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SYSTEM PERFORMANCE REPORTS

Prostate Cancer Control in Canada

A SYSTEM PERFORMANCE SPOTLIGHT REPORT

NOVEMBER 2015

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The Canadian Partnership Against Cancer
1 University Avenue, Suite 300
Toronto, Ontario, Canada M5J 2P1

Tel: 416.915.9222
Toll free: 1.877.360.1665

partnershipagainstcancer.ca

For more information on this publication, please email:
info@systemperformance.ca

Media inquiries, please contact:
media@partnershipagainstcancer.ca

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PROSTATE CANCER EXPERT PANEL

Dr. Robert Bristow, Researcher, Princess Margaret Cancer Centre

Dr. Peter Chung, Assistant Professor and Director of the Fellowship Program, Department of Radiation Oncology, University of Toronto

Dr. James Dickinson, Professor, Family Medicine and Community Health Sciences, University of Calgary

Dr. Neil Fleshner, Head of Division of Urology, Princess Margaret Hospital

Dr. Martin Gleave, Director, Vancouver Prostate Centre

Mr. Winston Isaac, Prostate cancer patient

Ms. Leah Jamnicky, Registered Nurse, Canadian Nurses Association

Dr. Anne Katz, Adjunct Professor, Faculty of Health Sciences, School of Nursing, University of Manitoba

Dr. Verna Mai, Expert Lead, Population Health and Oncology, Canadian Partnership Against Cancer

Dr. Andrew Matthew, Clinical Psychologist, Department of Psychosocial Oncology and Palliative Care, Princess Margaret Hospital

Dr. Anthony Miller, Associate Director and Professor, Dalla Lana School of Public Health, University of Toronto

Ms. Wanda Miller, Prostate cancer patient family member

Dr. Tom Pickles, Professor and Radiation Oncologist, Radiation Oncology, BC Cancer Agency

Dr. Fred Saad, Professor and Chief of Urology and Director of G-U Oncology, University of Montreal Hospital Centres

Dr. Rob Siemens, Professor and Head, Department of Urology, Queen's University

Dr. John Srigley, Chief of Laboratory Medicine, Credit Valley Hospital

Mr. Jim Sullivan, Prostate cancer patient

Dr. Kiril Trpkov, Associate Professor and Pathologist, Department of Pathology and Laboratory Medicine, Calgary Laboratory Services and University of Calgary

Dr. Peter Venner, Medical Oncologist, University of Alberta

Dr. Richard Wassersug, Prostate cancer patient and Adjunct Professor, Department Urologic Sciences, University of British Columbia

SYSTEM PERFORMANCE STEERING COMMITTEE

(includes past* and present members)

Dr. Monica Behl, Vice-President, Medical Services and Senior Medical Officer, Saskatchewan Cancer Agency

Dr. Andy Coldman*, former Vice-President, Population Oncology, BC Cancer Agency

Dr. Peter Craighead*, Medical Director, Tom Baker Cancer Centre, and Chair, Department of Oncology, University of Calgary

Dr. Carman Giacomantonio*, former Chief Medical Director, Cancer Care Nova Scotia

Dr. Marc Kerba, Radiation Oncologist, Tom Baker Cancer Centre, Alberta

Dr. Hagen Kennecke, Medical Oncologist and Professional Practice Leader, BC Cancer Agency

Dr. Eshwar Kumar, Co-Chief Executive Officer, New Brunswick Department of Health, New Brunswick Cancer Network

Dr. Jean Latreille, Directeur, Direction québécoise de cancérologie, Ministère de la Santé et des Services sociaux (Québec)

Dr. Robin McLeod, Vice-President, Clinical Programs and Quality Initiatives, Cancer Care Ontario

Dr. Sri Navaratnam, President and Chief Executive Officer, CancerCare Manitoba

Ms. Elaine Warren, Program Director, Cancer Care Program, Eastern Health

SYSTEM PERFORMANCE TECHNICAL WORKING GROUP

Ms. Rebecca Anas, Director, Cancer Quality Council, Cancer Care Ontario

Dr. Grlica Bolesnikov, Co-ordinator, Quality Management and Accountability, New Brunswick Department of Health, New Brunswick Cancer Network

Ms. Élise Cabanne, Agente de recherche et de planification socio-économique, Direction québécoise de cancérologie, Ministère de la Santé et des Services sociaux (Québec)

Ms. Farah McCrate, Clinical Epidemiologist, Cancer Care Program, Eastern Health

Ms. Colleen McGahan, Biostatistical Lead, Cancer Surveillance and Outcomes, Population Oncology, BC Cancer Agency

Dr. Lorraine Shack, Director, Surveillance and Reporting, Alberta Health Services

Ms. Heather Stuart-Panko, Director, Cancer Registry, Saskatchewan Cancer Agency

Dr. Donna Turner, Epidemiologist and Provincial Director, Population Oncology, CancerCare Manitoba

Mr. Gordon Walsh, Epidemiologist, Surveillance and Epidemiology Unit, Cancer Care Nova Scotia

Ms. Kim Vriends, Manager, Prince Edward Island Cancer Registry

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Executive Summary

Prostate cancer is the most commonly diagnosed cancer affecting Canadian men. One in eight men will be diagnosed with this disease in their lifetime.[1] Men who receive a diagnosis of prostate cancer face considerable anxiety, especially when it comes to their treatment options. This is exacerbated by the fact that while many prostate cancer tumours are slow-growing and may not require immediate treatment, others can be quite aggressive requiring prompt surgery and/or radiation and systemic therapy.

For this and other reasons, caring for men with prostate cancer is challenging. While surgery, chemotherapy, radiation and hormonal therapy can all be effective in targeting the tumour, the potential side effects of treatment, such as urinary incontinence and sexual dysfunction can significantly affect men's quality of life, even as they survive their disease.

Research has improved the understanding of factors that help inform choices about treatment. Clinicians are better able to predict how likely it is that a specific cancer will respond to treatment, and to determine men's risk for recurrence of the disease after treatment. But despite these and other advances, prostate cancer is still the third leading cause of cancer deaths in Canada.[1]

Until now, there had been little comparable pan-Canadian information available on how well cancer systems across the country are doing with regards to diagnosing, treating and providing follow-up and supportive care to prostate cancer patients. The 2015 *Prostate Cancer Control in Canada: A System Performance Spotlight Report* sheds light on specific topics relevant to the control and management of prostate cancer across the country. It also includes the Special Feature, *Reflections of Canadian Men with Prostate Cancer*, and considers the person-centred perspective throughout the dimensions of the cancer control continuum—from diagnosis and treatment through survivorship and palliative care.

This report is organized along the dimensions of the cancer control continuum. Indicator results are generally compared by province or territory, age group and sex. Where appropriate, comparisons with international jurisdictions are discussed, highlighting potential best practices and benchmarks. Commentary on emerging evidence or studies either nationally or internationally is also provided.

The report was produced in close collaboration with partners at the national, provincial and territorial levels. Provincial cancer agencies and programs provided the data needed to develop and calculate many of the indicators included in the report. Our national partners at Statistics Canada, the Canadian Institute for Health Information, the National Research Corporation Canada, and the Canadian Cancer Research Alliance also contributed data and/or analysis.

Subject matter expertise was provided by the Prostate Cancer Expert Panel comprising clinicians, epidemiologists and researchers with specific expertise in various aspects of prostate cancer—from population health to pathology, and from radiation oncology to urology and psychology. A number of prostate cancer survivors and family members from across the country brought their own unique experiences and perspectives to the panel's deliberations.

Results Highlights

Burden and Outcomes

- Prostate cancer incidence rates appear to have declined slightly since 1992, although the decline is not statistically significant. Prostate cancer incidence was highest in men aged 65-79, which may reflect higher rates of prostate-specific antigen (PSA) testing for men in this age group.
- Mortality rates, on the other hand, have declined significantly since 1992. Mortality was highest in men over the age of 80.
- The causes of prostate cancer are not fully understood. To date, the only well-established risk factors are age, family history and ethnicity.
- Currently, there is a lack of consensus on the role of PSA testing in reducing prostate cancer mortality and wide variation in the interpretation of existing evidence. As such, no population screening programs for prostate cancer exist in Canada. Opportunistic testing is often offered. Several Canadian organizations recommend using an informed decision-making approach to PSA testing, in which each man's preferences and risk profile are considered and he makes an informed choice given the potential harms and benefits.
- The latest survey results suggest that, depending on the province or territory, 15.8% to 35.5% of men aged 35 and older self-reported undergoing a PSA test in the last year. PSA testing was more common among older men aged 65-79. In this age group, 50.4% of men reported undergoing a PSA test in the last year, compared to 34.2% of those aged 50-64.

Diagnosis and Staging

- Prostate cancer was most commonly diagnosed at Stage II and least commonly at Stage IV.
- Most men with prostate cancer were categorized as low- or intermediate-risk according to risk stratification guidelines. Overall, the proportion of men with localized prostate cancer who had higher-risk disease at diagnosis increased with increasing age at diagnosis. Most (72.0%) men over age 80 were classified as high-risk compared to a much smaller percentage (12.0%) of those in the 35-49 age group.
- There was interprovincial variation in the age-standardized incidence rates by risk level. Incidence rates for low-risk disease ranged from the 22.2 cases in British Columbia to 124.6 cases (both per 100,000) in Prince Edward Island. For high-risk disease, the incidence rates ranged from 44.5 cases in New Brunswick to 88.5 cases (both per 100,000) in Manitoba. At least some of this variation could be due to data inconsistencies between provinces in the prognostic information used to derive risk.

Treatment

- In the 2010 diagnosis year, surgical resection by radical prostatectomy was the most commonly used treatment for men with low-risk prostate cancer, followed by radiation therapy.
- Because of the often indolent nature of prostate cancer and the potential for debilitating side effects caused by treatment, the cancer control community is increasingly concerned about over-diagnosis and over-

treatment.[2] Alternatives to immediate treatment, including active surveillance and watchful waiting until the disease progresses or symptoms become worse, are increasingly used.[2-5] The data show that, depending on the province, between 41.5% and 76.4% of low-risk patients had no record of treatment, and could be assumed to be on active surveillance or watchful waiting.

- In 2014, there was wide interprovincial variation in wait times for prostate cancer surgery and radiation therapy. The 90th percentile wait time for surgery (from booking date to date of surgery) ranged from 59 days in New Brunswick to 105 days in Saskatchewan. The 90th percentile wait time for radiation therapy (from ready-to-treat to start of treatment) ranged from 18 days in Ontario to 40 days in British Columbia. Prostate cancer patients waited longer for radiation therapy than patients with breast, colorectal or lung cancers in all reporting provinces.
- Radical prostatectomy (RP) is one of the standard treatments for patients with localized prostate cancer and can be performed using either an open or laparoscopic approach. There was much variation across provinces in the type of surgical approach used for men with prostate cancer. In Saskatchewan and Alberta, most RPs were performed using a laparoscopic approach, while in British Columbia, Manitoba, Ontario, Quebec and New Brunswick, most RPs were performed using an open approach. In Prince Edward Island, Nova Scotia and Newfoundland and Labrador, all RPs were done using an open approach. The choice of procedure, along with the surgeon's level of experience with the procedure, can have implications on surgical and patient outcomes.

Person-Centred Perspective

- Results from the Ambulatory Oncology Patient Satisfaction Survey from several provinces indicated that many prostate cancer patients may have unmet needs related to emotional support and getting enough information on their care. Responses to questions within these dimensions suggest that prostate cancer patients may not always get needed referrals for help with anxiety and fears and may not always be given enough information on possible physical, emotional and practical side effects.
- While many men with prostate cancer are long-term survivors, some develop advanced disease and experience pain from bone metastasis. Data on radiation therapy use at the end of life among men who died from prostate cancer suggest that palliative radiation therapy for symptom management (including pain) may be underused in Canada. Among men who died from prostate cancer in 2011, fewer than 40% received radiation therapy during the last year of their lives in all reporting provinces.
- While many men with prostate cancer would prefer to die at home with adequate supports, of those who died, only a minority died at home. Data show that the proportion of prostate cancer deaths that occurred at home varied considerably by province, ranging from 0% to 30.4%. While issues related to data definition may be involved here, the size of the differences between provinces suggests there may be unmet needs. More can be done to ensure that men who are dying from prostate cancer have adequate resources and supports so they can spend their last days in their setting of choice.

Research

- Providing adequate support for research directed to specific cancers helps to advance the state of the science and to accelerate the translation of discoveries for the benefit of patients. In 2012, $541.6M was invested in cancer research in Canada; of that, more than half ($286.2M) was invested in cancer site-specific research, with $37.9M (13.2%) invested directly to scientists studying prostate cancer. While this was proportionately less than the site-specific research investment for breast cancer (26.5%), it was double the investments for research into lung cancer (6.7%) and colorectal cancer (6.7%). The major investments were in research related to *Early detection, diagnosis and prognosis* and *Treatment*; this accounted for 55.1% of the overall funding from the top five funders in 2012.
- In 2013, the ratio of patients enrolled in clinical trials to cancer incident cases for prostate cancer was 0.032. For adults with the four most common disease sites, the same ratio ranged from 0.012 for lung cancer to 0.050 for breast cancer. Provincially, the clinical trial participation ratio for prostate cancer ranged from 0.019 in Nova Scotia to 0.052 in Saskatchewan.

SPECIAL FEATURE

Reflections of Canadian Men with Prostate Cancer

The special feature found within the *Person-Centred Perspective* chapter of this report contains highlights from a series of conversations held with Canadian men from six provinces previously diagnosed with and treated for prostate cancer. Several family members who supported their loved ones during this experience also participated.

Participants talked about how they felt when they received the prostate cancer diagnosis and what it was like to undergo treatment such as surgery, radiation therapy or hormonal therapy. Their comments, which appear in the special feature as well as throughout this report, cover a range of topics including: how involved they felt when making decisions about their treatment; examples of helpful and not-so-helpful interactions with their care providers; a discussion about the challenges of living with the physical and emotional effects of treatment; and how more support for themselves and their family members would have been appreciated throughout the prostate cancer journey.

Looking Ahead

We had three goals in mind when planning and preparing for this spotlight report on prostate cancer control in Canada: to update knowledge about prostate cancer control across the cancer journey; measure how well Canada's health care systems are doing in meeting the needs of prostate cancer patients and their families; and to explore the experiences and perspectives of Canadians affected by prostate cancer.

Because prostate cancer is most commonly diagnosed at an older age, as the baby boom population in Canada moves into its 70s and 80s, we expect the number of prostate cancer cases to increase sharply in the coming years. The Canadian Cancer Society projects that, by 2030, the number of prostate cancer patients diagnosed each year will increase to 42,000 from the current 24,000.[1] The health care system must start preparing to meet that challenge now. But as we prepare to do more, we must also do less of what the evidence shows is unnecessary and/or harmful.

Progress in the diagnosis and treatment of prostate cancer is being made on many fronts, especially as our understanding of this disease increases:

- New methods and models are being researched and developed to guide early detection for prostate cancer. For example, mathematical algorithms are being explored as a way to help guide decision-making by clinicians around prostate cancer risk.
- Several initiatives led or funded by the Canadian Partnership Against Cancer are under way, aimed at improving how cancer care systems identify and respond to prostate cancer patients' needs for information and emotional support. For example, the *Experiences of Cancer Patients in Transition* study will help us better understand the challenges that people with cancer—including those with prostate cancer—face after primary treatment ends, and explore what system-related improvements could be made to address those challenges.
- Finally, a new health information and biosample database built through the Canadian Partnership for Tomorrow Project (CPTP) will allow researchers to explore how factors such as genetics, behaviour, environment and lifestyle contribute to the development of cancer and other chronic diseases. The hope is that knowledge gained by this long-term study will yield new interventions aimed at preventing prostate and other cancers.

Prostate cancers range from being slow-growing and non-life-threatening to aggressive and deadly. But while the disease and its evidence-based management strategies are diverse, we should understand why we see a high level of inconsistency in the experiences of prostate cancer patients, particularly when they have similar stage and risk levels.

As stewards of a Canadian health care system that places a high value on equitable, high-quality care, we need to better understand these inconsistencies and listen more attentively to patients and their families who are more than willing to share their first-hand experiences. This will allow us to develop strategies aimed at ensuring that all men with prostate cancer receive appropriate and evidence-based diagnosis, treatment and follow-up care—regardless of where they live and who is providing their care.

The Canadian Partnership Against Cancer will continue to work with the cancer control community and partners across the country towards reducing the incidence of prostate cancer, lessening the chance that men will die from the disease, and encouraging system changes that will improve patients' quality of life before, during and after treatment.

About the Canadian Partnership Against Cancer

*The **Canadian Partnership Against Cancer** (the Partnership) was created in 2007 by the federal government with funding through Health Canada. Since then, our primary mandate has been to move Canada's cancer control strategy into action and to help it succeed through coordinated system-level change across the full cancer care continuum—from prevention and treatment through survivorship and palliative care.*

We work closely with national, provincial and territorial partners to stimulate and support the generation of knowledge about cancer and cancer control, and to promote the exchange and uptake of best practices across the country to help those most affected by cancer. The outcomes we collectively work towards are reduced rates of cancer incidence and mortality, and a better quality of life for those affected by cancer.

About the System Performance Initiative

The Partnership's System Performance Initiative is a collective national effort to identify aspects of the cancer control system that need to be measured or are under-measured, to define performance indicators, to collect and analyze valid and comparable data, and to report findings in an integrated manner that allows for synthesis of results and interpretation of patterns towards informing system improvements.

Findings are published in a series of reports targeted at the cancer control community, in particular provincial cancer agencies, departments or ministries of health, clinicians, researchers and cancer patients and their families. Other ways that pan-Canadian system performance information is disseminated include: publishing peer-reviewed articles in relevant journals; delivering presentations and workshops at conferences; and most recently through a specialized web application. Such knowledge is intended to aid policy-makers, health planners, researchers and clinicians in identifying best practices and opportunities for quality improvements in cancer control across Canada.

System Performance information, including previous reports, can be accessed at systemperformance.ca.

About This Publication

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The ***Prostate Cancer Control in Canada: A System Performance Spotlight Report*** *features the most recently available pan-Canadian data on the burden of prostate cancer, along with findings on risk factors, early detection, diagnosis, treatment, research and long-term outcomes.*

The report contains a chapter on the person-centred perspective, which includes new data on patient satisfaction with prostate cancer care, as well as the Special Feature, *Reflections of Canadian Men with Prostate Cancer*. This special feature contains findings from several focus groups held across the country in late 2014 to ask Canadian men with prostate cancer and their families about their experiences with the disease and the health care system. These findings, along with direct quotations, are inserted throughout the chapters of the report as a complement to the quantitative data.

This publication follows two previous system performance spotlight reports that focused on breast cancer (2012) and lung cancer (2011), and a special feature on colorectal cancer that appeared in our *2010 Cancer System Performance Report*. These can be accessed at systemperformance.ca.

Why Report on Prostate Cancer?

One has only to consider the statistics to understand the real-world impact prostate cancer is having and will continue to have on Canadians themselves and on our health care system:

- Four thousand Canadian men die of prostate cancer each year.
- More than 176,000 men—fathers, husbands, brothers, sons, friends, neighbours and colleagues—who have already been diagnosed with the disease are currently living with it.
- While the incidence of prostate cancer has declined slightly in the past four years, it is still the most common cancer affecting Canadian men, expected to account for 24% of new cancer cases and 10% of cancer deaths in men in 2015. This translates to an estimated 24,000 new cases each year, which is projected to grow to over 42,000 new cases annually by 2030.[1]

The report was prepared and is being released in the context of those statistics. The report provides data on several relevant topics in the diagnosis and management of prostate cancer, including:

- variations in rates of PSA testing by province and how that variation compares to stage-specific incidence and risk distribution, which helps assess the impact of PSA testing on follow-up care and subsequent outcomes;
- patterns of prostate cancer treatment across the country stratified by stage, risk and age, and particularly on the rate of active surveillance or watchful waiting versus curative treatment;
- variations in the patterns of prostate cancer surgical care across the country along with comparisons to outcomes will provide

important evaluative information on the different treatment approaches; and

- acknowledging the growing movement within the cancer control system to ensure that care is driven by and centered on the needs and circumstances of the patients themselves.

This report presents findings from a series of focus groups held earlier this year in several Canadian provinces where men with prostate cancer and their families were asked to share their experiences and perspectives, both with the disease and with the health care system.

How the Report Was Informed

The report was produced in close collaboration with partners at the national, provincial and territorial levels. It was further informed by consultations with subject matter experts and knowledge leaders from across the country.

This included a dedicated Prostate Cancer Expert Panel. This advisory group comprised clinicians, epidemiologists and researchers with specific expertise in various aspects of prostate cancer—from population health to pathology, and from radiation oncology to urology and psychology. A number of prostate cancer survivors and family members from across the country brought their own experiences and perspectives to the panel's deliberations. The Expert Panel was consulted on the methodology and interpretation of results (see the *Acknowledgements* section for a listing of members).

At the provincial level, the Steering Committee and Technical Working Group for System Performance, each comprising locally-appointed representatives from all 10 Canadian provinces, guided the planning and development of the report. Provincial cancer agencies and programs provided data from each of their jurisdictions, which were needed to calculate and develop most indicators in the report—particularly in the domains of diagnosis, treatment, research and person-centred perspective. Detailed data specifications and calculation methodologies were developed and used to collect and analyze data at the provincial cancer agency level to ensure consistency and comparability across provinces.

At the national level, the Canadian Partnership Against Cancer (the Partnership) worked with data maintained by Statistics Canada including the Canadian Cancer Registry, the National Vital Statistics Database, and the Canadian Community Health Survey (CCHS). The Partnership also worked with the Canadian Institute for Health Information (CIHI) to access and analyze data on prostatectomy rates and the use of open versus laparoscopic and robotic procedures based on data and analyses by CIHI.

The National Research Corporation Canada provided access to results from the Ambulatory Oncology Patient Satisfaction Survey, which informed patient satisfaction indicators in the dimension of person-centred perspective and end-of-life care. Data on prostate cancer research investment were provided by the Canadian Cancer Research Alliance (CCRA) which, together with the Partnership, guides the coordination and continuation of cancer research funding across Canada.

Prostate Cancer Canada provided input and support towards the focus groups and interviews conducted in the fall of 2014 that included residents from six Canadian provinces. The aim of the focus groups was to provide some insights into prostate cancer patients' and survivors' experiences through their cancer journey—from diagnosis and treatment, to post-cancer care and survivorship.

How the Report is Organized

The report covers key areas relevant to prostate cancer. An introduction to each chapter provides background on the specific area being covered, describes the data sources used, and provides other relevant information. This introduction is followed by a section including selected quotes from Canadian men who took part in a series of focus groups conducted in the fall of 2014 to gather their experiences and perspectives with the disease and the health care system. Data for each indicator are then presented in text, along with findings expressed either graphically, in tabular format or both. Each chapter includes the following common elements:

- **What are we measuring and why?** This section describes each indicator involved and provides the rationale for reporting on it. Relevant contextual information is also supplied where appropriate. Detailed information on data specifications and calculation methodology for each indicator is available at the Partnership's System Performance web application (systemperformance.ca).
- **What are the results?** This section provides a narrative description of the findings, highlighting notable patterns and trends. It also suggests any specific methodological considerations that should be taken into account when interpreting figures and tables.
- **What do the results mean?** This section discusses the patterns and trends that were observed—specifically what they imply for target audiences and patient outcomes. Where relevant, the section provides similar metrics from international jurisdictions and mentions national or international targets that have been established related to these indicators.
- **What else do we know?** The report provides relevant details and commentary related to the indicator results or cancer domain under discussion, which can help create a broader context for the indicator results. These are drawn from regional, national and/or international sources.
- **Data and measurement considerations** This section discusses relevant facts about data sources and broad methodological considerations (e.g., limitations) which readers should take into account when evaluating and interpreting the figures.

Special Feature: *Reflections of Canadian Men with Prostate Cancer* Found within the *Person-Centred Perspective* chapter, this section contains highlights from a series of conversations held across six provinces with Canadian men previously diagnosed with and treated for prostate cancer. Several family members who supported their loved ones during this experience also participated.

1. Burden and Outcomes

1. Burden and Outcomes

Prostate cancer is the most commonly diagnosed cancer among men in Canada, with 24,000 new cases expected in 2015, and it is the third leading cause of cancer death among men. One in eight men will be diagnosed with prostate cancer in their lifetime.[1]

The only well-established risk factors for prostate cancer are non-modifiable: age, family history and ethnicity.[6] As more men in Canada move into the older age groups, the number of prostate cancer cases is expected to increase.[1] But there is new evidence that maintaining a healthy body weight could reduce the risk of developing advanced prostate cancer and that higher levels of physical activity may impact survival and reduce mortality in men diagnosed with prostate cancer.[7, 8] While much contradictory evidence has been published about modifiable risk factors for prostate cancer, further research is needed to establish these links and to identify other possible risk factors.

No organized population-based screening programs for prostate cancer exist anywhere in Canada; however, many doctors continue to recommend prostate-specific antigen (PSA) testing, often in conjunction with a digital rectal examination (DRE), for patients on an individual case basis. The PSA test has been a commonly used screening test for prostate cancer since the early 1990s. Currently, there is a lack of consensus on the role of PSA testing in reducing prostate cancer mortality and wide variation in the interpretation of existing evidence. This has resulted in multiple contrasting guidelines published by various Canadian organizations, including the Canadian Task Force on Preventive Health Care, Prostate Cancer Canada and the Canadian Urological Association, on whether and when men should be tested. Though none of these organizations call for population-based screening programs using PSA testing, much of the lack of agreement centres around whether PSA testing should be used to establish a baseline risk for prostate cancer for men in their 40s and for monitoring men at higher risk of developing prostate cancer.[9-11] Data in this report show that, depending on the province or territory, anywhere from 15.8% to 35.5% of men aged 35 and older self-reported undergoing at least one PSA test in the past year (Figure 1.5).

This chapter presents age-standardized incidence and mortality rates for prostate cancer in Canada, information on risk factors for prostate cancer and self-reported rates of PSA testing. The data presented are restricted to men aged 35 and older, as prostate cancer is extremely rare in men under age 35. The chapter begins with reflections from some men with prostate cancer on how their journey began and the specific role of PSA testing and DRE in their diagnosis.

Reflections of Men with Prostate Cancer

This section presents common themes identified from focus groups and interviews conducted across Canada with prostate cancer patients, survivors and caregivers about their experience with prostate cancer. The quotes listed here are intended to illustrate the views and experiences of those focus group participants based on specific questions posed to them and should not be taken as generalizable findings. Many of the men were recruited mostly through their previous participation in prostate cancer support groups. The perspectives of men diagnosed with prostate cancer who did not receive treatment are not reflected here.[a]

For many of the men who took part in the prostate cancer focus groups and interviews, their cancer journey began with a PSA test and/or DRE.

"[For many years] I've been having … annual check-ups which included PSA and everything was routine, standard. The PSA [was] always down in the 1 and 2, and that kind of level, down in that range. Nobody ever raised any issues about whether or not the PSA was a matter of concern. And then in 2012, I had my annual check-up and he did the digital examination, and the family physician said 'something is there that I think you should have checked out.'"
focus group participant from Manitoba

While several of the participants were aware of the controversy surrounding PSA testing, many men wanted to discuss the value of early and routine surveillance. Some also talked about wishing that they had been more proactive in discussing screening tests with their doctors earlier. Because all the participants had been diagnosed with and were treated for prostate cancer, these perspectives naturally reflect their individual experience (i.e., a PSA test was instrumental in diagnosing their cancer).

"GPs are reluctant to do PSAs or DREs—especially the young ones … [But] that's all we have at this point … until there's something better, we've got to make sure that more people that are susceptible to the disease are getting tested early." **province not identified**

"If I could go back in time, I would ask the doctor to do this test and not only expect him to do it." **from Quebec**

"Just try to educate yourself and also be proactive with your doctors." **province not identified**

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[a] For a more complete description of findings and the methods used, see the Special Feature in Chapter 4: *Person-Centred Perspective*.

Few men who took part in the focus groups talked about prevention and risk factors for prostate cancer, as specific questions on this topic were not asked. But for several, a family history of cancer made their own diagnosis less of a surprise.

"I had a brother who died of prostate cancer at a relatively early age, so I'm not surprised, I'm 74. I know this is a disease … [that it's] just a game of probability. Eventually the probabilities catch up to you. And so … I honestly can say I was not shocked in the least." **from Manitoba**

Most participants spoke of discussions with their physicians, during which they were told that they would likely have many years of life ahead of them and that chances were good that they would die of something completely unrelated to prostate cancer.

"…He said [in effect], 'You still have lots of runway in front of you, you're a young man and chances are that you'll die from something else.' So I don't worry about it." **from Ontario**

"I would tell [other men] don't panic. I know people who were diagnosed 25 years ago [and] are perfectly healthy today … It's not the end of the world, there's all sorts of stuff that gives you lots of hope and a good reason to be optimistic." **from Manitoba**

"[When I was diagnosed], my urologist told me, 'With the state that you're at right now, with all the information we have, you could take out a 10-year GIC and be able to cash it.' I said, 'I'll hold you to that.'" **from New Brunswick**

Long-Term Outcomes

What are we measuring and why?

This section presents age-standardized incidence and mortality rates for prostate cancer in men aged 35 and older in the general population. The findings are reported over time, by age and by province.

- The annual number of new prostate cancer cases in Canada is expected to nearly double in the next 15 years, from 24,000 to over 42,000 by 2028-2032, largely due to Canada's changing demographic profile and the aging of the Canadian population. Prostate cancer will continue to be one of the four major cancer types in Canada over this time period (along with breast, lung and colorectal cancers).[1] While demographics affect the overall number of cases diagnosed, *age-standardized incidence rates* allow us to identify whether the proportion of men diagnosed with prostate cancer is changing, controlling for the age and size of the male population.

What are the results?

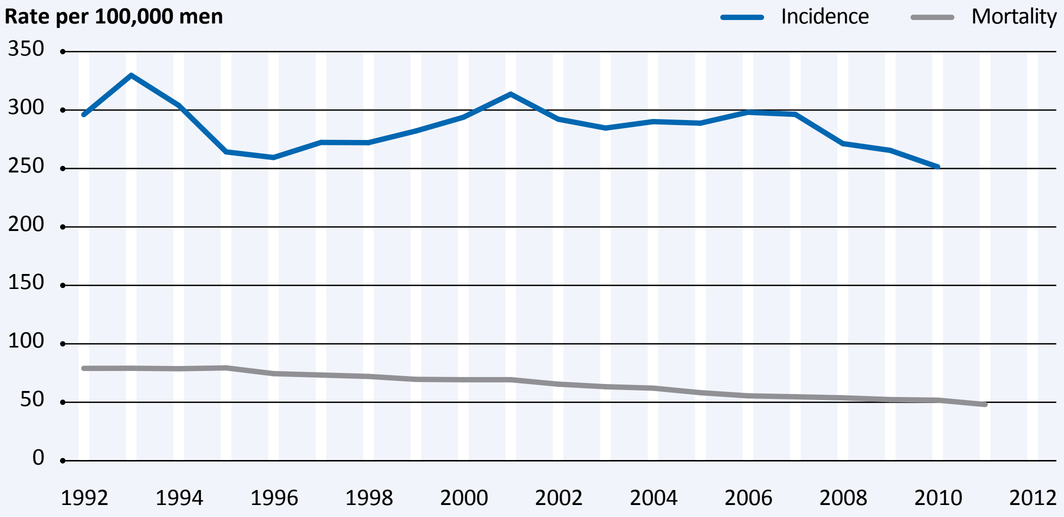
- Between 1992 and 2010, there was a slight, non-significant decrease in the age-standardized incidence rate (ASIR) for prostate cancer in Canadian men aged 35 and older, from 296.1 cases per 100,000 in 1992 to 251.4 cases per 100,000 in 2010 (annual percent change = -0.45) (Figure 1.1).
- The incidence of prostate cancer peaked sharply in 1993 (329.7 cases per 100,000) and again in 2001 (313.6 cases per 100,000) (Figure 1.1).
- The relative difference in ASIR (for men aged 35 and older) between the lowest and highest provinces was 56.8%. The ASIR ranged from 218.7 cases per 100,000 in Quebec to 343.0 cases per 100,000 in New Brunswick (based on 2008-2010 data) (Figure 1.2).
- The age-standardized mortality rate (ASMR) for prostate cancer in men aged 35 and older decreased significantly, from 79.0 deaths per 100,000 in 1992 to 48.1 deaths per 100,000 in 2011 (annual percent change = -2.69) (Figure 1.1).
- The ASMR in men aged 35 and older ranged from 45.9 deaths per 100,000 in Quebec to 64.6 deaths per 100,000 in Saskatchewan, a relative difference of 40.7% (based on 2009-2011 data) (Figure 1.3).
- Prostate cancer ASIRs increased sharply with age, from 12.9 cases per 100,000 in the 35-49 age group to 662.5 cases per 100,000 in the 65-79 age group (based on 2008-2010 data). There was a slight decline in ASIR in the 80+ age group. ASMRs, on the other hand, were highest among men in the 80+ age group, accounting for 468.9 deaths per 100,000 (Figure 1.4).

Data and measurement considerations

- Age-standardized incidence rate (ASIR) and age-standardized mortality rate (ASMR): crude incidence and mortality rates for prostate cancer were calculated for men aged 35 and older, standardized to the age structure of the 2011 Canadian population (aged ≥ 35).
- Incidence and mortality data by age group were also age-standardized to account for any differences that might exist due to the relatively wide age range within each age group.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

FIGURE 1.1

Incidence and mortality rates for prostate cancer (men aged ≥ 35), Canada, age-standardized to the 2011 population — from 1992 to 2011



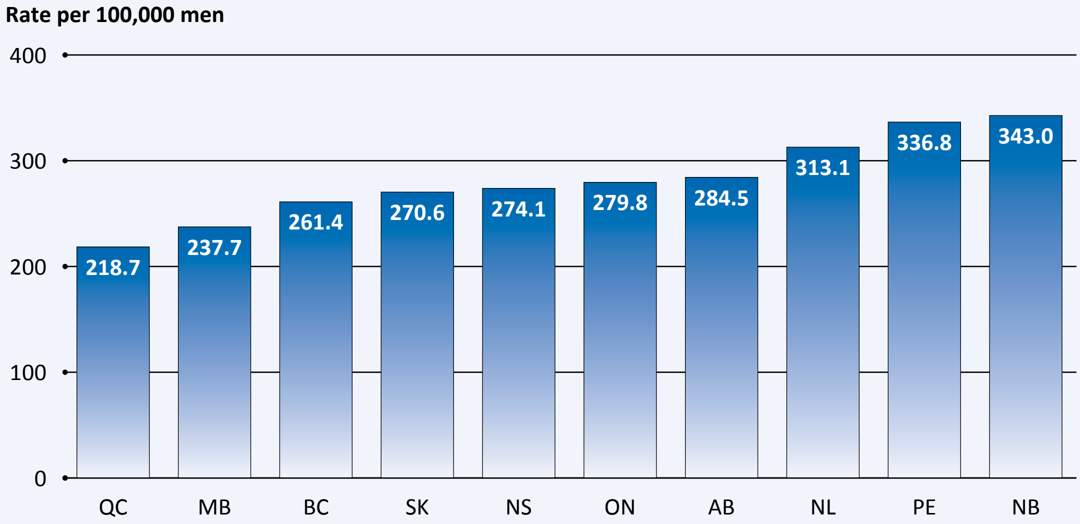
Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

Peaks in Prostate Cancer Incidence

- In Canada, the incidence of prostate cancer spiked in 1993 and again in 2001. The 1993 peak was likely due to the introduction of prostate-specific antigen (PSA) testing, which became widely used in the early 1990s and increased the detection of prostate cancer; the 2001 peak might have been due to increased awareness and PSA testing activity.[12-14] Additionally, the introduction of extended biopsy practice (increasing the number of cores sampled per biopsy from 6-8 to 10 or more), which took place around the year 2000, may have also contributed to the second peak in the detection of prostate cancer.[15]
- Similar peaks in incidence were seen internationally. Those in the United States (in both the early 1990s and early 2000s) and in Australia (in the early 1990s only) were higher than peaks that occurred in Canada; however, European countries did not reach the incidence levels Canada did at these points in time.[16, 17]

FIGURE 1.2

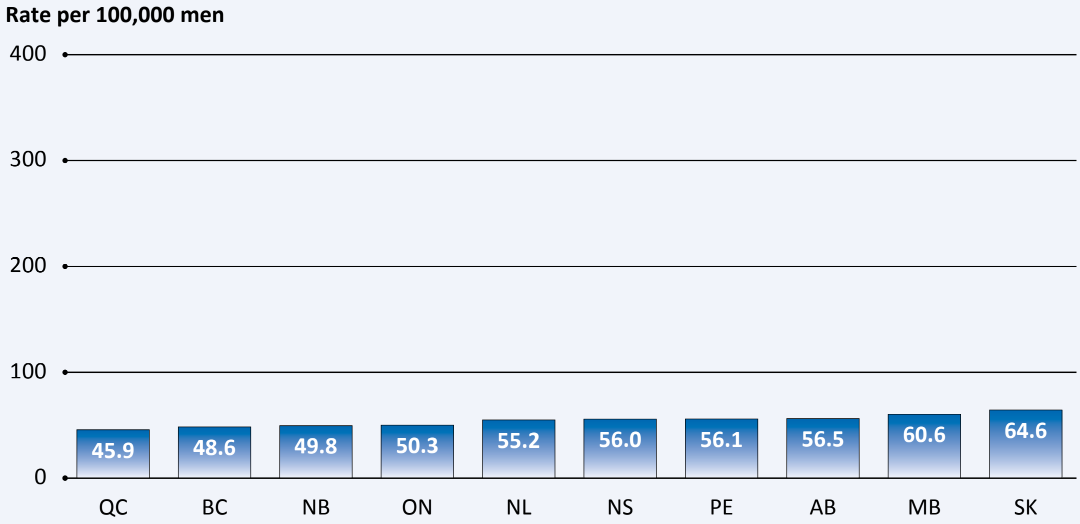
Incidence rates for prostate cancer (men aged ≥ 35), by province, age-standardized to the 2011 population — 2008-2010 combined



Data source: Statistics Canada, Canadian Cancer Registry.

FIGURE 1.3

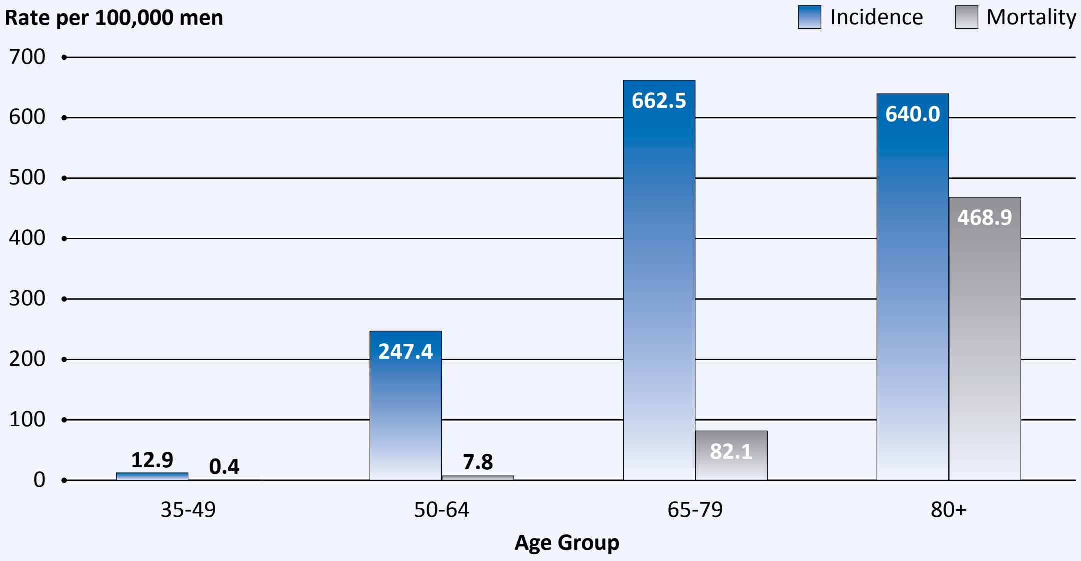
Mortality rates for prostate cancer (men aged ≥ 35), by province, age-standardized to the 2011 population — 2009-2011 combined



Data source: Statistics Canada, Vital Statistics Death Database.

FIGURE 1.4

Incidence† and mortality†† rates for prostate cancer (men aged ≥ 35), by age group, Canada, age-standardized to the 2011 population — 2008-2010 combined and 2009-2011 combined



† Incidence data: 2008-2010 combined.

†† Mortality data: 2009-2011 combined.

Data source: Statistics Canada, Canadian Cancer Registry and Vital Statistics Death Database.

What do the results mean?

- Incidence rates of prostate cancer in men aged 35 and older appear to be decreasing slightly in Canada after rising dramatically in the late 1980s and early 1990s—a pattern also seen in the United States and Australia. However, rates are increasing in the United Kingdom and other parts of Europe. This is likely due to differences in PSA testing practices and the more gradual adoption of PSA testing in the United Kingdom and Europe.[12, 18]
- Because no organized screening programs for prostate cancer currently exist in Canada, funding of PSA testing varies across provinces and territories.[19] The resulting differences in PSA testing practices may impact provincial incidence rates. This is because such testing has clearly been shown to increase the detection of early stage or low-risk prostate cancers that would not necessarily impact men's health if left untreated.[20, 21] This testing also results in a reduction of late-stage cancers, which is reflected in lower ASIRs for Stage III and IV disease relative to earlier stages, as reported in the *Diagnosis and Staging* chapter of this report.
- Prostate cancer incidence rates were highest in men aged 65-79 years of age, which reflects the high rates of self-reported PSA testing for men in this age group and the resulting detection of prostate cancers (see the *PSA Testing* section of this chapter). By contrast, the prostate cancer mortality rate was substantially higher in the 80+ age group than in younger age groups. This is likely due to the fact that prostate cancer is often a slow-growing cancer that may not progress to be symptomatic in younger men.[22-24]
- Mortality rates are substantially lower than incidence rates, as patients generally have a

good prognosis after being diagnosed and survival rates are generally quite high. Based on data from the CONCORD-2 study, five-year net survival for prostate cancer in Canada was 91.7% for cancers diagnosed between 2005 and 2009.[25]

- Autopsy studies (done on men who died from causes other than prostate cancer) have shown that the prevalence of prostate cancer increases with age.[24, 26] For example, in men aged 40-49, the autopsy detection rate was around 40%; this jumped to 70% in men aged 70-79 and to 80% of men age 90 and older.[9, 27] These studies provide further evidence that many men often die with prostate cancer, not from it.
- The decline in prostate cancer mortality reported here is probably the result of a combination of factors. Improvements in the treatment of prostate cancer have likely contributed substantially to the observed reduction in mortality. While screening and early detection may also have contributed to this decline, there is lack of clear agreement in the research on the magnitude of its role.[9, 28] Some recent studies, including the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial (USA), showed that early detection of prostate cancer through PSA testing appeared to have no effect on the decreasing mortality rate.[29, 30] Other studies, including the European Randomized Study of Screening for Prostate Cancer (Europe), showed a mortality benefit resulting from PSA testing[31] (for more information on the two trials, see the *PSA Testing* section of this chapter).
- Overall, mortality rates from prostate cancer have been decreasing in many jurisdictions, including North America, Oceania, Western Europe and parts of northern Europe.[32] This aligns with the pattern observed in Canada between 1992 and 2011.

What else do we know?

- In its 2014 publication, *Examining Disparities in Cancer Control*, the Partnership reported that, despite higher rates of PSA testing, higher-income men had slightly higher rates of advanced (Stages III and IV) prostate cancer than lower-income men.[33]
- Recently, the Public Health Agency of Canada published the *Canadian Cancer Incidence Atlas* for the years 2000-2006.[34] The purpose of this atlas is to present the spatial variation of cancer incidence in Canada, including prostate cancer, comparing the overall age-standardized incidence rates for each health region with the rate for Canada as a whole. Lower rates of prostate cancer were reported in Newfoundland and Labrador, Quebec, Manitoba, British Columbia and Nunavut, while higher rates were reported in Prince Edward Island, Nova Scotia, New Brunswick, Ontario, Saskatchewan and Alberta. While these patterns differ slightly from what is presented here, particularly for Newfoundland and Labrador, this may be the result of differences in the time period reported on. The *Canadian Cancer Incidence Atlas* presents earlier data (2000-2006), while this report presents incidence data for 2008-2010.

Risk Factors

- Prevention is a key cancer control strategy overall; however, when it comes to prostate cancer, the causes of the disease remain poorly understood.
- Most of the evidence that does exist on modifiable risk factors for prostate cancer tends to be weak, inconclusive and often contradictory. Currently, the only established risk factors for prostate cancer are not modifiable and include older age, family history and ethnicity (Table 1.1).[6, 35, 36]
- In 2014, the World Cancer Research Fund published a report on diet, nutrition, physical activity and prostate cancer.[8] While there was no conclusive evidence about the role that diet, nutrition and physical activity play in the overall incidence of prostate cancer, the report concluded that greater body fatness (marked by higher BMI, waist circumference and waist-hip ratio) is probably correlated with advanced prostate cancer. These data suggest that maintaining a healthy body weight could reduce the risk of developing advanced prostate cancer.
- New research also suggests that higher levels of physical activity may impact survival and reduce mortality in men diagnosed with prostate cancer.[7]
- Further research is needed to definitively identify modifiable risk factors for prostate cancer.

TABLE 1.1

Known risk factors for prostate cancer

Risk Factor	Effect on Prostate Cancer
Age	• Risk of prostate cancer increases with age. • Prostate cancer is rare before the age of 50, with most diagnoses occurring after the age of 65.[37] • Canadian incidence rates demonstrate the pattern of increased risk with age. Rates were much higher in men aged 65-79 (662.5 cases per 100,000) and in men aged 80+ (640.0 per 100,000), compared to men aged 35-49 and 50-64 (12.9 and 247.4 cases per 100,000, respectively) (Figure 1.4). • This increase in risk with age is more dramatic for prostate cancer than for other cancers. Comparison data from Statistics Canada showed that prostate cancer incidence in men aged 70-74 was around 23 times higher than in men aged 45-49. By contrast, breast cancer incidence was approximately two times higher in women aged 70-74 than women aged 45-49. Colorectal cancer incidence was about six times higher in men aged 70-74 than men aged 50-55.[14]
Family History	• Prostate cancer can cluster in families. • If there is a history of prostate cancer in one first-degree relative (i.e., father or brother), a man's own risk of getting the disease is higher. This risk becomes greater with an increasing number of first-degree relatives who have a history of prostate cancer.[6, 36, 38] • Men with a brother affected by prostate cancer are more likely to develop it themselves, compared to men whose father was the only family member with this history.[6, 36, 38]
Ethnicity	• Prostate cancer incidence and mortality rates are known to be lowest in Asian populations.[17, 37] • Incidence is generally highest in men of African ancestry—about 60% higher than it is for Caucasian men. These men tend to be diagnosed at a younger age and develop more aggressive tumours.[37] • The reasons for these differences are unknown, though genetic susceptibility or lifestyle factors could play a role.[22, 39]

PSA Testing

What are we measuring and why?

This indicator measures the percentage of men aged 35 or older who reported having at least one prostate-specific antigen (PSA) test in the past one year, two years or ever. The indicator is presented by province and by age group for the combined years of 2010 to 2013 and is based on data from the Canadian Community Health Survey.

- PSA testing can detect prostate cancer between five and 12 years before men experience symptoms, allowing for early follow-up and treatment.[40] However, PSA testing results in more frequent diagnosis of latent or early-stage prostate cancers that are unlikely to cause harm or lead to death. Data from randomized controlled trials have been used to estimate that up to 60% of PSA-detected prostate cancers are overdiagnosed.[b, 42, 43] The subsequent treatment may negatively impact men's quality of life due to persistent urinary, bowel and sexual dysfunction without the benefit of reducing mortality.[44]
- There is variation in Canadian guidelines on whether or not individual men should undergo PSA testing, on the role of PSA testing for establishing baseline risk levels, and on the use of PSA testing to monitor men at high risk[c] for developing prostate cancer. For example, three Canadian organizations have published recommendations; one is against PSA testing, while two are in favour:
    - *The Canadian Task Force on Preventive Health Care (CTFPHC), 2014.* Guidelines recommend not screening the general population for prostate cancer using PSA testing (i.e., in men not previously diagnosed with prostate cancer) because of an increased risk of harm caused by such screening and active testing—including false-positive results, overdiagnosis, unnecessary biopsies and treatments—with little benefit.[9]
    - *Prostate Cancer Canada, 2013.* Men in their 40s should establish a baseline PSA level. Any decision on whether or not to be tested for prostate cancer should be made by individual men and their physicians. Particularly, men at high risk for prostate cancer should begin these conversations early, before age 40.[11]
    - *The Canadian Urological Association (CUA), 2011.* PSA testing should be offered to men over age 50 who have at least a 10-year life expectancy, and should be stopped at age 75. Establishing a baseline PSA level in men aged 40-49 could be beneficial. Men who are high-risk should be offered PSA testing beginning at age 40.[10] The Canadian Urological Association reinforced its guidelines after the release of the new CTFPHC guidelines in 2014.[47]

What screening tests are currently being used in the early detection of prostate cancer?

- ***Prostate-Specific Antigen (PSA) Testing:*** A blood test used to detect levels of prostate-specific antigen (a protein). Elevated levels of PSA in the blood could indicate development of prostate cancer; however, there are many conditions that can cause elevated PSA, including an enlarged prostate, inflammation or recent medical tests on the prostate.[45]
- ***Digital Rectal Examination (DRE):*** A physical examination used to investigate abnormalities in the prostate and to detect prostate cancer early. The procedure is done by a health care provider who inserts a gloved finger into the rectum.[46]

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[b] *Overdiagnosis* refers to the detection of a cancer that was not destined to present clinically (i.e., cause symptoms) in that individual during his or her lifetime.[41]

[c] Men with a family history of prostate cancer or who are of African descent are considered at higher risk for developing prostate cancer.[10,11] See the *Risk Factors* section for more information.

- None of these organizations recommend using PSA testing as a population-based screening tool for men of average risk, due to a lack of reliable evidence on the benefit of using PSA testing in this manner. Prostate Cancer Canada, the CUA and the Canadian Cancer Society all support an informed decision-making approach, where men make decisions about PSA testing based on their individual needs and characteristics. This involves talking to their doctors about their personal risk of developing prostate cancer, discussing the benefits and risks of PSA testing, and reviewing the next steps for surveillance or treatment if an abnormality is found.[11, 45, 47] Many provinces, including British Columbia, Alberta and Nova Scotia, support this informed decision-making approach.[48-50] The CTFPHC also acknowledges the value of informed decision-making for men in the 55-69 age group.[9]

What are the results?

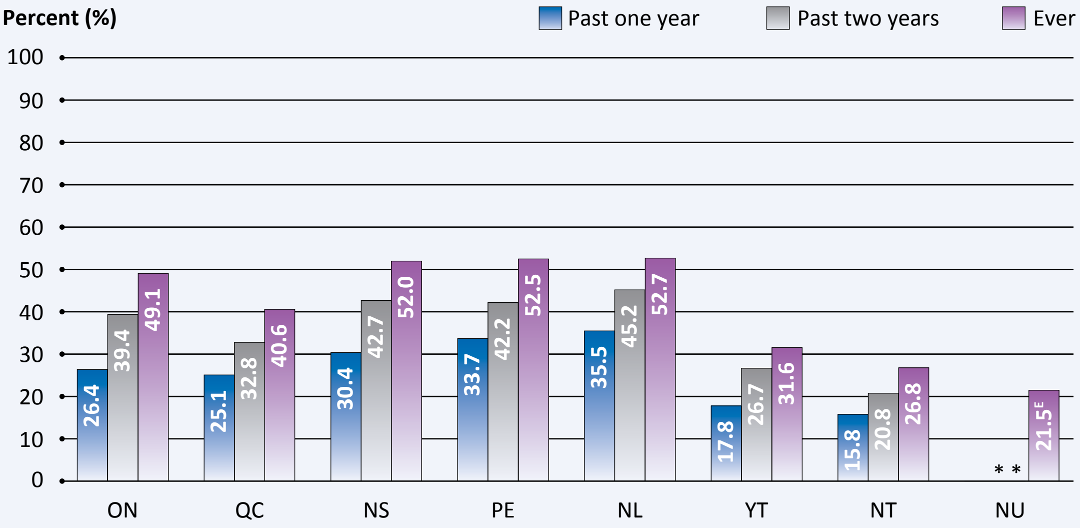
- The percentage of men aged 35 and older who reported having a PSA test in the past year ranged from 15.8% in the Northwest Territories to 35.5% in Newfoundland and Labrador. The percentage who reported having a PSA test in the past two years ranged from 20.8% in the Northwest Territories to 45.2% in Newfoundland and Labrador. The percentage who reported ever having a PSA test ranged from 21.5% in Nunavut to 52.7% in Newfoundland and Labrador (Figure 1.5).
- Men in the 65-79 age group had the highest percentage reporting a PSA test in the past year (50.4%), compared to those in the 50-64 age group (34.2%) and those in the 80+ (34.1%) age group. A similar pattern was seen for men reporting a PSA test in the past two years: the highest reported uptake was in the 65-79 age group; the lowest was in the 35-49 age group. The highest percentage of men who reported ever having a PSA test was in the 65-79 age group (78.8%). As expected, men in the 35-49 age group had the lowest percentage (18.7%) (Figure 1.6).

Data and measurement considerations

- Data collected for this indicator are based on respondents aged 35 and older who reported having a PSA test for any of the following reasons: family history, a regular check-up, routine screening, age or race. The indicator excludes testing for: follow-up of a problem, follow-up of prostate cancer treatment and those tested for any other reason.
- This indicator comprises data from four combined years (2010-2013). This is because the prostate cancer questions in the Canadian Community Health Survey were optional content (i.e., content selected by health authorities to address regional or provincial priorities). This allowed for a larger sample size and more valid results.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

FIGURE 1.5

Percentage of men (aged ≥ 35) reporting at least one PSA test[†] in the past one year, two years or ever, by province/territory — 2010-2013 reporting years combined



† Excludes tests done to investigate symptoms.

* Suppressed due to small numbers.

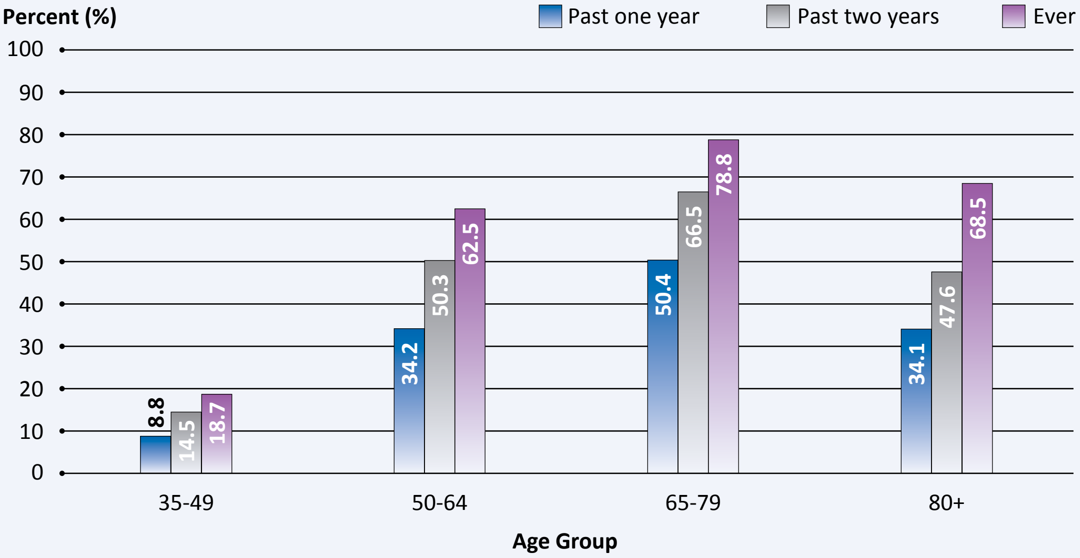
E Interpret with caution owing to large variability in the estimate.

Data include: ON (2011, 2012), QC (2013), NS (2010, 2011, 2012), PE (2010), NL (2010), YT (2010, 2013), NT (2010, 2011, 2012, 2013), NU (2011).

Data source: Statistics Canada, Canadian Community Health Survey.

FIGURE 1.6

Percentage of men (aged ≥ 35) reporting at least one PSA test[†] in the past one year, two years or ever, by age group, Canada — 2010-2013 reporting years combined



† Excludes tests done to investigate symptoms.

Data include: ON (2011, 2012), QC (2013), NS (2010, 2011, 2012), PE (2010), NL (2010), YT (2010, 2013), NT (2010, 2011, 2012, 2013), NU (2011).

Data source: Statistics Canada, Canadian Community Health Survey.

What do the results mean?

- Currently, no organized population screening programs for prostate cancer exist in any Canadian province, due to lack of reliable evidence on the effectiveness of population-based PSA testing in reducing prostate cancer mortality. Provinces vary in their funding of PSA testing.[19] For example, Ontario and British Columbia do not fund PSA tests for men without symptoms of prostate cancer.[51] This may contribute to the variability in testing rates across the country observed in the results.
- Differences in PSA testing rates across provinces and territories may also reflect different demographics. Population age structures vary among provinces and territories. For example, the Atlantic provinces have the oldest populations in the country, with the highest proportion of people over the age of 65. These provinces also have the highest self-reported PSA testing rates. By contrast, the territories, which show the lowest rates of PSA screening, have some of the youngest populations in Canada.[52]
- The higher reported uptake of PSA testing in men over 65 years of age is to be expected, since the risk of prostate cancer increases with age and men are most frequently diagnosed after age 65.[37] These results are comparable to PSA age-specific testing rates in other jurisdictions, including Australia and the United States.[53, 54]

What are some examples of efforts in this area?

- Alberta, Nova Scotia, Ontario, Quebec, Saskatchewan and the Northwest Territories have guidelines or policies for the funding, use and delivery of PSA testing, either in place or being developed.[19]
- In 2009, the Partnership published a PSA Toolkit that provides information on PSA screening and testing. The toolkit identifies principles of PSA testing, potential risks and benefits, and areas for future research and development. Based on available evidence, the Expert Panel, who guided development of the report, suggested that PSA testing should not be expanded beyond current practices.[27]

What else do we know?

- Two large-scale randomized controlled trials were conducted to investigate the effect of annual PSA testing on prostate cancer mortality: the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial (PLCO; USA) and the European Randomized Study of Screening for Prostate Cancer (ERSPC; Europe). The two studies came to different conclusions on the benefits of PSA testing, contributing to the variation in evidence available for interpretation. While the ERSPC found that PSA testing can reduce the risk of dying from prostate cancer by up to 21%,[40] the PLCO found that PSA testing had no effect on prostate cancer mortality.[30]
- DREs are often done in conjunction with PSA tests. Additional data from the Partnership (not shown in this report) show the level of DRE use in Canada. The percentage of men aged 35 and older who reported undergoing a DRE in the past year ranged from 15.6% in the Northwest Territories to 30.0% in Prince Edward Island. The percentage of men who reported having a DRE in the past year was highest in the 65-79 age group (43.1%), followed by those aged 50-64 (30.5%).
- Mathematical algorithms have been explored as a way to help guide decision-making by clinicians around prostate cancer risk. The models combine multiple variables such as DRE, PSA, age, race, family history of prostate cancer and genetic data to determine an individual patient's risk of developing prostate cancer.[55-57]

2. Diagnosis and Staging

2. Diagnosis and Staging

As with most other cancers, diagnosing prostate cancer can involve many steps. First, a potential problem is identified. This includes changes in urinary patterns or blood in the urine, elevated or rising prostate specific-antigen (PSA) values and/or abnormal findings from a digital rectum exam (DRE). Next, the diagnosis must be resolved so that if cancer is confirmed, a treatment plan can be determined as soon as possible. This process involves several tests and procedures. They commonly include a conventional image-guided needle core biopsy to determine if the patient has prostate cancer. The follow-up tests and procedures carry some risk of harms to the patient.

Once a pathologist has analyzed tissue taken from the core biopsy and established a diagnosis of prostate cancer, a staging workup and risk level evaluation will occur. While cancer stage is an important indicator of a patient's disease, several other prognostic factors are now routinely considered in prognosis and treatment planning. The most commonly used risk categorization systems are based on a combination of clinical T stage[d], PSA values[e] and Gleason score[f].

In system surveillance and performance measurement, tracking prostate cancer incidence rates by stage and risk level can provide insights into the use and potential impact of early detection efforts including PSA testing. Such information can also be helpful in identifying patterns of care and treatment outcomes.

This chapter provides data on prostate cancer incidence by stage at diagnosis (I, II, III and IV) and by risk level (low, intermediate and high).

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[d] Clinical T stage findings are based on a DRE and/or on transrectal ultrasound testing (which may involve microscopic analysis of tissue). Clinical T staging also helps determine whether or not the patient is a good candidate for specific treatments such as radical prostatectomy (surgical removal of the prostate gland), external beam radiation therapy, brachytherapy, cryosurgery and/or hormonal therapy prior to treatment.

[e] Prostate-specific antigen (PSA) is a protein produced within the prostate gland and secreted into the seminal fluid. PSA is mostly found in semen, but a small amount of PSA in the blood is normal. A PSA test measures the amount of PSA in the blood. A high PSA reading may indicate the presence of early cancer, but it can also lead to unnecessary tests and treatment. This is why doctors consider the patient's other risk factors before recommending a specific treatment or other approach.

[f] The Gleason score reflects the grade of the tumour—specifically how cells removed via biopsy look under a microscope. A score of between 2 and 6 suggests a low-grade prostate cancer which is likely to grow very slowly; scores between 2 and 5 are rarely given. A score of 7 is considered an intermediate-grade tumour that will grow at a moderate rate. A score of 8 to 10 indicates a high-grade cancer that is likely to grow more quickly.

Reflections of Men with Prostate Cancer

This section presents common themes identified from focus groups and interviews conducted across Canada with prostate cancer patients, survivors and caregivers about their experience with prostate cancer. The quotes listed here are intended to illustrate the views and experiences of those focus group participants based on specific questions posed to them and should not be taken as generalizable findings. Many of the men were recruited through their previous participation in prostate cancer support groups. The perspectives of men diagnosed with prostate cancer who did not receive treatment are not reflected here.[g]

The presence or absence of elevated PSA levels or abnormal findings from a DRE seemed to prepare some men in the focus groups to receive their diagnosis of prostate cancer.

"I was expecting it a little bit…the urologist decided to pass a small camera to [check] things out … together with a blood test (the PSA) was quite high, so she took the biopsy and that's when she told me I had prostate cancer, but I was expecting it a little bit." **focus group participant from Quebec**

"I was shocked that I was diagnosed with prostate cancer. I was showing all kinds of symptoms but the manual [digital rectum exam] was negative and so I didn't think I would have it. The biopsy came back and I had two patches." **from Nova Scotia**

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[g] For a more complete description of findings and the methods used, see the Special Feature in Chapter 4: *Person-Centred Perspective*.

Men recalled their emotional reactions upon hearing the news that they had prostate cancer.

"It was pretty devastating when I got the results." **from Manitoba**

"While I thought I was prepared for the worst, when it was confirmed, I felt like I had been given a death sentence. I wondered, what do I do next, how do I tell my family, friends, etc. What are the next steps? Where do I go for more information?" **from Ontario**

"We were just shocked. He was 48 years old…and wham, you have cancer." **from New Brunswick**

"The diagnosis is the difficult one…You get angry, you get depressed, you get sad, you get anxious, you get all sorts of things. And then eventually that settles down and then you focus on the treatment. And that's where [my] doctor was very reassuring." **from Quebec**

Although many participants said they had positive experiences with their health care providers, one man felt improvement is needed in how some clinicians communicate a cancer diagnosis.

"I think the health care workers, the front-line workers who have to tell patients that they have cancer… should maybe see less patients in a day so they're not stressed out and can take time to give the news gently. Because I mean, it's really a terrible shock, and I'll always remember that time in my life when I was told." **from Quebec**

Stage-Specific Incidence

What are we measuring and why?

This indicator examines the age-standardized incidence rates for non-metastatic prostate cancer by stage at diagnosis (I, II, III, IV). Only men aged 35 or older were included, as prostate cancer is extremely rare in men under age 35.

- As of 2010, population-level stage data were available in nine of 10 Canadian provinces for the four most common cancers including prostate cancer. The availability of such data provides new opportunities: they can be used to support system-level surveillance of cancer trends, to more accurately measure system performance, and to evaluate the impact of differences in early detection and screening efforts across the country—in particular, how they affect patient outcomes.

What are the results?

- In the 2010 diagnosis year, Stage II was the most common stage for prostate cancer in all provinces, with the exception of Prince Edward Island where the Stage I age-standardized incidence rate was highest.
- The incidence of Stage I prostate cancer showed great variation across the country in the 2010 diagnosis year, ranging from 12.9 cases per 100,000 in British Columbia to 141.0 cases per 100,000 in Prince Edward Island.
- The incidence of Stage II prostate cancer ranged from 75.8 cases per 100,000 in British Columbia to 164.7 cases per 100,000 in Newfoundland and Labrador.
- The incidence of Stage IV prostate cancer was the least frequent in most provinces, ranging from 15.3 cases per 100,000 in British Columbia to 36.3 cases per 100,000 in Saskatchewan.

Data and measurement considerations

- Age-standardized incidence rate: crude incidence rates for prostate cancer were calculated for men aged 35 and older, standardized to the age structure of the 2011 Canadian population (aged ≥ 35).
- Stage-specific incidence rates measure the number of people per 100,000 diagnosed at each stage of disease for a specific type of cancer, at the time of diagnosis.
- Assigning a case as *stage unknown* means that the pathological and/or clinical diagnosis was not complete or that the information available in patient charts was not sufficient to ascertain a stage. In the 2010 stage-specific incidence data used in this indicator, the cases deemed to be *stage unknown* was particularly high in British Columbia: 54.9 cases per 100,000 compared to a range of 1.4 to 16.3 per 100,000 in other provinces (this is at least partially due to a lack of available documentation providing PSA and Gleason score information for patients not referred to the BC Cancer Agency). The high rate of *stage unknown* can compromise the ability to compare provincial stage-specific incidence rates.
- *Blank stage* means that the collaborative stage (CS)[h] algorithm was not run or resulted in an error.
- The wide interprovincial variation in Stage I incidence rates could be explained by several factors. In the 7th edition of the American Joint Committee on Cancer

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[h] **Collaborative stage data collection system (CS)** Using a specific computer-based methodology, trained coders—known as certified tumour registrars—are given access to all patient charts that contain clinical findings along with any pathological test results (i.e., analysis of tumour tissue or cells). The registrar receives and reviews the data, makes coding assessments and then inputs the data into the relevant fields. A computer generates the appropriate stage but also allows the inclusion of additional prognostic factors. This information is captured and stored in provincial cancer registries.

(AJCC) Cancer Staging Manual, the addition of PSA and Gleason score has changed the way prostate cancer is staged, resulting in a greater number of Stage I cases. It is possible that some provinces may still be using the 6th edition of the AJCC Cancer Staging Manual and would, therefore, be expected to have a lower incidence of Stage I disease. Also, provinces with higher levels of PSA testing would be expected to have higher incidence of Stage I prostate cancer.

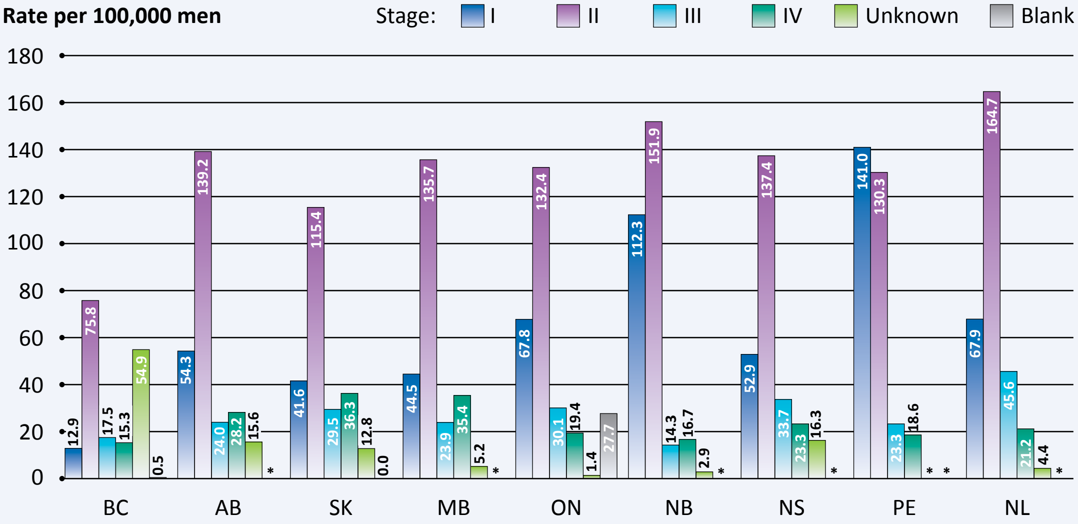
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

What do the results mean?

- The interprovincial variation in the stage-specific incidence rates could reflect differences in the use of PSA testing across jurisdictions or staging data issues (see *Data and measurement considerations*). Those with a higher rate of PSA testing would be expected to have a higher incidence of early-stage prostate cancer. In order to reliably link stage-specific incidence patterns to differences in PSA testing rates across the country, we need reliable data on PSA testing rates for all provinces; these are not available.

FIGURE 2.1

Stage-specific incidence rates for prostate cancer (men aged ≥ 35), by province, age-standardized to the 2011 population — 2010 diagnosis year



* Suppressed due to small numbers.

QC: Stage data not available in 2010.

Unknown: Data entered in the CS algorithm were not sufficient to ascertain a stage.

Blank: CS algorithm was not run or resulted in an error.

Data source: Statistics Canada, Canadian Cancer Registry; Provincial cancer agencies (BC and SK).

What else do we know?

- Calculating stage-specific incidence (i.e., the incidence rate for each cancer stage group) is preferable to the more commonly used measure of stage distribution (i.e., the percentage of patients diagnosed with a particular cancer at each stage of disease). This is because overdiagnosis of early stage cancer may not be easily identified by examining stage distribution data, and may in fact falsely reassure us regarding late stage disease. For example, overdiagnosis may result in an apparent reduction in the proportion of late stage cancers, even though the actual incidence rates of advanced stage disease may not have changed. This may be of special concern for cancers—such as prostate and breast—where levels of early detection and screening activities are high. Failure to properly understand the findings could compromise our ability to understand the true impact of differences on cancer control efforts. Stage-specific incidence rates are not subject to this type of potential interpretation bias.

Risk Profile

What are we measuring and why?

This indicator examines the age-standardized incidence rates for non-metastatic prostate cancer by risk category (low, intermediate and high). The indicator also examines the distribution of prostate cancer risk profiles by age group. Only men aged 35 or older were included, as prostate cancer is extremely rare in men under age 35.

- While stage is among the most useful tools for determining prostate cancer prognosis and treatment options, risk categorization systems are commonly used for evaluating patients with localized prostate cancer (i.e., whose cancers have not spread) as they 1) better clarify prognosis and 2) can help guide decisions about treatment for patients with localized prostate cancer. The most commonly used risk categorization systems for prostate cancer are based on a combination of clinical-based pre-treatment prognostic factors: PSA value, biopsy Gleason score and Clinical T-Stage.
- These three prognostic factors—which are rolled up into a more global risk category for each patient with localized prostate cancer—may help track and evaluate overall patterns of care (see the *Patterns of Care* indicator in Chapter 3: *Treatment*).
- Risk categorization can predict how likely a specific cancer will respond to treatment and may help determine the risk for recurrence of disease after treatment.[58]
- For this report, non-metastatic prostate cancer patients were categorized into three risk categories based on the Genitourinary Radiation Oncologists of Canada (GUROC) Canadian Consensus definition. Table 2.1 lists the prognostic characteristics within each risk category based on the GUROC guidelines.[59] (Note: Not all prostate cancer cases were captured, due to incomplete data for one or more of the three prognostic factors used to calculate risk. See the following *Data and measurement considerations* section for details.)

TABLE 2.1

Criteria for which risk categories were assigned for non-metastatic prostate cancer cases based on the definition set out by Genitourinary Radiation Oncologists of Canada

Risk Category	PSA Value	Gleason Score	Clinical T Stage
Low (must have all)	≤10 ng/mL	≤6	T1-T2a
Intermediate (must have all if not low risk)	≤20 ng/mL	7	T1/T2
High (any one is sufficient)	>20 ng/mL	8-10	T3a-T4

Data and measurement considerations

- Age-standardized incidence rate: crude incidence rates for prostate cancer were calculated for men aged 35 and older, standardized to the age structure of the 2011 Canadian population (aged ≥ 35).
- Prostate cancer patients are grouped into three categories according to the GUROC Canadian Consensus risk categories: low-risk refers to cancer that is not likely to grow or spread for many years; intermediate-risk cancer refers to cancers that are not likely to grow or spread for a few years; and high-risk cancer is likely to grow or spread within a few years.[60]
- The criteria for assigning risk include non-metastatic patients only; therefore, metastatic patients were excluded from the current analysis. Metastatic disease makes up a small proportion of the total prostate cancer patient population.[61]
- The risk factors indicator uses collaborative stage data from the provincial cancer registries. Three collaborative stage data elements were used to derive risk category: site-specific factor 1 (PSA value), site-specific factor 8 (Gleason score) and CS extension (Clinical T-Stage). Not all cases were captured, due to incomplete data for one or more of the three prognostic factors used to calculate risk. For example, 38% percent of cases in British Columbia were not assigned to a risk category due to the lack of PSA or Gleason score information for patients who were not referred to the BC Cancer Agency. Efforts are currently under way in British Columbia to address this issue.
- The low incidence of low-risk prostate cancer cases in some provinces might be related to the number of unassigned risk cases in those jurisdictions. This correlation might apply specifically to low-risk cases because data on *all three* prognostic factors are required to assign men to the low-risk category. However, data from *just one of the three* prognostic factors is enough to assign cases to the high-risk category. So it is possible that the size of the low-risk population in these provinces is being under-reported.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

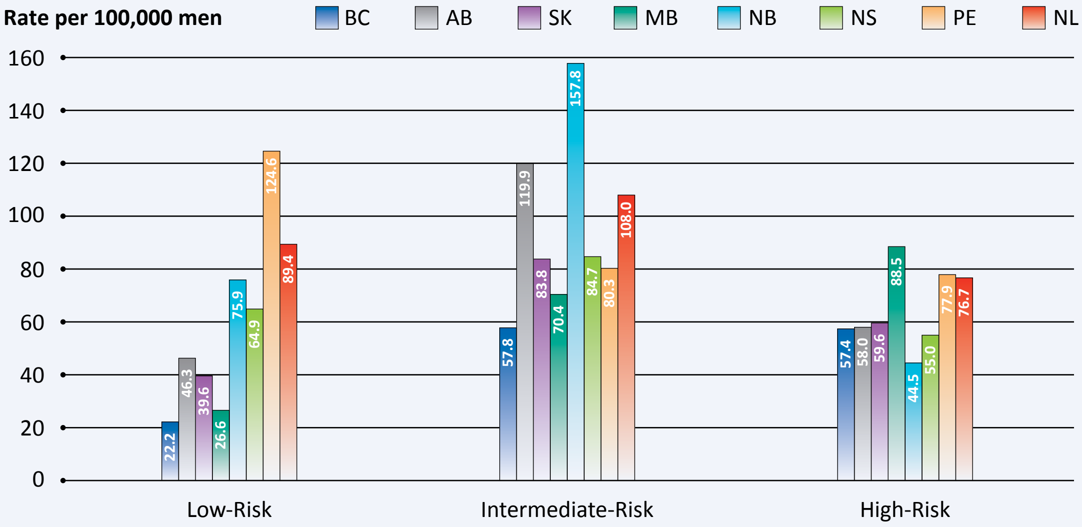
What are the results?

- Figure 2.2 shows that most cancer patients were categorized as low- or intermediate-risk; but the data suggest substantial differences in the distribution of risk categories between provinces. Age-standardized incidence rates of low-risk prostate cancer ranged from 22.2 cases (British Columbia) to 124.6 cases (Prince Edward Island) per 100,000 men. For intermediate-risk prostate cancer, the incidence rates ranged from 57.8 cases (British Columbia) to 157.8 cases (New Brunswick) per 100,000 men. For high-risk prostate cancer, incidence rates were significantly lower, ranging from 44.5 cases (New Brunswick) to 88.5 cases (Manitoba) per 100,000 men. There was less interprovincial variation in the incidence of high-risk disease. One reason for this may be that variations in PSA testing patterns tend to reflect as differences in early stage prostate cancer incidence rates.
- New Brunswick reported a high incidence of low- and intermediate-risk prostate cancers and a low incidence of high-risk cancers. Prince Edward Island and Newfoundland and Labrador reported the highest incidence rates of low-risk cancers but also reported some of the highest incidence rates of high-risk cancer (Figure 2.2).

- Alberta, Saskatchewan and Manitoba reported relatively low incidence rates of low-risk prostate cancer and relatively high incidence rates of high-risk cancer (Figure 2.2). Further analysis is needed to link these patterns more definitively to differences in rates of PSA testing and other diagnostic investigations.
- Overall, the proportion of localized prostate cancer patients who had higher-risk disease at diagnosis increased with increasing age at diagnosis. Most (72.0%) men over age 80 were classified as high-risk compared to a much smaller percentage (12.0%) of those in the 35-49 age group (Figure 2.3). It is important to note that prostate cancer is rare in younger men. (See Chapter 1: *Burden and Outcomes* for details on age-standardized incidence rates by age group).

FIGURE 2.2

Incidence rates for non-metastatic prostate cancer (men aged ≥ 35)[†], by province, by risk category, age-standardized to the 2011 population — 2012 diagnosis year



Risk category - Unable to classify

Province	**BC**	**AB**	**SK**	**MB**	**NB**	**NS**	**PE**	**NL**
Rate per 100,000 men	84.2	14.6	14.9	38.0	5.1	36.7	28.7	13.5

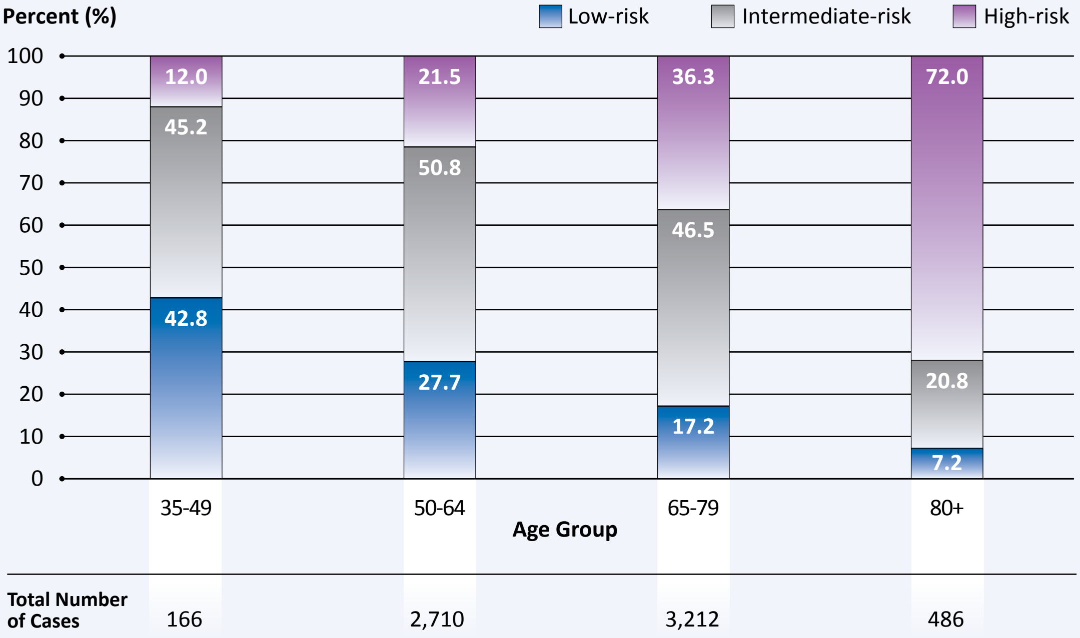
[†] Estimated using risk category data from 2012 diagnosis year and age-standardized incidence rates from 2010; see the Technical Appendix available at systemperformance.ca for more details.

A total of 93.9% of men had non-metastatic prostate cancer; 6.1% of cases were metastatic and were excluded from the analysis.

Data source: Provincial cancer agencies and Statistics Canada, Canadian Cancer Registry.

FIGURE 2.3

Distribution of non-metastatic prostate cancer cases (men aged ≥ 35), by risk category, by age group — 2012 diagnosis year



Data include: BC, AB, SK, MB, NB, NS, PE, NL.
Data source: Provincial cancer agencies.

What do the results mean?

- As of the 2010 diagnosis year, collaborative staging for prostate cancer cases had been implemented in nine of 10 provinces. Because collaborative staging includes more data points than the usual "tumour-node-metastasis" (TNM) anatomic-based staging system, the analysis of important prognostic factors such as PSA and Gleason score was enabled. Since these factors are used to determine appropriate treatment strategies at the patient level, population-level analysis can yield valuable information about overall treatment patterns and patient outcomes. For example, in Figure 2.3, the observation that older men are more likely to be categorized as high-risk may help plan cancer care services for these patients. (It is important to note that there was interprovincial variation in the completeness of data available to assign risk categories; as such, it is possible that patterns observed could reflect some data quality issues.)
- The interprovincial variation in the incidence of prostate cancer by risk category could reflect differences in the use of PSA testing across jurisdictions. Those with a higher rate of PSA testing would be expected to have a higher incidence of low-risk prostate cancer. In order to reliably link risk category incidence patterns to differences in PSA testing rates across the country, we need reliable data on PSA testing rates for all provinces; these are not available (see Chapter 1: *Burden and Outcomes* for details on provincial variation in funding of and recommendations for PSA testing). Meanwhile, patterns of age-standardized prostate cancer incidence rates by risk category should continue to be monitored. This will help track whether more patients are being diagnosed as low-risk and whether this is accompanied by a decrease in mortality rates.
- Older patients were more likely to be assigned a high-risk profile at diagnosis (Figure 2.3). These results are consistent with age-specific risk profiles in other jurisdictions, including the United States.[62]

What are some examples of efforts in this area?

- Risk categories are important for assessing the appropriate use of diagnostic procedures such as bone scans and pelvic imaging at the system level. *Choosing Wisely Canada*®, a campaign aimed at reducing unnecessary tests, treatments and procedures, recommends against routine imaging of the pelvis for low-risk prostate cancer patients. This recommendation is in place because the chance of metastases is low and because of the potential harm to patients caused by "false-positive" findings and radiation exposure.[63] Sweden has been successful in its nationwide efforts to reduce routine use of diagnostic imaging for men with low-risk prostate cancer, and this experience could be used to inform decisions in other jurisdictions.[64]
- In Ontario, an initiative called Prostate Cancer Risk Stratification Proof of Concept is aimed at developing a strategy to systematically collect those data elements required to stratify prostate cancer cases by risk. The goal is to produce high-quality, complete data at a systems level that can be used to inform treatment patterns and cancer service needs for the future.[65]

What else do we know?

- Several other risk stratification systems that use the three prognostic factors discussed here (PSA level, biopsy Gleason score and Clinical T-Stage) exist. In 1998, D'Amico et al., proposed the three-group system based on biochemical failure after primary treatment (i.e., patients' PSA levels went up rather than down).[58] Since then, the Genitourinary Radiation Oncologists of Canada (GUROC) has published a consensus statement and redefined prostate cancer risk categories. Cancer and urological organizations such as the National Comprehensive Cancer Network (NCCN, United States), the National Institute for Health and Care Excellence (NICE, the United Kingdom), the American Urological Association (AUA, United States), and the European Association of Urology (EAU) have also developed stratification systems. The NICE guidelines are consistent with the GUROC system; however, both the AUA and EUA have endorsed the D'Amico system.[66]
- In the future, it is likely that the GUROC stratification system will be re-examined to ensure the following: that it is updated by recent evidence; that it is clinically relevant; and that it reflects current practice patterns. Changes to the existing stratification system may reflect new PSA cut-offs, the number of biopsy cores that were positive, prognostic grade grouping and the addition of other prognostic factors.[66, 67]

3. Treatment

3. Treatment

This chapter presents indicators that measure important aspects of the treatment journey for men with prostate cancer. We examine wait times for surgery and for radiation therapy; patterns of treatment by risk category; and the various surgical approaches being used for radical prostatectomy, one of the common treatments for localized prostate cancer.

After a man is diagnosed with prostate cancer, he is often presented with several treatment options. These options are evaluated based on various factors, including the stage and risk profile of his disease, his age, the presence of any co-morbid conditions and his personal preferences and quality of life considerations.

Treatment for non-metastatic prostate cancer is delivered with the intent to cure. It may also be given to control symptoms and to relieve pain (palliation) in men with advanced disease. While surgery and radiation therapy are intended to eliminate the cancer, these treatments sometimes can lead to other problems, such as incontinence and erectile dysfunction. The side effects can be short-lived or long-lasting, and can have a negative impact on men's quality of life.

Because of the often slow-growing nature of prostate cancer and the potential for debilitating side effects caused by treatment, the cancer control community is increasingly concerned about overdiagnosis and overtreatment.[2] As a result, clinicians are increasingly providing definitive treatment to lower-risk patients only if the disease progresses or until symptoms become worse—these include approaches known as "active surveillance" and "watchful waiting."[2-5] See *About Active Surveillance and Watchful Waiting* for more details.

In general, guideline-recommended treatment options for men with low-risk prostate cancer include active surveillance, radiation therapy or surgery (the removal of the prostate gland via prostatectomy). The treatment options for men with intermediate-risk or high-risk prostate cancer include surgery, radiation therapy and/or hormone therapy; active surveillance is not recommended for these higher risk groups.

About Active Surveillance and Watchful Waiting

A growing number of men with low-risk prostate cancer are being managed using **active surveillance**. This involves monitoring levels of prostate-specific antigen (PSA) in the blood every several months, along with regular prostate biopsies and rectal exams until there is evidence (if any) of cancer progression. At that point definitive treatment is often initiated.

This is now the preferred option for men with low-risk prostate cancer and a current life expectancy of 10 years or more at the time of diagnosis.[2] This option means that the patient avoids immediate treatment of an indolent (slow-growing) tumour until and unless the disease progresses.[3, 68]

Watchful waiting[i] (also known as observation) is another option for those who have a current life expectancy of less than 10 years, mainly because of their age at diagnosis (i.e., men diagnosed in their late 70s or 80s).[4, 5] This approach involves less intensive monitoring and does not include surveillance biopsies. If there is evidence of disease progression or symptoms, palliative therapy is started, aimed at managing symptoms and keeping the patient comfortable. This is the preferred option for men who have comorbidity that is likely to outcompete the prostate cancer; that is, their prostate cancer is unlikely to cause mortality or significant morbidity.

The advantage of these approaches is that treatment-related side effects are avoided or at least delayed. Physical complications that could arise from primary treatment include urinary incontinence, erectile dysfunction and rectal problems, which may or may not lessen over time.[69]

The disadvantages of active surveillance and watchful waiting include patient anxiety related to not getting treatment for a confirmed diagnosis of cancer; the burden of multiple follow-ups; and the possibility that treatment at a later stage of the disease may be more complex and lead to more side effects.[2]

In Canada, a large proportion of prostate cancer patients receive surgery and/or radiation therapy. Applying the results of research carried out in other countries to the Canadian context leads to a suggestion that about half of these patients probably did not require immediate treatment and could have been safely managed with active surveillance or watchful waiting.[70, 71] This is an important realization as the management of post-treatment complications (if any) following initial treatment for prostate cancer may have a lasting impact on patients' lives. It also places a significant burden on the health care system.[72]

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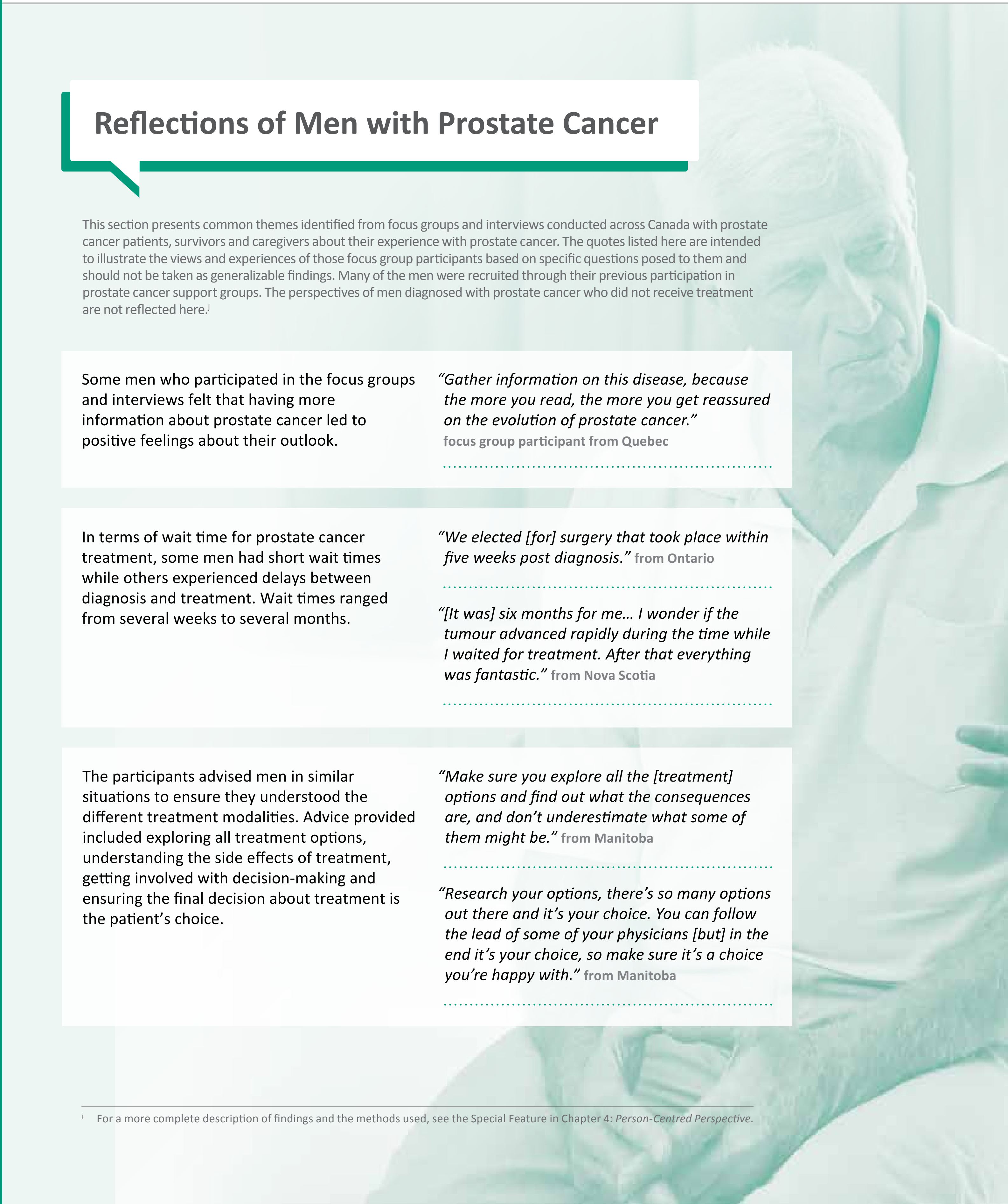
[i] It should be noted that not all organizations or doctors agree on the definitions of the terms used above. In some cases, "active surveillance" and "watchful waiting" are used interchangeably.[2] However, for this report we are using the definitions issued by Prostate Cancer Canada and the American Cancer Society.[4, 5]



Reflections of Men with Prostate Cancer

This section presents common themes identified from focus groups and interviews conducted across Canada with prostate cancer patients, survivors and caregivers about their experience with prostate cancer. The quotes listed here are intended to illustrate the views and experiences of those focus group participants based on specific questions posed to them and should not be taken as generalizable findings. Many of the men were recruited through their previous participation in prostate cancer support groups. The perspectives of men diagnosed with prostate cancer who did not receive treatment are not reflected here.[j]

Some men who participated in the focus groups and interviews felt that having more information about prostate cancer led to positive feelings about their outlook.

"Gather information on this disease, because the more you read, the more you get reassured on the evolution of prostate cancer." **focus group participant from Quebec**

In terms of wait time for prostate cancer treatment, some men had short wait times while others experienced delays between diagnosis and treatment. Wait times ranged from several weeks to several months.

"We elected [for] surgery that took place within five weeks post diagnosis." **from Ontario**

"[It was] six months for me… I wonder if the tumour advanced rapidly during the time while I waited for treatment. After that everything was fantastic." **from Nova Scotia**

The participants advised men in similar situations to ensure they understood the different treatment modalities. Advice provided included exploring all treatment options, understanding the side effects of treatment, getting involved with decision-making and ensuring the final decision about treatment is the patient's choice.

"Make sure you explore all the [treatment] options and find out what the consequences are, and don't underestimate what some of them might be." **from Manitoba**

"Research your options, there's so many options out there and it's your choice. You can follow the lead of some of your physicians [but] in the end it's your choice, so make sure it's a choice you're happy with." **from Manitoba**

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[j] For a more complete description of findings and the methods used, see the Special Feature in Chapter 4: *Person-Centred Perspective*.

Men reported mixed experiences in terms of how aware they had been about potential short- and long-term side effects of their treatment.

“My experience was that I didn’t learn about the side effects or anything until really after the treatment. So I feel like I was cheated in some way. Not being offered you know, something up front before I got the treatments.” **from Manitoba**

“I found it was self-explanatory with side effects. The discussion after the operation we had helped [me] make the right decision. I recovered faster because I did have my prostate out. With the radiation I did lose my energy.” **from Manitoba**

Some men provided details about effects of treatment on their mental, physical and emotional well-being.

“The treatment messes with…your mind a lot; it throws you into that dark place.” **from Manitoba**

“I’ve been out of radiation for a few months now, but the fatigue is the one that was really hard to deal with.” **from Quebec**

“I’m on the hormone pill. As far as the sexual part goes, it’s just about wiped out.” **from Nova Scotia**

“I have had serious problems with fear of reoccurrence of the cancer. I’m 82 years of age now…if I have a pain in my knee, I immediately think, will that be cancer? And it is very hard to know what is cancer and what is not.” **from Ontario**

Wait Times for Surgery

What are we measuring and why?

This indicator measures the wait time for men with prostate cancer from the booking date of a surgery to when the surgery actually takes place. The booking date is considered to represent the point at which the patient and physician agree that surgery is the treatment of choice and that the patient is ready to have the surgery. Results are presented for surgeries occurring in 2014.

- Due to the slow-growing nature of most prostate cancers, wait times of a few weeks for treatment are often unlikely to affect outcomes. However, a prolonged delay between cancer suspicion and treatment is stressful and can lead to excess anxiety for patients and their family members.[73, 74] For system managers and health care planners, having reliable surgical wait times data is crucial for assessing system capacity and demand, and for managing the use of resources.
- The surgery performed to remove prostate cancer is radical prostatectomy (RP), which involves removal of the prostate gland, surrounding tissues and the seminal vesicles. The main intent of RP is curative. Pelvic lymphadenectomy, which involves removal of the pelvic lymph nodes, may also be done to improve prognosis.
- Transurethral resection of the prostate (TURP), where the prostate tissue is removed via the urethra, may be performed as a palliative procedure for men with advanced prostate cancer to relieve symptoms related to urination.[2]

What are the results?

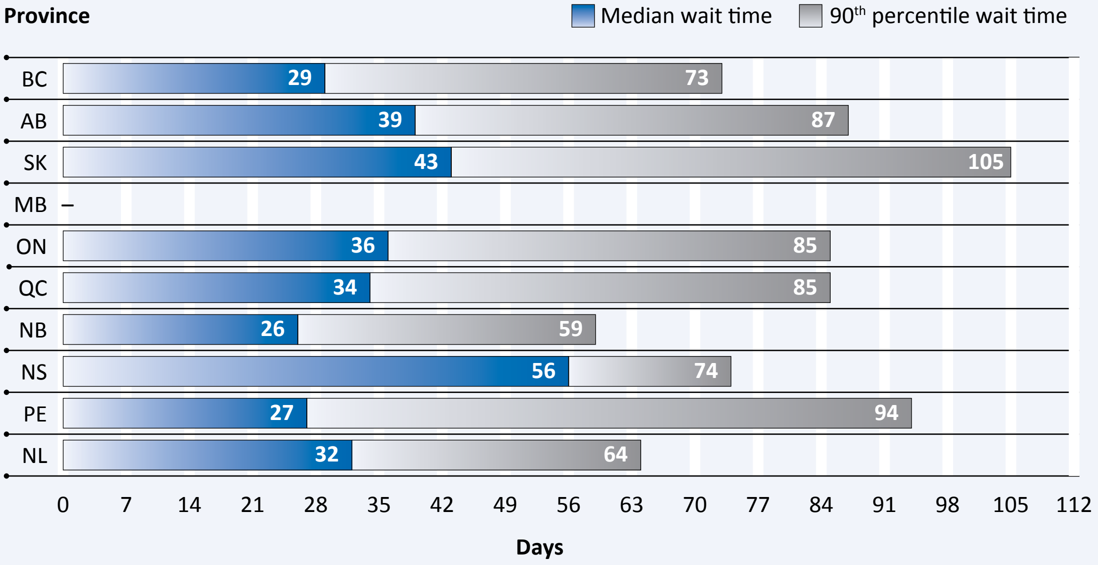
- Median wait times from booking date to day of surgery ranged from a low of 26 days in New Brunswick to a high of 56 days in Nova Scotia (Figure 3.1).
- There was also wide interprovincial variation for the 90th percentile wait time (defined as the number of days by which time 90% of men have had their surgery). In New Brunswick, 90% of men had their surgery within 59 days of the booking date compared to 105 days in Saskatchewan.

Data and measurement considerations

- The results presented here are based on data provided by the provinces to the Canadian Institute for Health Information (CIHI). The data include men 18 years and older with proven or suspected prostate cancer (new, recurrent, metastatic) who had surgery to treat or manage prostate cancer. It excludes patients who only had a biopsy, who only received neo-adjuvant therapy (i.e., given before the main treatment) and who were emergency cases.
- The definition of prostate cancer cases, cancer surgeries and start date may vary across provinces. See figure footnotes and refer to CIHI’s Wait Times website (http://waittimes.cihi.ca/All/prostate) for more details.

FIGURE 3.1

Median and 90th percentile surgery wait times from booking date to surgery for prostate cancer, by province — 2014



"–" Data not available.

AB: Includes biopsies as the sole procedures; includes patient unavailable days; includes neo-adjuvant therapy.

SK: Includes radical prostatectomy cases only.

ON: Includes endoscopic cases.

QC: Start date is the date the surgeon signs the surgical request.

PE: Includes emergency cases; includes days when the patient was unavailable.

NL: Excludes suspected cases.

Data source: Canadian Institute of Health Information (CIHI).

What do the results mean?

- Wait times may be affected by various factors, including risk category of the cancer, whether neo-adjuvant treatment is being undertaken and delays that are patient-driven. But these factors are not expected to vary substantially between provinces. The majority of inter-provincial variation in wait times for prostate cancer surgery is likely related to differences in system capacity available for prostate cancer surgery (e.g., the number of urologists, availability of hospital operating rooms and surgical beds).
- A recent report by CIHI showed that the wait time for prostate cancer surgery in 2013 and 2014 was longer than the wait times for surgery for bladder, breast, colorectal and lung cancers.[75] Because of the slow-growing nature of localized prostate cancer, surgery may not be considered as urgent as it is for other cancers; as a result, system resources may be intentionally organized so that prostate cancer surgeries are booked further out. This could be one explanation for the longer wait times.
- It is important to keep in mind that the time period measured here is just one phase in the patient journey; other key points (e.g., time from suspicion to diagnosis, time from diagnosis to decision-to-treat) are also important when assessing person-centred care and system effectiveness.

What are some examples of efforts in this area?

- There is currently no national target for wait times for prostate cancer surgery although a few provinces have established a specific approach, including targets for reducing wait times. In Manitoba, these are specified only for head and neck cancers. In Ontario and Saskatchewan, wait times targets are specified for different priority levels (i.e., based on urgency). In Ontario, the target 90th percentile wait time for cancer surgery is 84 days.[76]
- Efforts have been made to let patients know about current wait times for cancer treatment in their jurisdictions. Many provinces (British Columbia, Alberta, Saskatchewan, Ontario, Quebec, New Brunswick, Nova Scotia and Newfoundland and Labrador) report wait times for prostate cancer surgery data on their websites. For example, New Brunswick's website provides patients with current wait time information for hospitals within the province on a quarterly basis.[77] British Columbia's website can show wait times by specialist.[78]
- In Australia, the national average wait time for prostate cancer surgery was reported as 42 days; however, this varied widely by hospital.[79] Information on wait times by hospital is also available to the public online.[80]

Wait Times for Radiation Therapy

What are we measuring and why?

This indicator measures wait times, starting from the time men with prostate cancer are ready to be treated with radiation therapy to the actual start of treatment (for 2013). This measure is expressed as the percentage of prostate cancer patients treated within the national target wait time (28 days) as well as the 90th percentile wait times in days. The indicator also examines the median and 90th percentile wait times in days by patient risk category (as per the GUROC Canadian Consensus definition).

- A prolonged delay between cancer suspicion and treatment is stressful and can lead to excess anxiety for patients and their family members.[73, 81] National wait time targets have been set and provincial initiatives to reduce wait times have been implemented.[82]
- Radiation is one of the primary treatment modalities for men with low-, intermediate- and high-risk prostate cancer as per evidence-based guidelines. It is commonly used post-operatively (adjuvant therapy) to reduce risk of recurrence and when pathology reports indicate positive surgical margins (i.e., cancer cells were found at the edges of the removed tumour).[83]
- Many studies have demonstrated that prostate cancer patients wait longer for radiation therapy compared to patients with other types of cancer.[81] Longer wait times may be expected due to the nature of prostate cancer; in many men, prostate cancer is slow-growing so treatment may be considered less urgent for prostate cancer than for other cancers.
- Analyzing radiation therapy wait times by prostate cancer risk profile may help to identify whether delays exist. This in turn may help efforts aimed at optimizing wait times for treatment. It is important to note that not all patients need to receive radiation therapy with the same urgency.

What are the results?

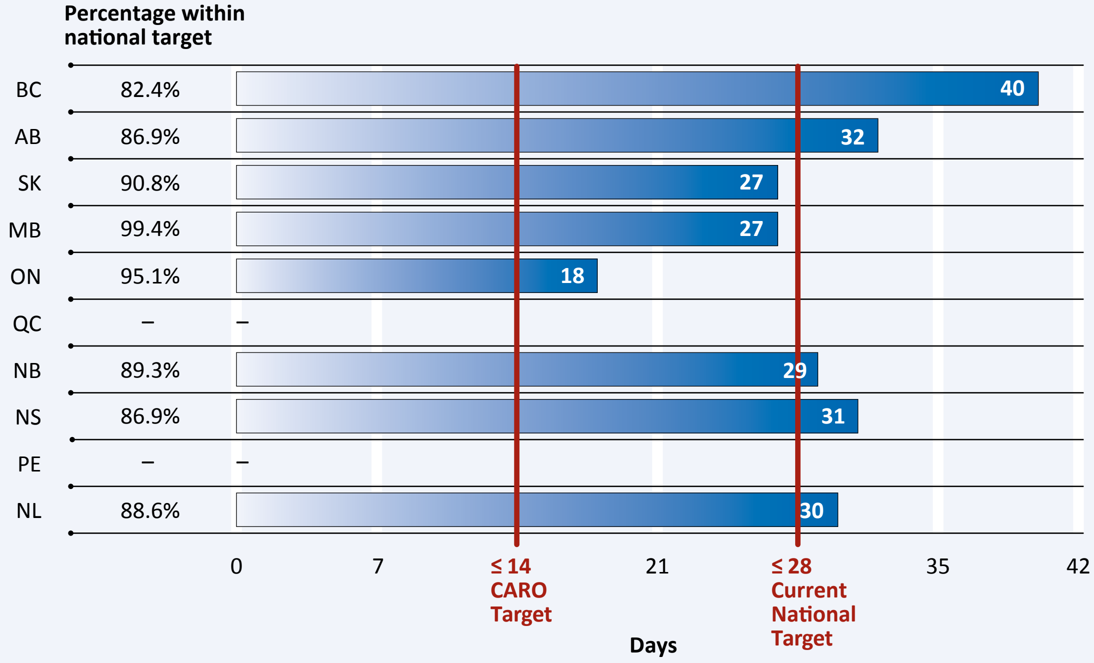
- Prostate cancer patients waited longer for radiation therapy than patients with breast, colorectal or lung cancers in all reporting provinces (data not shown).
- In the 2013 treatment year, Ontario's 90th percentile wait time for radiation therapy (18 days) to treat prostate cancer was the shortest in the country; the 90th percentile wait time in British Columbia was the longest (40 days) (Figure 3.2).
- The percentage of prostate cancer patients treated within the national wait time benchmark (28 days from ready-to-treat) ranged from 82.4% to 99.4%. Three of the eight reporting provinces achieved the target wait time (Figure 3.2).
- British Columbia's 90th percentile wait times showed timing of radiation therapy may be prioritized based on patients' risk levels: higher-risk patients waited less time for radiation therapy to start compared to patients deemed to be at lower-risk (Figure 3.3). However, of the five reporting provinces, British Columbia had the longest 90th percentile wait times for intermediate- and low-risk patients; Saskatchewan had the shortest.

Data and measurement considerations

- The criteria for assigning risk based on the GUROC Canadian Consensus definition include non-metastatic patients only. This means that metastatic patients were excluded from the analysis showing wait times by risk category (Figure 3.3). For other analyses of radiation therapy wait times, all prostate cancer patients (non-metastatic and metastatic) were included (Figure 3.2).
- The indicator examining the median and 90th percentile wait times by risk category includes data on patients who received treatment to the primary cancer site only (the prostate gland) (Figure 3.3). Indicator data on the 90th percentile wait times (not by risk category) are consistent with provincial wait times definition, which means that waits could be reported by primary site (prostate gland) or by the site receiving treatment (i.e., metastatic site) (Figure 3.2).
- "Ready-to-treat" is the starting point for the wait time measurement. While considerable effort has gone into developing and adopting a standardized definition for this term, interprovincial variations may persist.
- Radiation therapy wait times include wait times for external beam radiation therapy (EBRT) or brachytherapy where available.
- The Canadian Association of Radiation Oncology (CARO) has set a target of 10 working days (14 calendar days) from the day of consultation or requisition to the start of radiation therapy for all cancer patients.[84] This target is shown in the figures along with the national target of 28 days.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

FIGURE 3.2

90th percentile radiation therapy wait times from ready-to-treat to start of radiation for prostate cancer, by province — 2013 treatment year



"–" Data not available.

Wait time is from ready-to-treat to start of radiation.

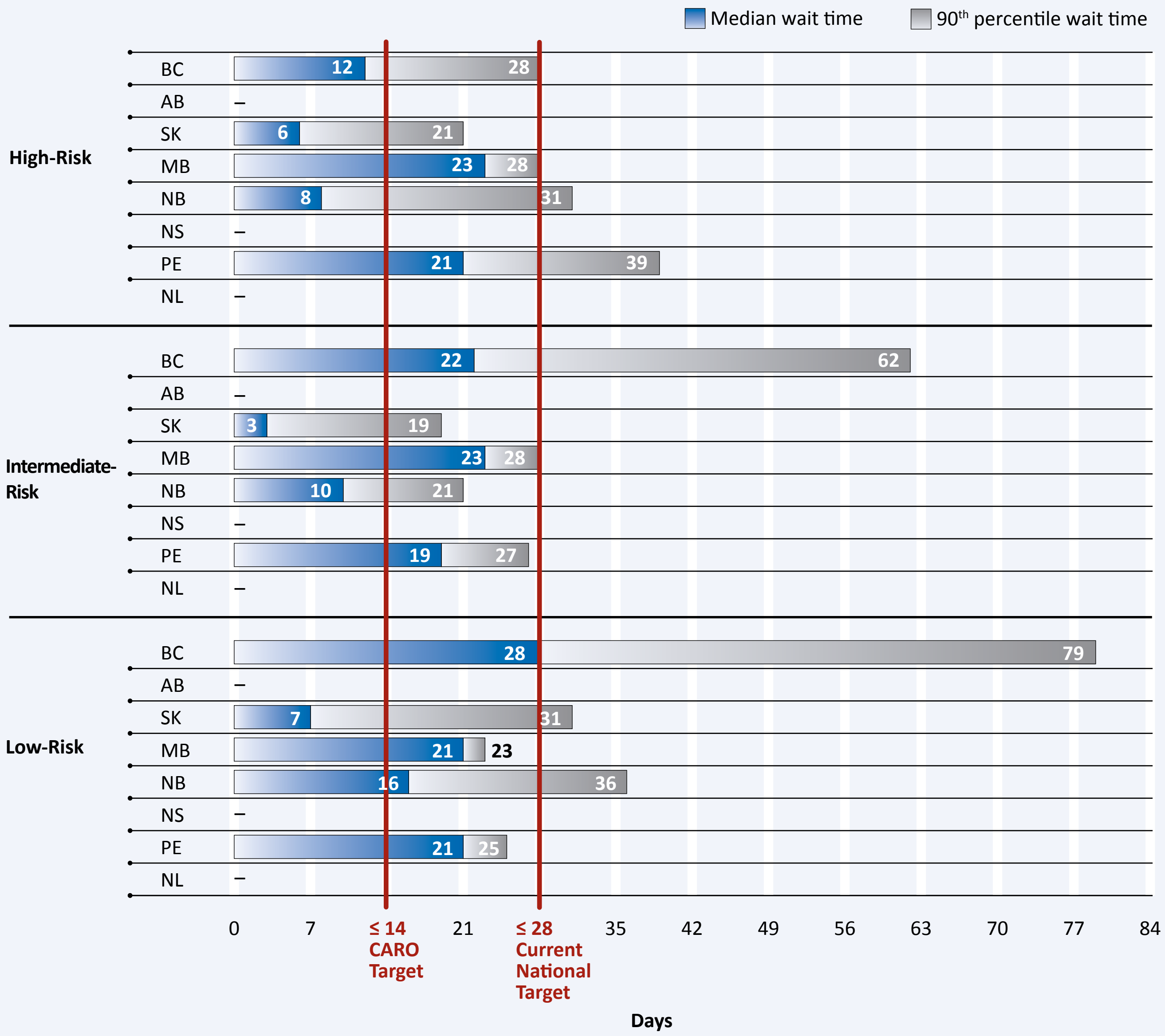
The Canadian Association of Radiation Oncology (CARO) has set a target of 14 days (10 working days) from consultation to first radiation therapy fraction.

The national target is for 90% of patients to receive radiation therapy within 28 days from ready-to-treat to start of treatment.

Data source: Provincial cancer agencies.

FIGURE 3.3

Median and 90th percentile radiation therapy wait times from ready-to-treat to start of radiation for prostate cancer, by province, by risk category — 2013 treatment year



"–" Data not available.

AB: Risk group cannot be assigned for more than 55% of patients.

NS: Data were not available due to incomplete disease information for 2013 cases.

The Canadian Association of Radiation Oncology (CARO) has set a target of 14 days (10 working days) from consultation to first radiation therapy fraction.

The national target is for 90% of patients to receive radiation therapy within 28 days from ready-to-treat to start of treatment.

Data source: Provincial cancer agencies.

What do the results mean?

- Examining wait times interprovincially can help identify potential benchmarks. Only three of eight reporting provinces achieved the target of 90% of patients receiving radiation therapy within the national wait time benchmark of 28 days from ready-to-treat.
- Urgency of treatment seems to be a key factor in wait times. A study was undertaken to identify delays in the process from diagnosis to radiation treatment among prostate cancer patients who received curative radiation therapy treatment at the Odette Cancer Centre in Toronto, Ontario.[81] This study found that the time interval between diagnosis and delivery of a first fraction of radiation therapy was appropriately shorter for intermediate- and high-risk patients (124 days) compared to wait times for low-risk patients in the group (178 days).

What are some examples of efforts in this area?

- The System Performance Steering Committee has recognized that taking a more person-centred approach to wait time measurement is valuable—that is, going beyond just measuring the time between ready-to-treat and start of treatment. The Committee examined two options: measuring the time between consultation with an oncologist and the start of treatment; and measuring the time from diagnosis to the start of treatment. This would allow us to capture a broader segment of the patient journey, and identify opportunities for process improvement. This may be further explored in future System Performance work.
- In 2011, a research initiative began examining the impact of delayed wait times on the treatment of patients with intermediate- and high-risk prostate cancer. The retrospective study is evaluating how patient outcomes are affected by the amount of time between prostate biopsy and the start of treatment.[85]

Patterns of Care: Radiation and Surgical Treatment

What are we measuring and why?

This indicator measures the percentage of non-metastatic prostate cancer patients, aged 35 years and older, who received various forms of primary treatment by risk category (as per the GUROC Canadian Consensus definition). This indicator compares results for patients diagnosed in 2010 by participating provinces. Also, treatment patterns by patient age at diagnosis (≤75 years of age and >75 years of age) are compared by risk category.

- Assessing patterns of care by risk category allows jurisdictions to examine their clinical practices against those in other jurisdictions. This knowledge may also help provinces enhance alignment with clinical guidelines.
- The type of treatment received by men with non-metastatic prostate cancer depends on their individual risk category (low-, intermediate- or high-risk) and other patient characteristics, such as age at the time of diagnosis as per the National Comprehensive Cancer Network (NCCN) guidelines (see the *Risk Profile* section in Chapter 2: *Diagnosis and Staging* for a description of prostate risk categories).[83] Analysis at the population-level may help evaluate treatment patterns and assess outcomes.
- Prostate cancer patients with non-metastatic disease may undergo curative primary treatment. This may involve radical prostatectomy (removal of the prostate gland along with nearby tissue) or radiation therapy, which may be administered with or without androgen deprivation therapy (ADT).[83] Some patients may undergo a combination of surgery and adjuvant (i.e., given after surgery) radiation therapy. Two types of radiation therapy are used: external beam radiation therapy (EBRT) and interstitial prostate brachytherapy. Prostate cancer patients may also be placed on active surveillance or watchful waiting, which allows them to delay or even avoid treatment (see *About Active Surveillance and Watchful Waiting* at the beginning of this chapter).
- Certain factors are known to increase the risk of cancer recurring after surgical removal of the prostate. These include positive resection margins (where cancer cells are found on the outer edges of the resected tumour). Rates of positive margins in men who have undergone surgery for prostate cancer have ranged from 10% to 36%.[86, 87] Men whose surgeries leave positive margins may gain additional benefit from adjuvant radiation therapy. Radiation therapy may be administered early after surgery (generally within one year) in the case of adjuvant therapy or when PSA levels have risen, which is referred to as salvage therapy (generally after one year).

What are the results?

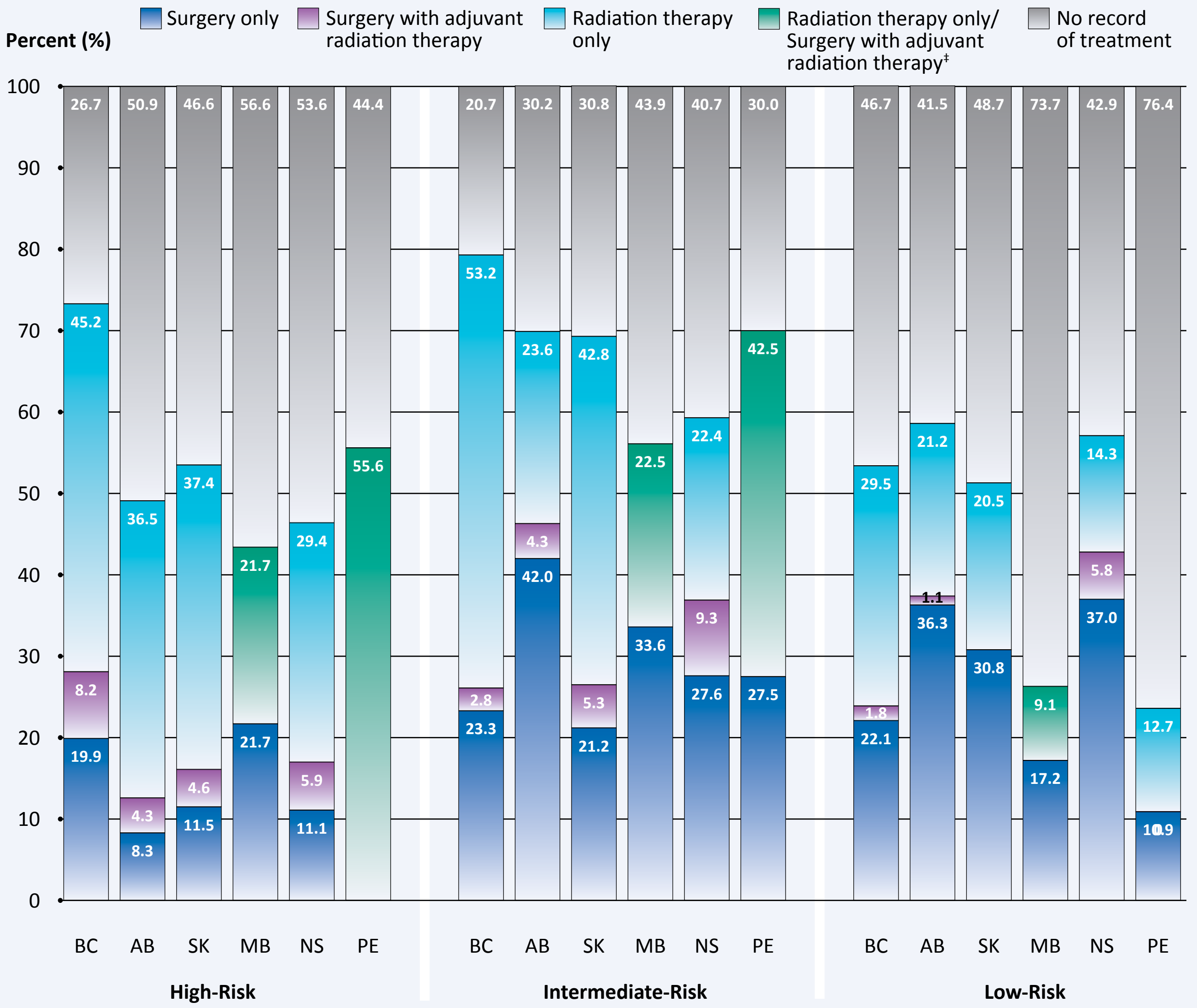
- Patterns of primary treatment for men with non-metastatic prostate cancer varied across the country, depending on men's risk categories. Radical prostatectomy was the most commonly used treatment for men with low-risk prostate cancer in most provinces (Figure 3.4); radiation therapy was the most common primary treatment modality for low-risk patients in Prince Edward Island and British Columbia.
- For men in the high-risk group, treatment patterns were quite different: radiation therapy was the most common treatment modality.
- A considerable proportion of low-risk (41.5% to 76.4%) and high-risk (26.7 % to 56.6%) patients had no record of surgical or radiation treatment in the data. This was seen primarily among low-risk patients in Manitoba and Prince Edward Island, and among high-risk patients in Manitoba and Nova Scotia (Figure 3.4).
- Overall, among men who had surgery, only a small proportion received adjuvant radiation therapy (Figure 3.4).
- Figures 3.5 and 3.6 describe primary treatment patterns by patients' age at diagnosis and risk category, and shows the extent to which patient age influences treatment decisions. In general, most men over 75 years of age had no record of surgical or radiation treatment across all risk categories (Figure 3.6). Some exceptions were noted: for example, British Columbia reported a relatively high percentage of patients over 75 years of age who received some form of treatment across all risk groups. These findings may reflect a collaborative stage data quality issue (See *Data and measurement considerations* for more information on how risk profiles were derived).
- Compared to older men in intermediate- and high-risk categories, a greater proportion of low-risk men age 75 and under had no record of treatment. Prince Edward Island and Manitoba reported the highest percentage (72.9% and 71.1%, respectively) (Figure 3.5).
- Among men who received radiation therapy, low-risk prostate cancer patients were more likely to receive brachytherapy alone compared to intermediate- and high-risk patients (Figure 3.7). This finding is similar to results from previous studies.[72] The highest proportionate use of brachytherapy in the low-risk group was in British Columbia; the lowest was in Saskatchewan (the data suggest no patients received brachytherapy in Nova Scotia during the time period of this analysis although some patients may have travelled out of province to access this treatment). Nearly all high-risk patients received external beam radiation therapy alone (Figure 3.7).

Data and measurement considerations

- Treatment patterns were examined for prostate cancer patients aged 35 years and older using data collected by provincial cancer agencies.
- Metastatic prostate cancer patients were excluded from the patterns of care analysis, as GUROC risk categories are only pertinent to localized disease.
- Data on the risk profiles of men with prostate cancer were not captured by the provinces, so a decision was made to deduce the profiles statistically. This was done by looking at three types of prognostic data contained in various administrative datasets: site-specific factor 1 (PSA value), site-specific factor 8 (Gleason Score), and CS extension (Clinical T-Stage). The risk factors indicator uses collaborative stage data from the provincial cancer registries. This information was extracted from patient charts, providing a contemporary risk profile of prostate cancer patients in Canada. Not all cases were captured due to incomplete data for one or more of the three prognostic factors used to calculate risk. Overall, approximately 2% to 17% of cases were excluded due to incomplete data.
- This indicator looks at treatment patterns within one year of diagnosis and within one year post-surgery for adjuvant radiation therapy. This time frame will more likely differentiate active surveillance from primary treatment, and will more likely capture patients receiving adjuvant radiation therapy for the first time as opposed to those undergoing salvage therapy (i.e., treatment given after the cancer has not responded to other treatments).
- As per the information presented in the *Diagnosis and Staging* chapter of this report, British Columbia had a high percentage of cases deemed as “stage unknown.” Risk category may not be identifiable for those cases. This may affect the comparability of the patterns of care analysis by risk category.
- Data were not consistently available to allow us to examine use of androgen deprivation therapy (ADT), a form of hormone therapy. Similarly, no consistent data were available about observation approaches (i.e., active surveillance, watchful waiting) or other treatment options such as chemotherapy. Only data on EBRT, brachytherapy and surgery were available for the patterns of care indicator. So it is possible that men diagnosed in 2010 who did not have a record of treatment within one year post-diagnosis might have been suitable candidates for active surveillance or watchful waiting; they might have been treated with cryotherapy or high-intensity focused ultrasound (HIFU); they might have been prescribed ADT alone; or they might have been prescribed ADT with the intent that they would receive surgery or radiation therapy after one year. It is also possible that these men chose not to undergo treatment at that time.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

FIGURE 3.4

Percentage of prostate cancer patients (men aged ≥ 35) receiving various types of treatment,[†] by risk category, by province — 2010 diagnosis year



[†] This indicator looks at treatment patterns within one year of diagnosis and within one year post-surgery for adjuvant radiation therapy.

[‡] The categories ‘Radiation therapy only’ and ‘Surgery with adjuvant radiation therapy’ were combined due to small numbers and/or to avoid residual disclosure.

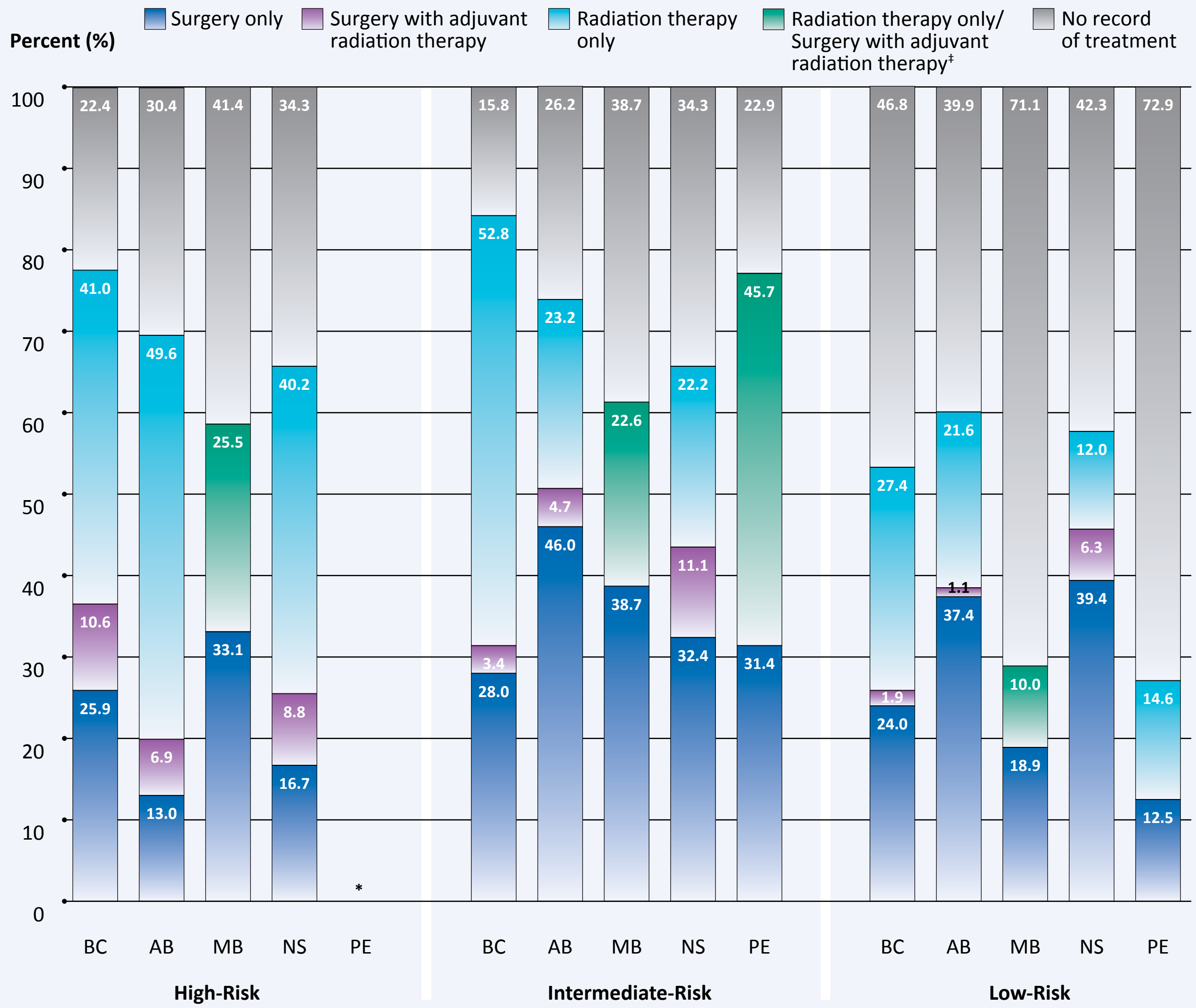
No record of treatment may include, but is not limited to, surgeries other than radical prostatectomy, active surveillance, watchful waiting, hormone therapy, chemotherapy and patient refusal.

Radiation therapy includes both external beam radiation therapy and brachytherapy. Surgery includes radical prostatectomy.

Data source: Provincial cancer agencies.

FIGURE 3.5

Percentage of prostate cancer patients receiving various types of treatment[†] for men aged 75 or younger, by risk category, by province — 2010 diagnosis year



† This indicator looks at treatment patterns within one year of diagnosis and within one year post-surgery for adjuvant radiation therapy.

‡ The categories 'Radiation therapy only' and 'Surgery with adjuvant radiation therapy' were combined due to small numbers and/or to avoid residual disclosure.

* Suppressed due to small numbers.

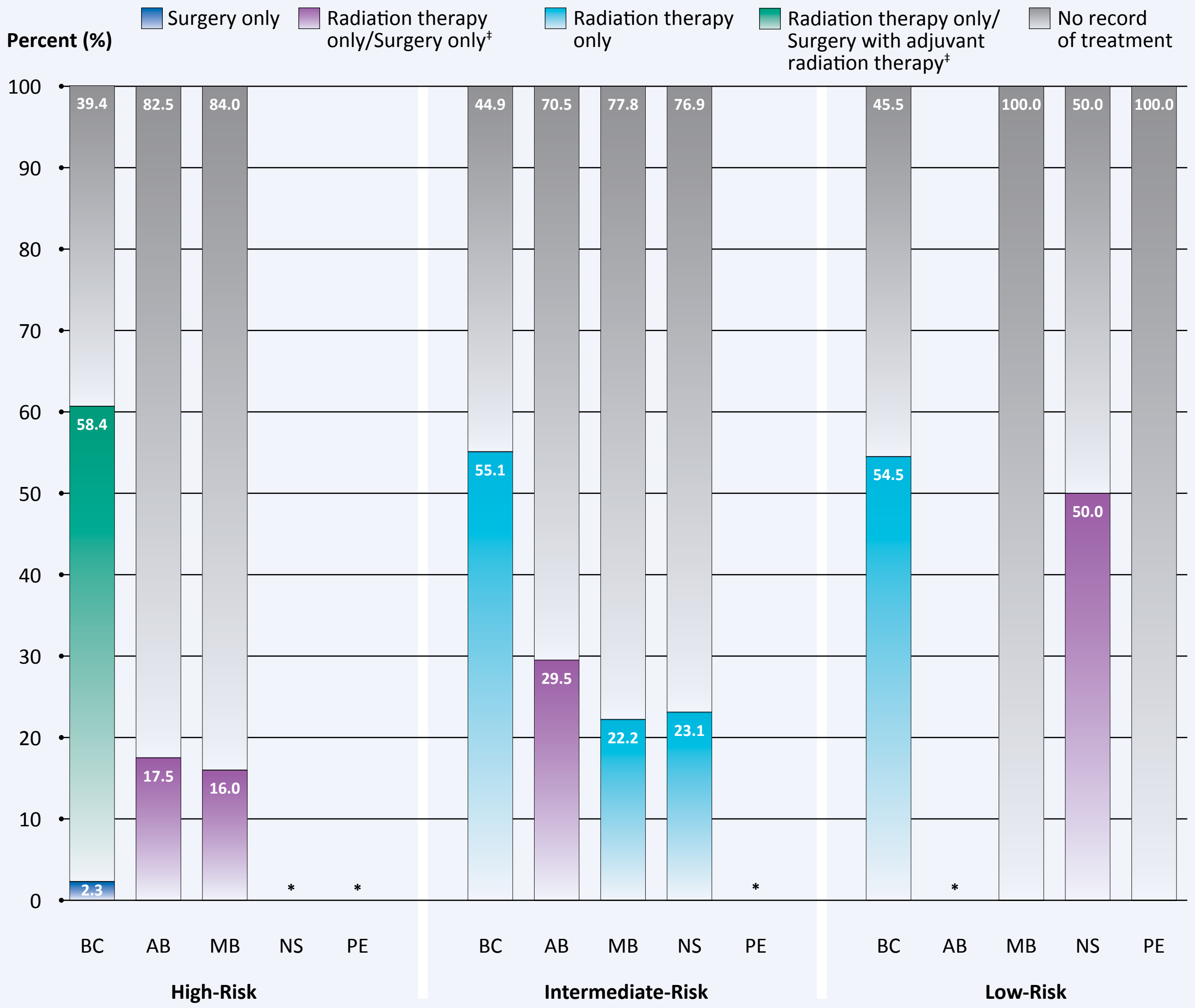
Radiation therapy includes both external beam radiation therapy and brachytherapy. Surgery includes radical prostatectomy.

No record of treatment may include, but is not limited to, surgeries other than radical prostatectomy, active surveillance, watchful waiting, hormone therapy, chemotherapy, and patient refusal.

Data source: Provincial cancer agencies.

FIGURE 3.6

Percentage of prostate cancer patients receiving various types of treatment† for men over age 75, by risk category, by province — 2010 diagnosis year



† This indicator looks at treatment patterns within one year of diagnosis and within one year post-surgery for adjuvant radiation therapy.

‡ The categories 'Radiation therapy only' and 'Surgery with adjuvant radiation therapy' were combined due to small numbers and/or to avoid residual disclosure. The categories 'Radiation therapy only' and 'Surgery only' were combined for the same reason.

* Suppressed due to small numbers.

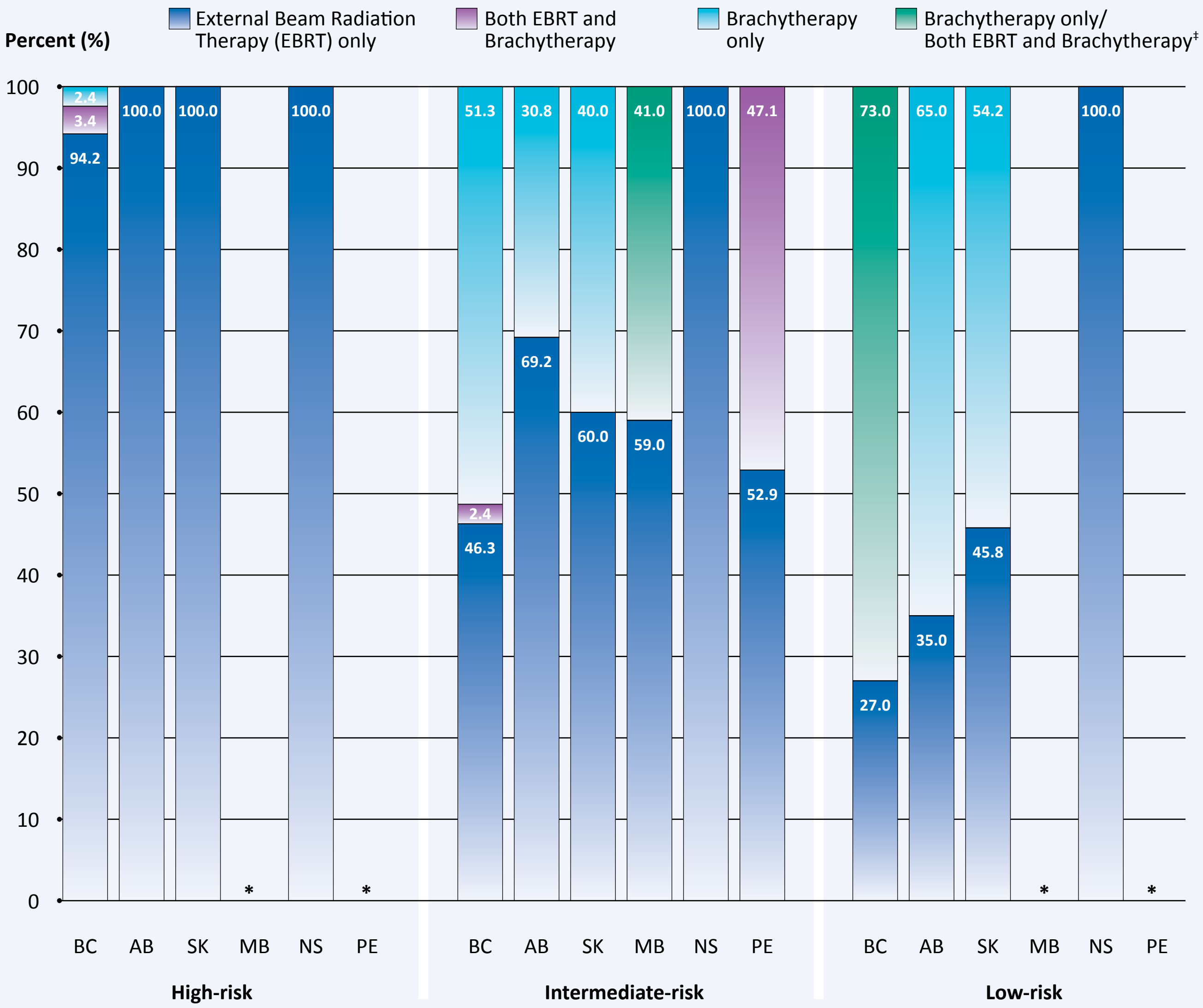
Radiation therapy includes both external beam radiation therapy and brachytherapy. Surgery includes radical prostatectomy.

No record of treatment may include, but is not limited to, surgeries other than radical prostatectomy, active surveillance, watchful waiting, hormone therapy, chemotherapy, and patient refusal.

Data source: Provincial cancer agencies.

FIGURE 3.7

Percentage of prostate cancer patients (men aged ≥ 35) receiving various types of radiation therapy,† by risk category, by province — 2010 diagnosis year



† This indicator looks at treatment patterns within one year of diagnosis and within one year post-surgery for adjuvant radiation therapy.

‡ The categories ‘Brachytherapy Only’ and ‘Both EBRT and Brachytherapy’ were combined due to small numbers and/or to avoid residual disclosure.

* Suppressed due to small numbers.

NS: During the time period of this analysis some patients may have travelled out of province to access this service.

Data source: Provincial cancer agencies.

What do the results mean?

- Patterns of primary treatment for men with non-metastatic prostate cancer varied based on the risk category of the disease. Men with low-risk disease were most commonly treated with radical prostatectomy, while men with high-risk disease were most commonly treated with radiation therapy. These findings are comparable to a systematic review conducted by Sanyal et al. in 2013. Their study found that patients with low- to intermediate-risk profiles primarily received radical prostatectomy, while patients with a high-risk profile received radiation therapy.[72] This variability in treatment patterns for men with prostate cancer should continue to be monitored to optimize outcomes.

RADICAL PROSTATECTOMY

- Radical prostatectomy rates varied depending on the patients' risk category and age at diagnosis (Figures 3.4, 3.5 and 3.6). Surgery rates were highest among men in the intermediate-risk category (those aged 75 years and under). Rates of surgery were low (below 7.1%) among men over age 75 (data not shown).

- Previous studies found a relationship between surgical volume and patient outcomes; surgeons who perform higher annual volumes of radical prostatectomy have been associated with improved outcomes such as lower rates of positive surgical margins.[88] Based on a steep surgical learning curve (i.e., it has been shown that a surgeon must perform at least 250 RPs to reach the plateau of the learning curve and to maximize cancer control) and the need for continuous practice, annual RP minimum volume thresholds have been suggested.[89] For example, annual thresholds of 20 and 50 RPs have been proposed, but only a small proportion of surgeons in the United States and Europe reach these numbers.[90, 91]

NO RECORD OF TREATMENT (POTENTIALLY ACTIVE SURVEILLANCE OR WATCHFUL WAITING)

- Based on data reported here, most men over age 75 had no record of treatment across risk categories. This was most pronounced in the low-risk group (Figure 3.6). It was determined that age 75 is an approximation for a current 10-year life expectancy, which evidence suggests should be the criterion for curative treatment.[83] This may explain the high percentage of patients over age 75 who had no record of treatment.

- These results are consistent with age-specific treatment patterns observed in other jurisdictions, including the United States. A recent American study showed that 61% of men aged 75 and older diagnosed with prostate cancer did not undergo surgery or radiation therapy.[92]

- While the actual percentage of prostate cancer patients on active surveillance or watchful waiting could not be captured and reported here, we could assume that at least a portion of low-risk prostate cancer patients with no record of treatment were on active surveillance or watchful waiting. Similarly, we could assume that a portion of high-risk patients were receiving ADT alone, and therefore would appear in the data under "no record of treatment." ADT is a primary systemic therapy for men with advanced prostate cancer and is also used as neoadjuvant/concomitant/adjuvant therapy in combination with radiation therapy for men with non-metastatic disease.[2]

ADJUVANT RADIATION THERAPY

- GUROC recommends that men who undergo radical prostatectomy have a consultation with a radiation oncologist soon after surgery to discuss the benefits and risks of adjuvant radiation therapy. If therapy is deemed appropriate (indications include positive surgical margin(s), Gleason score 8-10, extra-prostatic extension or seminal vesicle invasion), radiation therapy should begin within six months of surgery.[2, 93]

- Based on results reported here, only a small percentage of patients received adjuvant radiation therapy (Figure 3.4). If these data accurately reflect clinical practice, it may suggest that surgeons are not consistently referring patients to radiation oncologists following surgery.

USE OF BRACHYTHERAPY

- Brachytherapy involves placing radioactive material into the prostate gland, allowing the slow, targeted release of radiation. The use of brachytherapy varied across participating provinces (Figure 3.7). This may reflect differences among provinces in their eligibility criteria (i.e., by patient risk category) for funding brachytherapy.

What are some examples of efforts in this area?

- In Ontario, an initiative called the *Prostate Cancer Patterns of Care Project* has been established. Its goal is to encourage appropriate referrals for prostate cancer patients, allowing them to make more informed decisions about their treatment.[65] This includes initiating referrals prior to treatment and enabling early discussion about adjuvant therapies if appropriate.
- *Choosing Wisely Canada®* is a campaign aimed at helping physicians and patients engage in conversations about unnecessary tests, treatments and procedures. It recommends that care providers discuss the option of active surveillance before initiating treatment in men with low-risk prostate cancers.[95, 96] The Prostate Cancer Intervention Versus Observation Trial (PIVOT) showed that radical prostatectomy had no benefit over active surveillance among low-risk prostate cancer patients randomly assigned to receive either radical prostatectomy or active surveillance. The prostate cancer-specific mortality rates were 5.8% (surgery) and 8.4% (active surveillance). (This difference was not considered to be statistically significant).[97]
- While certain jurisdictional brachytherapy programs offer the high-dose rate (HDR) method of brachytherapy, plans are under way to expand this method for use in other Canadian cities including St. John’s, Halifax, Edmonton, Calgary and Saskatoon.[94]
- The Partnership-funded *Electronic Synoptic Pathology Reporting Initiative (ESPRI)* aims to facilitate the implementation of electronic synoptic pathology reporting for some cancers including prostate cancer. Using a standardized template for reporting may help yield additional information that will prove useful in understanding surgical practices, such as interprovincial variations in positive resection margin rates. To date, ESPRI has been implemented in two provinces (Ontario and New Brunswick); roll-out is being phased in at sites across four other provinces (British Columbia, Manitoba, Prince Edward Island and Nova Scotia).

Androgen Deprivation Therapy (ADT)

- No data are routinely collected to allow for a pan-Canadian review of androgen deprivation therapy (ADT) use. This section summarizes some of what we know about ADT use in Canada.
- Prostate cancer patients with advanced or metastatic disease are usually treated with ADT (a hormone therapy) and chemotherapy. ADT may be used before, during and after radiation therapy in men with intermediate- and high-risk non-metastatic prostate cancer to improve outcomes over radiation alone. For men with metastatic disease, ADT is considered the "gold standard" treatment.[83]
- In most cases, ADT involves using medication (chemical castration). Less commonly, men with advanced disease undergo a surgical procedure called orchiectomy—the surgical removal of both testicles. This stops nearly all production of the male hormone, which prostate cancer usually needs to continue growing.
- The effective use of radiation therapy with the addition of ADT in intermediate- and high-risk patients is supported by randomized controlled trial results, which have shown a clinical benefit.[98] No survival benefit has been observed from combining radiation therapy and ADT for low-risk prostate cancers, so ADT should not be recommended as a treatment option for these men.[83]
- Based on a recent chart review of Canada's radiation therapy cancer centres, more than half of high-risk prostate cancer patients (54%) and a proportion of intermediate-risk patients (39%) received ADT.[99] It is estimated that most men with metastatic prostate cancer take ADT for its survival benefit.
- Prostate cancer patients usually respond to ADT initially, but within a few years the treatment may become insufficient. At this point, the patient is said to be "castrate-resistant." The next step may be to place him on new generation hormonal therapy or chemotherapy to improve survival and prevent or control pain.[100]

What else do we know?

- Focal therapy is a relatively new treatment option for prostate cancer and is still considered "experimental in guidelines."[101] Similar to lumpectomy in breast cancer, focal therapy involves treating only a part of the prostate gland in men with low- and intermediate-risk prostate cancer. Methods such as cryotherapy, brachytherapy, high-intensity focused ultrasound and other modalities are being developed for use with MRI imaging to guide such focal intervention. Focal therapy may prove to be a good option—somewhere between active surveillance and radical treatments. However, there is concern that using focal therapy will contribute to overtreatment, especially in men who might have been eligible for observation management approaches (active surveillance or watchful waiting).[102]

Radical Prostatectomy: Open versus Laparoscopic Surgery

What are we measuring and why?

This indicator measures the percentage of radical prostatectomies (RP) by type of surgical approach by province in 2013-2014. RP can be performed using an open or a laparoscopic approach.

- Radical prostatectomy is performed using either an open approach (the surgeon makes a cut in the abdominal or perineal area to reach the prostate gland) or a laparoscopic approach (the gland is removed via several smaller incisions using specialized surgical instruments and guided by a specialized camera).
- The laparoscopic approach is a more technically complex procedure to perform but less invasive for the patient. Some procedures are robotically-assisted (using a Da Vinci robot). This procedure is known as robotic-assisted laparoscopic prostatectomy (RALP). Such robotic assistance gives the surgeon a high-definition, three-dimensional view of the surgical area, providing better magnification and improved control.[103, 104] However, RALP remains controversial due to the lack of strong evidence that it provides better cancer control compared to the less costly open radical prostatectomy approach.

What are the results?

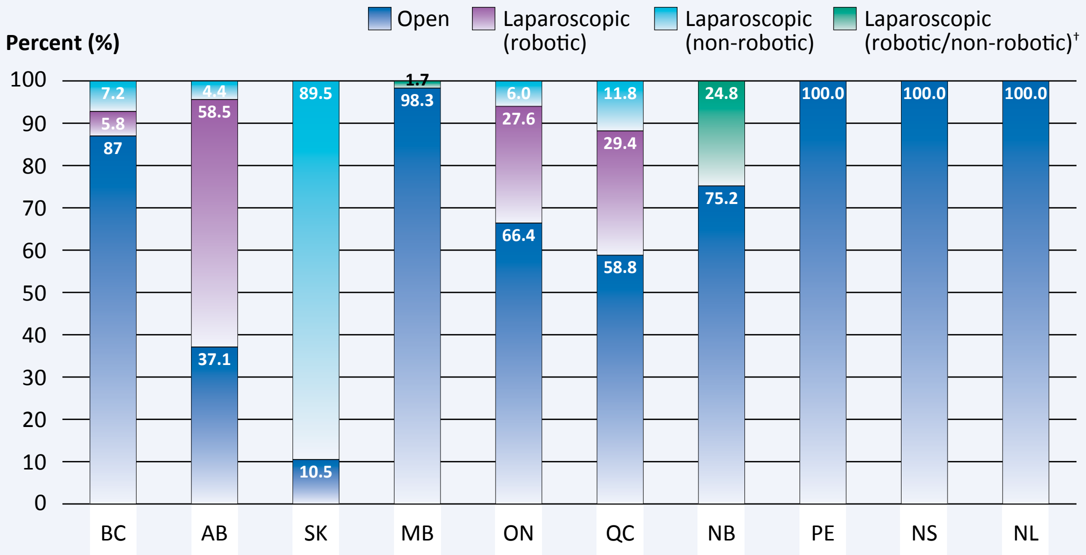
- There was much variation across provinces in the type of surgical approach used (Figure 3.8). In Saskatchewan and Alberta, most RPs were done using a laparoscopic approach, while in British Columbia, Manitoba, Ontario, Quebec and New Brunswick, most RPs were performed using an open approach. In Prince Edward Island, Nova Scotia and Newfoundland and Labrador, all RPs were done using an open approach.
- There were also marked differences in the type of laparoscopic technique used (Figure 3.8). Among those provinces that did laparoscopic RPs, the reported use of robotic technology varied. Almost all laparoscopic RPs done in Alberta were robotic-assisted, while use of this technique varied in the other provinces.
- The number of RPs performed by provinces during the period under study ranged from a low of 17 surgeries in Prince Edward Island to 2,418 surgeries in Ontario.

Data and measurement considerations

- Indicator results presented here are provided by the Canadian Institute for Health Information (CIHI). They were derived from inpatient and day surgery records from 2013-2014 for men with a documented diagnosis of prostate cancer and who had a procedure indicating prostate removal.
- Provincial results are based on where the surgery occurred, not where the patient lived at the time.
- For more details on the methodology see the Technical Notes from CIHI's Prostate Cancer Surgery Report (www.cihi.ca/web/resource/en/prostate_surgery_technotes_en.pdf).

FIGURE 3.8

Percentage of prostate cancer patients receiving radical prostatectomies, by surgical approach, by province — 2013-2014 combined



Number of radical prostatectomies performed, by province — 2013-2014

	BC	AB	SK	MB	ON	QC	NB	PE	NS	NL
Total	1,000	684	181	179	2,418	1,701	117	17	200	125

† The categories ‘Laparoscopic (robotic)’ and ‘Laparoscopic (non-robotic)’ were combined due to small numbers and/or to avoid residual disclosure in NB and MB.

Data source: Canadian Institute of Health Information (CIHI).

What do the results mean?

- It is clear that the technique used for RP depends on the province in which the surgery is done. The variation shown here may be explained by differences in system resources, as well as by surgeon and patient preferences.
- In Canada, it appears that there is still uncertainty regarding the need for laparoscopic rather than open RP procedure. While there are no published studies on Canadian surgeon preferences related to RP, a survey of 56 Canadian urology residents attending a training course in 2010 revealed that most did not regard laparoscopic RP as the gold standard approach; almost half of these residents were unsure about the future of robotic-assisted laparoscopy.[105] One explanation could be the evidence that the rate of complications from open RP—when performed by an experienced surgeon—is relatively low.[106]
- RALP is associated with high capital and operating costs. On a per patient basis, a systematic review and meta-analysis found that RALP cost an average of $3,860 more per patient than open surgery, and $4,625 more per patient than non-RALP laparoscopic surgery.[107] Among the provinces that offer laparoscopic RP, patients from provinces in which robotic-assisted technology is covered by their provincial health insurance may be more likely to undergo RALP. In fact, from 2013-2014, the province with the highest use of RALP was Alberta, where RP was covered regardless of surgical approach. On the other hand, in British

Columbia, robotic-assisted RP was not covered; use of this approach was found to be low, despite the availability of the technology.

- The decision by a hospital or a province to use surgical robotic technology has system cost implications, which likely influenced the provincial results shown here. Purchasing the robot has a high initial capital cost and annual maintenance costs. The cost-effectiveness of the Da Vinci robot depends on having a high volume of surgeries; results reported here show that many provinces had fewer than 200 surgeries per year. And those numbers may stabilize or decrease as the recommendation for active surveillance among men with low-risk prostate cancer becomes more widespread.

What are some examples of efforts in this area?

- As of 2011, there were 11 robotic-assisted surgical systems in 11 tertiary care hospitals in six Canadian cities; four of these systems were located in Alberta.[108, 109] London Health Sciences Centre in London, Ontario is the exclusive training centre for robotic surgery in Canada.[110]
- In 2012, the Canadian Agency for Drugs and Technologies in Health (CADTH) released a report comparing the current evidence on robotic-assisted technology for several procedures including RP. The report included an evaluation of the budget impact on provinces and territories that have adopted robotic technology.[107] While the report stated that the technology could have positive clinical impact on patient outcomes (i.e., reduction in blood loss and transfusion rates, shorter length of hospital stay and reduction of positive surgical margins when compared to open prostatectomy), it added that cost effectiveness must be monitored given the high cost of purchasing and maintaining the robots.[107]
- In 2014, Health Quality Ontario's Ontario Health Technology Advisory Committee commissioned an analysis by the Institute of Clinical Evaluative Sciences (ICES) to compare hospital-related outcomes in Ontario following RALP and other types of radical prostatectomy. The analysis showed that patients who had RALP had fewer blood transfusions (≤ 0.8% vs. 11.4%), fewer complications related to stricture and bladder neck contracture (4% vs. 12.1%) and shorter lengths of hospital stay compared to patients who underwent other types of radical prostatectomy.[111] The group recommended that a Provincial Steering Committee on robotic-assisted minimally invasive surgery be established to advise on the systematic collection of outcomes data, report on performance indicators associated with RALP and recommend surgeon training on the use of RALP.[111] However, conclusions about the effectiveness of RALP need to be drawn carefully given the lack of randomized trials and studies with conflicting findings.

What else do we know?

- Based on hospital data reported here, RP is increasingly being centralized regionally, but none of the provinces have an active policy in this area. Hospitals with a high volume of RPs (any type) have shorter lengths of hospital stay, lower rates of post-operative complications, lower rates of reported long-term urinary problems and lower rates of positive margins.[112] In Canada, recent CIHI analysis showed that those hospitals with the highest RP volumes performed over 60% of RPs in the country.[113]
- Studies comparing patient outcomes from open RP and laparoscopic RP found results were similar for both approaches;[106, 114, 115] however, more recent studies done in the United States have demonstrated that using laparoscopic RP led to better peri- and post-operative outcomes such as less blood loss, lower rates of blood transfusion and shorter lengths of stay in hospital. But this group of patients also had higher rates of post-operative incontinence and erectile dysfunction compared to patients who underwent open RP. [116-118]
- RALP and open RP have been found to have comparable outcomes (e.g., in terms of postoperative complications, hospital readmission and the need for additional cancer therapies); however, RALP has also been associated with a lower risk of blood transfusion, a shorter length of hospital stay, improved urinary continence recovery and improved potency recovery, although increased operative time was also found.[108, 116, 119-122]
- Several recent studies have shown better post-surgery outcomes among patients who had RALP versus those who underwent other RP procedures.[103, 104, 111, 123-125] Because using robotic technology in RP is still a relatively new approach, long-term outcomes need to be studied further.
- Using RALP could translate to savings in terms of shorter hospital stays, fewer procedures and a reduced need for medication related to post-surgical complications.[103] However, it is still debatable whether robotic assistance is cost-effective even with shorter hospital stays, given that each RALP costs a few thousand dollars more than the average open RP procedure.[126, 127]

4. Person-Centred Perspective

4. Person-Centred Perspective

A diagnosis of prostate cancer has a significant impact on a man's life. Throughout his cancer journey, he may experience a range of physical, social, emotional, psychological and practical challenges, and there may be long-term effects lasting many years after treatment has ended.

The number of men in Canada who currently have or had prostate cancer is increasing. This is largely due to Canada's aging demographics but also to the fact that many men with prostate cancer survive a long time after their disease is diagnosed. With these factors in mind, the focus of care has shifted: in addition to paying attention to the quality of care provided to men with prostate cancer during the treatment phase, there is a growing emphasis on ensuring the best possible quality of life following treatment, during remission, throughout the survivorship phase and at the end of life.[130]

Traditionally, assessment of quality of care includes measures of accessibility, appropriateness and effectiveness of services. But the quality of our cancer control system also depends on whether it delivers person-centred care and support to patients and their families as they deal with the challenges posed by cancer. At the same time we must keep in mind the "balance between optimal medical treatment and patient-tailored care."[131]

This section presents available indicator data that can supply insight into whether the system is providing person-centred care and where opportunities for improvements may exist.

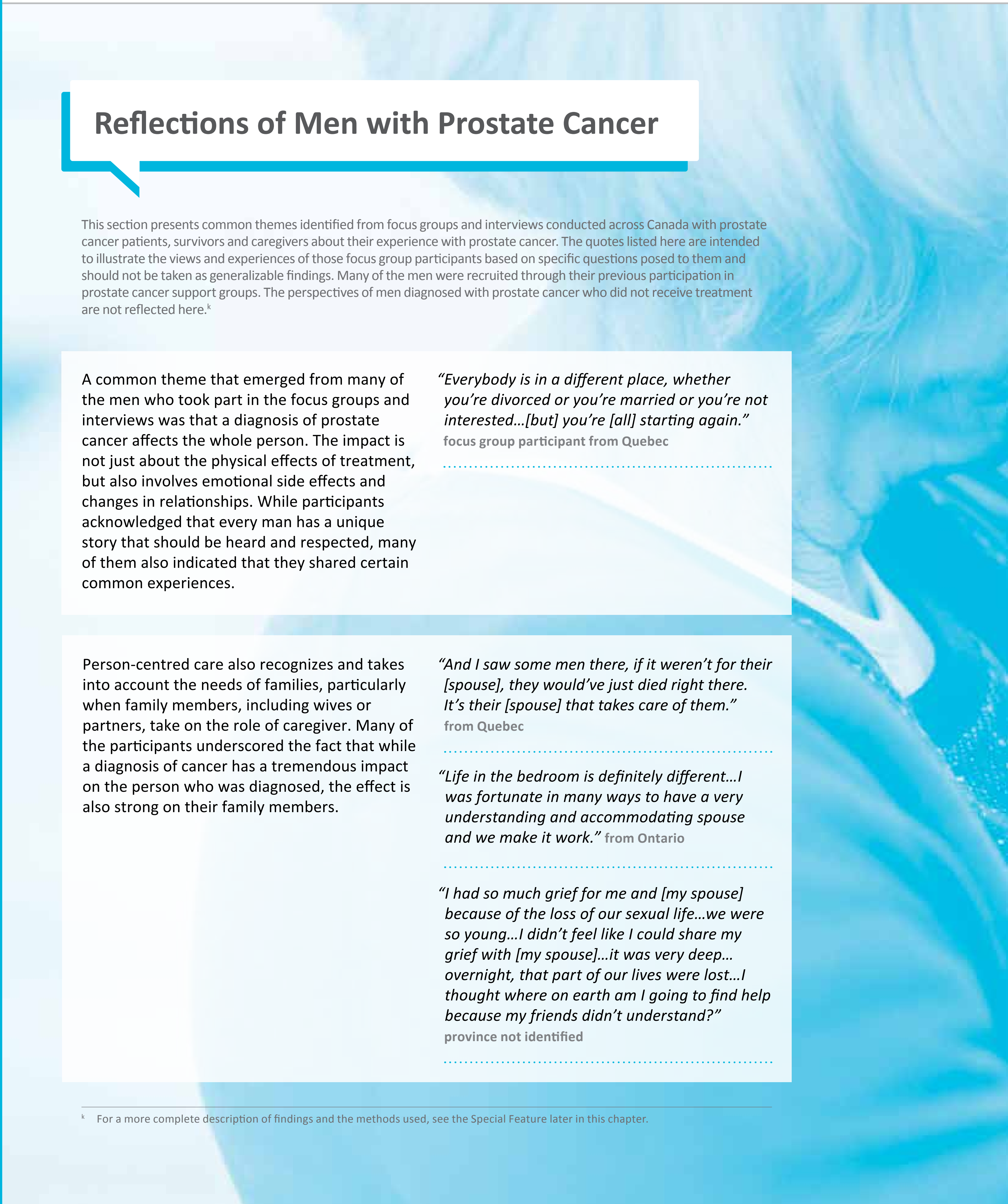
First, we examine findings from a patient satisfaction survey, focusing on aspects of care related to emotional support, along with information and communication needs.

Then, we present two indicators that assess care near or at the end of life. One indicator is a proxy for the percentage of prostate cancer patients who received palliative radiation; the other examines place of death (home versus hospital).

Finally, we report findings from several focus groups undertaken to add patient voices to this prostate cancer Spotlight Report. The groups involved 47 men from six provinces who had been diagnosed and treated for localized or metastatic prostate cancer. We also conducted one focus group involving three family members, asking them what it was like to have a relative or loved one diagnosed with and treated for this disease. Quotations from these participants, which appear at the beginning of each chapter, have been included here to reflect some of the feelings and experiences of individuals affected by prostate cancer.

What is person-centred care?

- There have been recent efforts to transform the health system from one that delivers disease-centred or provider-centred care to a model that is more person-centred.[128] Such care is based on and driven by the individual needs, values and priorities of the person receiving the care, within the parameters of evidence and quality.
- The core components of person-centred care are: *dignity and respect, communication and information-sharing, collaboration* and *participation*.[129]
- Examples of person-centred care can include scheduling all tests and appointments on one day and in one place so that it is convenient for the patient, and designing and delivering a treatment plan that is driven by the well-informed patient's preferences and quality of life considerations.
- Embedding the person-centred perspective into the cancer control system involves intentional planning and delivery of care that is respectful of the experiences and perspectives of people affected by cancer.



Reflections of Men with Prostate Cancer

This section presents common themes identified from focus groups and interviews conducted across Canada with prostate cancer patients, survivors and caregivers about their experience with prostate cancer. The quotes listed here are intended to illustrate the views and experiences of those focus group participants based on specific questions posed to them and should not be taken as generalizable findings. Many of the men were recruited through their previous participation in prostate cancer support groups. The perspectives of men diagnosed with prostate cancer who did not receive treatment are not reflected here.[k]

A common theme that emerged from many of the men who took part in the focus groups and interviews was that a diagnosis of prostate cancer affects the whole person. The impact is not just about the physical effects of treatment, but also involves emotional side effects and changes in relationships. While participants acknowledged that every man has a unique story that should be heard and respected, many of them also indicated that they shared certain common experiences.

"Everybody is in a different place, whether you're divorced or you're married or you're not interested…[but] you're [all] starting again." **focus group participant from Quebec**

Person-centred care also recognizes and takes into account the needs of families, particularly when family members, including wives or partners, take on the role of caregiver. Many of the participants underscored the fact that while a diagnosis of cancer has a tremendous impact on the person who was diagnosed, the effect is also strong on their family members.

"And I saw some men there, if it weren't for their [spouse], they would've just died right there. It's their [spouse] that takes care of them." **from Quebec**

"Life in the bedroom is definitely different…I was fortunate in many ways to have a very understanding and accommodating spouse and we make it work." **from Ontario**

"I had so much grief for me and [my spouse] because of the loss of our sexual life…we were so young…I didn't feel like I could share my grief with [my spouse]…it was very deep… overnight, that part of our lives were lost…I thought where on earth am I going to find help because my friends didn't understand?" **province not identified**

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[k] For a more complete description of findings and the methods used, see the Special Feature later in this chapter.

Many of the participants diagnosed with prostate cancer also talked about the need for and the impact of having support from providers, family and peers. Support was important at the time of diagnosis, during treatment and after treatment, but sometimes it was hard to know how to find that support, especially initially.

"While I thought I was prepared for the worst, when it was confirmed, I felt like I had been given a death sentence. I wondered what do I do next, how do I tell my family, friends, etc. What are the next steps? Where do I go for more information? How do I proceed?" **from Ontario**

"The local support group provided me with people who had been through the experience. Some just barely ahead of me, but lots of chances…These were people I had never met before and would never have met if it hadn't been for the diagnosis of prostate cancer." **from New Brunswick**

"I've never felt that I've travelled the journey alone and still don't." **from Ontario**

Another important aspect of person-centred care involves effective communication and information-sharing among patients, families and care providers within the health system. Some men expressed how important it was for them to be able to access providers when they had important questions or concerns during and after treatment.

“The oncologist…kept explaining things in a way I didn’t understand.” **from Ontario**

“[The doctor] took the time to give me a detailed explanation of what I was suffering from, outlined the different treatment options for me, and I felt a lot safer.” **from Quebec**

“The first oncologist I went to was evasive, [he had] no empathy, he was disorganized…but the radiation oncologist was truthful, we connected, and made decisions together.” **from Ontario**

Some men who took part in the focus groups said that coordination of care and continuity of care were important from their point of view—especially since the individual patient is often treated at more than one facility and more than one care professional may be involved in helping him manage side effects (if any).

“I got a booklet and a phone number and I got sent home...The booklet said that my health team would be looking after me…[When I started having pain], I tried to call [the nurse]… but that person was on holidays. Eventually I got a call back from them but [it took] days...I was left to follow up with my health team—I didn’t get any calls to follow up after the surgery...I took it upon myself to talk to my GP...It was really frustrating.” **from Nova Scotia**

“I think the aftercare/follow-up is important and needs to be a little more reinforced. I didn’t get the number for the resident until I pushed and asked for it. When I got my new urologist, I was told I would get an [appointment] when the urologist wanted to see me.” **from Nova Scotia**

“It appears that if I wanted to talk to a doctor about something it had to be about a particular subject. He would examine me for my prostate and he didn’t talk about anything else. There should have been a doctor that said ‘Sir, what are the problems you’re having right now? Why are you looking for a colonoscopy right now that you haven’t had for two years?’ There’s no one looking at the whole picture.” **from Nova Scotia**

When asked about palliative care and end-of-life care, many men and their family members did not feel that this topic was of immediate significance and that they had focused mainly on their treatment. Some participants said that their doctors had told them that survival rates among men with prostate cancer are high, so many of them felt that talking about palliative care options was premature.

These comments likely reflect the fact that few of the participants had metastatic prostate cancer. Many had completed treatment and were in relatively good health at the time of the interviews. It should be noted that these are viewpoints of the participants and may not necessarily reflect recommended practice (i.e., to have initial discussions about palliative care early on).

“[With prostate cancer,] chances are that you’ll die from something else. So I don’t worry about it, deal with it as it comes, and that’s just kind of the approach I’m taking like some of the other gentlemen. Just [keep a] positive attitude and carry on.” **from Ontario**

“I don’t think it would be helpful in our case.” **province not identified**

“I think it would have been scary.” **province not identified**

Patient Satisfaction with Care

What are we measuring and why?

In providing person-centred care, it is important to identify and understand patients' needs, expectations and preferences, and to assess and monitor how well the system is addressing them.

This indicator reflects "satisfaction with care" scores reported by patients (who had prostate cancer based on analysis of information from the survey) from seven provinces using the Ambulatory Oncology Patient Satisfaction Survey (AOPSS). Patients responding to the survey had received outpatient treatment at a cancer centre or hospital.

- The results are presented as the percentage of negative ratings for each question across each selected dimension of the survey. These dimensions include: *physical comfort, information, communication and education*, *coordination and continuity of care, emotional support* and *overall quality of care*. Detailed results for the *emotional support* and *information, communication and education* dimensions are also presented.
- Results are shown via a negative rating (as a proxy for dissatisfaction) to highlight the unmet needs of patients. The intent was to encourage focus on areas where opportunities exist to improve the patient experience. The negative rating was derived by mapping the survey's multiple-choice answers to a "negative" category (as opposed to "neutral" and "positive" categories). (Details on how the negative response rating was calculated are provided at systemperformance.ca.)

What are the results?

- Based on these responses to the AOPSS, prostate cancer patients responding to the survey generally felt good about the overall quality of care received during their visit; however, some concerns were identified regarding specific dimensions of care.
- The emotional support dimension received the most negative rating out of all the dimensions included in this report. Negative ratings—that is, the proportion of men who provided answers reflecting a negative response to the question—ranged from 8.5% in Prince Edward Island to 22.9% in Alberta (Figure 4.1).
- In almost all reporting provinces, the dimension related to *information, communication and education* had the next most negative rating. Results ranged from 6.7% in Ontario to 12.7% in British Columbia.
- The other three dimensions—*coordination and continuity of care, physical comfort* and *overall quality of care*—had generally positive ratings across provinces.
- Within the emotional support dimension, the individual questions that may warrant the most concern were the two that related to whether the patient had been referred to another provider for help with anxieties and fears (Figure 4.2). Among those who identified having anxiety and fears when first diagnosed, 15.0% of respondents in Saskatchewan reported they had not been referred to a provider for help; the percentage was 70.5% of respondents in British Columbia. Among those

What is the AOPSS?

- The Ambulatory Oncology Patient Satisfaction Survey (AOPSS) is a retrospective survey tool that assesses the overall experience of cancer patients who received cancer care services at participating cancer centres or hospitals in an outpatient setting three to six months prior to receiving the survey. This tool, which uses a set of standardized questions, was developed and is administered by the National Research Corporation Canada (NRCC). This report includes data from provinces that are paying NRCC for this service and that agreed to provide the Partnership with their data.

respondents who had experienced anxieties and fears later on (and within the last six months), well over 50% reported that they did not receive a referral to another provider for emotional support, ranging from 57.3% in Ontario to 77.6% in Alberta.

- Only about 5% of men with prostate cancer who responded to the AOPSS said that they had not been given their diagnosis in a sensitive manner. Similarly, among all reporting provinces, the percentage of respondents reporting that hospital staff did not go out of their way to help them or make them feel better during their visit was less than 6%. Results for many provinces were suppressed here, which reflects the small number of negative responses for this question.
- When it came to the topic of feeling informed—specifically about possible emotional and relationship changes during prostate cancer treatment and recovery—in many provinces, more than 20% of men gave negative ratings (although there was some variation in these results by province). Many men also said they did not receive much help in figuring out how to pay for extra costs related to cancer care.
- Within the *information, communication and education* dimension, the question that elicited the most concerns was whether someone on the care team had explained why they had to wait for their first consultation appointment with a specialist. More than 30% of respondents in British Columbia, Alberta, Saskatchewan, Ontario and Nova Scotia said they were not given an explanation (Figure 4.3).
- Although results varied considerably, in some provinces over 15% of respondents reported that not enough information had been given to them about possible changes to their physical appearance, to work and usual activities, to their energy and fatigue levels and about their nutritional needs (Figure 4.3).

Data and measurement considerations

- Patients responding to the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) were asked to identify their primary type of cancer by selecting from a list that groups prostate and testicular cancers together. For the results presented here, we only included surveys in which respondents identified being age 50 years or older.[l] This makes it likely that the vast majority of respondents whose data are included here were diagnosed with prostate cancer.
- Due to differences in the way data were collected in Manitoba and British Columbia, results presented here for those two provinces only include men definitively diagnosed with prostate cancer (i.e., there was no chance that the particular survey sent to them related to treatment for testicular cancer).
- While the provincial surveys used to produce the patient satisfaction results were all based on the AOPSS tool, there may be some variation in inclusion criteria for patients in different provinces. Although progress has been made, work is still needed to ensure that inclusion and exclusion criteria are consistent across all hospitals and jurisdictions. This is important if we wish to accurately compare results within and between jurisdictions. See systemperformance.ca for a description of any deviation from these criteria; these should be taken into consideration when interpreting results.
- Depending on the province, the surveys are administered with different frequency. The results presented in this report came from surveys that were conducted between 2011 and 2013; interprovincial comparisons must be made with a certain degree of caution. See systemperformance.ca for details.
- The provincial results combine survey responses from patients who received different treatment modalities (e.g., surgery, radiation, chemotherapy). While it is possible that patients receiving different types of treatment may have different experiences of their care, this is not accounted for in these results.
- All respondents completed the survey within three to six months of receiving treatment in an ambulatory care setting (i.e., as outpatients). In Manitoba, Ontario, Nova Scotia and Prince Edward Island, respondents had received disease-oriented treatment within three months of the survey period; however, in British Columbia, Alberta and Saskatchewan, patients had been treated within six months of the survey.
- The survey consistently captures data on patients receiving radiation treatment. However, because the location of chemotherapy treatment can vary by province, data collection for those being treated with chemotherapy may vary by province. For example, some provinces report only on intravenous chemotherapy while others include patients who received oral chemotherapy as well. See systemperformance.ca for further details.

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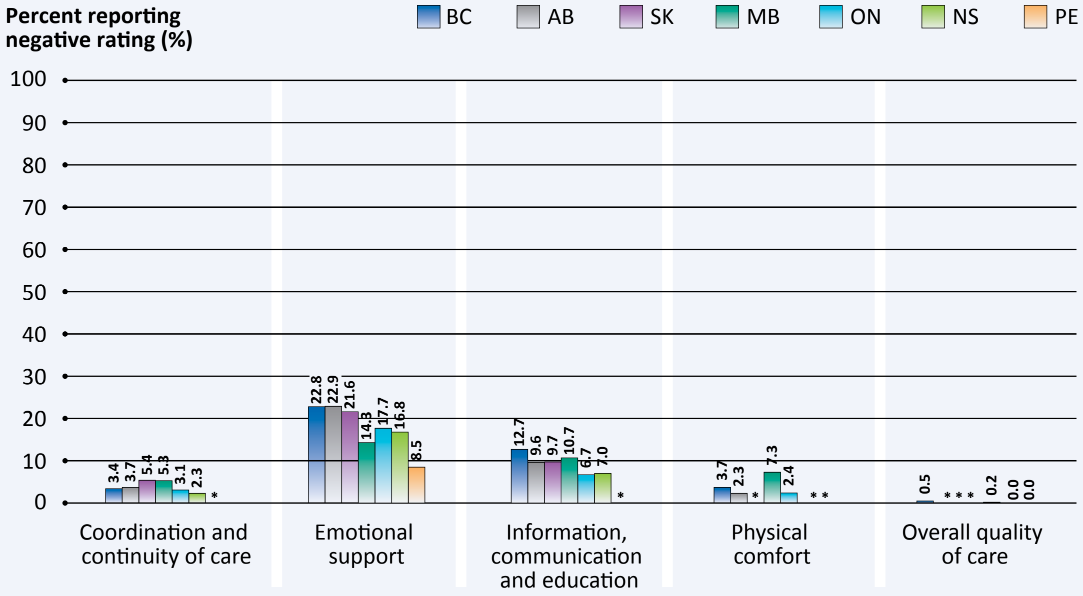
[l] Data on age-related cancer incidence from Canada and the United Kingdom show that 98% of men with prostate cancer were at least 50 years old, while just 10% of those with testicular cancer were over 50.[132-134] Given that the incidence rate of testicular cancer is relatively low, the actual number of testicular cancer cases among men over 50 years old would be very small.

- Methodologies used to analyze AOPSS results may differ across jurisdictions, so results published elsewhere may differ from what is reported here.
- The results presented here include responses collected from approximately 2,000 patient surveys. The number of responses within each province varied significantly by dimension and by question. Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

FIGURE 4.1

Percentage of prostate cancer patients reporting a negative experience rating across dimensions of care, by province — ranging from 2011 to 2013



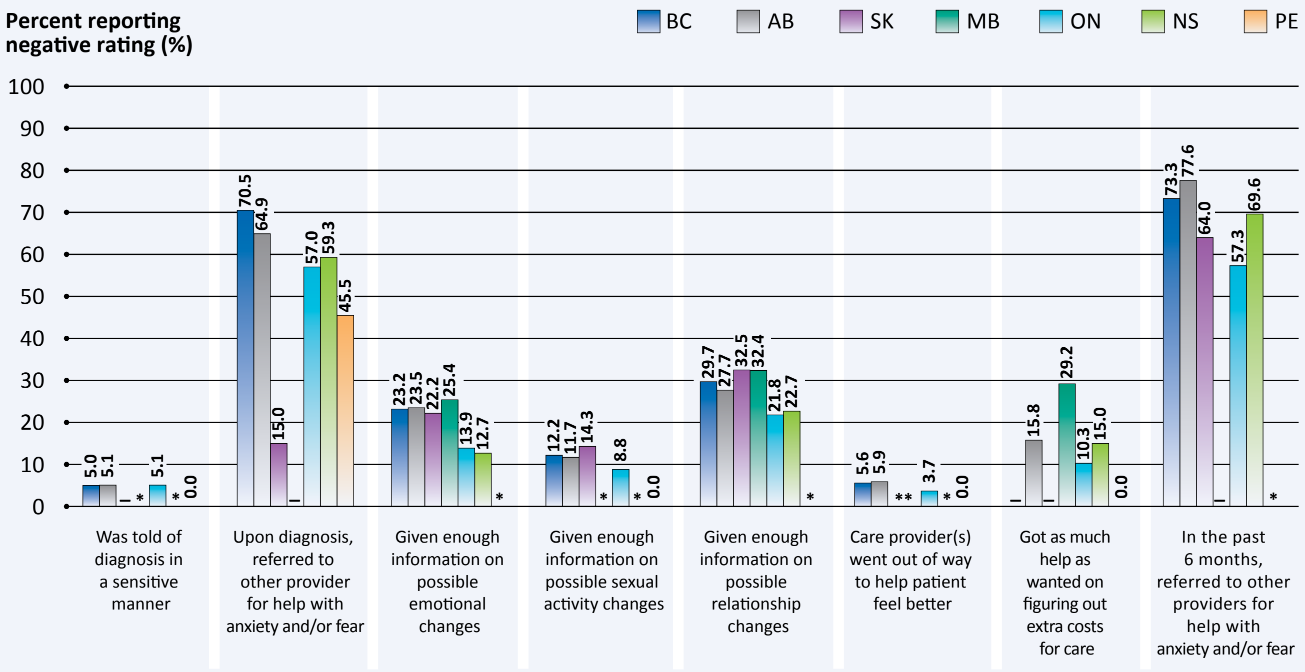
* Suppressed due to small numbers.

BC: Jun-Dec 2012; AB: Feb-Aug 2012; SK: Apr-Jun 2011; MB: Jun-Oct 2011; ON: Apr-Jun 2012; NS: Jun-Sep 2012; PE: Nov 2012-Jan 2013.

Data source: Ambulatory Oncology Patient Satisfaction Survey, National Research Corporation Canada, with permission from the individual provincial cancer agencies.

FIGURE 4.2

Emotional support dimension: Percentage of prostate cancer patients reporting a negative experience rating, by province — ranging from 2011 to 2013



* Suppressed due to small numbers.

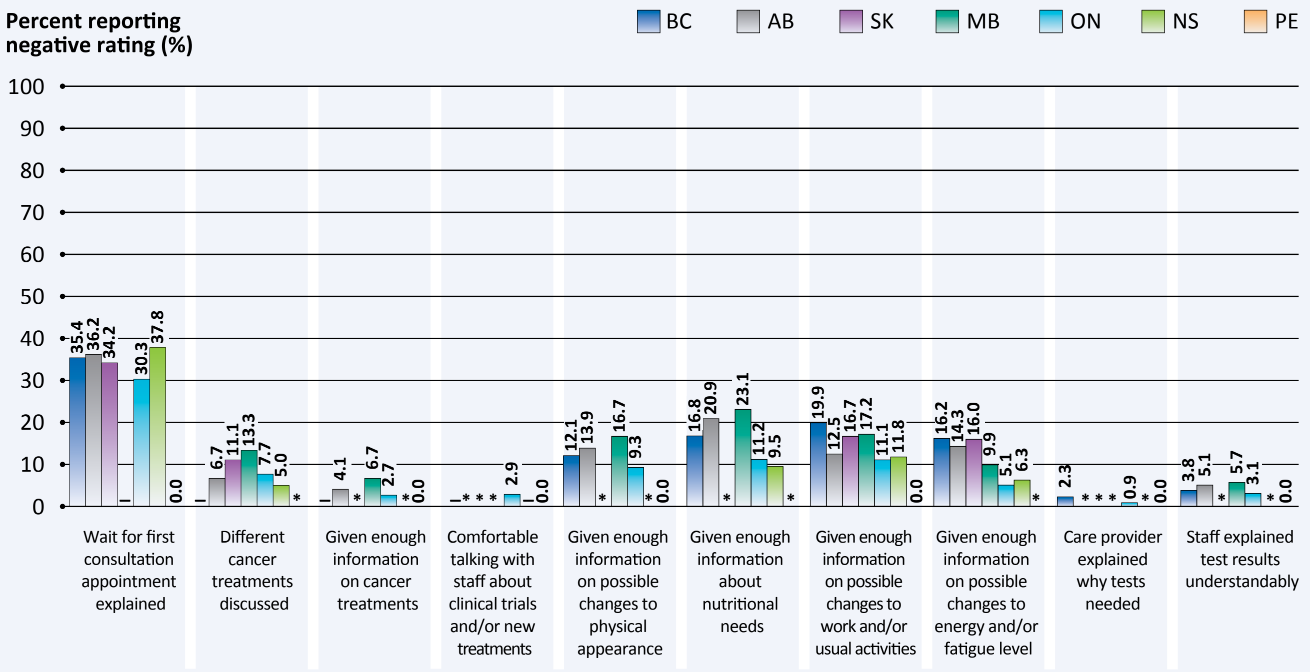
"–" Data not available because this question was not asked.

BC: Jun-Dec 2012; AB: Feb-Aug 2012; SK: Apr-Jun 2011; MB: Jun-Oct 2011; ON: Apr-Jun 2012; NS: Jun-Sep 2012; PE: Nov 2012-Jan 2013.

Data source: Ambulatory Oncology Patient Satisfaction Survey, National Research Corporation Canada, with permission from the individual provincial cancer agencies.

FIGURE 4.3

Information, communication and education dimension: Percentage of prostate cancer patients reporting a negative experience rating, by province — ranging from 2011 to 2013



* Suppressed due to small numbers.

"–" Data not available because this question was not asked.

BC: Jun-Dec 2012; AB: Feb-Aug 2012; SK: Apr-Jun 2011; MB: Jun-Oct 2011; ON: Apr-Jun 2012; NS: Jun-Sep 2012; PE: Nov 2012-Jan 2013.

Data source: Ambulatory Oncology Patient Satisfaction Survey, National Research Corporation Canada, with permission from the individual provincial cancer agencies.

What do the results mean?

- The survey findings show that some men with prostate cancer felt they needed more information on emotional, sexual and relationship changes that may occur with the diagnosis and treatment of prostate cancer. These results echo findings from published research.[135-137] For example, patients with prostate cancer have reported not being satisfied with information and support provided by their medical team regarding changes in sexual well-being.[130] In particular, insufficient or misleading information given by physicians can lead to feelings of frustration. On the other hand, studies have also shown that even when clinicians do provide the information, some patients may not recall receiving some or all of it.[138-140]
- Data from the participating provinces suggest that many patients with prostate cancer received information about different treatments and options. Other research has found that men with prostate cancer who were more involved in decision-making related to their care reported higher levels of satisfaction and higher levels of health-related quality of life (see the following box, *Involvement in Decision-Making*).[131, 141]
- The findings reported here suggest that some patients would like clearer communication from their health care team. This is reflected in the relatively high negative ratings surrounding whether or not newly diagnosed men received any explanation about why they had to wait for their first consultation appointment; however, it is not clear whether patients felt the wait was too long or whether they simply were not given any explanation for the wait.
- Many patients with prostate cancer experience anxiety and depression at some point in their cancer journey, and most, when asked, wanted help for these issues.[142] Within the emotional support dimension, the questions that showed the highest areas of need were related to not getting referrals for help with anxiety and fears—either at the time the person was diagnosed or within the last six months.[m]
- Research shows that patients' anxiety levels tend to be highest around the time of diagnosis.

Involvement in Decision-Making

- There is evidence that patients who feel involved in decision-making have higher levels of satisfaction with care and experience less regret about their choices.[131, 143, 144] Because treatment options for localized prostate cancer have similar survival outcomes but varying levels of side effects, it is important that the patient and his partner and family are meaningfully involved in the decision-making process. The goal is to ensure that the chosen treatment option aligns with their needs, wants and preferences.
- Studies have shown that without such patient involvement in the decision-making process, specialist physicians will usually recommend the treatment that they specialize in delivering.[145] With the increasing focus on person-centred care, physicians should consider not just the curative aspect of treatment but also its impact on quality of life for the patient and their family members.
- Educational aids, risk calculators and decision aids are tools that patients and physicians can use to guide conversations about treatment options. Decision aids (DAs) present easy-to-understand information on the benefits, risks and outcomes associated with each option. This allows men to reflect on how their needs, wants and preferences may influence their treatment decisions.[144] DAs appear to be effective in improving patients' knowledge, facilitating communication between patients and their physicians, fostering patient involvement and encouraging more informed decisions.[145-147]

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[m] Patients who did not volunteer having any anxieties or fears at those two time points (i.e., at diagnosis or within the last six months) would have replied, "I did not have any anxieties or fears." Those results were not part of the denominator in this analysis.

A small qualitative study done in Australia that included prostate cancer patients who accessed support groups found that just over 40% were referred for psychosocial support at the time of diagnosis.[137] This is comparable to what is being reported here for some provinces.

- Men who are not referred for emotional support may not be aware that such resources exist; others may choose not to seek them out; and others may not feel the need for support at that time. However research suggests that those who did ask for psychosocial support often felt it was helpful.[137]
- Baseline (pre-treatment) health status and changes in quality of life following treatment for prostate cancer affects how a patient perceives his care and whether he would report feeling satisfied with that care. Other research suggests that prostate cancer patients with poorer baseline health status, lower health-related quality of life or poorer health status post-treatment may be at higher risk for dissatisfaction.[148] While we did not look at baseline health status for this analysis, a previous System Performance report showed that respondents with poorer health status reported higher negative ratings for questions in the AOPSS. This was especially true in the emotional support dimension (all cancer types).[149]
- Such findings underscore how important it is for clinicians to conduct careful assessments—both while discussing treatment options with prostate cancer patients and prior to starting treatment. It also speaks to the value of having a systematic approach for gathering patient-reported outcomes and patient-reported experience measures to identify an early and appropriate approach to patients' needs.

What are some examples of efforts in this area?

- The Prostate Cancer Information Service (PCIS) was launched in 2014 to provide resources and support to patients and other people affected by prostate cancer. Services include phone and email support, as well as referrals to support programs and health information.[150] The PCIS is provided by Prostate Cancer Canada in partnership with the Canadian Cancer Society. Prostate Cancer Canada has a comprehensive suite of evidence-based health information in multiple formats including expert videos, webinars, brochures and web content. For more information visit prostatecancer.ca.
- The British Columbia Ministry of Health recently launched a prostate cancer supportive care program for prostate cancer patients and their partners.[151] The program covers topics addressing physical and psychological needs. Areas of focus include treatment options, lifestyle management and sexual functioning.
- Prostate Cancer Canada, with funding from the Movember Foundation, is launching pilot programs within a pan-Canadian survivorship program called True NTH.[152] This project brings together a network of key leaders, decision-makers, experts, survivors and caregivers and addresses physical and psychosocial concerns across the entire prostate cancer care continuum. Members of the Network collaborate to develop intervention proposals in various areas, such as patient navigation programs, education programs for patients, and support programs for survivors and caregivers. The project is a collaboration between member organizations across Canada that have expertise in survivorship, including academic, clinical, private and community partners. More information can be found at prostatecancer.ca/TrueNTH.
- CancerChatCanada provides patients and their family with access to online support groups that are led by professional facilitators.[153] This initiative is largely funded by the Partnership; its central office is located in and supported by the BC Cancer Agency's Provincial Psychosocial Oncology Program. In 2013, a patient-centred group for couples affected by a diagnosis of prostate cancer was piloted (Prostate Cancer Couples Study). There are also plans to organize patient groups specifically for prostate cancer patients in the near future.

Access to Palliative Radiation

What are we measuring and why?

While radiation therapy plays an important role in the curative treatment of non-metastatic prostate cancer, it is also used as an effective palliative therapy option for patients with advanced stage disease that is causing pain and other discomfort—particularly for men whose cancer has spread to their bones.[83, 154, 155] Ensuring men with end stage prostate cancer have access to palliative radiation therapy when needed is an important aspect of quality care.

- Given the large impact of debilitating pain on a person's quality of life, it is important to monitor access to treatments that can help manage distressing physical and emotional symptoms. It is also important to understand why these treatments may be used differently across jurisdictions.
- Because reliable information on treatment intent is not routinely collected in provincial data sources, we are examining the use of palliative radiation therapy indirectly. This has been achieved by measuring the percentage of prostate cancer patients receiving radiation therapy within one year prior to death from prostate cancer. Using this time frame increases the likelihood that the radiation therapy was delivered for palliative intent. Data (where available) were provided by the provincial cancer agencies and include men who died from prostate cancer in 2011.

What are the results?

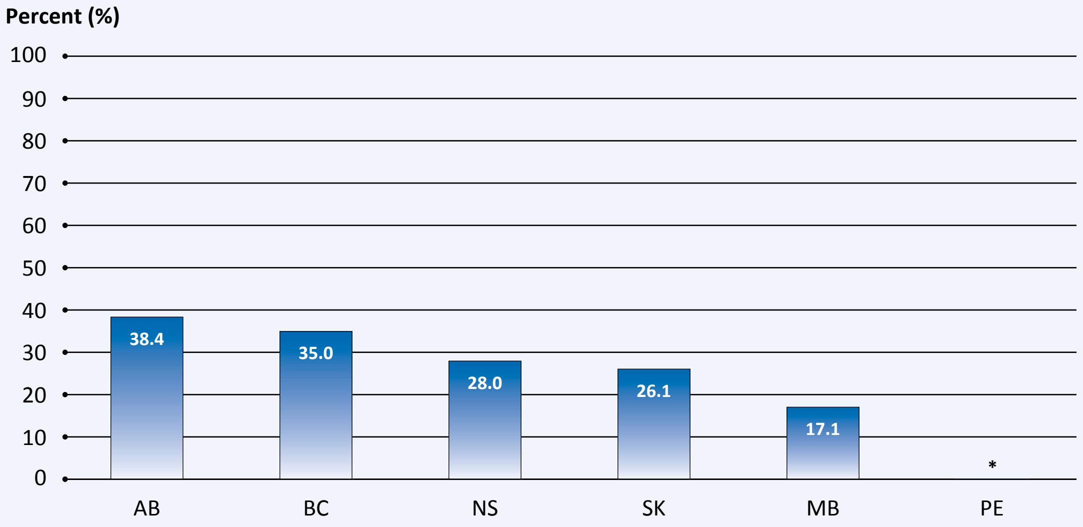
- Among men who died from prostate cancer in 2011, fewer than 40% received radiation therapy during the last year of their lives (Figure 4.4).
- There was some variation across reporting provinces in the use of radiation therapy within the last year of life among men who died from prostate cancer. Rates of use ranged from 17.1% in Manitoba to 38.4% in Alberta.

Data and measurement considerations

- This indicator only provides insight about the proportion of men who received palliative radiation therapy (PRT) during the study period. It does not quantify the period of time during which they received treatment, the number of fractions received or the length of time since their last PRT treatment.
- From the data submitted, we do not know the reason for radiation therapy treatment. We cannot confirm that such treatment was undertaken for palliative purposes; however, it is likely that most men with prostate cancer who received radiation therapy within the last year of life did so for palliation (i.e., pain relief).
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

FIGURE 4.4

Percentage of men with prostate cancer receiving radiation therapy within one year prior to death, by province — 2011



* Suppressed due to small numbers.

AB: Includes deceased patients whose residence addresses were in Alberta. Radiation therapy received does not include out-of-province treatment.

Data source: Provincial cancer agencies.

What do the results mean?

- The underuse of palliative radiation therapy (PRT) is well-documented in the research literature, despite the evidence of its effectiveness for managing pain.[156, 157] The results shown here may support those findings.

- Physician referral practices have been identified as one of the most influential drivers of PRT uptake. For men with metastatic prostate cancer, the referring physician can be a radiation oncologist, medical oncologist, palliative care specialist or primary care physician. Several factors may influence a physician's decision to refer a patient for such therapy. These include the patient's age, the type and stage of his prostate cancer, the presence of other comorbid conditions, the patient's personal preference and the patient's proximity to a radiation centre.[154, 156, 157] It can also include the physician's awareness and understanding of PRT as an effective way to manage pain.[158]

- Other research has found that older men with prostate cancer were less likely to receive palliative radiation therapy than younger men.[159] In provinces with an older population, men may be less likely to be referred for PRT; however, according to demographic information from 2011, Alberta and Manitoba were the provinces with the fewest men aged 65 years and older, yet as shown here, these provinces had the highest and lowest PRT rates, respectively.[160]

- Provinces with regional rapid PRT programs in place may also have higher rates of use. These clinics provide more streamlined access to radiation therapy: patients can be seen quickly for consultation and treatment. For example, Alberta has such a program in place at the Cross Cancer Institute in Edmonton;[161] this could explain the relatively higher PRT use in Alberta reported here.

- A study from Nova Scotia found that fewer than 30% of men who died from prostate cancer between 2000 and 2005 had received palliative radiotherapy[157]—which is similar to the rate of 28% for Nova Scotia presented in this report.

What are some examples of efforts in this area?

- Efforts have been made to increase awareness about PRT referral models. For example, family physicians are being offered continuing medical education on radiotherapy, and cancer centres are working to promote the availability of their rapid referral radiotherapy programs.[156]
- Studies have shown that a single fraction of radiation therapy can be as effective as multiple fractions,[162] while also considering the added benefit of patient and caregiver convenience. As such, as part of the *Choosing Wisely Canada®* campaign, the Canadian Association of Radiation Oncologists recommends that single versus multiple fractions be used where possible when palliative radiation is given for pain due to bone metastasis. It is hoped that this will reduce the need for multiple trips to a radiation centre, which can be a barrier for some patients.[163] (The *Choosing Wisely Canada®* campaign is aimed at initiating discussions between patients and physicians about the use of unnecessary tests, treatments and procedures.)

What else do we know?

- Several studies have suggested that a major reason that the uptake of palliative radiation therapy (PRT) has been relatively low is a lack of awareness among family physicians that PRT provides effective pain relief. Some of these physicians may not be aware of the number of treatments required to achieve palliation of symptoms.[156, 157, 161, 164, 165] There is strong evidence that one fraction of radiation therapy can be just as effective at managing pain symptoms as several fractions.[162] Capitalizing on this information may help to increase PRT uptake, particularly for patients who live far away from a radiation centre.
- Family physicians who treat patients needing palliative pain relief may not be aware that they can directly refer such patients for PRT or that specialized programs for “rapid” PRT may exist nearby. A 2002 survey of family physicians in Ottawa—nearly all of whom treated cancer patients—revealed that only 56% had referred patients for PRT.[156] Also, fewer than 20% of these family physicians were aware of a nearby rapid palliative radiotherapy program located in their community. It is possible that not knowing about the programs could have influenced their decisions on whether or not to refer patients for PRT.
- It is estimated that two-thirds of men who die from prostate cancer have bone metastasis.[166] However, it is unclear how many patients captured in these data who died from prostate cancer actually had symptoms that would have benefited from PRT. Many patients can be asymptomatic.
- Opioids and/or bisphosphonates may also be recommended for effective pain management; such drugs can be administered in the home.[167]
- For some patients with metastatic, hormone-resistant prostate cancer, chemotherapy may be used with palliative intent.[168]

Place of Death

What are we measuring and why?

This indicator measures the percentage of deaths due to prostate cancer that occurred in a hospital versus in a private home or at some other location. The findings are based on information contained in the national vital statistics database for 2011 (by province). National results showing the location of deaths due to prostate, breast, lung and colorectal cancer in percentages are also provided.

- Findings from several Canadian surveys have shown that, if given a choice, many cancer patients would prefer to die at home or in a hospice rather than in a hospital.[169, 170] However, a lack of awareness about the availability of appropriate palliative care resources or services at home (e.g., to ensure effective symptom management) may make death at home less achievable.[171]
- Knowing where prostate cancer patients die is important for two reasons: it enables a better understanding of health system resource allocation, and it could give us clues on the extent to which health care system use at the end of life aligns with patient preferences. Policy enablers to dying at home may include provincial health plan coverage of pain control medication delivery in the home.
- While the results presented here provide a relatively crude measure, they can highlight potential opportunities for end-of-life planning and show how better data collection and analysis can be used to support health system improvements.

What are the results?

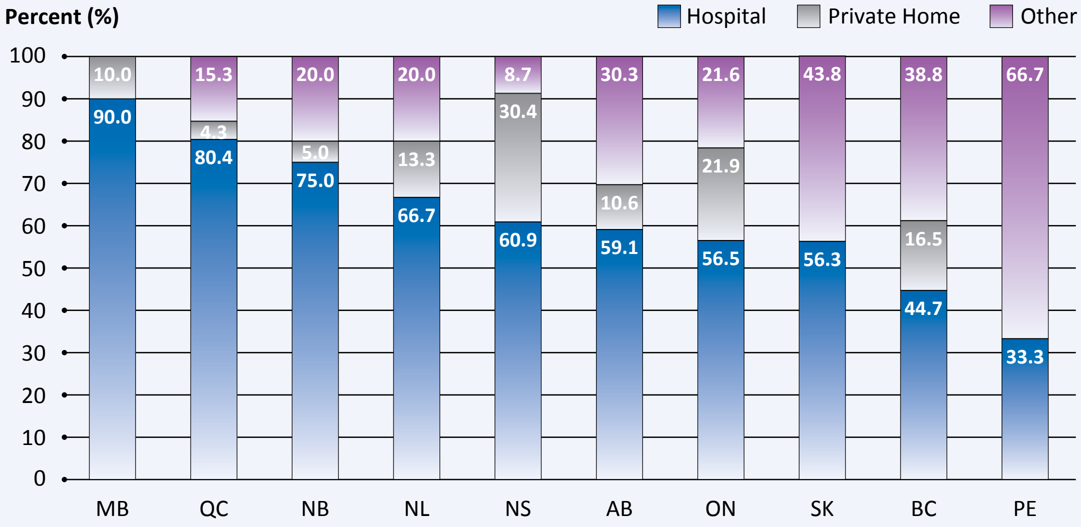
- There was much variation across provinces in terms of the location of death for men who died from prostate cancer: in Manitoba, the data suggest that 90.0% of deaths occurred in hospitals compared to 33.3% of deaths in Prince Edward Island (Figure 4.5). The percentage of deaths reported as occurring in private homes also varied considerably—from 30.4% of men in Nova Scotia to 0.0% in Saskatchewan and Prince Edward Island. It is important to note that provincial variations exist in how location of death is categorized on death certificates, as well as in how different settings (i.e., designation of hospital-based hospices or palliative care units) are classified. Manitoba has indicated, for example, that many of the in-hospital deaths recorded in the province’s vital statistics data actually occurred in hospital-based hospices or palliative care units as opposed to in acute care hospital beds.
- In the data reported for 2011, a slightly lower percentage of men who succumbed to prostate cancer died in hospital compared to patients who died from breast, lung and colorectal cancers (Figure 4.6).

Data and measurement considerations

- Data for this indicator were collected by the provinces based on information recorded on the official registration of death. Data were then submitted to Statistics Canada to be included in the Vital Statistics Database. This database contains data elements that identify cause of death and location of death. “Location” is grouped into the following categories: hospital, other health care facility (e.g., long-term care or chronic care facility), private home or any other specified locality, or “unknown.” Depending on the province, a hospice can be categorized as “other health care facility” or “other specified locality or unknown.” (For this analysis we grouped the “other” categories together.)
- The definition of “hospital” varied across provinces. In Quebec, this category included residential and long-term care centres. In Manitoba, designated palliative care units were included as part of the hospital category in their data collection, while in other provinces this type of bed might have been considered part of long-term care, which puts it in the “other” category in the charts presented here.[172] As a result, percentages of hospital deaths for Quebec and Manitoba may appear higher relative to other provinces but do not necessarily indicate any actual differences in the delivery of services.
- There is also variation in the way palliative care beds are designated in hospitals across the provinces. The impact of this on reported variations in deaths that occurred in hospital is not known.[172] Further investigation is needed to determine the true influence on the results presented here.
- Coding on death certificates also varies by province. In Saskatchewan and Prince Edward Island, a very small proportion of deaths are recorded at home, which suggests that most in-home deaths may likely be recorded in the “Other” category (Statistics Canada, personal communication).
- This indicator only examines the location of the patient at the time of death and does not take into account time spent in other settings during the weeks leading up to death. As such, it does not fully reflect the patient’s use of health system resources during the end of life.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

FIGURE 4.5

Percentage of prostate cancer deaths occurring in hospital, private home or other, by province — 2011



"Other" includes other specified locality and other health care facilities (excludes unknown localities).

Data source: Statistics Canada, Vital Statistics Death Database.

What do the results mean?

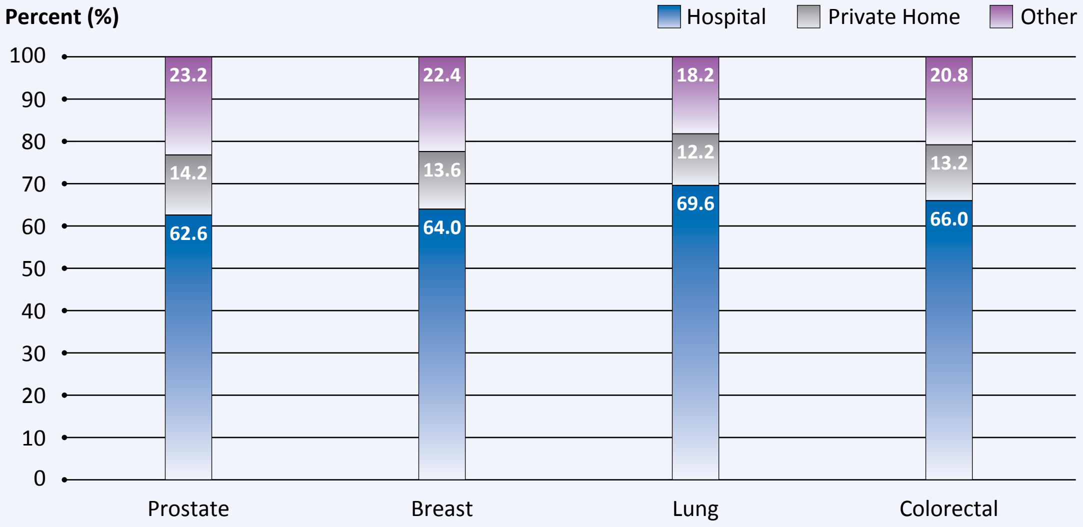
- Findings that some provinces had a lower proportion of deaths in hospital may reflect the existence of more options for community-based care (e.g., home care, hospice) in those jurisdictions. These provinces may also offer more resources that support home-based end-of-life care. For example, some provinces cover the cost of pain medication delivered in-home while others do not. Certain provinces may also have developed more strategic initiatives for advanced care planning.

- Patient and family preferences may also play a role in influencing where patients die. While patient surveys have indicated that the hospital is the least preferred setting for end-of-life care, other factors such as the availability of health services and resources may influence what actually happens. In reality, symptom management resources, emotional support from caregivers or loved ones, and/or financial resources needed to support dying at home are not always available or realistically achievable at home. It is important to be aware that patient and caregiver preferences or needs may also change over time due to clinical, psychological or practical challenges. For some people, the preferred end-of-life setting may eventually be in the hospital or in a hospital-like setting.

- Prostate cancer tends to have a longer disease course than other cancers, which suggests that health care teams may have more opportunities to introduce palliative care discussions and arrange hospice care earlier on. In the United States, reported use of hospices by men with prostate cancer varied from 18% to 53%.[173, 174] A recent study found that the use of these services during the final weeks or months of life has increased over time.[174]

FIGURE 4.6

Percentage of prostate, breast, lung and colorectal cancer deaths occurring in hospital, private home or other, Canada — 2011



"Other" includes other specified locality and other health-care facilities (excludes unknown localities).

Data source: Statistics Canada, Vital Statistics Death Database.

- A study of palliative care services in Wales showed that prostate cancer patients had a lower average number of inpatient admissions per year for palliative services compared to patients with breast, lung and colorectal cancers.[175] However, once admitted to hospital, prostate cancer patients had the longest length of stay. More investigation is needed into the reasons for the initial admission to hospital and why patients remain there.
- An analysis by the Canadian Institute for Health Information showed that 53% of cancer patients (all types) who died in acute care hospitals had palliative care documented as the main reason for hospitalization.[172] While some of these patients may have been cared for in designated palliative care units, most of them were not.

What are some examples of efforts in this area?

- All Canadians may not have equal access to the resources and supports needed to die comfortably at home. For that reason, alternatives to hospitals and private homes, such as residential hospices, have emerged. These are free-standing homes that provide palliative care services and may be funded from provincial subsidies and donations.[176]
- National efforts are under way to integrate palliative and end-of-life care into health systems, through increasing support, access to information and enhancing clinical delivery. Though these efforts are not specifically aimed at prostate cancer patients, this population will still benefit from these initiatives. An example is *The Way Forward*, a federally-funded initiative that has developed a national framework to help support integrated

community-based palliative care, so that patients can access palliative care resources and services when and where they need them.[177] This work is led by the Quality End-of-Life Care Coalition and the Canadian Hospice Palliative Care Association. As another example, the True NTH Advanced Care Planning initiative is developing online and print resources for men with prostate cancer, their partners, families and caregivers. The goal is to encourage them to engage in their diagnosis and treatment plans, increasing the chance that their preferences and wishes for care will be met through all stages of their journey.[178]

- The Partnership supports the Palliative and End of Life Care National Network (PEOLC NN) in engaging ministry and cancer agency and program representatives from each province and territory, patient and family representatives, and key organizations such as the Canadian Medical Association, the College of Family Physicians of Canada, the Canadian Nurses Association, the Canadian Virtual Hospice, the Canadian Society of Palliative Physicians, the Royal College of Physicians and Surgeons and the Canadian Hospice and Palliative Care Association. The purpose of the PEOLC NN is to work collaboratively to improve palliative and end-of life-care and outcomes for patients and families. Their priorities for the next two years are to focus on four key areas: educating health professionals; integrating palliative care; goals of care and advanced care planning; and measuring palliative and end-of-life care indicators at the national level.
- Current efforts led by the Partnership to collect more pan-Canadian data on palliative care and end-of-life care are aimed at developing a suite of palliative care and end-of-life care measures that will lead to a better understanding of the palliative and end-of-life experiences of Canadians with cancer and to identify opportunities for system improvement.

Special Feature:
Reflections of Canadian Men with Prostate Cancer

Introduction

In 2015, more than 24,000 Canadian men will be diagnosed with prostate cancer, and over 4,100 will die from the disease.[1] The most recent prevalence statistics suggest that more than 175,000 men alive today have been diagnosed with prostate cancer at some point in time.[1]

But while statistics are useful, they do not represent a complete picture of the impact of prostate cancer in Canada. While there may be common experiences among men diagnosed with prostate cancer, each one of those 175,000 men also has a unique story to tell about his own prostate cancer experience. A comprehensive review of prostate cancer control in Canada cannot be considered complete unless an effort is made to give voice to some of those stories.

System Performance reports have tended to rely heavily on statistical indicators and other quantitative measures. In this special feature prepared for our Spotlight report on prostate cancer, we share some examples of the prostate cancer experience from a group of men in Canada who were previously diagnosed with and received treatment for the disease. This is done through presenting common themes as recounted through the recollections of these prostate cancer patients and survivors and a few family members, and by providing illustrative examples through a selection of their quotations. These perspectives were obtained from focus groups conducted in the fall of 2014 that included residents from six Canadian provinces. By including these viewpoints here, we complement the results from traditional performance metrics in the rest of the report, and provide an opportunity to view the results from a more person-centred lens.

This special feature provides a brief summary of the common themes associated in the reflections of the focus group participants for each of the cancer control domains as described in the Report chapters (*Burden and Outcomes*, *Diagnosis and Staging*, *Treatment*, and *Person-Centred Perspective*) and a more in-depth description of several other important themes not fully covered in the chapters. They are: *informed and shared decision-making; emotional support; survivorship and living with the outcomes of treatment;* and *support for caregivers.*

The approach we followed

ABOUT THE FOCUS GROUPS

The aim of the focus groups and subsequent content analysis was to provide some insights into prostate cancer patients' and survivors' experiences through their cancer journey (from diagnosis and treatment, to post-cancer care and survivorship).

Three methods were used to collect the patients' experiences. They included: four face-to-face focus groups; four moderated online and telephone focus groups; and eight one-to-one interviews.

To obtain a pan-Canadian perspective, men and family members from across the country were invited to participate. The in-person sessions were held in Winnipeg, Montreal and Halifax. Other sessions involved participants from the Greater Toronto Area, from other cities in Quebec and from British Columbia, New Brunswick and Nova Scotia.

In total, there were 50 participants in the sessions (47 men and three family members). The Canadian market research company, Ipsos Reid, was commissioned by the Partnership to plan and coordinate the execution of the focus groups and analysis of results.

ABOUT THE PARTICIPANTS (SEE TABLE 4.i)

- Participants resided in six provinces. Most came from Ontario, Quebec and Nova Scotia. Most were living in urban centres.
- All participants were over 45 years old. Forty percent of the participants were 45-65 years old; and just over 50 percent were 66-80 years old.
- Half of the men had been diagnosed with prostate cancer between the ages of 45 and 65; just over a quarter were diagnosed between the ages of 66 and 80.
- While a few participants mentioned that they had initially been managed by active surveillance,[n] all of them eventually had definitive treatment.
- Most of the men were treated with surgery or radiation therapy. Several were treated with hormone therapy (androgen deprivation) or chemotherapy. Some were given a combination of some or all of these treatment modalities.
- Twenty-six percent of the participants were treated within the last three years; 42% were treated within the past four to six years.
- At the time participants were recruited, certain characteristics were collected (i.e., current age, age at diagnosis, where they lived, and the types of treatment they had received). However, we were not able to determine in a standard way whether each man had localized or metastatic prostate cancer. As well, we did not collect other demographic characteristics such as socioeconomic status and ethnic background; therefore, we cannot assess what impact these factors might have had on their responses.
- Each quotation is followed by the participant's province of residence (where available). This information was taken from the session recordings and also confirmed using the pre-screening questionnaire; however, in a few cases, an accurate province of residence could not be determined or it was not included because of privacy and confidentiality considerations.
- It should also be noted that this study was not designed in a way to capture comprehensive information about each patient's specific trajectory of care or his risk profile for developing prostate cancer. While we collected information such as age at diagnosis, current age, and some general idea of the stage of their disease and the type of treatment received, the addition of more demographic and clinical information as qualifiers for each quotation would have led to further privacy and confidentiality limitations in many cases.

METHODS

Session facilitators were recruited by the Partnership, and included researchers and health care providers with expertise in qualitative research, psychosocial research, person-centred care and/or patient experience in the area of cancer care.[o] The interviewer for the Toronto-based one-on-one discussions, who was referred by Ipsos Reid, also had clinical and research methods expertise. Research Ethics Board approval was obtained from universities and/or academic health science centres and hospitals affiliated with the facilitators for the face-to-face sessions. Participants were provided with a small monetary incentive.

The participants were recruited for the sessions using a variety of methods. For the one-on-one sessions, recruitment was done through the facilitators at cancer clinics or cancer centres where they held an academic affiliation. For the online and phone sessions and one-on-one interviews, men were enlisted through Prostate Cancer Canada (PCC). For the online session offered in French, recruitment was done through Ipsos Reid.

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[n] Refer to Chapter 3: *Treatment* for more details on *active surveillance.*

[o] Refer to the *Acknowledgements* section at the front of the Report.

The discussion guide for the sessions was prepared based on the proposed chapters and indicators to be included in this report. It was also reviewed and commented on by all session facilitators. All interviewers collaborated on their approach to interviewing participants and used a script of semi-structured, open-ended questions for consistency in data collection. To ensure that the perspectives were captured accurately, the main points of each discussion session were reviewed with the participants.

Once all the sessions were completed, content analysis was done; this process involved searching the session transcripts for common themes, words and messages. Overarching themes that crossed all stages of the journey were derived, along with key concepts related to the cancer control domains across the prostate cancer journey and advice to other men collected from the participants.

For information about the strengths and limitations of the approach, refer to the end of this Special Feature.

TABLE 4.i

Focus group and interview participants: Demographic information

	Number (%)
Province	
British Columbia	2 (4)
Manitoba	7 (14)
Ontario	15 (30)
Quebec	12 (24)
New Brunswick	3 (6)
Nova Scotia	11 (22)
Geography	
Urban	39 (78)
Semi-urban	6 (12)
Rural	5 (10)
Current age	
45-65	20 (40)
66-80	26 (52)
Over 80	2 (4)

	Number (%)
Age at diagnosis	
45-65	25 (50)
66-80	14 (28)
Over 80	1 (2)
Number of years since diagnosis	
< 1	2 (4)
1-3	12 (24)
4-6	21 (42)
> 7	5 (10)
Type of treatment	
Surgery/Radiation	32 (64)
Hormone therapy/Chemotherapy	10 (20)
Other	5 (10)
Unknown	10 (20)

For *age at diagnosis, current age* and *number of years since diagnosis*, the total shown is less than 50; this is because some participants did not provide this information. For *type of treatment,* the total is more than 50 because some men indicated they had undergone more than one type of treatment.

What we heard

OVERARCHING THEMES

During the various sessions and interviews, participants were asked about their experiences of being diagnosed, making treatment decisions, coping with treatment and living with the effects of treatment and follow-up care. The following overarching themes were elicited across all stages of the cancer journey:

- Personal support from health care providers and peers is very important.
- Patients, spouses and family members want to be empowered to take personal action before, during and after treatment so they can feel they have some control over the situation.
- An individual with prostate cancer is a whole person and should not be defined by his tumour. Treatment is not "one size fits all" and clear information and communication from health care providers is important.
- Most men with prostate cancer will survive their disease. It's essential for those within the cancer control system and the health care system in general to hear their voices.

HIGHLIGHTS ACROSS THE ENTIRE CANCER JOURNEY

The common themes identified within selected cancer control domains by the focus group participants are presented throughout the report, along with some quotations to provide examples directly heard from the participants.

- **Testing** Many of the men discussed the use of prostate-specific antigen (PSA) testing. Despite the controversy surrounding screening and testing for prostate cancer, most participants said they believed that PSA testing is valuable. It should be noted that these focus groups only included men who were diagnosed with cancer; it did not include men who had a false positive due to PSA testing (i.e., the test suggested prostate cancer, which led to more interventions, but ultimately led to a finding that there was no cancer).
- **Diagnosis** Many of the men talked about their emotional reactions to being diagnosed. Although many had positive experiences with their health care providers, some felt these providers needed to improve how they communicate a cancer diagnosis to the patient.
- **Treatment** Many of the participants said that having more information about prostate cancer led to them having a more positive outlook. There were mixed experiences in terms of how aware the men were about the possible short- and long-term side effects of their treatment. A few felt they did not have enough information on treatment side effects. Many of the men talked about the negative effects of treatment on their mental, physical and emotional well-being.
- **Person-centred perspective** Many of the participants talked about the need for person-centred care that also took into account the impact of the disease on their families. Effective communication and information-sharing among patients, their families and their providers were mentioned as important—as well better communication and information sharing between various clinicians and other care providers who are involved in caring for men with prostate cancer. Many of the participants said their physicians counselled them about their long-term outcomes, saying that they would likely die from something unrelated to prostate cancer. As a result, in response to questions about palliative care and end-of-life planning, many participants did not feel that such discussions with their providers were needed at the time. These comments are likely a reflection that many had completed treatment and were in relatively good health at the time of the interviews. As well, based on the discussions, it appeared that a larger proportion of participants had been treated for localized prostate cancer.

IN-FOCUS THEME #1: INFORMED AND SHARED DECISION-MAKING

One of the hallmarks of a person-centred health system is empowering the patient so that he/she is an active and indispensable participant in decisions related to his/her care. This requires the individual to have a thorough understanding of the risks and benefits associated with different care options; he/she must also make choices that are consistent with his/her particular circumstances, values and quality of life preferences—to the extent that this is possible.

Most focus group participants indicated they wanted to be informed on a variety of topics:

- the process and timelines between diagnosis and start of treatment;
- the different treatment options available to them;
- potential treatment side effects and how to manage them; and
- lifestyle modifications, such as specific dietary adjustments, exercise regimes and other strategies to help them in their recovery.

Men who took part in the focus groups referred to a broad range of resources they sought to gather information on their condition. Peer support, either in person or online, was identified as a particularly valuable resource. A common source of information was the Internet, although the participants agreed they had to choose their online resources carefully to ensure that they were accessing reliable information. According to many of the participants, providers (particularly urologists and oncologists) were identified as both the best and worst information sources, depending on each man's personal experience.

But beyond being well informed, most focus group participants felt strongly that being treated by clinicians who encouraged them to be meaningfully involved in decisions related to their care was very important.

> *"Make sure you explore all the options and find out what the consequences are, and don't underestimate what some of them might be."* **focus group participant from Manitoba**

Several of the men felt that their clinicians had made a particular effort to ensure they were well-informed about their condition and fully engaged in decisions around their care.

> *"There were a number of options. And I was very fortunate in that I had that choice to make. The urologist was very respectful and did not try to influence me. He made it very clear that you definitely have a choice. It's your decision. [He said] 'I'll respect that decision.' And he gave me all the facts in terms of the outcome and the percentages and the side effects. I just instinctively knew that I didn't want an operation. I wanted the radiation."* **from Quebec**

But not all men felt that they had been engaged by their clinicians or that they even knew they had options. Several indicated that they were simply told what the treatment would be and they went on to receive it. Only after the fact did they realize that they possibly could have been presented with choices. Others reported that they had to push hard to get their clinicians to consider their preferences.

> *"I got referred to an oncologist. He told me that a decision had to be made. I wanted to have HIFU, he didn't recommend it. Then I said ok then, I want to go for brachytherapy. So he signed the order and walked away. I felt like I was being treated as a potential buyer for a car. It's just a feeling I had that I was being railroaded into buying a particular car, or a particular treatment. I don't want to be pushed into those kinds of things. I want(ed) to be able to make a rational decision about where I was going to go with this."* **from Nova Scotia**

Some of the men acknowledged that in certain cases, because of existing co-morbidities (other illnesses) or other factors, they did not always have choices around treatment. But they added that even in those cases, they still wanted to be informed about their condition and what to expect. Some participants noted that feeling both respected as a person and reassured as a patient was important to help them through this journey.

IN-FOCUS THEME #2: EMOTIONAL SUPPORT

Earlier in this report, we presented data from a patient satisfaction survey involving men with prostate cancer who had received out-patient care (see the section *Patient Satisfaction with Care* earlier in this chapter). Findings from several provinces showed that those prostate cancer patients who responded to the survey had the most negative responses in the area of emotional support during diagnosis, treatment and follow-up care.

In line with those findings, the focus group participants spent a good amount of time talking about the need for emotional support from their care team and others. This included support for themselves, but also for their family members. While they expressed a clear need for emotional support throughout the cancer journey, many said that it was most critical at the time of diagnosis. Many participants said that they needed time to deal with their own emotional reactions to the diagnosis (and those of partners and family members) before they felt prepared to start gathering information and making decisions about treatment.

> *"The diagnosis is the difficult one. It is like…a grief. You get angry, you get depressed, you get sad, you get anxious, you get all sorts of things. And then eventually that settles down and then you focus on the treatment."* **from Quebec**

> *"The tough part for me emotionally [was]…telling your wife and your kids, 'I've got cancer.'"* **from Manitoba**

During the treatment phase, many participants felt that peer support was particularly important as they looked for help dealing with both physical and emotional issues. That sense of community and having shared experiences provided them with information and with hope. Some men emphasized the important role played by their spouses and partners in providing both emotional and practical support (i.e., driving them to and from treatment, visiting them while they were in the hospital).

> *"The local support group provided me with people who had been through the experience…some just barely ahead of me…These were people I had never met before and would never have met if it hadn't been for the diagnosis of prostate cancer."* **from New Brunswick**

Many men talked about how important it was after their treatment ended to be supported as they dealt with the emotional and relationship impacts caused by the physical side effects of treatment—particularly sexual dysfunction. Many said they had not been made aware of any formal programs or services that could help them deal with problems related to sexual changes or relationship changes. Indeed, sexual dysfunction after prostate cancer surgery was a common topic in the focus group sessions; some men said this had been a determining factor in their thoughts about treatment, although deciding to avoid surgery was not always possible.

> *"[Sexual dysfunction] causes stress, it causes emotional anxiety and all those other things but again you have to get past that and fortunately for us we were able to do so and make it work, and it goes forward."* **from Ontario**

Many participants said they looked to others for advice regarding potential side effects; they were eager to share their struggles, successes and continued experiences. Similar themes emerged during the session with caregivers (wives and children of men with prostate cancer). Some men added that being helped by other men in support groups had pushed them to become more actively involved in supporting others. However, there were also examples of participants who struggled at first to seek support.

"I'm part of a private Facebook group for prostate cancer patients only and it has been immensely helpful to me. I check in with it every day and it's just a place where men can let it all hang out, no topic is not covered. There's humour and we share the joys and the sorrows. It's what we call a 'reluctant brotherhood'." **from New Brunswick**

"Some of my issues… you can't really share with a friend… [There] are some of the emotional things I'm going through. You know, I've got some other things going on in my life too which are weighing in on this, and here's where I'm at and you know, just, maybe a sympathetic ear to listen and talk to [would have been helpful]. Just something like that." **from Nova Scotia**

Some participants said they felt gaps existed in emotional support for men (i.e., it was not readily available or accessible, or they did not know it was available), primarily at the provider or system level. This was especially true among participants who were being treated away from their places of residence.

Other participants reported that emotional support from individual providers or within a care team was inconsistent. For example, some described having positive experiences with one of the providers on their care team but negative experiences with others. While some participants named their family doctors or physician specialists as the best sources of support, others felt they had been treated insensitively or perfunctorily, particularly at diagnosis or referral.

IN-FOCUS THEME #3: SURVIVORSHIP AND LIVING WITH SIDE EFFECTS OF TREATMENT

As the population ages, the number of new cases of prostate cancer is expected to rise. As the use of active surveillance as a way to manage some prostate cancers also increases and treatments improve, a growing number of men are living many years after a diagnosis of prostate cancer. For these reasons, survivorship is an important and continuing phase of the journey.

During the focus groups, the men shared their post-treatment experiences, both physical and emotional. Many expressed frustration with some of the lingering side effects from treatment, while others said they had adapted to the "new normal" of living with or without these after effects. Their experiences were mixed in terms of how aware they had been about these short-term side effects, about long-term outcomes and about the actual extent of various post-treatment challenges.

"I'm not happy about the choices that I made. I had the feeling that I was not given the whole truth about the procedure. Physically I can't do things that I did before I was healthy. And I don't know if it's because of the brachytherapy [that] gives my whole attitude a negative aspect." **from Nova Scotia**

"The treatment messes with your mind a lot; it throws you into that dark place." **from Manitoba**

"You've got to make plans, stay involved, take the chance to book something in the future [like trips], and with each year that goes by, say 'I got one more year'." **from Ontario**

While most of the participants had either surgery or radiation therapy as treatment, others had hormone therapy, chemotherapy or a combination of different treatments. The most frequently mentioned physical side effects from treatment were sexual dysfunction, fatigue and incontinence. Some noted the emotional challenges that accompanied these physical side effects, including a perceived loss of masculinity for some.

Participants, both patients and caregivers, noted that there were gaps between the side effects they expected might occur and those that actually did. Some participants said that clear communication can help manage expectations and alleviate stress and anxiety because patients and families will be better prepared for how things might unfold.

> *"I require much more sleep than before cancer…Also [I have] urine retention [which] requires that I carry catheters and supplies every time I go out."* **from Nova Scotia**

> *"The whole sexual function—it's problematic and it's very individual. You still have your libido. So that sort of adds to the distress in a sense…It's double stress because you have the desire but not the ability."* **from Quebec**

> *"Guys won't talk about erectile dysfunction even to their doctors, so I talk about it [in support groups]."* **from Ontario**

For many of the participants, fear of cancer recurrence was another lingering concern, and was also identified by several participants as the most challenging effect of a cancer diagnosis.

> *"I think we all have that fear. The slightest ache is metastasis."* **from Ontario**

There were some general comments about the challenges with accessing post-treatment care and the need to reinforce follow-up and aftercare. Many participants mentioned positive experiences receiving coordinated care between providers and facilities, but several spoke of a disjointed process between practitioners and confusion about where to go for help if needed.

Some participants expressed frustration that they could only make an appointment to see their surgeon or oncologist if their question was specifically related to their treatment. If not, they were not offered any options for support.

> *"I would've loved to have had a phone number of resources in the hospital where I could say, 'I'm having a bad day' [and then get some support], instead of 'Poof!' and everyone disappears."* **from Nova Scotia**

Although these discussions mostly focused on the physical and emotional effects after treatment, many participants also mentioned other practical post-care challenges (e.g., how to get to follow-up appointments, financial burdens).

IN-FOCUS THEME #4: SUPPORT FOR CAREGIVERS

Person-centred care for men with prostate cancer must also take the needs, values and perspectives of family members into account since they, too, are affected by a diagnosis of prostate cancer.

While many participants said their spouses or partners had been included in all conversations with their physicians, most were not aware that any formal supports were available to their spouses from within the health care system. Such support—mainly access to information about the condition and care of their loved one—would enable family members to participate more fully as part of the care team. Information about spouses' own needs as caregivers, including how to look after themselves, would also be helpful. This lack of resources for spouses or caregivers (or knowledge about resources), was identified as a gap by both the men and family members.

Some participants in the caregiver session said that peer support groups or patient forums tend to focus their membership and the content of discussions on men with cancer, with limited focus on spouses or other family members. However, several patient participants stated that their own support groups were exceptional in this way and remarked on the benefits of including spouses in their membership. For example, a sense of family developed among those sharing difficult experiences. Some participants said this had helped them enormously throughout the journey, including long after treatment had ended.

> *"In our particular group, the ladies are as much a part of everything we do as the men. We've had a couple of people who have lost their spouses and they're suddenly…at a loss, so it's one of those things that as a group we try to be there for them—it's a big family."* **from Ontario**

In summary

System performance indicators—for example, one that does a province-by-province comparison of how many men with prostate cancer underwent a prostatectomy—can yield useful information about oncology practice patterns. But understanding how men felt about making a decision about which treatment to have is also important and offers a clearer picture of the quality of care provided. Did the men who underwent prostatectomy understand the potential risks and benefits of the surgery? Were they offered any alternatives?

Similarly, measuring outcomes such as age-standardized incidence rates and relative survival rates are important surveillance metrics that help to evaluate our efforts toward improving cancer control in Canada. But a much richer portrait emerges when survival rates are presented alongside candid comments from survivors about how cancer has affected them physically, emotionally and socially.

By including reflections from patients and survivors about their journey following treatment, this report has opened a small window into the experiences of some men who have finished treatment and are now in the sometimes equally challenging survivorship phase of their journey. This is particularly important, given that prostate cancer is the most common cancer affecting Canadian men.

So what did we learn from them? First, while some focus group participants said they had felt completely informed about the treatment choices available to them and were active participants in the decisions around their care, many others felt they had been left the dark about their options. Some said they had rushed into their surgery or radiation therapy without full knowledge of potential side effects.

We learned that one of the biggest unmet needs was for emotional support, particularly as the men we interviewed coped with the initial cancer diagnosis and then struggled with the physical effects of treatment—particularly erectile dysfunction and incontinence.

And finally we learned that spouses and other family members felt they could have been better supported with information that would have allowed them to better and more fully care for their loved ones during both the treatment and post-treatment phases. We heard that family members would also benefit from knowing more about the availability of emotional support services which would allow them to attend groups, either on their own or with their partners.

But while we certainly heard about the hardships and challenges of prostate cancer, we also heard some uplifting recounts about clinicians who consistently took the time to learn about their patients and to engage them fully in every aspect of their care. We heard about the important role played by men's spouses, partners and family members—especially when they were empowered with information and support.

We were also impressed and touched by the courage of those men who volunteered to take part in our focus groups and other sessions. Many said they wanted to speak openly about their often-difficult experiences. They said they hoped the information might help improve the experiences of thousands of Canadian men who will be diagnosed with prostate cancer in the future and also help inform care providers and decision-makers involved in meeting their needs.

Strengths and limitations

The strengths of our approach to engaging in these consultations include:

- multiple methods for data collection and representation across multiple provinces;
- collaboration with qualitative researchers at Ipsos Reid and with our expert facilitators; and
- recurrence of similar expressions from the participants across the sessions, which suggested that the sample size was sufficient to obtain a reasonable range of perspectives for the specific questions posed.

We acknowledge some limitations:

- Findings represent the views of 47 men and the three family caregivers who answered specific questions related to their experiences.[p]
- To be included, men had to have been treated for prostate cancer; therefore, the views and experiences of men who did not receive treatment have not been captured.
- All the participants were volunteers. While volunteers in research are often more involved, informed and willing to discuss their perspectives, they may not necessarily reflect the views of others within a population.
- Many participants were recruited via existing prostate cancer support groups and networks, which meant that many were familiar and comfortable with sharing their thoughts in a group setting, mostly in a positive and constructive manner. As well, men who choose to seek help from support groups may experience more side effects than those who do not.
- Only a small number of family members participated; however, the key themes that were brought up were confirmed by our facilitators as commonly heard themes from their own practice or research.

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[p] The interview guide can be found in the Technical Appendix at systemperformance.ca.

5. Research

5. Research

Canada has an active prostate cancer research community. Several Canadian agencies support prostate cancer research, including the Canadian Institutes of Health Research (CIHR), Prostate Cancer Canada (PCC), the Terry Fox Foundation (TFF) and the Canadian Cancer Society (CCS). Despite this, our ability to measure the performance and impact of cancer research activity is limited by the lack of readily available data.

Specifically, we lack the ability to measure and track the process, output and outcomes of clinical research activity at a pan-Canadian level (e.g., the impact of prostate cancer research on clinical outcomes).

This chapter presents data on three indicators that can yield useful information about prostate cancer research activity and its role within the cancer control system:

- a breakdown of cancer research funding by cancer site compared to the relative burden of those cancers;
- the distribution of funding across areas of prostate cancer research; and
- clinical trial participation ratios for prostate cancer relative to other cancers.

The first two indicators use information on research spending reported to the Canadian Cancer Research Alliance (CCRA). Because data are not available to calculate the actual clinical trial participation or the percentage of qualifying patients who are enrolled in various clinical trials, we present a "proxy indicator," which is widely used. This indicator measures the ratio of the total number of adult prostate cancer patients newly enrolled in Phase I to IV clinical trials (cancer-related therapeutic trials or clinical research studies) in 2013 to the number of cancer incident cases in the same year.

Cancer Research Investment

What are we measuring and why?

This indicator examines the breakdown of site-specific cancer research funding estimates for prostate, breast, colorectal and lung cancers, using information on research spending reported to the Canadian Cancer Research Alliance (CCRA) in 2012. This information compares the allocations of funding to the relative burden of these cancers in terms of incidence (2010) and mortality (2011). This section also presents data from the five largest prostate cancer research funders in Canada and examines the distribution of their investment into various areas of prostate cancer research in 2005 and 2012. The provincial per capita investment in prostate cancer research for 2005 and 2012 are also examined for all provinces.

- Adequate support of research directed to specific cancers helps advance the state of the science and accelerate translating discoveries for the benefit of patients. Priorities for prostate cancer research include: developing specific diagnostic tests; identifying novel biomarkers and imaging technologies that can distinguish indolent from aggressive disease; reducing treatment-related toxicities; and developing guidelines aimed at identifying men with prostate cancer who might be considered eligible for active surveillance or watchful waiting (i.e., rather than immediate treatment).
- The chapter also looks at pooled data from the five largest research funders in Canada and examines the distribution of their investment against the Common Scientific Outline (CSO) in 2005 and 2012. The CSO includes seven categories intended to capture a wide array of research areas (see Table 5.3).[179]

What are the results?

- In 2012, $541.6M was invested in cancer research in Canada; of that, $286.2M was invested in cancer site-specific research, with $37.9M (13.2%) invested in prostate cancer. This was proportionally less than the site-specific research investment for breast cancer (26.5%), but higher than the investments for research into lung cancer (6.7%) and colorectal cancer (6.7%) (Figure 5.1).
- Prostate cancer accounted for 5.3% of cancer deaths in Canada that year and received 13.2% of site-specific research dollars in 2012 (Figure 5.1).
- The top five prostate cancer research funding agencies in 2012 represented 72.5% of total research into prostate cancer in 2012 (Table 5.1). In both 2005 and 2012, the Canadian Institutes of Health Research (CIHR) had the highest level of investment, representing 17.7% and 28.7% of the overall prostate cancer research investments, respectively (Tables 5.1 and 5.2). Prostate Cancer Canada was the second largest investor in 2012; this represents more than a seven-fold increase from 2005. While the Canada Foundation for Innovation (CFI) was the second largest funder in 2005, it was the eighth largest investor in 2012 (Table 5.2; data not shown). The Ontario Institute for Cancer Research (OICR) was the sixth largest funder in 2005 and the third largest investor in 2012, due to its major investment in the Canadian Prostate Cancer Genome Network (CPC-GENE) (data not shown; Table 5.1). The CPC-GENE project aims to decode the prostate cancer genome and then develop personalized cancer therapies for patients, which may decrease overtreatment. Prostate Cancer Canada is also a major investor in the CPC-GENE project.
- Figure 5.2 shows the changing pattern of cancer research investment distribution by area of science in 2005 and 2012 for the top five prostate cancer research funding agencies. While the distribution of investment into areas of prostate cancer research changed over those seven years, the investment amount increased across all CSO-defined areas of research except for *Cancer control, survivorship and outcomes research*. Funding for this area decreased from approximately $884K (7.2%) in 2005 to $630K (2.3%) in 2012 (Figure 5.2).
- The major investments during the seven-year period were in research related to *Early detection, diagnosis and prognosis* and *Treatment*; this accounted for 55.1% of the overall funding from the top five funders in 2012 (Figure 5.2).

- The highest percentage change in the distribution of investment among the top five funders from 2005 to 2012 was for research into *Early detection, diagnosis and prognosis*; funding went from 19.3% in 2005 to 35.8% in 2012. The investment in research looking at *Etiology* also increased by 8.2% from 2005 to 2012 (Figure 5.2).
- The per capita investment in prostate cancer research in 2005 and 2012 was also examined for the Canadian male population for each province. In 2012, the largest investment was in British Columbia ($4.18 per man); the lowest was in Saskatchewan at $0.09 per man (Figure 5.3).
- Per capita investments in Alberta, Manitoba, Ontario, Quebec, New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador were higher in 2012 than in 2005; per capita investments in British Columbia and Saskatchewan were lower in 2012 than in 2005 (Figure 5.3).

Data and measurement considerations

- Data come from the Canadian Cancer Research Survey (CCRS), which is carried out by the Canadian Cancer Research Alliance (CCRA). In 2012, the survey captured funding information from 42 organizations including governmental and voluntary sectors across Canada.
- The CCRS captures research investments by federal agencies and programs, provincial government organizations and voluntary organizations; however, it does not capture investments made by hospital foundations (e.g., the BC Cancer Foundation, the Princess Margaret Hospital Foundation); organizations outside the country that fund Canada-based research (e.g., the National Cancer Institute in the United States); or industry-sponsored research and development. The survey captures at least 65% of the total estimated investment in cancer research.
- For this analysis, investment in research that was relevant to all cancer sites or not site-specific was excluded. That is, only projects or grants in which the prostate cancer share of the total was greater than 1% were included.
- Research areas are based on Common Scientific Outline (CSO) codes. Where more than one CSO code was assigned to a research project, the investment was distributed equally among the codes.
- Burden of disease (as defined by incidence and mortality) is just one way to assess research investment; many other indicators are used to assess health burden. For the purpose of this report, however, only incidence and mortality were considered.
- Project equivalents (Figure 5.3) refers to the sum of projects weighted by their cancer relevance. For example, in British Columbia in 2005, there were 53 projects in total. When their cancer relevance was accounted for, the number of projects decreased slightly to 47.7.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

TABLE 5.1

Investment in prostate cancer research by top five funders — 2012

Top five funders in 2012	Sector	Investment in 2012	Percent of total investment
Canadian Institutes of Health Research (CIHR)	Government: Federal	$10.86M	28.69%
Prostate Cancer Canada (PCC)	Voluntary	$7.08M	18.69%
Ontario Institute for Cancer Research (OICR)	Government: Provincial	$4.48M	11.83%
Terry Fox Foundation (TFF)	Voluntary	$2.55M	6.74%
Canadian Cancer Society (CCS)	Voluntary	$2.48M	6.54%
TOP FIVE FUNDERS		**$27.45M**	**72.49%**
TOTAL: ALL FUNDERS		**$37.87M**	**100%**

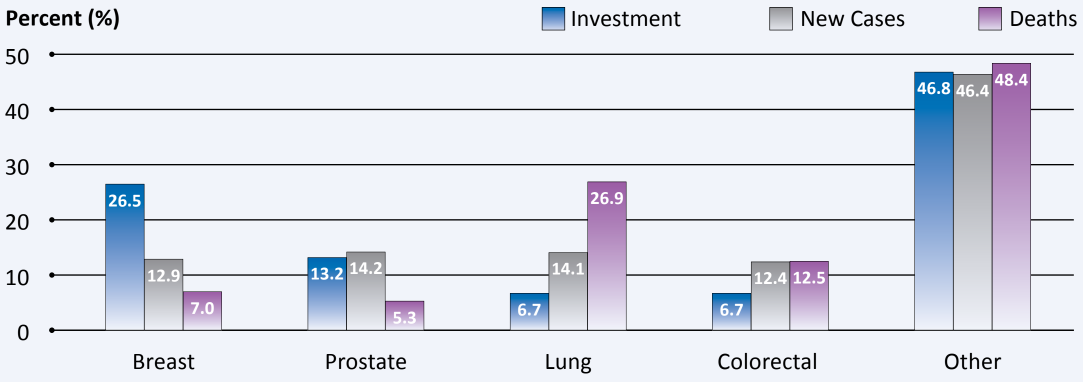
TABLE 5.2

Investment in prostate cancer research by top five funders — 2005

Top five funders in 2005	Sector	Investment in 2005	Percent of total investment
Canadian Institutes of Health Research (CIHR)	Government: Federal	$3.79M	17.66%
Canada Foundation for Innovation (CFI)	Government: Federal	$2.86M	13.31%
Canadian Cancer Society (CCS)	Voluntary	$2.55M	11.87%
Terry Fox Foundation (TFF)	Voluntary	$2.16M	10.05%
Prostate Cancer Canada (PCC)	Voluntary	$901,647	4.20%
TOP FIVE FUNDERS		**$12.27M**	**57.09%**
TOTAL: ALL FUNDERS		**$21.48M**	**100%**

FIGURE 5.1

Distribution of cancer research investment (2012), new cancer cases (2010) and cancer deaths (2011), by disease site, Canada



"Other" refers to the remaining primary types of cancer listed in ICD-O-3. Included are all other invasive types and in situ for bladder.

Data source for cancer research investment: Canadian Cancer Research Alliance, Canadian Cancer Research Survey.

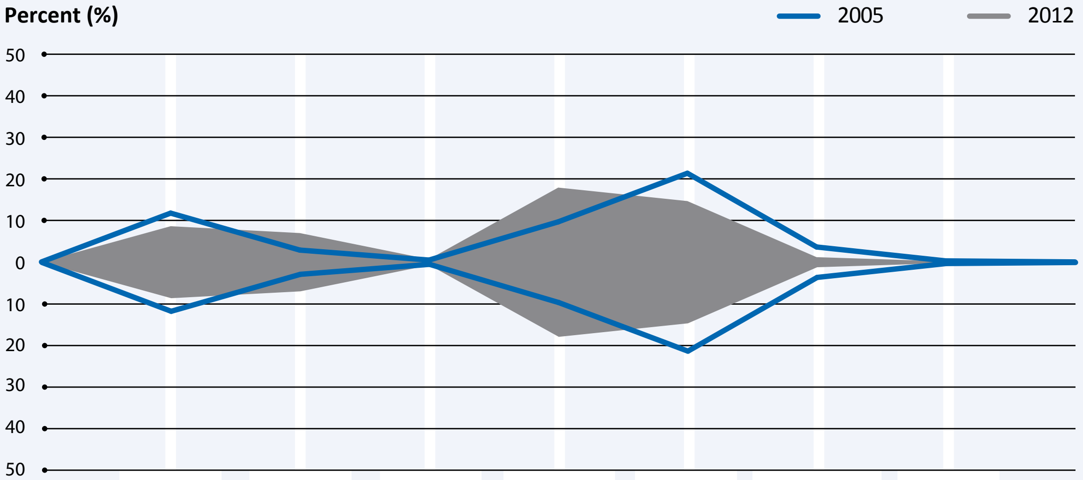
Data source for new cancer cases: Statistics Canada, Canadian Cancer Registry.

Data source for cancer deaths: Statistics Canada, Vital Statistics Death Database.

Source: CANSIM Table 103-0553 for cancer cases, CANSIM Table 102-0552 for cancer deaths.

FIGURE 5.2

Distribution of investment in prostate cancer research across areas of research for top five funders, Canada — 2005 and 2012



Year	Biology	Etiology	Prevention	Early detection, diagnosis and prognosis	Treatment	Cancer control, survivorship and outcomes research	Scientific model systems	Total
2005	$2,885,966	$705,091	$113,940	$2,369,396	$5,240,114	$884,055	$67,229	**$12,265,791**
2012	$4,732,781	$3,803,243	$345,494	$9,829,473	$8,036,790	$630,182	$71,397	**$27,449,360**

Research areas are based on Common Scientific Outline Codes (see Table 5.3).

Data source: Canadian Cancer Research Alliance, Canadian Cancer Research Survey.

TABLE 5.3

Common Scientific Outline codes

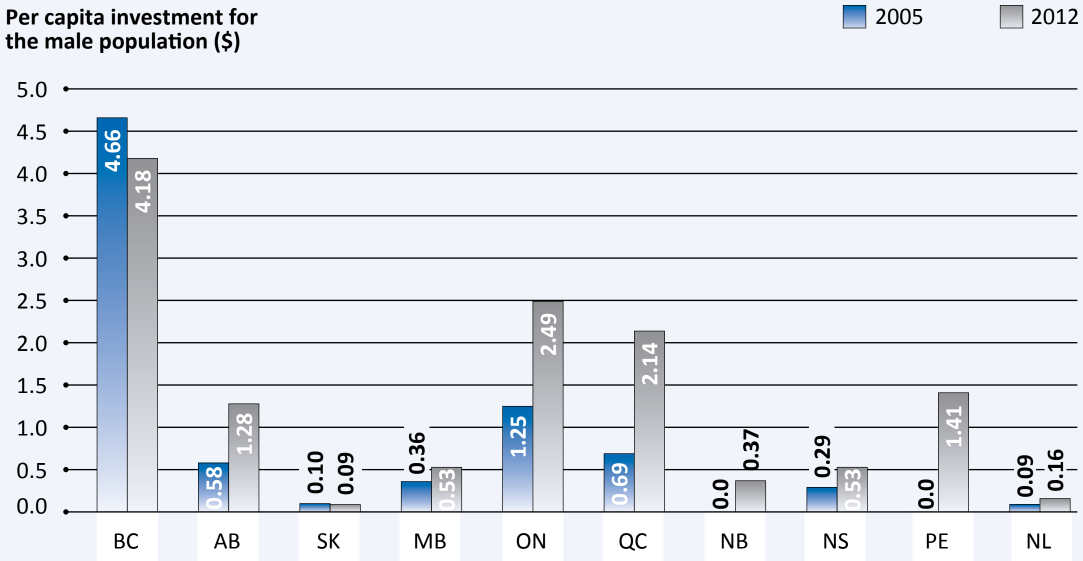
Common Scientific Outline (CSO) code	Description
Biology	How cancer starts and progresses, as well as normal biology relevant to these processes (e.g., epigenetics, growth factor receptors).
Etiology	Causes or origins of cancer—genetic, environmental and lifestyle, and the interactions between these factors (e.g., smoking, HPV infection, BRCA1).
Prevention	Identifying interventions that reduce risk by reducing exposure to cancer risks and increasing protective factors. Interventions may target lifestyle (i.e., physical activity, nutrition, sun exposure) or may involve drugs or vaccines.
Early detection, diagnosis and prognosis	Identifying and testing cancer markers and imaging methods that can detect and diagnose cancer (e.g., quality assurance, biomarkers).
Treatment	Identifying and testing treatments (such as radiotherapy, surgery, chemotherapy) and non-traditional treatments (supplements, herbs). Includes clinical trials.
Cancer control, survivorship and outcomes research	Patient care and pain management; tracking cancer cases in the population; clinical outcomes; beliefs and attitudes that affect behaviour regarding cancer control; education approaches for patients and professionals; supportive and end-of-life care; health care delivery in terms of quality and cost effectiveness.
Scientific model systems	Development of new animal models, cell cultures and computer simulations and their application to other studies in cancer research.

The CSO is a framework organized into seven broad areas of scientific interest. It was developed and is used by the International Cancer Research Partnership (ICRP). The ICRP is a partnership made up of cancer research funders from the United States, Canada, the United Kingdom, France, the Netherlands, Australia and Japan.

Source: International Cancer Research Partnership.[179]

FIGURE 5.3

Per capita investment (male population) in prostate cancer research, by province — 2005 and 2012



Project Equivalents	BC	AB	SK	MB	ON	QC	NB	NS	PE	NL
2005	47.7	20.1	0.5	7.6	83.4	51.1	0.0	3.8	0.0	0.5
2012	72.3	15.5	2.5	7.3	129.7	72.3	0.1	7.7	1.0	1.3

Project equivalents refers to the sum of projects weighted by their cancer relevance.

The male population includes males of all ages.

Data source: Canadian Cancer Research Alliance, Canadian Cancer Research Survey.

What do the results mean?

- Assessing research funding relative to disease burden helps cancer research funders identify important areas and gaps where additional research funding may be needed.
- The National Cancer Research Institute (NCRI) in the United Kingdom has reported that the highest levels of funding were allocated to breast cancer research compared to spending for research involving other cancer sites. In 2011, the United Kingdom (unlike Canada) provided less funding (7.7% of site-specific funding) for prostate cancer research than it did for research into colorectal cancer.[180]
- The National Cancer Institute (NCI) in the United States allocated $255.6 million to prostate cancer research in 2013. Using the CSO codes, most of the NCI-funded research for prostate cancer was invested in *Biology* (24%), followed by *Treatment* (23%) and *Early detection, diagnosis and prognosis* (18%).[181]
- In Canada, we have seen a large shift in the distribution of funding *to Early detection, diagnosis and prognosis* research. Some differences among the top five funders emerged—specifically the Ontario Institute for Cancer Research (OICR) and Prostate Cancer Canada (PCC). These research agencies invested a significant proportion of their funding into *Early detection, diagnosis and prognosis*. This likely reflects the inauguration of a joint project between OICR and PCC's Canadian Prostate Cancer Genome Network (CPC-GENE). As explained earlier, the CPC-GENE project aims to decode the prostate cancer genome, in order to develop personalized cancer therapies for patients and to decrease overtreatment.[182] The increased investment into *Etiology* also reflects the large investment into the CPC-GENE project.
- Another project that likely contributed to the investment shift in this area is the Medical Imaging Trial Network of Canada (MITNEC), a project funded by the Canadian Institutes of Health Research (CIHR). This network facilitates multi-centre clinical trials that will ultimately lead to approval of the new radio-pharmaceutical products by Health Canada and their subsequent uptake into clinical practice.[183] Although a number of provinces are involved in MITNEC, the nominated principal investigator is located in Quebec.[183]
- Projects are under way that affect Quebec's large per capita investment in prostate cancer research. One is the Quebec Research Program for Prostate Cancer Prevention administered by the Cancer Research Society; funding comes from both the Cancer Research Society and the Quebec government.[184]
- A considerable number of Canadian men (an estimated 176,361 in 2009) are living with or beyond prostate cancer.[185] Yet there was a decrease in investment in *Cancer control, survivorship and outcomes research* 2012. It is important to determine what types of survivorship research would most likely address the unmet needs of prostate cancer.

What are some examples of efforts in this area?

- The Canadian Partnership for Tomorrow Project (CPTP) is a significant, long-term research initiative designed to explore how factors such as genetics, behaviour, environment and lifestyle contribute to the development of cancer and other chronic diseases. The project is funded by the Partnership and partner organizations and includes more than 300,000 Canadians aged 35-69. CPTP has been specifically designed to look at the etiology of diseases, including cancer. The hope is that knowledge gained via this long-term study will yield new interventions aimed at preventing prostate and other cancers.
- A five-year strategic plan for cancer research (2015-2020) is now being developed by the Canadian Cancer Research Alliance (CCRA). One proposed priority is to develop a survivorship research framework to help identify important gaps in research that might benefit from strategic funding.[186]

- In the future, more indicators related to prostate cancer research may be explored in the Partnership's System Performance reports, including the number of publications and the top prostate cancer researchers in Canada and their global stature.

What else do we know?

- Investments in prostate cancer research have led to breakthroughs across the cancer control continuum, from basic cancer biology to cancer survivorship. A few of the research studies currently taking place are discussed below.
- The Terry Fox Foundation, with support from the Partnership, embarked on the pan-Canadian Cancer Biomarker Initiative (2010-2016). This project aims to develop new prognostic tools that will allow clinicians to stratify low-grade tumours requiring immediate treatment versus those that could be safely managed using active surveillance. This project also aims to identify biomarkers for patients at increased risk of disease progression or recurrence who might benefit from neoadjuvant or adjuvant therapies.[187]
- In 2014, a new national research initiative from Prostate Cancer Canada was introduced. Called the Movember Translation Acceleration Grants (TAG), this funding program aims to distinguish men who need to be treated aggressively from those who do not. Three major research teams in Edmonton, Alberta, Toronto, Ontario and Sherbrooke, Quebec were awarded close to $5M for projects designed to prevent the overtreatment of prostate cancer.[188]
- The OICR is funding the Active Surveillance Magnetic Resonance Imaging Study Trial (ASIST). The goal is to examine whether MRI, coupled with transrectal ultrasound (TRUS)-guided biopsy, can be used to identify indolent versus aggressive prostate tumours.[189]
- Based on a report by Prostate Cancer Canada, a large investment in prostate cancer treatment research went towards initial funding (resources and infrastructure) for the Prostate Centre's Translational Research Initiative for Accelerated Discovery and Development (PC-TRiADD). PC-TRiADD focuses on developing targeted therapeutics and imaging and robotic tools in order to improve outcomes in prostate cancer. PC-TRiADD received support from the Canada Foundation for Innovation (CFI), the Michael Smith Foundation for Health Research (MSFHR) and other British Columbia government resources.[190] Furthermore, PC-TRiADD is supported as a Centre of Excellence for Commercialization and Research (CECR) by the Networks of Centres of Excellence until 2018.

Clinical Trials Participation

What are we measuring and why?

This indicator examines adult cancer clinical trial participation for prostate cancer relative to other major disease sites (breast, lung and colorectal). Clinical trial participation rates for adults are expressed as the ratio of cancer patients aged 19 years and older, newly enrolled in cancer-related therapeutic clinical trials or clinical research studies in 2013, to the number of cancer incident cases in 2013.

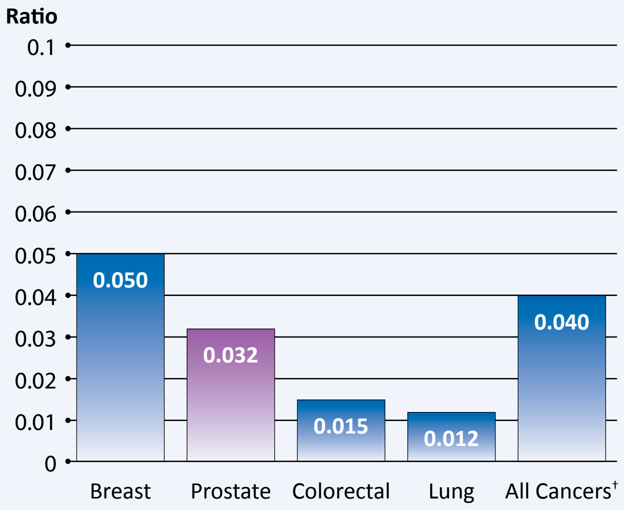
- Clinical trials are essential for developing new evidence-based methods and treatments. They introduce novel effective therapies into clinical practice and may reduce the use of ineffective and/or adverse therapies. The hoped-for endpoint is to improve patient outcomes.
- Data from other sources suggest that the cancer clinical trials system in Canada is facing difficulties for several reasons. These include increasing clinical trial complexity, a more onerous regulatory environment, and increasing workloads for research ethics boards. In addition, although the number of cancer clinical trials opened per year had remained the same or increased from 2000-2010, patient enrolment per year had plateaued or decreased.
- Uncertainty around appropriate treatment options for prostate cancer patients is partially due to lack of randomized controlled trials investigating the benefits of different treatment options.[191] Studies are needed to produce recommendations and guidelines that will identify those men who are eligible for active surveillance and those who should undergo primary treatment. However, there have been some important trials to date that may change clinical practice (See the following *What else do we know?* section to read more about pivotal clinical trial research).
- The National Comprehensive Cancer Network (NCCN) states in its *Clinical Practice Guidelines in Oncology* that the best management for cancer patients can be found within a clinical trial. Participation in clinical trials is especially encouraged for men with advanced prostate cancer.[83] Cancer Care Ontario's Disease Pathway Management (DPM) model states that clinical trials should be considered for men in all phases of the prostate cancer treatment pathway (i.e., where trials are available and patients meet eligibility requirements).[192]

What are the results?

- In 2013, the adult clinical trial participation ratio for the four most common disease sites ranged from a low of 0.012 for lung cancer to a high of 0.050 for breast cancer (Figure 5.4). Prostate cancer had a clinical trial ratio of 0.032.
- There was interprovincial variation in adult clinical trial participation for prostate cancer. In 2013, the ratio of adult patients enrolled in clinical trials to cancer incident cases ranged from 0.019 in Nova Scotia to 0.052 in Saskatchewan (among the six reporting provinces) (Figure 5.5).

FIGURE 5.4

Ratio of adult prostate cancer patients enrolled in clinical trials to number of incident cases, by disease site, four most common cancers and all cancers[†] — 2013 enrolment year



† All cancers may include non-melanoma skin cancer patients.

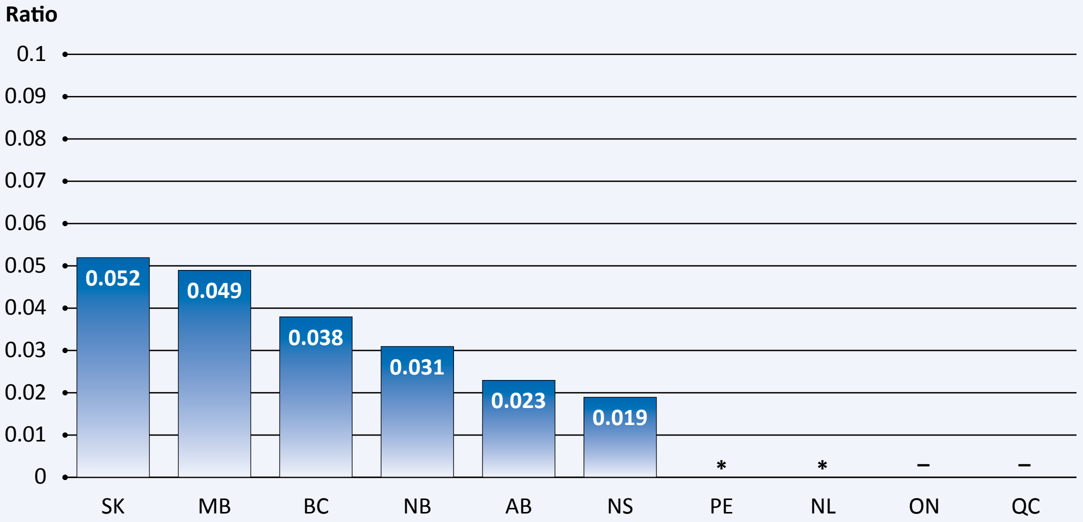
The overall clinical trial cases and incident cases included BC, AB, SK, MB, NB, NS, PE and NL.

Incident cases are estimated for 2013 from the Canadian Cancer Society's Canadian Cancer Statistics.

Data source: Provincial cancer agencies; Canadian Cancer Society, Canadian Cancer Statistics

FIGURE 5.5

Ratio of adult prostate cancer patients enrolled in clinical trials to number of incident cases, by province — 2013 enrolment year



* Suppressed due to small numbers.

"–" Data not available.

Incident cases are estimated for 2013 from the Canadian Cancer Society's Canadian Cancer Statistics.

Data source: Provincial cancer agencies; Canadian Cancer Society, Canadian Cancer Statistics.

Data and measurement considerations

- The adult clinical trial indicator is a ratio not a rate. As such, the numerator is not a complete subset of the denominator. Cases included in the numerator could have been diagnosed in previous years and could be recurrent cases. The numerator is the total number of adult cancer patients (aged 19+) newly enrolled in all phases of therapeutic clinical trials or research studies (radiation, systemic, and surgery trials only; curative, adjuvant/neoadjuvant or palliative) at provincial cancer centres in 2013. The denominator is the number of cancer incident cases in 2013. The projected cancer incident cases reported by the Canadian Cancer Society (CCS) were used for the purpose of this proxy indicator only; they should not be compared with the long-term outcomes incident cases.
- The Alberta Clinical Trials (ACCT) database includes patients who were living outside Alberta, as long as they were enrolled in a clinical trial taking place in Alberta.
- Data tables for this indicator (including confidence intervals), along with detailed calculation methodology contained in the full Technical Appendix, are available at systemperformance.ca.

What do the results mean?

- Adult clinical trial participation rates in Canada are low. This is similar to rates in other countries worldwide including the United States; fewer than 3% of American cancer patients participate in clinical trials.[193] In contrast, the United Kingdom has a high rate of cancer clinical trial participation: in 2007/2008, 12% of adults diagnosed with cancer in the United Kingdom participated in cancer trials.[194]
- Several barriers to and facilitators of enrolment in prostate cancer clinical trials have been investigated. A Canadian study was the first to examine in detail the factors influencing enrolment.[195] This study reported that younger patients were more likely to enrol in trials. Having their physicians recommend they take part in a clinical trial along with a desire to help those who will develop prostate cancer in the future were cited as strong facilitators to enrolment. As for barriers, men expressed concern about the randomization in clinical trials (i.e., they might be given a placebo vs. the treatment being studied and thus gain no benefit). Men also mentioned being worried about the time required to participate.

What are some examples of efforts in this area?

- The National Cancer Research Network was established in 2001 by the United Kingdom’s Department of Health to provide the National Health Service (NHS) with the infrastructure to support cancer clinical trials and to enhance recruitment to trials. Through this initiative, overall accrual to clinical trials in the United Kingdom rose from less than 4% to 14% by 2006. By 2010, recruitment of patients to cancer network studies in the United Kingdom had quadrupled since 2001—from 1 in 26 patients to 1 in 6.[196]
- The Canadian Cancer Clinical Trials Network (3CTN) was created to act as a national coordinating centre for clinical trial centres. The coordinating centre—housed at the Ontario Institute for Cancer Research (OICR) in Toronto, Ontario—has been launched with funding support from the OICR, the Canadian Partnership Against Cancer, the Canadian Breast Cancer Foundation (CBCF), CancerCare Manitoba, the BC Cancer Foundation, the Alberta Cancer Foundation, the New Brunswick Health Research Foundation and the Nova Scotia Health Research Foundation. The

initiative's goals are: to improve patient access to academic clinical trials; to improve site performance of academic trials; to improve the trial environment for the conduct of academic clinical trials through collaboration and facilitation of important national trial initiatives; and to demonstrate impact of the Network and academic trials on the Canadian health system.

- The European Clinical Research Infrastructures Network launched International Clinical Trials' Day on May 20, 2005, to raise awareness of the importance of clinical trials in advancing medicine and human health. In Canada, International Clinical Trials' Day was celebrated for the first time in 2006.[197]
- In the future, additional indicators may be investigated in System Performance reports including an indicator of activity such as the number of trials opened and number of trials closed.

What else do we know?

- Randomized controlled trials have yielded several advances in prostate cancer research. There have been some important trials that may change clinical practice, including the early detection trials. For example, the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial (PLCO) showed that organized prostate cancer screening via PSA testing did not lower the overall number of deaths due to prostate cancer.[198] The European Randomized Study of Screening for Prostate Cancer (ERSPC) found that PSA screening lowered the number of deaths due to prostate cancer by 20%. However, the number of men who would need to be screened and treated to save one life was extremely high and the disadvantages of early detection (e.g., increase in overdiagnosis of prostate cancer) need to be considered.[199] In October 2014, the Canadian Task Force on Preventive Health Care (CTFPHC) updated its recommendation against screening for prostate cancer using PSA testing in the general population, stating that evidence still shows the harms of testing outweigh the benefits.[9]
- The Selenium and Vitamin E Cancer Prevention Trial (SELECT), which enrolled more than 35,000 men age 50 and older (including some Canadian men), starting in 2001 was scheduled to go through to 2011. The trial was stopped in 2008 when researchers found that selenium supplements provided no benefit and that data suggested an increased risk of cancer from vitamin E.[200] Some men are still being followed and new data will continue to emerge.
- The Prostate Cancer Intervention Versus Observation Trial (PIVOT) showed that men receiving active treatment did not benefit in terms of survival compared to men on active surveillance. The exception to this involved men with high-risk disease.[201]
- The Radiotherapy and Androgen Deprivation in Combination After Local Surgery study (RADICALS) is a Canadian trial examining the timing of adjuvant radiation therapy and the role of androgen deprivation therapy after surgery. Enrolment in this trial will not close until 2015-2016.[202]
- The Prostate Testing for Cancer and Treatment trial (ProTECT) will compare active surveillance, radical prostatectomy and radiotherapy in men with early stage prostate cancer. The goal is to determine the benefits of surveillance. Enrolment will remain open until 2015.[203]

Looking Ahead

Prostate cancer remains the most commonly diagnosed cancer and the third leading cause of cancer death among men in Canada.[1] However, prostate cancer mortality in Canada has generally been declining in recent years.

Given that prostate cancer is most commonly diagnosed at an older age, as the baby boom population in Canada moves into its 70s and 80s, the number of prostate cancer cases will increase sharply in the coming years. The Canadian Cancer Society projects that, by 2030, the number of prostate cancer patients diagnosed each year will increase to 42,000 from the current 24,000.[1] The health care system must start preparing to meet that challenge now. As we prepare to do more, however, we must also do less of what the evidence shows is unnecessary and/or harmful.

Here are some recent developments in prostate cancer that are worth watching for:

Early detection

New methods and models are being researched and developed to guide screening for prostate cancer. For example, mathematical models that account for variables including digital rectal examination (DRE), prostate-specific antigen (PSA), age, race and family history, as well as genetic data, may be able to predict a patient's risk of developing prostate cancer.[55-57]

The funding and use of PSA testing for the early detection of prostate cancer vary across Canadian provinces. Monitoring PSA testing rates and provincial guidelines related to prostate cancer testing over time could help further assess the impact of PSA testing on outcomes, including those related to harm from over-diagnosis.

Treatment

Choosing Wisely Canada® is a national campaign to identify low-value, unnecessary or potentially harmful clinical interventions that may be frequently practiced in Canada. In 2014, 10 oncology-specific recommendations were developed; one recommendation suggests that care providers avoid initiating treatment in men with low-risk prostate cancers until they discuss the option of active surveillance.[95, 96] The Partnership, through collaboration with provincial partners, has developed performance indicators that will be used to assess the extent to which clinical practice is consistent with a subset of the *Choosing Wisely Canada*® evidence-based recommendations. Indicator results will serve as a baseline for future monitoring and will inform opportunities for improvement.

Person-centred perspective

Several initiatives are under way at the Partnership to help support the systematic collection of patient-reported outcome and experience measures. This information can be used to drive improvements in how cancer care systems identify and better respond to prostate cancer patients' needs. For example, a study on the experiences of cancer patients in transition will help us better understand the challenges prostate cancer patients, among others, face during the immediate survivorship period, and how different sectors of the health care system can work better together to address those challenges.

Research

Research into the causes of prostate cancer continues in Canada and elsewhere, and may yield new information that will improve how the disease is managed. For example, the Canadian Partnership for Tomorrow Project (CPTP) is a significant, long-term research initiative designed to explore how factors such as genetics, behaviour, environment and lifestyle contribute to the development of cancer and other chronic diseases. The project is funded by the Partnership and partner organizations. The CPTP has been specifically designed to look at the root causes of cancer in the hope that knowledge gained will yield new interventions aimed at preventing prostate and other cancers.

In conclusion

Prostate cancers range from being slow-growing and non-life-threatening to aggressive and deadly. The diverse nature of this disease requires that we take a targeted approach to management. But while the disease and its evidence-based management strategies are diverse, we should understand why we are seeing inconsistency in how the same types of cases are managed in different provinces and/or by different providers. And we should also understand why we see such a level of variation in the experiences of prostate cancer patients who may have similar stage and risk levels but who report marked differences in their care and their involvement in that care.

The data in this report, along with the perspectives of the men that participated in the focus groups, suggest that inconsistency of care and experience is prevalent. As stewards of a Canadian health care system that places a high value on equitable, high-quality care, we must understand the reasons behind these variations and develop effective strategies to ensure that all men with prostate cancer receive care that is appropriate and evidence-based, regardless of where they live and who is providing their care.

The Partnership will continue to work with the cancer control community and partners across the country towards reducing the incidence of prostate cancer, lessening the chance that men will die from the disease, and encouraging system changes that will improve patients' quality of life before, during and after treatment.

References

1. Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2015. Toronto (ON): Canadian Cancer Society; 2015 May. 150 p.
2. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Prostate Cancer Version 1.2015. Chicago (IL); 2015.
3. Morash C TR, Agbassi C, Klotz L, McGowan T, Srigley J, Evans A, and the Active Surveillance Guideline Development Group. A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO): Active Surveillance for the Management of Localized Prostate Cancer. Toronto (ON); 2014 Dec 10. 60 p. Report No.: Evidence-Based Series 17-9.
4. American Cancer Society. Expectant management, watchful waiting, and active surveillance for prostate cancer [Internet]. 2015 [updated 2015 Mar 12; cited 2015 Mar 23]. Available from: http://www.cancer.org/cancer/prostatecancer/detailedguide/prostate-cancer-treating-watchful-waiting
5. Prostate Cancer Canada. Active surveillance [Internet]. [date unknown] [cited 2015 March]. Available from: http://www.prostatecancer.ca/Prostate-Cancer/Treatment/Active-Surveillance#.VZGkPvlVhBc
6. Gronberg H. Prostate cancer epidemiology. Lancet. 2003 Mar 8;361(9360):859-64.
7. Bonn SE, Sjolander A, Lagerros YT, Wiklund F, Stattin P, Holmberg E, et al. Physical Activity and Survival among Men Diagnosed with Prostate Cancer. Cancer Epidemiol Biomarkers Prev. 2014 Dec 19;24(1):57-64.
8. World Cancer Research Fund International/American Institute for Cancer Research. Continuous Update Project Report: Diet, Nutrition, Physical Activity, and Prostate Cancer. London (UK): World Cancer Research Fund International; 2014. 52 p.
9. Bell N, Connor Gorber S, Shane A, Joffres M, Singh H, Dickinson J, et al. Recommendations on screening for prostate cancer with the prostate-specific antigen test. CMAJ. 2014;186(16):1225-34.
10. Izawa JI, Klotz L, Siemens DR, Kassouf W, So A, Jordan J, et al. Prostate cancer screening: Canadian guidelines 2011. Can Urol Assoc J. 2011 Aug;5(4):235-40.
11. Prostate Cancer Canada. Prostate Cancer Canada: PSA recommendation. Know your number. Toronto (ON): Prostate Cancer Canada; 2013. 4 p.
12. Neutel CI, Gao RN, Blood PA, Gaudette LA. The changing age distribution of prostate cancer in Canada. Can J Public Health. 2007 Jan-Feb;98(1):60-4.
13. Fradet Y, Klotz L, Trachtenberg J, Zlotta A. The burden of prostate cancer in Canada. Can Urol Assoc J. 2009 Jun;3 (3 Suppl 2):S92-S100.
14. Navaneelan T, Janz T. Cancer in Canada: Focus on Lung, Colorectal, Breast and Prostate [Internet]. Ottawa (ON): Statistics Canada; 2011 [cited 2014 Dec 8]. Available from: http://www.statcan.gc.ca/pub/82-624-x/2011001/article/11596-eng.htm
15. Babaian RJ, Toi A, Kamoi K, Troncoso P, Sweet J, Evans R, et al. A comparative analysis of sextant and an extended 11-core multisite directed biopsy strategy. J Urol. 2000 Jan;163(1):152-7.
16. Quinn M, Babb P. Patterns and trends in prostate cancer incidence, survival, prevalence and mortality. Part I: international comparisons. BJU Int. 2002 Jul;90(2):162-73.
17. International Agency for Research on Cancer. Prostate Cancer Estimated Incidence, Mortality and Prevalence Worldwide in 2012 [Internet]. Lyon (France): International Agency for Research on Cancer; 2012 [cited 2014 Sep 12]. Available from: http://globocan.iarc.fr/Pages/fact_sheets_cancer.aspx
18. Jemal A, Center MM, DeSantis C, Ward EM. Global patterns of cancer incidence and mortality rates and trends. Cancer Epidemiol Biomarkers Prev. 2010 Aug;19(8):1893-907.
19. Cancerview.ca. Prostate Cancer Screening Guidelines Across Canada: Environmental Scan. Toronto (ON): Canadian Partnership Against Cancer; 2014 Apr. 9 p.
20. Klotz L. Prostate cancer overdiagnosis and overtreatment. Curr Opin Endocrinol Diabetes Obes. 2013 Jun;20(3):204-9.
21. Moyer VA, U.S. Preventive Services Task Force. Screening for prostate cancer: U.S. Preventive Services Task Force recommendation statement. Ann Intern Med. 2012 Jul 17;157(2):120-34.
22. American Cancer Society. Prostate Cancer Early Detection [Internet]. Atlanta (GA): American Cancer Society; 2013 [cited 2014 Sep 4]. Available from: http://www.cancer.org/cancer/prostatecancer/moreinformation/prostatecancerearlydetection/prostate-cancer-early-detection-toc
23. Feightner JW. Screening for prostate cancer. Canadian Task Force on the Periodic Health Examination Canadian Guide to Clinical Preventive Health Care. Ottawa: Health Canada; 1994. p. 812-23.
24. Bell KJ, Del Mar C, Wright G, Dickinson J, Glasziou P. Prevalence of incidental prostate cancer: A systematic review of autopsy studies. Int J Cancer. 2015 Mar 26.
25. Allemani C, Weir HK, Carreira H, Harewood R, Spika D, Wang XS, et al. Global surveillance of cancer survival 1995-2009: analysis of individual data for 25 676 887 patients from 279 population-based registries in 67 countries (CONCORD-2). Lancet. 2014 Nov 26; 385(9972):977-1010.

26. Stamatiou K, Alevizos A, Agapitos E, Sofras F. Incidence of impalpable carcinoma of the prostate and of non-malignant and precarcinomatous lesions in Greek male population: an autopsy study. Prostate. 2006 Sep 1;66(12):1319-28.

27. Screening Action Group. PSA toolkit: PSA screening and testing for prostate cancer. Toronto (ON): Canadian Partnership Against Cancer. 2009 Jul. 34 p.

28. Etzioni R, Tsodikov A, Mariotto A, Szabo A, Falcon S, Wegelin J, et al. Quantifying the role of PSA screening in the US prostate cancer mortality decline. Cancer Causes Control. 2008 Mar;19(2):175-81.

29. Coldman AJ, Phillips N, Pickles TA. Trends in prostate cancer incidence and mortality: an analysis of mortality change by screening intensity. CMAJ. 2003 Jan 7;168(1):31-5.

30. Andriole GL, Crawford ED, Grubb RL, 3rd, Buys SS, Chia D, Church TR, et al. Prostate cancer screening in the randomized Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial: mortality results after 13 years of follow-up. J Natl Cancer Inst. 2012 Jan 18;104(2):125-32.

31. Roobol MJ, Kerkhof M, Schroder FH, Cuzick J, Sasieni P, Hakama M, et al. Prostate cancer mortality reduction by prostate-specific antigen-based screening adjusted for nonattendance and contamination in the European Randomised Study of Screening for Prostate Cancer (ERSPC). Eur Urol. 2009 Oct;56(4):584-91.

32. Center MM, Jemal A, Lortet-Tieulent J, Ward E, Ferlay J, Brawley O, et al. International variation in prostate cancer incidence and mortality rates. Eur Urol. 2012 Jun;61(6):1079-92.

33. Canadian Partnership Against Cancer. Examining disparities in cancer control: A system performance special focus report. Toronto (ON): Canadian Partnership Against Cancer; 2014 Feb. 83 p.

34. Public Health Agency of Canada. Canadian Cancer Incidence Atlas—Volume 2, 2000-2006. Ottawa (ON): Public Health Agency of Canada; 2014.

35. Mandair D, Rossi RE, Pericleous M, Whyand T, Caplin ME. Prostate cancer and the influence of dietary factors and supplements: a systematic review. Nutr Metab (Lond). 2014;11:30.

36. Heidenreich A, Bastian PJ, Bellmunt J, Bolla M, Joniau S, van der Kwast T, et al. EAU guidelines on prostate cancer. Part II: Treatment of advanced, relapsing, and castration-resistant prostate cancer. Eur Urol. 2014 Feb;65(2):467-79.

37. Canadian Cancer Society. Risk factors for prostate cancer [Internet]. Toronto (ON): Canadian Cancer Society; 2014 [cited 2014 Sep 4]. Available from: https://www.cancer.ca/en/cancer-information/cancer-type/prostate/risks/?region=on#mutations#ixzz3BmlonzD7

38. Hemminki K. Familial risk and familial survival in prostate cancer. World J Urol. 2012 Apr;30(2):143-8.

39. Bostwick DG, Burke HB, Djakiew D, Euling S, Ho SM, Landolph J, et al. Human prostate cancer risk factors. Cancer. 2004 Nov 15;101(10 Suppl):2371-490.

40. Schroder FH, Hugosson J, Roobol MJ, Tammela TL, Ciatto S, Nelen V, et al. Prostate-cancer mortality at 11 years of follow-up. N Engl J Med. 2012 Mar 15;366(11):981-90.

41. Miller AB. Conundrums in screening for cancer. Int J Cancer. 2010 Mar 1;126(5):1039-46.

42. Welch HG, Black WC. Overdiagnosis in cancer. J Natl Cancer Inst. 2010 May 5;102(9):605-13.

43. Carter JL, Coletti RJ, Harris RP. Quantifying and monitoring overdiagnosis in cancer screening: a systematic review of methods. BMJ. 2015;350:g7773.

44. Sanda MG, Dunn RL, Michalski J, Sandler HM, Northouse L, Hembroff L, et al. Quality of life and satisfaction with outcome among prostate-cancer survivors. N Engl J Med. 2008 Mar 20;358(12):1250-61.

45. Canadian Cancer Society. Prostate-specific antigen (PSA) test [Internet]. Toronto (ON): Canadian Cancer Society; 2014 [cited 2014 Sep 10]. Available from: http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/tests-and-procedures/prostate-specific-antigen-psa/?region=on

46. Canadian Cancer Society. Digital rectal examination (DRE) [Internet]. Toronto (ON): Canadian Cancer Society; 2014 [cited 2014 Sep 10]. Available from: http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/tests-and-procedures/digital-rectal-examination/?region=on

47. Kassouf W. CUA responds to recommendations by the Canadian Task Force on Preventive Health Care (CTFPHC) on prostate cancer screening [Internet]. Montreal (QC): PR Newswire Association LLC; 2014 [cited 2015 May 27]. Available from: http://www.prnewswire.com/news-releases/cua-responds-to-recommendations-by-the-canadian-task-force-on-preventive-health-care-ctfphc-on-prostate-cancer-screening-281649721.html

48. Alberta Health Services. Primary Care Guide to Evaluation and Referral for Prostate Cancer [Internet]. Edmonton (AB): Alberta Health Services; 2010 [cited 2014 Sep 3]. Available from: http://www.topalbertadoctors.org/download/276/Prostate%20Cancer%20Guideline%20Eval%20&%20Referr.pdf

49. BC Cancer Agency. Patient Information Document: Screening for Prostate Cancer with PSA - Recommendations [Internet]. Vancouver (BC): BC Cancer Agency; 2012 [cited 2014 Sep 3]. Available from: http://www.bccancer.bc.ca/health-professionals/professional-resources/cancer-management-guidelines/genitourinary/prostate#Patient-Information-Document

50. Cancer Care Nova Scotia. Prostate Cancer Screening–Position Statement [Internet]. Halifax (NS): Cancer Care Nova Scotia; 2012 [cited 2014 Sep 10]. Available from: http://www.cancercare.ns.ca/site-cc/media/cancercare/Position%20Statement%20on%20Early%20Detection%20of%20Prostate%20Cancer%20FINAL.pdf

51. Prostate Cancer Canada. Frequently Asked Questions [Internet]. Toronto (ON): Prostate Cancer Canada; 2013 [cited 2014 Sep 10]. Available from: http://www.prostatecancer.ca/Prostate-Cancer/About-Prostate-Cancer/FAQs#.U_4ax_mwKVM

52. Statistics Canada. Annual Demographic Estimates: Canada, Provinces and Territories. Ottawa (ON): Statistics Canada; 2014 Sep. 188 p. Report No.: 91-215-X, no. 2.

53. Australian Institute of Health and Welfare. Prostate cancer in Australia. Cancer series no. 79. Cat. no. CAN 76. Canberra (Australia): Australian Institute of Health and Welfare; 2013. 73 p.

54. Prasad SM, Drazer MW, Huo D, Hu JC, Eggener SE. 2008 US Preventive Services Task Force recommendations and prostate cancer screening rates. JAMA. 2012 Apr 25;307(16):1692-4.

55. Herman MP, Dorsey P, John M, Patel N, Leung R, Tewari A. Techniques and predictive models to improve prostate cancer detection. Cancer. 2009 Jul 1;115(13 Suppl):3085-99.

56. Nam RK, Zhang WW, Trachtenberg J, Seth A, Klotz LH, Stanimirovic A, et al. Utility of incorporating genetic variants for the early detection of prostate cancer. Clin Cancer Res. 2009 Mar 1;15(5):1787-93.

57. Roobol MJ, Steyerberg EW, Kranse R, Wolters T, van den Bergh RC, Bangma CH, et al. A risk-based strategy improves prostate-specific antigen-driven detection of prostate cancer. Eur Urol. 2010 Jan;57(1):79-85.

58. D'Amico AV, Whittington R, Malkowicz SB, Schultz D, Blank K, Broderick GA, et al. Biochemical outcome after radical prostatectomy, external beam radiation therapy, or interstitial radiation therapy for clinically localized prostate cancer. JAMA. 1998 Sep 16;280(11):969-74.

59. Lukka H, Warde P, Pickles T, Morton G, Brundage M, Souhami L. Controversies in prostate cancer radiotherapy: consensus development. Can J Urol. 2001 Aug;8(4):1314-22.

60. National Comprehensive Cancer Network. NCCN Guidelines for Patients: Prostate Cancer Version 1.2014. 2014.

61. Salinas CA, Tsodikov A, Ishak-Howard M, Cooney KA. Prostate cancer in young men: an important clinical entity. Nat Rev Urol. 2014 Jun;11(6):317-23.

62. Shao YH, Demissie K, Shih W, Mehta AR, Stein MN, Roberts CB, et al. Contemporary risk profile of prostate cancer in the United States. J Natl Cancer Inst. 2009 Sep 16;101(18):1280-3.

63. Choosing Wisely Canada. Urology - Five Things Physicians and Patients Should Question [Internet]. 2014 [updated 2014 Oct 29; cited 2015 May 22]. Available from: http://www.choosingwiselycanada.org/recommendations/urology/

64. Makarov DV, Loeb S, Ulmert D, Drevin L, Lambe M, Stattin P. Prostate cancer imaging trends after a nationwide effort to discourage inappropriate prostate cancer imaging. J Natl Cancer Inst. 2013 Sep 4;105(17):1306-13.

65. Cancer Care Ontario. Prostate Cancer Disease Pathway Management Priorities for Action Report. Toronto (ON): Cancer Care Ontario; 2013. 23 p.

66. Rodrigues G, Warde P, Pickles T, Crook J, Brundage M, Souhami L, et al. Pre-treatment risk stratification of prostate cancer patients: A critical review. Can Urol Assoc J. 2012 Apr;6(2):121-7.

67. Pierorazio PM, Walsh PC, Partin AW, Epstein JI. Prognostic Gleason grade grouping: data based on the modified Gleason scoring system. BJU Int. 2013 May;111(5):753-60.

68. Klotz L. Active Surveillance: The Canadian Experience With an "Inclusive Approach." J Natl Cancer Inst Monogr. 2012(45):234-41.

69. American Urological Association. Guideline for the Management of Clinically Localized Prostate Cancer: 2007 Update. 2007. 254 p.

70. van Leeuwen PJ, Connolly D, Gavin A, Roobol MJ, Black A, Bangma CH, et al. Prostate cancer mortality in screen and clinically detected prostate cancer: estimating the screening benefit. Eur J Cancer. 2010 Jan;46(2):377-83.

71. Andriole GL, Crawford ED, Grubb RL, 3rd, Buys SS, Chia D, Church TR, et al. Mortality results from a randomized prostate-cancer screening trial. N Engl J Med. 2009 Mar 26;360(13):1310-19.

72. Sanyal C, Aprikian AG, Chevalier S, Cury FL, Dragomir A. Direct cost for initial management of prostate cancer: a systematic review. Curr Oncol. 2013 Dec;20(6):e522-31.

73. Dale W, Bilir P, Han M, Meltzer D. The role of anxiety in prostate carcinoma: a structured review of the literature. Cancer. 2005 Aug 1;104(3):467-78.

74. Gray RE, Fitch MI, Phillips C, Labrecque M, Klotz L. Presurgery experiences of prostate cancer patients and their spouses. Cancer Pract. 1999 May-Jun;7(3):130-5.

75. Canadian Institute for Health Information. Wait times for priority procedures in Canada, 2015. Ottawa (ON): CIHI; 2015 Apr 19 p.

76. Ontario Ministry of Health and Long-Term Care. Surgery and Diagnostic Imaging Results: Wait Times Provincial Trends [Internet]. Ontario Ministry of Health and Long-Term Care; 2014 [updated 2010 Apr 20; cited 2014 Sep 8]. Available from: http://www.ontariowaittimes.com/SurgeryDI/EN/wt_trend.aspx#4

77. New Brunswick Canada. Surgical Wait Time [Internet]. Government of New Brunswick; 2015 [updated 2015 Jan 12; cited 2015 Mar 16]. Available from: http://www1.gnb.ca/0217/surgicalwaittimes/Reports/Index-e.aspx?gp=29&tab=0

78. British Columbia Ministry of Health. Surgical Wait Times [Internet]. British Columbia Ministry of Health; 2015 [cited 2014 Sep 8]. Available from: https://swt.hlth.gov.bc.ca/

79. Men with prostate cancer wait longer for surgery than women with breast cancer [Internet]. News Corp Australia; 2014 [cited 2014 Sep 18]. Available from: http://www.news.com.au/lifestyle/health/men-with-prostate-cancer-wait-longer-for-surgery-than-women-with-breast-cancer/story-fneuzlbd-1226841284233

80. National Health Performance Authority. MyHospitals [Internet]. National Health Performance Authority; 2015 [cited 2014 Sep 18]. Available from: http://www.myhospitals.gov.au/

81. Stevens C, Bondy SJ, Loblaw DA. Wait times in prostate cancer diagnosis and radiation treatment. Can Urol Assoc J. 2010 Aug;4(4):243-8.

82. Health Canada. Final Report of the Federal Advisor on Wait Times. Ottawa (ON): Health Canada; 2006. 76 p.

83. National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Prostate Cancer Version 2.2014. Chicago (IL): American Joint Committee on Cancer; 2014. 98 p.

84. Canadian Association of Radiation Oncologists. Recommendations on the manpower and standards of care in radiation oncology committee on wait times for radiation therapy [about 1 screen] [Internet]. Canadian Association of Radiation Oncologists; 2001 [cited 2013 Oct 21]. Available from: http://www.caro-acro.ca/Assets/Newsletters/Feb+2001+CARO+eNews.pdf?method=1

85. Canadian Association of Radiation Oncologists. $200,000 to Nine Recipients: Canadian Association of Radiation Oncology announces Abbott Oncology ACURA Uro-Oncologic Radiation Awards [Internet]. Ottawa (ON): Canadian Association of Radiation Oncologists; 2011 [updated 2011 Apr 19]. Available from: http://www.caro-acro.ca/AssetFactory.aspx?did=864

86. Han M, Partin AW, Chan DY, Walsh PC. An evaluation of the decreasing incidence of positive surgical margins in a large retropubic prostatectomy series. J Urol. 2004 Jan;171(1):23-6.

87. Tyldesley S, Peacock M, Morris JW, So A, Kim-Sing C, Quirt J, et al. The need for, and utilization of prostate-bed radiotherapy after radical prostatectomy for patients with prostate cancer in British Columbia. Can Urol Assoc J. 2012;6(2):89-94.

88. Trinh Q-D, Bjartell A, Freedland SJ, Hollenbeck BK, Hu JC, Shariat SF, et al. A Systematic Review of the Volume–Outcome Relationship for Radical Prostatectomy. Eur Urol. 2013;64(5):786-98.

89. Steinsvik EA, Axcrona K, Angelsen A, Beisland C, Dahl A, Eri LM, et al. Does a surgeon's annual radical prostatectomy volume predict the risk of positive surgical margins and urinary incontinence at one-year follow-up? Findings from a prospective national study. Scand J Urol. 2013 Apr;47(2):92-100.

90. Savage CJ, Vickers AJ. Low annual caseloads of United States surgeons conducting radical prostatectomy. J Urol. 2009 Dec;182(6):2677-9.

91. Vesey SG, McCabe JE, Hounsome L, Fowler S. UK radical prostatectomy outcomes and surgeon case volume: based on an analysis of the British Association of Urological Surgeons Complex Operations Database. BJU Int. 2012 Feb;109(3):346-54.

92. American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2014-2015. Atlanta (GA): American Cancer Society; 2014. 48 p.

93. Pickles T, Morgan S, Morton G, Souhami L, Warde P, Lukka H. Adjuvant radiotherapy following radical prostatectomy: Genito-Urinary Radiation Oncologists of Canada Consensus Statement. Can Urol Assoc J. 2008 Apr;2(2):95-9.

94. Keyes M, Crook J, Morris WJ, Morton G, Pickles T, Usmani N, et al. Canadian prostate brachytherapy in 2012. Can Urol Assoc J. 2013 Jan-Feb;7(1-2):51-8.

95. Choosing Wisely Canada. Oncology: Ten Things Physicians and Patients Should Question [Internet]. 2014 [updated 2014 Oct 29; cited 2015 May 22]. Available from: http://www.choosingwiselycanada.org/recommendations/oncology/

96. Mitera G, Earle C, Latosinsky S, Booth C, Bezjak A, Desbiens C, et al. Choosing Wisely Canada cancer list: ten low-value or harmful practices that should be avoided in cancer care. J Oncol Pract. 2015 May;11(3):e296-303.

97. Wilt TJ, Brawer MK, Jones KM, Barry MJ, Aronson WJ, Fox S, et al. Radical prostatectomy versus observation for localized prostate cancer. N Engl J Med. 2012 Jul 19;367(3):203-13.

98. Keyes M, Crook J, Morton G, Vigneault E, Usmani N, Morris WJ. Treatment options for localized prostate cancer. Can Fam Physician. 2013 Dec;59(12):1269-74.

99. Brundage M, Danielson B, Pearcey R, Bass B, Pickles T, Bahary JP, et al. A criterion-based audit of the technical quality of external beam radiotherapy for prostate cancer. Radiother Oncol. 2013 Jun;107(3):339-45.

100. Saad F, Hotte S, Catton C, Drachenberg D, Finelli A, Fleshner N, et al. CUA-CUOG guidelines for the management of castration-resistant prostate cancer (CRPC): 2013 update. Can Urol Assoc J. 2013 Jul-Aug;7(7-8):231-7.

101. Tefekli A, Tunc M. Future prospects in the diagnosis and management of localized prostate cancer. ScientificWorldJournal. 2013;2013:1-9.

102. Giannarini G, Gandaglia G, Montorsi F, Briganti A. Will focal therapy remain only an attractive illusion for the primary treatment of prostate cancer? J Clin Oncol. 2014 May 1;32(13):1299-301.

103. Patel VR, Sivaraman A. Current status of robot-assisted radical prostatectomy: progress is inevitable. Oncology. 2012 Jul;26(7):616-19, 22.

104. Tholomier C, Bienz M, Hueber PA, Trinh QD, Hakim AE, Alhathal N, et al. Oncological and functional outcomes of 722 robot-assisted radical prostatectomy (RARP) cases: The largest Canadian 5-year experience. Can Urol Assoc J. 2014 May;8(5-6):195-201.

105. Preston MA, Blew BD, Breau RH, Beiko D, Oake SJ, Watterson JD. Survey of senior resident training in urologic laparoscopy, robotics and endourology surgery in Canada. Can Urol Assoc J. 2010 Feb;4(1):42-6.

106. Ficarra V, Novara G, Artibani W, Cestari A, Galfano A, Graefen M, et al. Retropubic, laparoscopic, and robot-assisted radical prostatectomy: a systematic review and cumulative analysis of comparative studies. Eur Urol. 2009 May;55(5):1037-63.

107. Ho C, Tsakonas E, Tran K, Cimon K, Severn M, Mierzwinski-Urban MC, et al. Robot-Assisted Surgery Compared with Open Surgery and Laparoscopic Surgery: Clinical Effectiveness and Economic Analyses. Ottawa (ON): Canadian Agency for Drugs and Technologies in Health; 2012. 298 p.

108. Ho C, Tsakonas E, Tran K, Cimon K, Severn M, Mierzwinski-Urban MC, et al. Robot-Assisted Surgery Compared with Open Surgery and Laparoscopic Surgery: Clinical Effectiveness and Economic Analyses. Ottawa (ON): Canadian Agency for Drugs and Technologies in Health; 2011. 298 p. Report No.: 137.

109. Alberta Health Services. Robots part of health team [Internet]. Alberta Health Services; 2010 [updated 2010 Aug 20; cited 2015 Mar 16]. Available from: http://www.albertahealthservices.ca/2409.asp

110. London Health Sciences Centre. London Health Sciences Centre designated as Canada's national training centre for robotic surgery [Internet]. London (ON): London Health Sciences Centre; 2013 [updated 2013 Jan 30; cited 2015 Mar 18]. Available from: http://www.lhsc.on.ca/About_Us/LHSC/Publications/Homepage/National-Training-Centre.htm

111. Ontario Health Technology Advisory Committee. Robotic-assisted minimally invasive prostatectomy: OHTAC recommendation. Toronto (ON): Health Quality Ontario; 2014. 11 p.

112. Joudi FN, Konety BR. The impact of provider volume on outcomes from urological cancer therapy. J Urol. 2005 Aug;174(2):432-8.

113. Canadian Institute for Health Information. The Delivery of Radical Prostatectomy to Treat Men with Prostate Cancer. Ottawa, ON: Canadian Institute for Health Information; 2014.

114. Dahl DM, Barry MJ, McGovern FJ, Chang Y, Walker-Corkery E, McDougal WS. A prospective study of symptom distress and return to baseline function after open versus laparoscopic radical prostatectomy. J Urol. 2009 Sep;182(3):956-65.

115. Jacobsen NE, Moore KN, Estey E, Voaklander D. Open versus laparoscopic radical prostatectomy: a prospective comparison of postoperative urinary incontinence rates. J Urol. 2007 Feb;177(2):615-9.

116. Hu JC, Gu X, Lipsitz SR, Barry MJ, D'Amico AV, Weinberg AC, et al. Comparative effectiveness of minimally invasive vs open radical prostatectomy. JAMA. 2009 Oct 14;302(14):1557-64.

117. Caras RJ, Lustik MB, Kern SQ, Sterbis JR, McMann LP. Laparoscopic radical prostatectomy demonstrates less morbidity than open radical prostatectomy: an analysis of the American College of Surgeons-National Surgical Quality Improvement Program database with a focus on surgical trainee involvement. J Endourol. 2014 Mar;28(3):298-305.

118. Kowalczyk KJ, Levy JM, Caplan CF, Lipsitz SR, Yu HY, Gu X, et al. Temporal national trends of minimally invasive and retropubic radical prostatectomy outcomes from 2003 to 2007: results from the 100% Medicare sample. Eur Urol. 2012 Apr;61(4):803-9.

119. Gandaglia G, Sammon JD, Chang SL, Choueiri TK, Hu JC, Karakiewicz PI, et al. Comparative effectiveness of robot-assisted and open radical prostatectomy in the postdissemination era. J Clin Oncol. 2014 May 10;32(14):1419-26.

120. Ficarra V, Novara G, Rosen RC, Artibani W, Carroll PR, Costello A, et al. Systematic review and meta-analysis of studies reporting urinary continence recovery after robot-assisted radical prostatectomy. Eur Urol. 2012 Sep;62(3):405-17.

121. Parsons JK, Bennett JL. Outcomes of retropubic, laparoscopic, and robotic-assisted prostatectomy. Urology. 2008 Aug;72(2):412-6.

122. Ficarra V, Novara G, Ahlering TE, Costello A, Eastham JA, Graefen M, et al. Systematic review and meta-analysis of studies reporting potency rates after robot-assisted radical prostatectomy. Eur Urol. 2012 Sep;62(3):418-30.

123. Ploussard G, de la Taille A, Moulin M, Vordos D, Hoznek A, Abbou CC, et al. Comparisons of the perioperative, functional, and oncologic outcomes after robot-assisted versus pure extraperitoneal laparoscopic radical prostatectomy. Eur Urol. 2014 Mar;65(3):610-19.

124. Silberstein JL, Su D, Glickman L, Kent M, Keren-Paz G, Vickers AJ, et al. A case-mix-adjusted comparison of early oncological outcomes of open and robotic prostatectomy performed by experienced high volume surgeons. BJU Int. 2013 Feb;111(2):206-12.

125. Trinh QD, Sammon J, Sun M, Ravi P, Ghani KR, Bianchi M, et al. Perioperative outcomes of robot-assisted radical prostatectomy compared with open radical prostatectomy: results from the nationwide inpatient sample. Eur Urol. 2012 Apr;61(4):679-85.

126. Lowrance WT, Eastham JA, Yee DS, Laudone VP, Denton B, Scardino PT, et al. Costs of medical care after open or minimally invasive prostate cancer surgery: a population-based analysis. Cancer. 2012 Jun 15;118(12):3079-86.

127. Stitzenberg KB, Wong YN, Nielsen ME, Egleston BL, Uzzo RG. Trends in radical prostatectomy: centralization, robotics, and access to urologic cancer care. Cancer. 2012 Jan 1;118(1):54-62.

128. Person-Centred Perspective Advisory Committee and M. Fitch. Embedding Person-Centred Perspective in Cancer Control. Toronto (ON): Canadian Partnership Against Cancer; 2014.

129. Institute for Family-Centered Care. Advancing the Practice of Patient- and Family-Centered Care: How to Get Started. Bethesda (MD): Institute for Family-Centered Care; 2008. 28 p.

130. Letts C, Tamlyn K, Byers ES. Exploring the impact of prostate cancer on men's sexual well-being. J Psychosoc Oncol. 2010;28(5):490-510.

131. Denis L, Joniau S, Bossi A, Baskin-Bey E, Fitzpatrick JM. PCA: prostate cancer, patient-centred approach or both? BJU Int. 2012 Jul;110(1):16-22.

132. Statistics Canada. Canadian Cancer Registry. 2008.

133. UK Cancer Research. Prostate Cancer Incidence Statistics: By Age [Internet]. London (England): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/uk-prostate-cancer-incidence-statistics#age

134. UK Cancer Research. Testicular Cancer Incidence Statistics: By Age [Internet]. London (UK): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/testis/incidence/

135. White K, D'Abrew N, Katris P, O'Connor M, Emery L. Mapping the psychosocial and practical support needs of cancer patients in Western Australia. Eur J Cancer Care (Engl). 2012 Jan;21(1):107-16.

136. Cockle-Hearne J, Faithfull S. Self-management for men surviving prostate cancer: a review of behavioural and psychosocial interventions to understand what strategies can work, for whom and in what circumstances. Psycho-Oncology. 2010 Sep;19(9):909-22.

137. Hanly N, Mireskandari S, Juraskova I. The struggle towards 'the New Normal': a qualitative insight into psychosexual adjustment to prostate cancer. BMC Urol. 2014;14:56.

138. Kessels RP. Patients' memory for medical information. J R Soc Med. 2003 May;96(5):219-22.

139. Marty H, Bogenstatter Y, Franc G, Tschan F, Zimmermann H. How well informed are patients when leaving the emergency department? Comparing information provided and information retained. Emerg Med J. 2013 Jan;30(1):53-7.

140. Selic P, Svab I, Repolusk M, Gucek NK. What factors affect patients' recall of general practitioners' advice? BMC Fam Pract. 2011;12:141.

141. Feldman-Stewart D, Brundage MD, McConnell BA, MacKillop WJ. Practical issues in assisting shared decision-making. Health Expect. 2000 Mar;3(1):46-54.

142. Sharpley CF, Bitsika V, Christie DR. 'Why I feel bad': refinement of the Effects of Prostate Cancer Upon Lifestyle Questionnaire and an initial exploration of its links with anxiety and depression among prostate cancer patients. Psycho-Oncology. 2010 Aug;19(8):839-46.

143. Fischer M, Visser A, Voerman B, Garssen B, van Andel G, Bensing J. Treatment decision making in prostate cancer: patients' participation in complex decisions. Patient Educ Couns. 2006 Nov;63(3):308-13.

144. Aning JJ, Wassersug RJ, Goldenberg SL. Patient preference and the impact of decision-making aids on prostate cancer treatment choices and post-intervention regret. Curr Oncol. 2012 Dec;19(Suppl 3):S37-44.

145. Lin GA, Aaronson DS, Knight SJ, Carroll PR, Dudley RA. Patient decision aids for prostate cancer treatment: a systematic review of the literature. CA Cancer J Clin. 2009 Nov-Dec;59(6):379-90.

146. Stacey D, Legare F, Col NF, Bennett CL, Barry MJ, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2014;1:CD001431.

147. Holmes-Rovner M, Stableford S, Fagerlin A, Wei JT, Dunn RL, Ohene-Frempong J, et al. Evidence-based patient choice: a prostate cancer decision aid in plain language. BMC Med Inform Decis Mak. 2005;5:16.

148. Resnick MJ, Guzzo TJ, Cowan JE, Knight SJ, Carroll PR, Penson DF. Factors associated with satisfaction with prostate cancer care: results from Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE). BJU Int. 2013 Feb;111(2):213-20.

149. Canadian Partnership Against Cancer. The 2014 Cancer System Peformance Report. Toronto (ON): Canadian Partnership Against Cancer; 2014 Mar. 170 p.

150. Prostate Cancer Canada and Canadian Cancer Society. Support for Those Affected by Prostate Cancer [Internet]. Toronto (ON): Canadian Cancer Society; 2014 [updated 28 Jan 2014; cited 2014 Oct 6]. Available from: http://www.cancer.ca/en/about-us/for-media/media-releases/national/2014/pcis/?region=on

151. Specialist services committee. Improving patient-centred care. BC Medical Journal. 2014 May;56(4).

152. Prostate Cancer Canada. About True NTH [Internet]. Toronto (ON): Prostate Cancer Canada; [cited 2014 Nov 21]. Available from: http://www.prostatecancer.ca/Support/Current-Programs/A-Survivorship-Action-Partnership/About-ASAP#.VHMuGN5quFI

153. Cancer Chat Canada. Professionally-led online support for Canadians affected by cancer [Internet]. Abbotsford (BC): Provincial Health Services Authority; 2014 [cited 2014 Dec 18]. Available from: https://www.cancerchatcanada.ca/

154. Huang J, Zhou S, Groome P, Tyldesley S, Zhang-Solomans J, Mackillop WJ. Factors affecting the use of palliative radiotherapy in Ontario. J Clin Oncol. 2001 Jan 1;19(1):137-44.

155. Boyer MJ, Salama JK, Lee WR. Palliative radiotherapy for prostate cancer. Oncology (Williston Park). 2014 Apr;28(4):306-12.

156. Samant RS, Fitzgibbon E, Meng J, Graham ID. Barriers to palliative radiotherapy referral: a Canadian perspective. Acta Oncol. 2007;46(5):659-63.

157. Lavergne MR, Johnston GM, Gao J, Dummer TJ, Rheaume DE. Variation in the use of palliative radiotherapy at end of life: examining demographic, clinical, health service, and geographic factors in a population-based study. Palliat Med. 2011 Mar;25(2):101-10.

158. Gillan C, Briggs K, Pazos AG, Maurus M, Harnett N, Catton P, et al. Barriers to accessing radiation therapy in Canada: a systematic review. Radiat Oncol. 2012;7:167.

159. Wong J, Xu B, Yeung HN, Roeland EJ, Martinez ME, Le QT, et al. Age disparity in palliative radiation therapy among patients with advanced cancer. Int J Radiat Oncol Biol Phys. 2014 Sep 1;90(1):224-30.

160. Statistics Canada. The Canadian Population in 2011: Age and Sex. Ottawa (ON): Ministry of Industry; 2012 May. 27 p. Report No.: 98-311-X2011001.

161. Fairchild A, Pituskin E, Rose B, Ghosh S, Dutka J, Driga A, et al. The rapid access palliative radiotherapy program: blueprint for initiation of a one-stop multidisciplinary bone metastases clinic. Support Care Cancer. 2009 Feb;17(2):163-70.

162. Lutz S, Berk L, Chang E, Chow E, Hahn C, Hoskin P, et al. Palliative radiotherapy for bone metastases: an ASTRO evidence-based guideline. Int J Radiat Oncol Biol Phys. 2011 Mar 15;79(4):965-76.

163. Choosing Wisely Canada. Ten Things Physicians and Patients Should Question [Internet]. Toronto (ON): Choosing Wisely Canada; [cited 2014 Oct 6]. Available from: http://www.choosingwiselycanada.org/recommendations/oncology/

164. Fitzgibbon EJ, Samant R, Meng J, Graham ID. Awareness and use of the Rapid Palliative Radiotherapy Program by family physicians in Eastern Ontario: a survey. Curr Oncol. 2006 Feb;13(1):27-32.

165. Thavarajah N, Zhang L, Wong K, Bedard G, Wong E, Tsao M, et al. Patterns of practice in the prescription of palliative radiotherapy for the treatment of bone metastases at the Rapid Response Radiotherapy Program between 2005 and 2012. Curr Oncol. 2013 Oct;20(5):e396-405.

166. Small EJ, Smith MR, Seaman JJ, Petrone S, Kowalski MO. Combined analysis of two multicenter, randomized, placebo-controlled studies of pamidronate disodium for the palliation of bone pain in men with metastatic prostate cancer. J Clin Oncol. 2003 Dec 1;21(23):4277-84.

167. Thompson JC, Wood J, Feuer D. Prostate cancer: palliative care and pain relief. Br Med Bull. 2007;83:341-54.

168. Weill Cornell Medical College. Metastatic Prostate Cancer and Chemotherapy [Internet]. New York (NY): Cornell University; [cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/uk-prostate-cancer-incidence-statistics#age

169. Canadian Cancer Society's Steering Committee. Canadian Cancer Statistics 2010. Toronto (ON): Canadian Cancer Society; 2010. 124 p.

170. Murray MA, Fiset V, Young S, Kryworuchko J. Where the dying live: a systematic review of determinants of place of end-of-life cancer care. Oncol Nurs Forum. 2009 Jan;36(1):69-77.

171. Canadian Hospice Palliative Care Association. The Pan-Canadian Gold Standard for Palliative Home Care: Toward Equitable Access to High Quality Hospice Palliative and End-of-Life Care at Home. Ottawa (ON): Canadian Hospice Palliative Care Association; 2006. 20 p.

172. Canadian Institute for Health Information. End-of-Life Hospital Care for Cancer Patients. Ottawa (ON): Canadian Institute for Health Information; 2013. 26 p.

173. Bergman J, Kwan L, Fink A, Connor SE, Litwin MS. Hospice and emergency room use by disadvantaged men dying of prostate cancer. J Urol. 2009 May;181(5):2084-9.

174. Bergman J, Saigal CS, Lorenz KA, Hanley J, Miller DC, Gore JL, et al. Hospice use and high-intensity care in men dying of prostate cancer. Arch Intern Med. 2011 Feb 14;171(3):204-10.

175. Green JS. An investigation into the use of palliative care services by patients with prostate cancer. Am J Hosp Palliat Care. 2002 Jul-Aug;19(4):259-62.

176. Priest L. Where quality of death can enhance quality of life. The Globe and Mail. 2012 Mar 17. [cited 2014 Oct 17] Available from: http://www.theglobeandmail.com/life/health-and-fitness/where-quality-of-death-can-enhance-quality-of-life/article534641/?page=all

177. Canadian Hospice Palliative Care Association and Quality End-of-Life Care Coalition of Canada. The Way Forward: About Us [Internet]. Ottawa (ON): Canadian Hospice Palliative Care Association; [cited 2014 Oct 6]. Available from: http://www.hpcintegration.ca/about-us.aspx

178. Canadian Hospice Palliative Care Association. Advance Care Planning: Support for Men with Prostate Cancer, their Partners, Families and Caregivers [Internet]. Ottawa (ON): Canadian Hospice Palliative Care Association; 2015 [cited 2015 Jun 10]. Available from: http://www.advancecareplanning.ca/making-your-plan/prostate-cancer.aspx

179. International Cancer Research Partnership. Common Scientific Outline [Internet]. International Cancer Research Partnership; 2012 [updated 2014 Dec 2; cited 2014 September 4]. Available from: https://www.icrpartnership.org/CSO.cfm

180. National Cancer Research Institute. Cancer research spend in the UK 2002-2011: An overview of the research funded by NCRI Partners. Institute NCR; 2013. 54 p.

181. National Cancer Institute. A Snapshot of Prostate Cancer [Internet]. National Cancer Institute; 2013 [updated 2014 Nov 5; cited 2014]. Available from: http://www.cancer.gov/researchandfunding/snapshots/prostate

182. Ontario Institute for Cancer Research. International Cancer Genome Consortium announces $20 million Canadian research project to decode the prostate cancer genome [Internet]. Toronto (ON): Ontario Institute for Cancer Research; 2011 [updated 2011 Feb 15; cited 2011]. Available from: https://oicr.on.ca/files/public/icgc_nr_february152011.pdf

183. Canadian Institutes of Health Research. Clinical translation: The Medical Imaging Trial Network of Canada (MITNEC) [Internet]. Ottawa (ON): Canadian Institutes of Health Research; 2012 [updated 2012 Jul 17; cited 2014 Sep 19]. Available from: http://www.cihr-irsc.gc.ca/e/45577.html#a5

184. Cancer Research Society. Quebec Research Program for Prostate Cancer Prevention [Internet]. Cancer Research Society; [cited 2014 Sep 4]. Available from: http://www.crs-src.ca/page.aspx?pid=1427

185. Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian Cancer Statistics 2013. Toronto (ON): Canadian Cancer Society; 2013. 114 p.

186. Canadian Cancer Research Alliance Executive Office. Personal communication. 2014.

187. The Terry Fox Research Institute. Translational Research [Internet]. The Terry Fox Research Institute; 2014 [cited 2014 Sep 4]. Available from: http://www.tfri.ca/en/research/translational-research.aspx

188. CNW. New research to determine low-risk from high-risk prostate cancer [Internet]. CNW; 2014 [updated 2014 Apr 29; cited 2014]. Available from: http://www.newswire.ca/en/story/1346387/-r-e-p-e-a-t-free-video-b-roll-available-via-cnw-new-research-to-determine-low-risk-from-high-risk-prostate-cancer

189. Ontario Institute for Cancer Research. OICR funds prostate cancer study to identify aggressive vs. non-aggressive disease [Internet]. Toronto (ON): Ontario Institute for Cancer Research; 2012 [updated 2012 Feb 17; cited 2014 Sep 4]. Available from: https://oicr.on.ca/files/public/OICR%20news%20release%20ASIST%20February%2017%202012_0.pdf

190. Prostate Cancer Canada. Enviornmental Scan of Prostate Cancer Research in Canada 2005-2011. 2012.

191. Grover SA, Coupal L, Zowall H, Rajan R, Trachtenberg J, Elhilali M, et al. The economic burden of prostate cancer in Canada: forecasts from the Montreal Prostate Cancer Model. CMAJ. 2000 Apr 4;162(7):987-92.

192. Cancer Care Ontario. Prostate Cancer Treatment Pathway Version 2012.11 [Internet]. Cancer Care Ontario; 2012 [cited 2014 Sep 4]. Available from: https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=298448

193. Sinha G. United Kingdom becomes the cancer clinical trials recruitment capital of the world. J Natl Cancer Inst. 2007;99(6):420.

194. Stead M, Cameron D, Lester N, Parmar M, Haward R, Kaplan R, et al. Strengthening clinical cancer research in the United Kingdom. Br J Cancer. 2011 May 10;104(10):1529-34.

195. Davison BJ, So A, Goldenberg SL, Berkowitz J, Gleave ME. Measurement of factors influencing the participation of patients with prostate cancer in clinical trials: a Canadian perspective. BJU Int. 2008 Apr;101(8):982-7.

196. Cancer Advocay Coalition of Canada. Report card on cancer in Canada, 2010-2011. Toronto (ON): Cancer Advocacy Coalition of Canada; 2011. 44 p.

197. Ontario Institute for Cancer Research. International Clinical Trials Day [Internet]. Toronto (ON): Ontario Institute for Cancer Research; 2014 [cited 2015 April 27]. Available from: http://oicr.on.ca/oicr-programs-and-platforms/translation-programs/high-impact-clinical-trials/high-impact-clinical--3

198. National Cancer Institute. Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial (PLCO) [Internet]. National Cancer Institute; [cited 2014 Sep 4]. Available from: http://prevention.cancer.gov/plco

199. Schroder FH. Screening for prostate cancer (PC)--an update on recent findings of the European Randomized Study of Screening for Prostate Cancer (ERSPC). Urol Oncol. 2008 Sep-Oct;26(5):533-41.

200. National Cancer Institute. Selenium and Vitamin E Cancer Prevention Trial (SELECT) [Internet]. National Cancer Institute; 2014 [cited 2014 Sep 19]. Available from: http://www.cancer.gov/newscenter/qa/2008/selectqa

201. Cheng JY. The Prostate Cancer Intervention Versus Observation Trial (PIVOT) in Perspective. J Clin Med Res. 2013 Aug;5(4):266-8.

202. Warde P, Mason M, Ding K, Kirkbride P, Brundage M, Cowan R, et al. Combined androgen deprivation therapy and radiation therapy for locally advanced prostate cancer: a randomised, phase 3 trial. Lancet. 2011 Dec 17;378(9809):2104-11.

203. U.S. National Institutes of Health. Active Surveillance, Radical Prostatectomy, or Radiation Therapy in Treating Patients With Localized Prostate Cancer [Internet]. U.S. National Institutes of Health; 2012 [cited 2014 Sep 4]. Available from: http://www.clinicaltrials.gov/show/NCT00632983

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1 University Avenue, Suite 300
Toronto, Ontario, Canada M5J 2P1

Tel: 416.915.9222
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