. *Other questions to help guide the discussion:* • *What more can CCMB do to help you live with your cancer diagnosis?*

cancer)? Or what do you need? (10 mins)	• *Talk more about supportive care services.* • *Now that you've had this experience, how have your views on life changed? I've heard other people say that they feel x more important.*
9. Summary and Wrap-up of Discussion (10 mins)	
10.Conclusion	Thank you and explain how we will use this information

3. Focus Group Questions for Parents of Paediatric Patients

- What are some of the challenges and quality of life implications of being diagnosed and treated for cancer?
- Where do these patients get their services?
- What are some of the major obstacles people have in accessing care at CCMB?
- What types of CCMB services have people used and what is their impression (satisfaction) with these services?
- Are patients aware of the full range of services offered by CCMB?
- What more can CCMB do for patients and families?

Agenda Item	Questions for Discussion
1. Arrive, Meet, Greet, Signing/Collecting Consent Forms	
2. Introductions (5 – 10 mins)	I will introduce myself, administrative support, and Fred and explain each role. Ice Breaker: Participants will be asked to briefly introduce themselves and talk about their cancer experience in brief if comfortable (i.e. when were you diagnosed? What kind of cancer are potential topics).
3. Discussion of Objectives (10 mins)	• Focus of our Community Health Assessment is Accessibility and how your and your child's quality of life has been impacted by the cancer diagnosis/experience and access to cancer services. • To learn more about your and your child's experiences as a cancer patient as you moved through the cancer care continuum from the point of diagnosis, through treatment to follow up. • To learn more about what services or experiences worked very well for you and what were some barriers to services (what did not work well for you).
4. Discussion: Before your child was diagnosed with cancer, what did you know about childhood cancers? (15 min)	**What did you know about childhood cancer?** *Other questions to help guide the discussion:* • *Did you know where to find information about cancer in children?* • *Did you know what some signs or symptoms of cancer might be?* • *What have been some barriers to accessing/receiving information about childhood cancer and risk factors? (knowledge, location, language, culture etc.)*

5. Brief Presentation (5 mins)	• Illustration of continuum of care from Diagnosis to Follow up. • Define/describe the services along the continuum of care.	• We may want to give participants a hand out with continuum of care and definitions of services.
6. Discussion: Thinking about the continuum of care, what was the most difficult or problematic time (for you as the family, for your child as the patient)? (25 mins)	**What was the most difficult or problematic time for you?** *Other questions to help guide the discussion:* • *What was your experience in the diagnostic process (i.e. did it take a long time, was your family doctor/pediatrician knowledgeable and helpful, did the family dr/ped know who to refer you to?)* • *What are some of the obstacles or challenges your child faces in living with cancer?* • *What have been some barriers to accessing/receiving services? (knowledge, location, language, culture etc.)*	• Flip chart
7. Discussion: What kinds of things help your family and your child to cope with the cancer diagnosis? (25 mins)	**What kinds of things help you and your child to cope with the cancer diagnosis?** *Other questions to help guide the discussion:* • *What kinds of things does your child rely on in order to live his/her life right now?* • *What does the family rely on?* • *Do you feel you have enough of, or enough access to these things?* • *Where do you and your child get most of your information about cancer services and treatment?* • *Who do you rely on for support right now?* • *What can your friends, family or community do to help you?* • *Talk about accessibility to specific programs at CCMB .*	• Definition of continuum of care and programs/services along continuum. • Flip chart
8. What kinds of things do children who have been diagnosed with cancer need to help their overall quality of life? (20 mins)	Some of these issues may have come up in the previous discussions. *Other questions to help guide the discussion:* • *What more can your family, community and CCMB do to*	• Flip chart

(what does the family need to support the child in achieving a good QOL?)	*help you and your child live with your cancer diagnosis? Talk more about supportive care services – talk about specific programs offered – do they know about these programs? Which may apply to them? Are they using them? Why / why not?*	
9. Summary and Wrap-up of Discussion (10 mins)		• Notes from Discussion (review of flip chart for key themes)
10. Conclusion	Thank you’s & explain how we will use this information	Supportive handout developed by Jill.

4. Focus Group Questions for Bereaved Family Members

- What kinds of services do family and friends need?
- How long do friends and family continue to need support services?
- What are some of the major obstacles people have in accessing care and services at CCMB?
- What types of CCMB services have people used and what is their impression (satisfaction) with these services?
- Are friends and families aware of the full range of services offered by CCMB?
- What more can CCMB do for patients and families?

Agenda Item	Questions for Discussion
1. Arrive, Meet, Greet, Signing/Collecting Consent Forms	
2. Introductions (5 – 10 mins)	I will introduce myself, administrative support, and support staff and explain each role. Ice Breaker: Participants will be asked to briefly introduce themselves and talk about their cancer experience in brief if comfortable (i.e. when were you diagnosed? What kind of cancer are potential topics).
3. Discussion of Objectives (10 mins)	• Focus of our Community Health Assessment is Accessibility and how peoples' lives have been impacted by a cancer diagnosis and access to cancer services. • To learn more about your experiences as a support person to a cancer patient as the patient moved through the cancer care continuum from the point of diagnosis, through treatment to follow up. • To learn more about what services or experiences worked very well for you and your loved one and what were some barriers to services (what did not work well for you).
4. Discussion: Before your friend or family member was diagnosed with cancer, what did you know about cancer? What did you know about CCMB? (15 min)	*Other questions to help guide the discussion:* • *Did you know where to find information about cancer?* • *Did you know about cancer screening? How to access it, who should be screened etc.* • *What have been some barriers to accessing/receiving information about cancer, prevention and risk factors? (knowledge, location, language, culture etc.)*
5. Brief Presentation (5 mins)	• Illustration of continuum of care from Screening to Follow up. • Define/describe the services along the continuum of care.

6. Discussion: Thinking about the continuum of care, what was the most difficult or problematic time (for you as the support person, for your loved one as the patient)? (25 mins)	**What was the most difficult or problematic time for you?** *Other questions to help guide the discussion:* • *What were some of the challenges your loved one faced in living with cancer?* • *What were some of the challenges you faced as a support person?* • *What were barriers to accessing/receiving services? (knowledge, location, language, culture etc.)* • *What kinds of things did your loved one rely on in order to live his/her life?* • *What did the family rely on?* • *Did you feel you and the patient had enough of, or enough access to these things?* • *Where did you get most of your information about cancer services and treatment?*
7. Discussion: What kinds of things helped you cope with the death of your loved one? (25 mins)	**What kinds of things helped you and your loved one cope?** *Other questions to help guide the discussion:* • *Who/what do you rely on for support right now?* • *What has/has not been helpful?* • *What other support services do you know about and/or use at CCMB? And in the community?* • *Talk about accessibility to specific programs at CCMB.*
8. What was the experience of transitioning from the treatment that was no longer effective for cancer to palliative care? (20 mins).	Some of these issues may have come up in the previous discussions. *For some of you it may have been that there was a period of time where the person received treatment like chemo and radiation therapy to help prolong life, or in some cases, there was hope there would be a cure, for the period where treatment was no longer working to palliative care.* *Other questions to help guide the discussion:* • *Were you well informed? Were you adequately informed about palliative care?* • *Were the caregivers clear?* • *Were you ready to hear this?* • *At what point did you know that the person was not going to recover?* • *Were you adequately supported?*

	• *Did you feel your family member was well informed?* • *Were there issues around pain management?* • *Spiritual care is term we use more and more these days – MB Health is interested in this etc. When you hear the word "spiritual care" what does that mean to you? Can we talk about your experiences with spiritual and psychosocial care? How do you think the system has or has not addressed these needs?* • *What more can your community and CCMB do to help people in this transition?* • *Note: you have to have a diagnosis with a life expectancy of less than 6 months and NOT on chemo to be eligible for palliative care (can be on radiation).* • *Where did the person die? At home, in hospital, in palliative care unit and in retrospect is that what you wanted? (and why didn't go way wanted – i.e. didn't have enough support etc.)*
9. If there were unlimited resources – what is most important?	*What message should I take back to CCMB that would help them in their strategic planning around services?* *For supportive care services, what would you want me to tell them.*
10. Summary and Wrap-up of Discussion (10 mins)	*Talk more about supportive care services – talk about specific programs offered – do they know about these programs? Which may apply to them? Are they using them? Why / why not?*
11. Conclusion	Thank you and explain how we will use this information

Urban Primary Care Oncology Network Focus Group Questions

- What are some of the major obstacles physicians encounter in referring their patients to CCMB?
- What are some of the major obstacles physicians encounter in getting information about their patients from CCMB?
- What are some of the major obstacles physicians encounter in staying involved with their patients' care once they are referred to CCMB?
- What can CCMB do to support the role of the Family Physician with primary health care patients?

Agenda Item	Questions for Discussion
1. Arrive, Greet, Signing, Collecting Consent Forms	
2. Introductions (5 mins)	I will introduce myself and ask each participant to introduce self and identify what area of the city they practice in and experience in treating cancer patients.
3. Discussion of Objectives (2 mins)	• Focus of our CHA is Accessibility. As a family physician as a gatekeeper to the speciality services of CCMB, we want to explore your experiences, concerns and suggestions.
4. What are some of the major obstacles physicians encounter in navigating and/or accessing the CCMB system? (30 mins)	• *What are some of the major obstacles physicians encounter in referring their patients to CCMB?* • *Ex: Written, telephone, getting patient appointments….* • *What are some of the major obstacles physicians encounter in getting information about their patients from CCMB?* • *What are some of the major obstacles physicians encounter in staying involved with their patients' care once they are referred to CCMB?*
5. What would enable physicians to be more involved in patient care? (20 mins)	• *Ex. Guidelines..* • *What can CCMB do to support the role of the Family Physician with primary health care patients*
6. What would you change about CCMB if you could? (20 mins)	• *Issues could relate to accessibility, communication, real partnerships etc.*
7. Summary and Wrap-up of Discussion (10 mins)	
8. Conclusion	Thank you and explain how we will use this information

QUESTIONS FOR KEY INFORMANT INTERVIEWS IN REGIONAL HEALTH AUTHORITIES

Begin with preamble about the Community Health Assessment something like as follows:

CancerCare Manitoba is undertaking a comprehensive Community Health Assessment as part of its strategic planning cycle. The purpose of this assessment is to gather information so that CCMB can plan for better programs and services. We are interviewing key stakeholders in each of the RHAs to discuss the theme of ***accessibility to services in their region throughout the cancer care continuum****, from prevention, early detection and screening, and diagnosis, through treatment, follow up, survivorship, recurrence, palliative care, and bereavement.*

Thank them for taking the time to talk with us. Tell them this interview should take about XXX minutes.

If you are recording the interview, ask permission and tell him/her what you will use tape for, that you will destroy it and when you will destroy it.

After you turn the tape on, thank them again and thank them for letting you tape the interview.

1. When you think about the ***accessibility to services throughout the cancer care continuum in your region,*** what do you see as the major strengths?

PROBES:
Prevention?
Early detection and screening?
At the time of diagnosis?
During treatment phase?
At follow-up phase?
For cancer survivors?
For those experience recurrent disease?
For palliative care, including bereavement?

2. When you think about the ***accessibility to services throughout the cancer care continuum in your region,*** what do you see as the major challenges/gaps?

PROBES:
Prevention?
Early detection and screening?
At the time of diagnosis?
During treatment phase?
At follow-up phase?
For cancer survivors?
For those experience recurrent disease?
For palliative care, including bereavement?

Now I would like to focus specifically on access to Supportive Care services.

The Canadian Strategy for Cancer Control defines Supportive Care as:

The provision of the necessary services as defined by those living with or affected by cancer to meet their physical, social, emotional, nutritional, informational, psychological, spiritual and practical needs throughout the spectrum of the cancer experience. These needs may occur during the diagnostic, treatment or follow up phases and encompass issues of survivorship, recurrence, palliative care, and bereavement. In one form or another, needs are applicable to all cancer patients, at all times during the cancer trajectory. (CSCC 2002)

3A. How is this kind of care (Supportive Care) delivered in your region specifically for people with cancer?

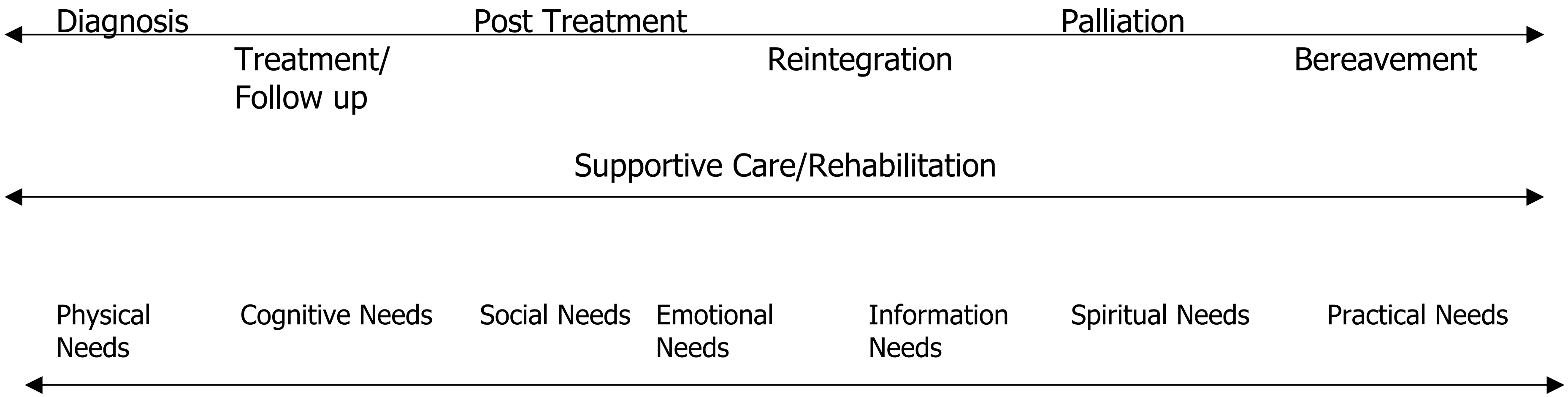
3B.Do individuals living with or affected by cancer (patients and families) in your health region have access to:

SERVICE	GENERALIST	CANCER SPECIFIC	OTHER COMMENTS
PSYCHOSOCIAL			
Social Work			
Psychologist			
Psychiatrist			
REGISTERED DIETITIAN			
REHABILITATION SERVICES:			
SLP (Speech Language Path)			
Occupational Therapist			
Physiotherapist			
SPIRITUAL CARE			
HOME CARE			
Adult			
Child			
PALLIATIVE CARE (specify services)			
PEER SUPPORT			
One on One			
Support groups • Peer Led • Professionally led			
OTHER SUPPORTIVE CARE (please specify)			

4. Are you aware of Supportive Care services provided by CCMB and how patient and families in your region access them? (Probe: ask them to specify which services they are aware of etc)

5. As a partner in cancer care delivery, how would you describe your RHA's relationship with CCMB – is there anything you would like to see changed in that relationship? How could we work together better to achieve our mutual goals?

Continuum of Cancer Care



The Canadian Strategy for Cancer Control defines *Supportive Care* as follows:

The provision of the necessary services as defined by those living with or affected by cancer to meet their physical, social, emotional, nutritional, informational, psychological, spiritual and practical needs throughout the spectrum of the cancer experience. These needs may occur during the diagnostic, treatment or follow up phases and encompass issues of survivorship, recurrence, palliative care, and bereavement. In one form or another, needs are applicable to all cancer patients, at all times during the cancer trajectory. (CSCC 2002)

2004 Community Health Assessment

Focus Group Participation
Consent Form

CancerCare Manitoba is required by Manitoba Health to undertake a comprehensive Community Health Assessment as part of its strategic planning cycle.

You are being asked to participate in a focus group for CancerCare Manitoba 2004 Community Health Assessment. The purpose of this assessment is to gather information about the experiences of people impacted by a diagnosis of cancer so that we can plan for better programs and services. The Focus Groups will discuss the theme of accessibility to services through the cancer care continuum.

You will be one of a group of about 8 to 12 participants who have been asked to discuss issues relating to their experiences with living with a cancer diagnosis, or caring for someone with a cancer diagnosis, or losing someone to cancer. The discussion will be led by a consultant who is working as a focus group facilitator for CancerCare Manitoba. The discussion is expected to last for about two hours.

Your participation in this discussion is completely voluntary, and you may change your mind at any time and decide not to participate. You may also choose not to answer any specific questions that may be asked. A decision to stop participation in a group or to decline to participate at all will not affect your health care in any way.

Being involved in this discussion is not anticipated to result in any known material benefit or risk to you. However, you may find yourself experiencing feelings related to your own or your loved one's cancer experience either during the focus group or afterward. If you wish, the focus group facilitators can refer you to appropriate and available resources for counselling. You are also welcome to contact the Department of Psychosocial Oncology at CancerCare Manitoba directly should you wish to discuss any feelings or issues that may have arisen for you by calling (204) 787 1325.

The information you give to us in the discussion will remain confidential. If we choose to reference any of your words used in the discussion, we will attribute them only to "a focus group participant". Your name, or any other identifying information, will not be used in a final report or in any other document available to the public.

Refreshments will be served at the discussion and you will be provided with a small compensation ($5.00) to help cover parking and/or travel costs. Other than this, you will not be paid or otherwise compensated for your participation.

If you have any questions, please call Patrick Saydak at CancerCare Manitoba at (204) 787-2148. If you would like to speak with someone not involved in the CancerCare Manitoba Community Health Assessment project, you may call Shirley Dzogen of Manitoba Health at (204) 786-7293.

Thank you for your participation.

CancerCare Manitoba Focus Group Consent Form

I have read the statement on the previous attached page regarding my participation in a focus group discussion regarding my experience with a diagnosis of cancer (either myself or a family member).

I understand that:

- My participation is voluntary.
- I may leave at any time.
- I may choose not to answer any of the questions asked of me.
- There are no anticipated harms or known benefits to me resulting from my participation in this focus group.
- Information I give during the discussion may be used in a report.
- My name will not be published.
- Other than a small payment ($5.00) to help with parking and/or transportation, I will not be paid or otherwise compensated for my participation.

☐ Yes ☐ No

I agree to participate in this focus group.

☐ Yes ☐ No

____

Printed Name of Participant

____

Signature of Participant

____

Date

LIST OF ACRONYMS

BMI	Body Mass Index
CAMRT	Canadian Association of Medical Radiation Technologists
CAPCA	Canadian Association of Provincial Cancer Agencies
CBC	Complete Blood Count
CCHS	Canadian Community Health Survey
CCMB	CancerCare Manitoba
CCP	Community Cancer Program
CCPN	Community Cancer Programs Network
CDC	Centers for Disease Control and Prevention
CHA	Community Health Assessment
CIO	Clinical Investigation Office
CNCR	Community Nurse Resource Centre
CTUMS	Canadian Tobacco Use Monitoring Survey
DSG	Disease Site Group
EFT	Equivalent Full Time
FOBT	Fecal Occult Blood Test
HIV	Human Immunodeficiency Virus
HPV	Human Papilloma Virus
LICO	Low Income Cut-Off
MANTRA	Manitoba Tobacco Reduction Alliance
MBSP	Manitoba Breast Screening Program
MCCN	Manitoba Cancer Care Network
MCCSP	Manitoba Cervical Cancer Screening Program
MCHP	Manitoba Centre for Health Policy
MICB	Manitoba Institute of Cell Biology

NAACCR	North American Association of Central Cancer Registries
NCI	National Cancer Institute
NOT	Not On Tobacco
NPHS	National Population Health Survey
PFSS	Patient and Family Support Services
PHCTF	Primary Health Care Transition Fund
PSA	Prostrate Specific Antigen
PYLL	Potential Years Of Life Lost
RHA	Regional Health Authority
SES	Socio-Economic Status
SLP	Speech Language Pathology
UPCON	Urban Primary Care Oncology Network
WRHA	Winnipeg Regional Health Authority

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