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SYSTEM
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REPORTS



Cancer System Performance

2017 Report

This report describes the **quality, equity, seamlessness and sustainability** of the cancer control system in Canada.



Quality refers to the effectiveness of care—high-quality care is evidence-based and improves health outcomes.

Equity refers to the absence of sociodemographic barriers, such as socio-economic status, place of residence and immigrant status, in accessing effective cancer control.

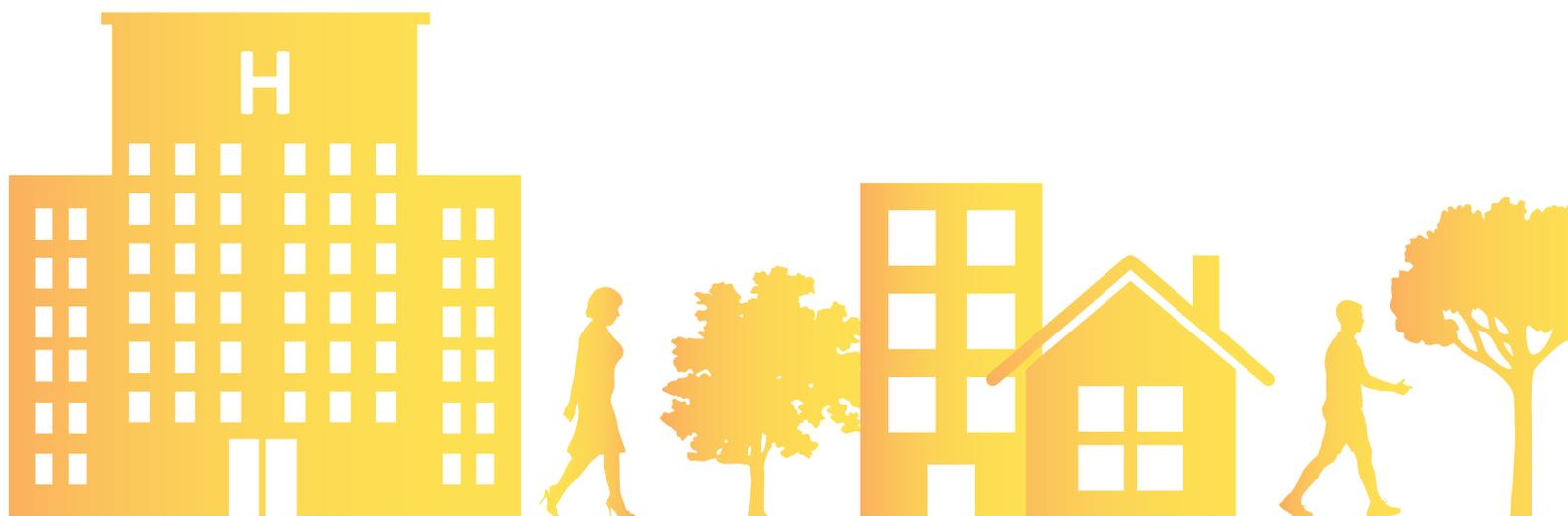
Seamlessness refers to an integrated, person-centred cancer control system that allows patients and their families to easily understand, access and navigate the system.

Sustainability refers to meeting the health care needs of the population in a way that optimizes the balance between resource use and patient outcomes.

Improving care in these areas will help us achieve a future where fewer people get cancer, fewer people die from cancer and more people with cancer experience better quality of life.

This report also highlights gaps in existing health system data. **Maximizing the impact of data** by making information on system performance more readily available will help us tell a more comprehensive story about the current state of cancer control.

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Introduction

Cancer is a disease that touches almost everyone, either personally or through the diagnosis of a friend or family member.

The cancer control community is entrusted with securing a future where fewer people get cancer, fewer people die from cancer and more people living with cancer have better quality of life. To achieve those goals, we must

- continue to improve the quality of cancer care,
- work to ensure that people can access cancer control services regardless of where they live or who they are,
- design a system that is informed by the perspectives of patients and their families and centred on their needs,
- ensure an optimal balance between resource use and patient outcomes so that our health care system is sustainable for future generations,
- broaden the reach, depth and availability of health system data.

BACKGROUND

The cancer control community has made tremendous strides in the fight against cancer. As a result of rapid scientific and care delivery advances, cancer patients today are more likely to survive than ever before and they enjoy a better quality of life. However, there are still opportunities to improve the care and experience of those affected by cancer.



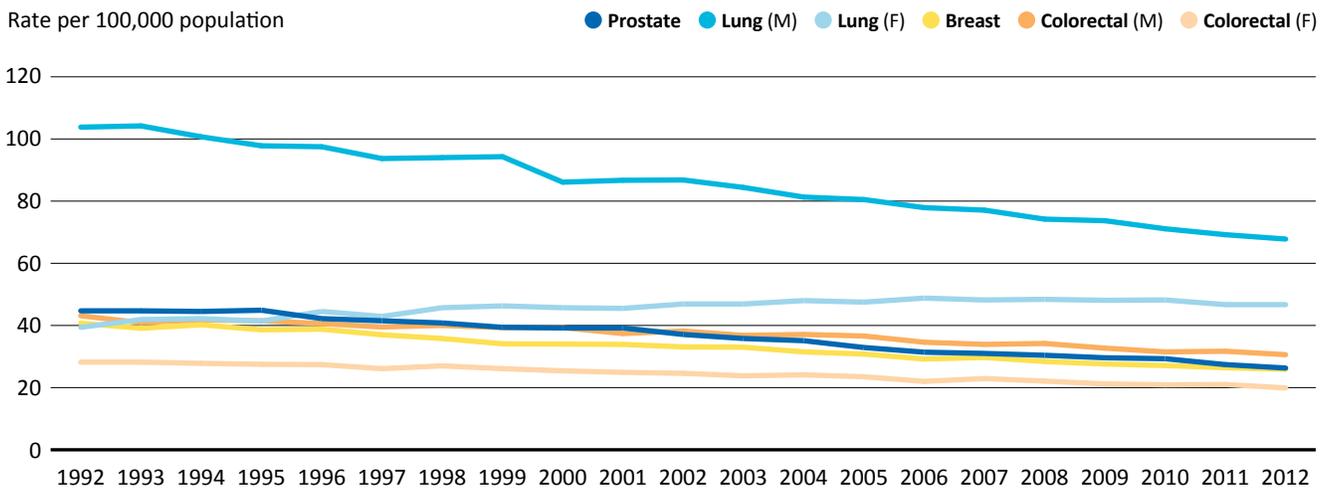
CURRENT STATE

The rates at which Canadians die from prostate, lung, breast and colorectal cancer have decreased.

Although the overall number of people dying from cancer continues to increase, age-standardized mortality rates have been decreasing for prostate, breast and colorectal cancer (Figure 1.1). Mortality rates for lung cancer have been decreasing in men and have stopped increasing in

women. These improvements are likely the result of more effective treatments, better uptake of screening and early detection (in the case of breast cancer), and declining incidence rates (particularly for lung cancer, as a result of reductions in tobacco use).

FIGURE 1.1
Mortality rates[†] for prostate, lung, breast (female) and colorectal cancer, Canada — 1992–2012



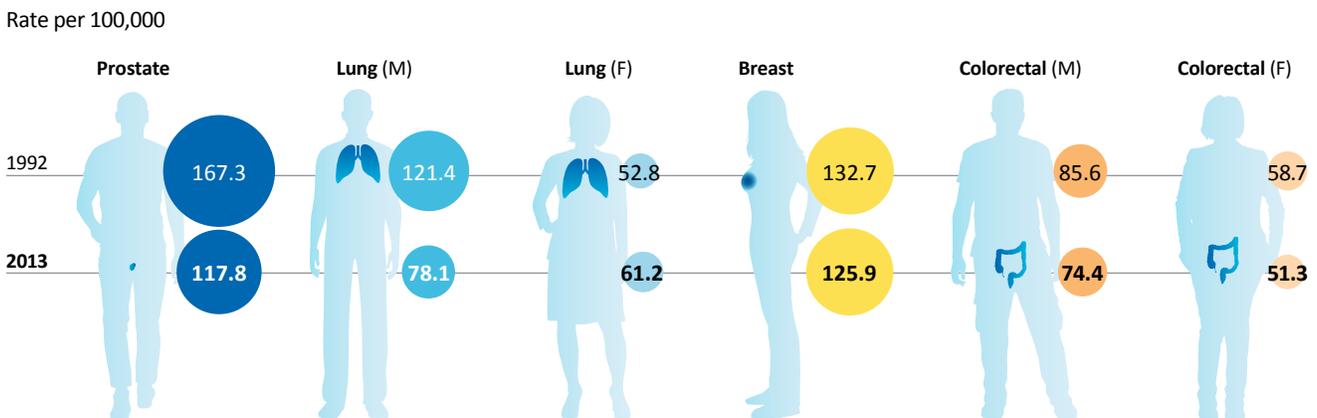
[†] Age-standardized to 2011 Canadian population. Data include all provinces and territories.

Data source: Statistics Canada, Vital Statistics Death Database.

The rates at which Canadians are being diagnosed with prostate, lung, breast and colorectal cancer have decreased.

Since the 1990s, the number of new cancer cases has increased steadily, largely because of the growing and aging population, but age-standardized incidence rates have generally decreased (except for lung cancer in women) [Figure 1.2].¹

FIGURE 1.2
Incidence rates[†] for prostate, lung, breast (female) and colorectal cancer, Canada — 1992 vs. 2013



[†] Age-standardized to 2011 Canadian population. Data include all provinces and territories.

QC: Incidence cases and population for 2013 are duplicates of 2010 values. Data source: Statistics Canada, Canadian Cancer Registry (CANSIM).

Most Canadians diagnosed with prostate or breast cancer have early-stage disease.

Early detection and screening can find cancers early when treatment is most effective.²⁻⁵

- Prostate cancer is most commonly diagnosed at Stage II (Figure 1.3).
- Breast cancer is most commonly diagnosed at Stage I or II (Figure 1.4).

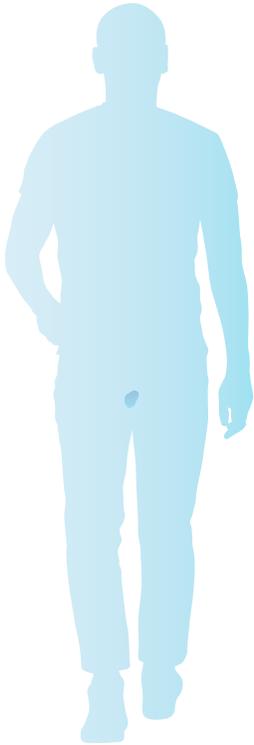
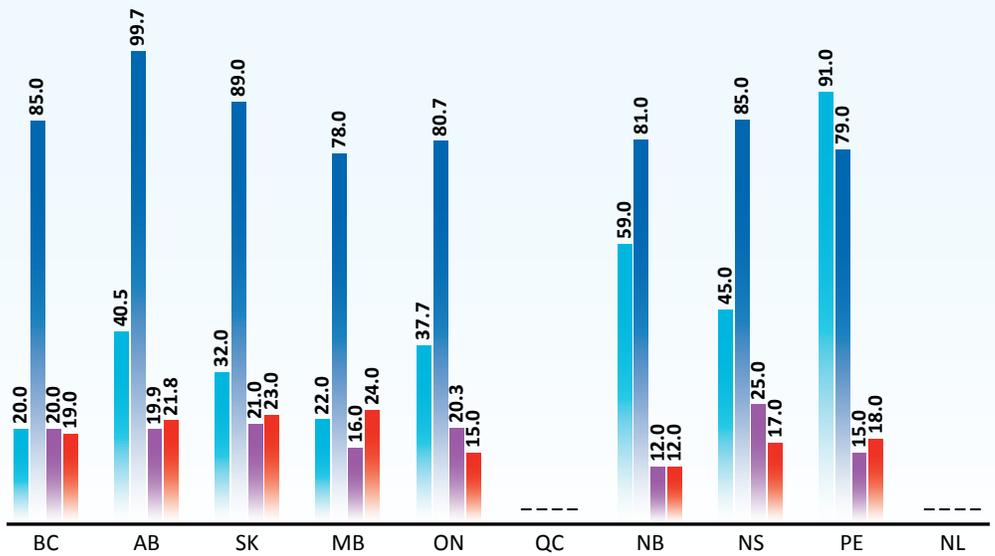


FIGURE 1.3

Incidence rates[†] for prostate cancer, by stage at diagnosis and province — 2011–13 diagnosis years combined

Rate per 100,000 population

● Stage I ● Stage II ● Stage III ● Stage IV



[†] Age-standardized to 2011 Canadian population.
⁻ Data not available.

Data source: Provincial cancer agencies and programs.

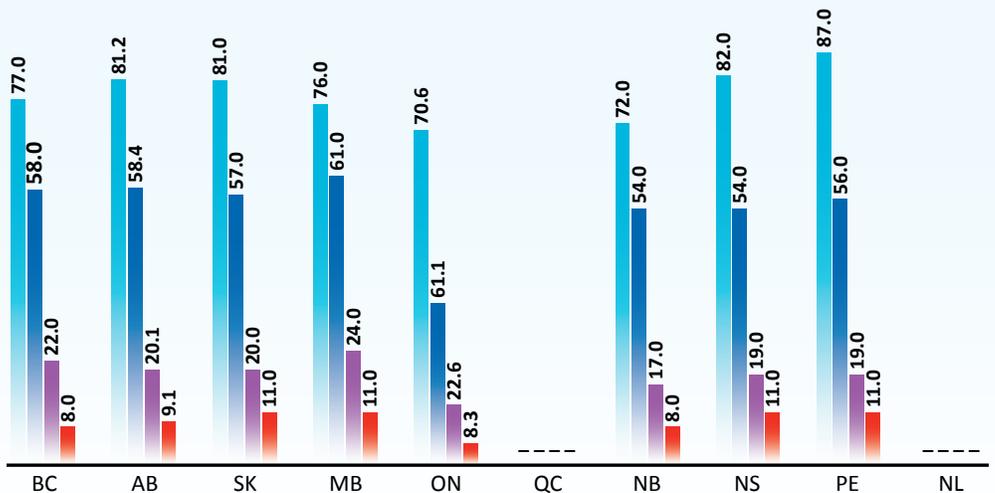


FIGURE 1.4

Incidence rates[†] for breast cancer in women, by stage at diagnosis and province — 2011–13 diagnosis years combined

Rate per 100,000 population

● Stage I ● Stage II ● Stage III ● Stage IV



[†] Age-standardized to 2011 Canadian population.
⁻ Data not available.

Data source: Provincial cancer agencies and programs.

A large proportion of Canadians with lung or colorectal cancer are still diagnosed at a later stage, when chances of cure and survival are lower.

Lung cancer is the leading cause of cancer-related death and is most commonly diagnosed at Stage IV (Figure 1.5).¹

- Only 1% of people diagnosed with Stage IV non-small cell lung cancer survive five or more years.⁶
- Most provinces and territories have tobacco use prevention and cessation programs and are considering implementing lung cancer screening programs.⁷

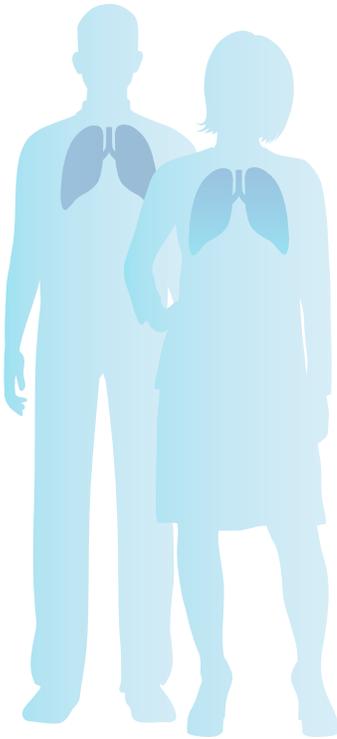
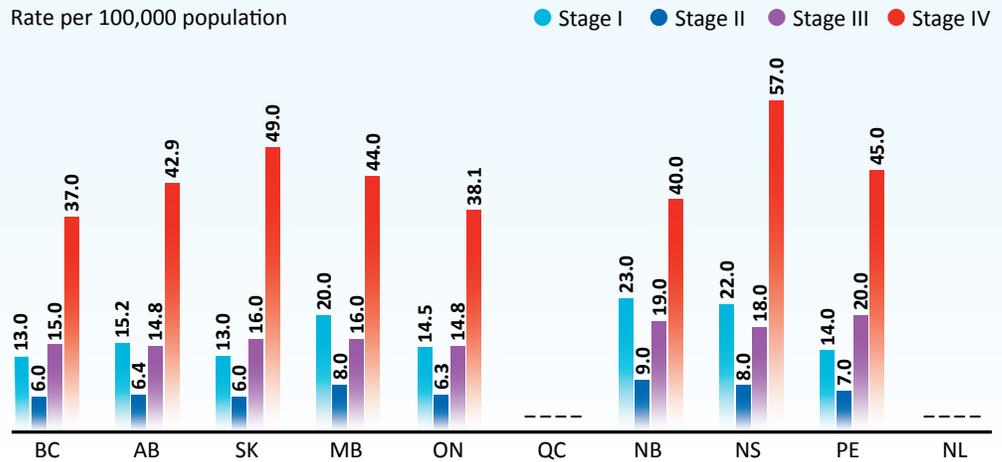


FIGURE 1.5
Incidence rates[†] for lung cancer, by stage at diagnosis and province — 2011–13 diagnosis years combined



[†] Age-standardized to 2011 Canadian population.
"—" Data not available.

Data source: Provincial cancer agencies and programs.

Colorectal cancer is the second leading cause of cancer-related death and is most commonly diagnosed at Stage III (Figure 1.6).¹

- By 2015, all 10 provinces had announced plans to implement colorectal cancer screening programs, which help detect precancerous polyps and early-stage disease.⁸

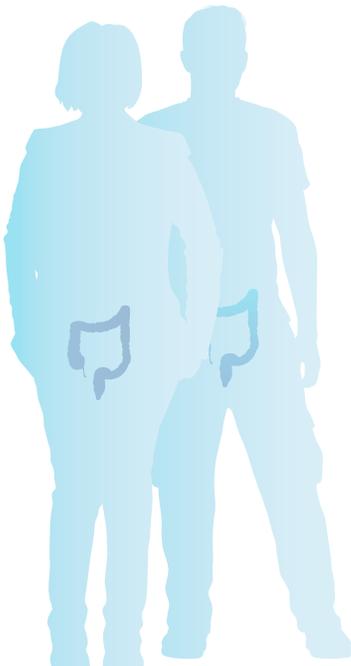
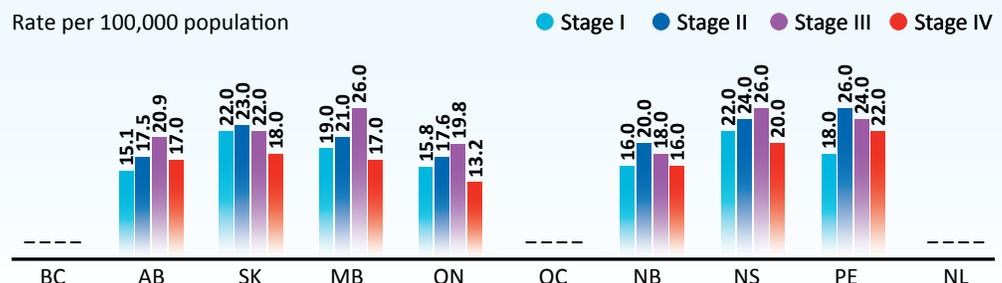


FIGURE 1.6
Incidence rates[†] for colorectal cancer,[‡] by stage at diagnosis and province — 2011–13 diagnosis years combined



[†] Age-standardized to 2011 Canadian population.
"—" Data not available.

[‡] Appendix (C18.1) was excluded.
Data source: Provincial cancer agencies and programs.

Quality

Are we delivering effective, evidence-based care?

In a high-quality cancer system, all people have access to services that are tailored to their needs and preferences, that follow best practices of care based on the latest established evidence and that yield the best outcomes with appropriate use of resources. These elements support individuals in achieving the highest possible level of health and quality of life while reducing future cancer burden.

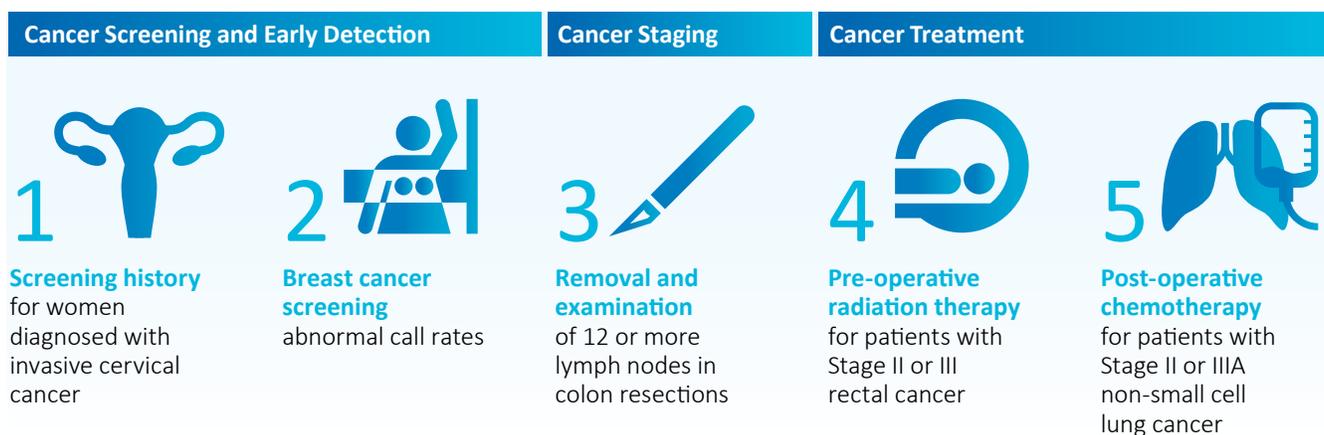


BACKGROUND

For Canadians, **quality of care and access to services** are among the most important features of our health care system.⁹

Quality is an all-encompassing dimension of performance that can be interpreted many ways. In general, quality of care can be defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”¹⁰ In addition to physical outcomes, high-quality cancer care integrates the psychosocial and practical needs of people with cancer.

This chapter focuses on the effectiveness of cancer care—that is, whether we are providing evidence-based care that improves health outcomes:



This chapter also discusses participation in clinical trials, which can lead to the development of more and better care options for people living with cancer.

Adult clinical trial participation



Screening

Effective evidence-based screening increases the chance of detecting cancer before it advances to a late stage, while minimizing potentially harmful testing.

BACKGROUND

Guideline-based screening can be life-saving. It provides the opportunity to detect cancer at a curable stage, improving chances of survival and preventing health complications associated with advanced disease.¹¹ Screening has some risks, however. Sometimes screening tests suggest cancer where there is none (false positives found on follow-up tests), miss cancer where present (false negatives) or identify cancer that would not have progressed to a threatening illness in the person's lifetime (over-diagnosis).¹²

These potential risks can be controlled and minimized in an organized cancer system that follows evidence-based guidelines, remains up to date in policy implementation and monitors both screening program performance and the population's health outcomes.

An effective cancer screening program does the following:^{10,13}

- Detects cancer when present, reducing cancer-related mortality. To attain this benefit, a large proportion of the target population needs to undergo guideline-recommended screening.
- Minimizes potential harm from over-screening and redundant follow-up tests and procedures, ensuring that screening benefits outweigh risks such as over-diagnosis and consequent over-treatment.
- Provides patients with objective information about the benefits and risks of screening in a way they understand and that allows them to make informed decisions.

CURRENT STATE

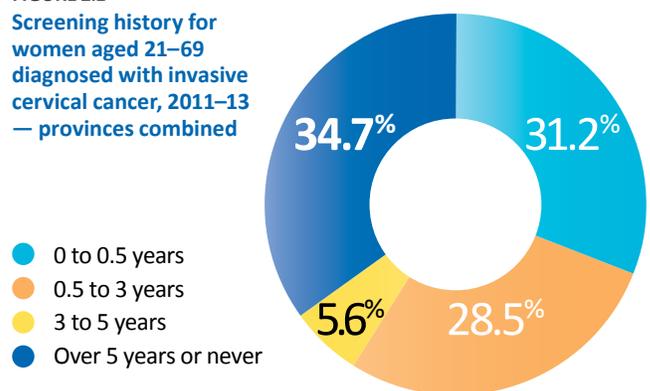
Three out of 10 women diagnosed with cervical cancer in Canada had not had a Pap test in at least five years.

In Canada, cervical cancer screening with Pap tests is offered every two or three years to sexually active women from age 21 to 69. The start age for cervical cancer screening varies across provinces and territories from 21 to 25 (or earlier in a few provinces and territories for sexually active women).¹⁴ Although the national participation rate is high, it remains below the 80% target, indicating that some women remain unscreened or under-screened.

- 34.7% of women diagnosed with invasive cervical cancer between 2011 and 2013 had never had a Pap test or had not had one in the past five years, missing opportunities for early detection and better health outcomes (Figure 2.1).
- Other industrialized countries with cervical cancer screening programs face a similar challenge. In a multi-centre Danish study, 45% of women diagnosed with invasive cervical cancer were unscreened or under-screened, and in France 33% had never had a Pap test or were under-screened.^{15,16}

In some cases, women who had undergone Pap testing every three years (as recommended by the Canadian Taskforce on Preventive Healthcare¹⁷) were still diagnosed with invasive cervical cancer. This result was more common for women with non-squamous cell carcinoma, which is more difficult to detect with a Pap test.

FIGURE 2.1
Screening history for women aged 21–69 diagnosed with invasive cervical cancer, 2011–13 — provinces combined



Data include BC, AB, SK, MB, NB and NL. BC includes data from 2011 and 2012.
Data source: Provincial and territorial cervical cancer screening programs.

Breast cancer detection rates within programs remain unchanged,^a but the rate of abnormal screening results is increasing. This finding suggests some women may be referred for potentially avoidable follow-up diagnostic tests.

National breast cancer screening guidelines recommend routine screening with mammography for average-risk women aged 50 to 74 every two to three years.¹⁸ When a specially trained radiologist identifies an abnormality on a mammogram, the woman is referred for further testing to reach a definitive diagnosis. Over the past few years, the rate of abnormal findings has been increasing nationally.

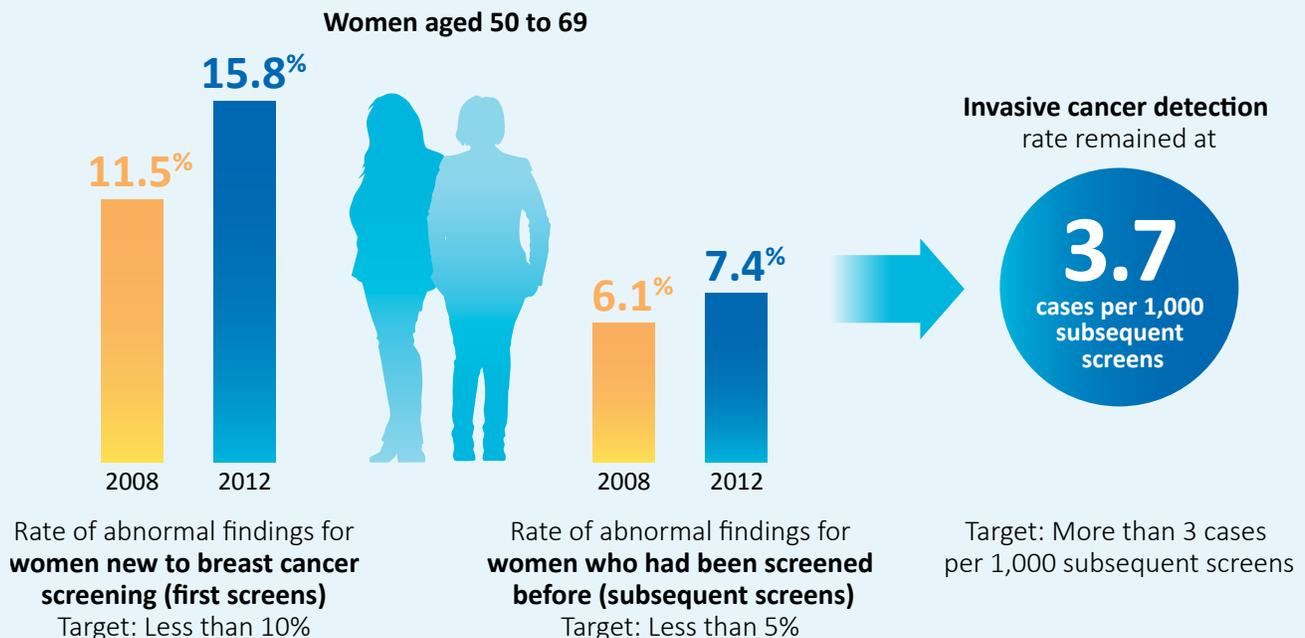
- Among women aged 50 to 69, the rate of abnormal findings for those new to breast cancer screening (first screens) increased from 11.5% in 2008 to 15.8% in 2012. For women who had been screened before (subsequent screens), the rate increased from 6.1% to 7.4%. This is above the national target of less than 10% abnormal calls for first screens and less than 5% for subsequent screens (Figure 2.2).

- Despite the increase in rates of abnormal findings, the invasive cancer detection rate remained at 3.7 cases per 1,000 subsequent screens in 2010–12.
- The rate of abnormal breast cancer screening results varies greatly across Canada. In 2011–12, abnormal call rates for subsequent screens ranged from 4.0% in Saskatchewan to 11.9% in Prince Edward Island. Only Saskatchewan, Manitoba and Northwest Territories met the national target (Figure 2.3).

The causes of the elevated number of abnormal findings and the interprovincial variation remain unclear and are likely multifactorial. Radiologists’ practice patterns, concern about missing a diagnosis and differences in imaging technology (e.g., digital vs. film mammography) can influence the rate of abnormal findings and referrals for further tests.^{19,20}

^a Excluding women who had a screening mammogram for the first time.

FIGURE 2.2
Abnormal call rate and invasive breast cancer detection among women aged 50–69 — 2008 and 2012 screening years



AB: Excluded from data prior to 2007 as the Alberta Breast Cancer Screening Program was launched in 2007.
QC: Complete diagnostic/cancer information was available to September 30, 2012.
Data source: Provincial and territorial breast cancer screening programs.

Although most women with an abnormal mammogram will not have breast cancer (false positive cases), additional and potentially avoidable testing to confirm a diagnosis can be harmful.^{12,13} Also, a false positive mammogram may reduce the likelihood of women coming back for later screenings, increasing the risk of late-stage breast cancer.²¹

Canadian women who had an abnormal mammogram in 2011–12 had the following additional tests (Figure 2.4):

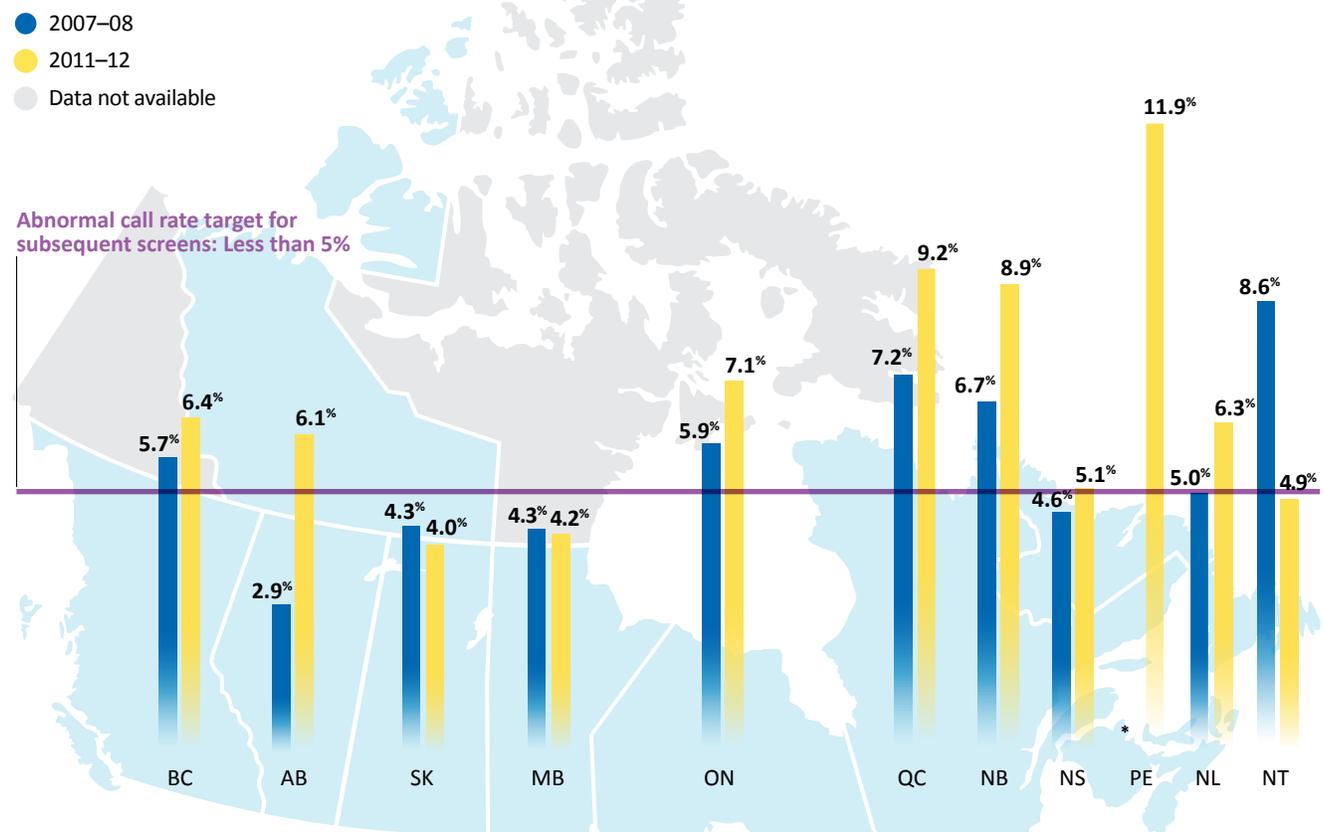
- 97.4% had further breast imaging, including mammography or ultrasounds.
- In addition to further imaging, 15.7% (or 28,684 women)

had a biopsy (surgical, core or both), which is invasive and carries the risk of potentially harmful complications. Besides the discomfort and inconvenience, complications such as lymph node swelling and surgical infection may occur in a small number of cases.¹¹

In addition to the physical risks, most women experience elevated stress and anxiety while waiting for a definitive result, and some women continue to worry even after cancer is ruled out.²²

FIGURE 2.3

Abnormal call rate among subsequent screens for women aged 50–69, by province — 2007–08 vs. 2011–12 screening years



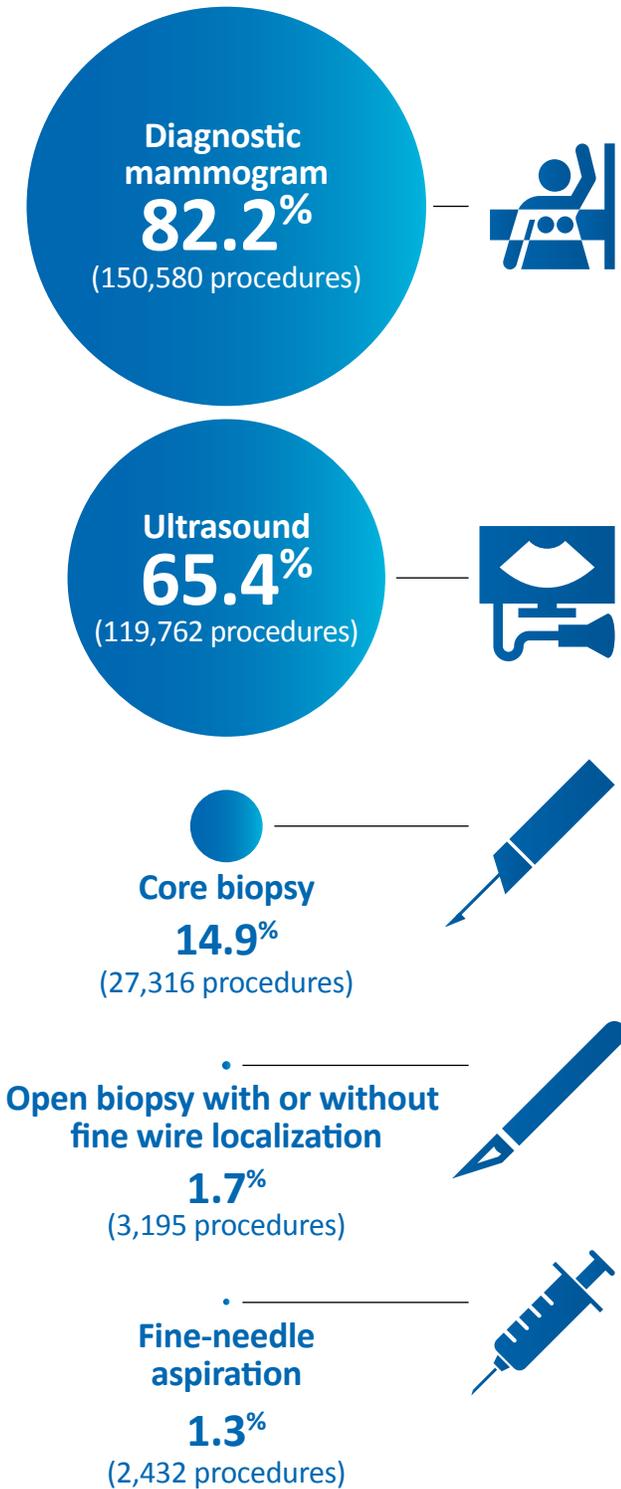
* Suppressed owing to small numbers.

QC: Complete diagnostic/cancer information was available for abnormal screens from January 1, 2011, to September 30, 2012.

AB: Excluded from data prior to 2007 as the Alberta Breast Cancer Screening Program was launched in 2007.

Data source: Provincial and territorial breast cancer screening programs.

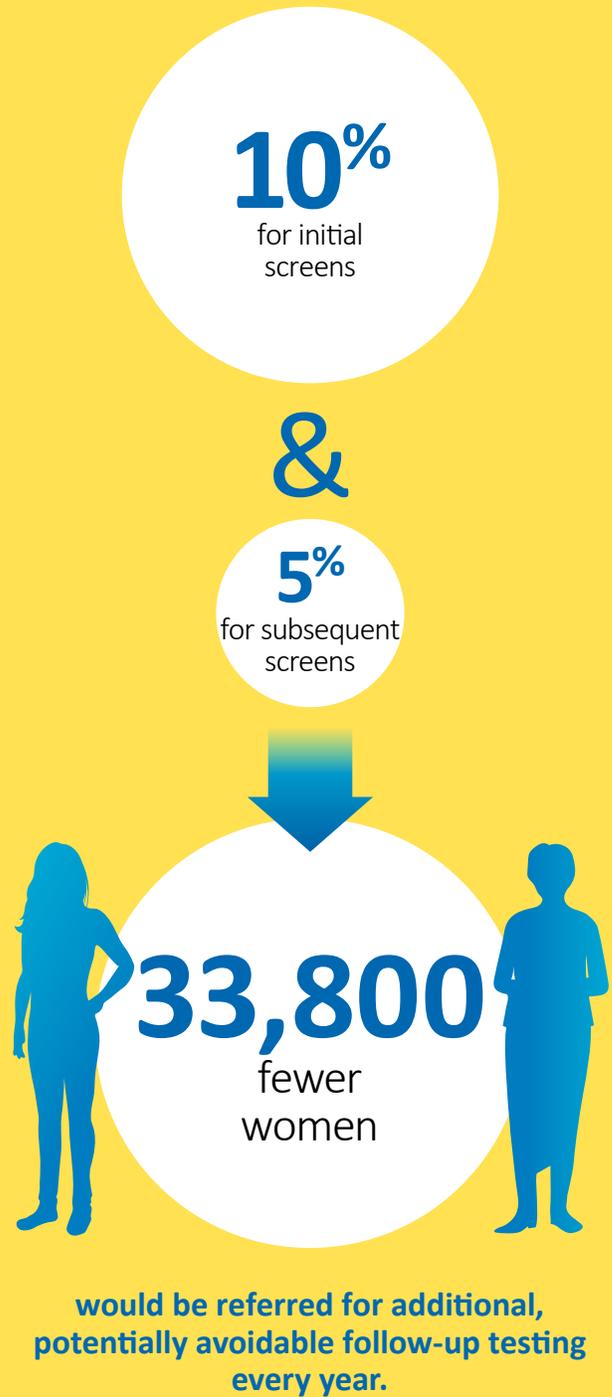
FIGURE 2.4
Diagnostic procedures undergone by women aged 50–69 after abnormal screen result, provinces combined — 2011 and 2012 screening years



AB: Excluded for data quality reasons.
 QC: Submitted aggregate data. National estimates are a weighted average of QC and the rest of Canada. Includes abnormal screens from January 1, 2011, to September 30, 2012, inclusive. Ultrasound numbers may be underestimated as tests performed in private clinics are not included.
 Data source: Provincial and territorial breast cancer screening programs.

FUTURE STATE

If we reduced abnormal mammogram findings to



Detailed calculation methodology is contained in the Technical Appendix available at systemperformance.ca.

Data Source: Provincial and Territorial Breast Cancer Screening Programs.

Treatment

High-quality cancer treatment starts with correct cancer staging.

BACKGROUND

To provide effective cancer treatment, starting with a timely and correct cancer diagnosis is essential. Diagnosis includes identifying the disease's location (site), cellular and other characteristics (histology, biomarkers, etc.) and how much it has spread (stage). This diagnostic and prognostic information helps clinicians determine which treatment regime will be most effective for each patient.

CURRENT STATE

Guideline-based lymph node resection and examination rates are increasing, suggesting that more people with colon cancer are being properly staged.

Colon cancer patients who have at least 12 lymph nodes removed and then examined by a pathologist are more likely to receive an adequate assessment of disease stage and have better survival than those with fewer than 12 lymph nodes resected. Therefore, pathologic assessment of at least 12 resected lymph nodes is recommended.²³

- All reporting provinces showed steady improvement between 2009 and 2012 (Figure 2.5). Positive factors such as published evidence-based guidelines, public reporting and implementation of quality improvement initiatives may have influenced this trend.

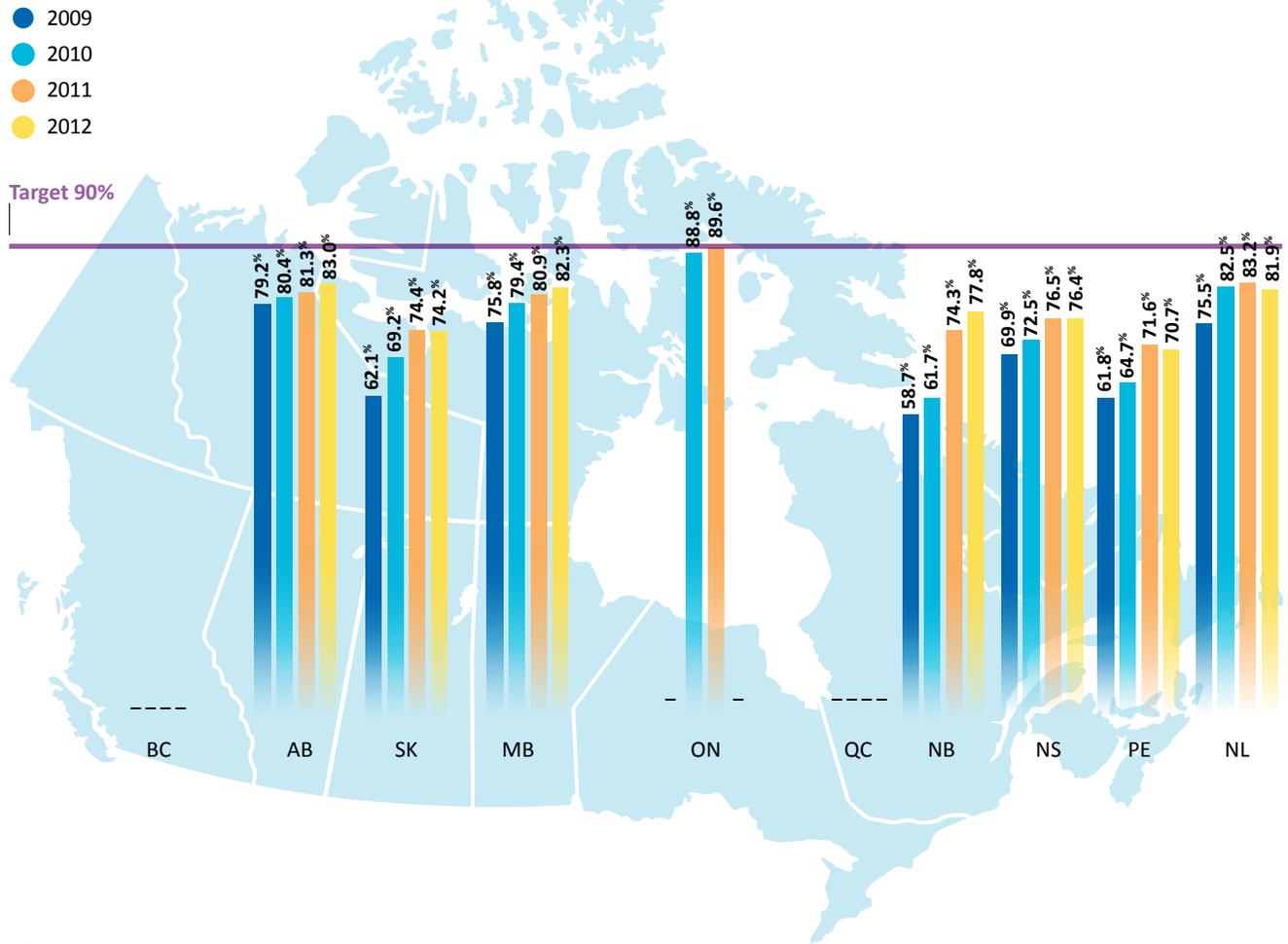
There is room for improvement, however:

- In 2012, none of the reporting provinces achieved the 90% target (Figure 2.5), indicating that some groups may still benefit from better staging.
- There was moderate variation across reporting provinces, with results ranging from 70.7% in Prince Edward Island to 82.3% in Manitoba in 2012. Ontario had the highest rate in 2011, but did not provide data for 2012 (Figure 2.5).

Resection of at least 12 lymph nodes is recommended for colon cancer patients



FIGURE 2.5
Percentage of colon resections with 12 or more lymph nodes removed and examined, by province — from 2009 to 2012 diagnosis years



“—” Data not available.

AB: All Alberta Cancer Registry coded surgeries (if there was no more definitive surgery as part of initial treatment, polypectomy might be included) were included as complete colon resection. C18.1 Appendix was excluded in 2012.

ON: Data represent colon cases with 12 or more nodes examined rather than cases diagnosed in corresponding year.

NS: Collaborative stage variables were used to identify resections. Resection dates were manually retrieved through chart review.

NL: Did not include out-of-province treatment for provincial residents.

Data inclusion and exclusion criteria were slightly different by year. Interpret with caution owing to the criteria changes.

(Refer to the Technical Appendix for details).

Data source: Provincial cancer agencies or programs.

Effective treatment planning is informed by evidence-based guidelines and is tailored to patient preferences and values.

BACKGROUND

Given the intricacies of treatment alternatives and the high specialization of cancer treatments, interdisciplinary consultations and evidence-based guidelines can be powerful tools to ensure an effective treatment regimen for each patient with cancer. Developing avenues to improve communication, coordination and decision making among health care professionals is essential for balanced consideration of evidence-based options and to improve health outcomes.²⁴ Equally important is sustained communication with patients to develop treatment plans that integrate individual preferences and values.²⁵

An effective treatment plan is guided by

- established evidence from guidelines and standards, encompassing all available treatment options that improve health outcomes,
- interdisciplinary consultations to ensure complex cases are properly assessed,
- the patient's preferences and values, making sure the patient is making an informed choice about treatment alternatives.

CURRENT STATE

Fewer than 51% of people with Stage II or III rectal cancer had recommended radiation therapy before surgery.

The delivery of preoperative radiation therapy (along with chemotherapy) improves local disease control and reduces toxicity better than surgery alone or with post-operative radiation.²⁶ Nevertheless, use of guideline-recommended preoperative radiation has not increased.

- In 2012, the rate of preoperative radiation therapy for people with Stage II or III rectal cancer ranged from 41.5% in Nova Scotia to 50.4% in Manitoba (Figure 2.6).

Note that cancers of the rectum and recto-sigmoid junction are included in this dataset. Since the recommendation is only for patients with cancers of the rectum, guideline concordance may be higher than reported. Future reporting on this indicator will include cancers of the rectum only.

Comorbidities and patient preferences may contribute to the low uptake of this treatment in Canada. But some patients may not have been referred to a radiation oncologist before surgery, indicating a need for improved interdisciplinary consultation. A 2008 chart review in five Canadian provinces examined radiation therapy treatment status and specialist referral for patients with Stage II or III rectal cancer:

- 90.8% of patients with Stage II or III rectal cancer were referred to an oncology specialist by a surgeon and 9.2% were not (Figure 2.7).
 - 25.5% of patients were not treated with radiation therapy. The main reasons were not being seen by a radiation oncologist (e.g., assessed by medical oncologist only) and patient choice.
 - Among patients whose surgeon did not refer them to an oncologist, the most common reason for non-referral was comorbidities (41%). In some cases no reason was documented.

FIGURE 2.6
Percentage of Stage II or III rectal cancer patients who received radiation therapy before surgery, by province — from 2009 to 2012 diagnosis years

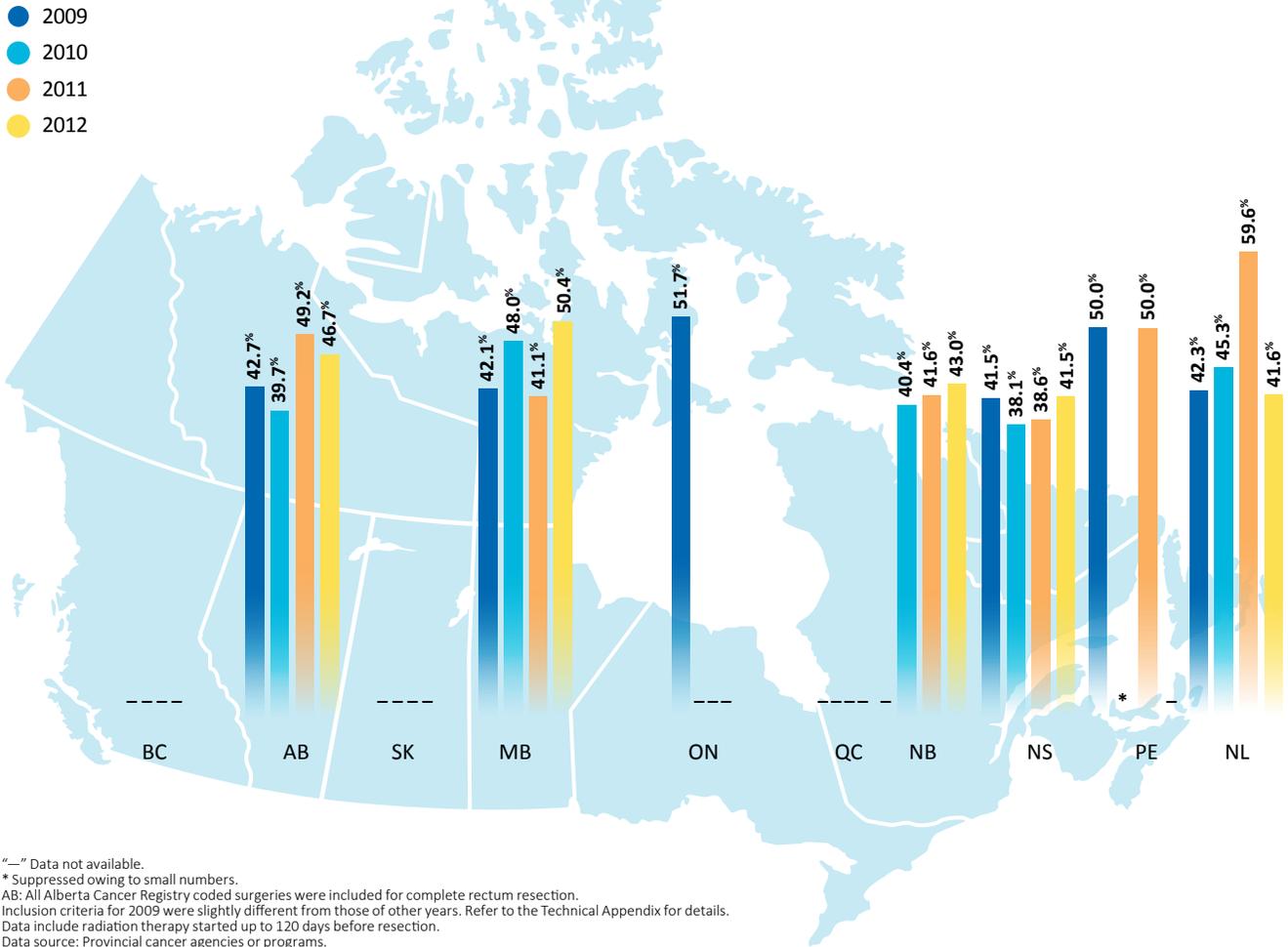
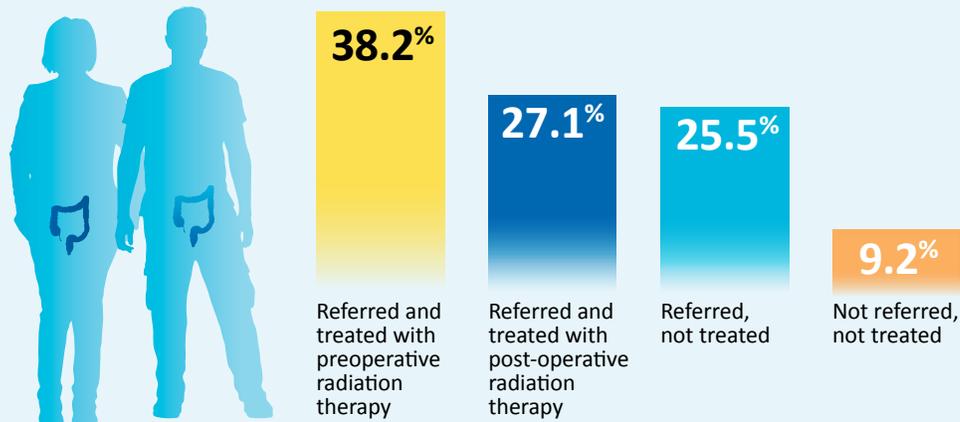


FIGURE 2.7
Referral and treatment status from chart review results: use of radiation therapy preceding or following resection for patients diagnosed with Stage II or III rectal cancer — 2008



N=369
 Data include AB, SK, MB, PE and NL.
 Referral is by surgeon who performed the resection to a radiation treatment centre.
 Data source: Canadian Partnership Against Cancer, 2008 chart review; Provincial cancer agencies and programs.

Older patients with locally advanced non-small cell lung cancer (NSCLC) are less likely to receive recommended post-operative chemotherapy than younger patients.

Post-operative chemotherapy for Stage II and IIIA (i.e., locally advanced) NSCLC after surgical resection improves overall survival for patients up to age 80.²⁷ Though older patients are more likely to have conditions that may preclude treatment, studies suggest that patients between 70 and 80 years with no contraindications can benefit from adjuvant chemotherapy and can tolerate it as well as younger patients.^{28,29} Despite that, the difference between post-operative chemotherapy use in younger and older Canadians with locally advanced NSCLC is significant (Figure 2.8).

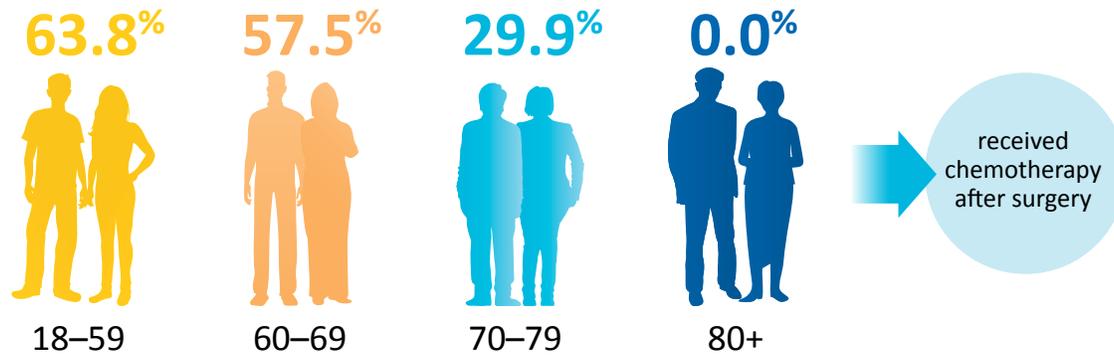
^b Oral chemotherapy information was included if available but may not be complete.

- In 2012, 63.8% of patients with locally advanced NSCLC aged 18–59 received chemotherapy after surgery, compared with 29.9% of patients aged 70–79.^b

These findings are consistent with a population-based study in Ontario that showed that NSCLC patients over age 70 were significantly less likely to have a post-operative oncology consultation than younger patients.³⁰ Although forgoing chemotherapy is often the appropriate choice for many older patients, it is important to ensure that these patients are aware of all their treatment options and that chemotherapy is available in those situations where it has benefit, regardless of the patient's age.

FIGURE 2.8

Percentage of Stage II or IIIA non-small cell lung cancer patients who received chemotherapy following surgical resection, by age group — 2012 diagnosis year



Data included AB, SK, MB and PE (provinces submitted comparable data for all four years).
 AB: All coded surgeries were included for complete lung resection.
 MB: Oral chemotherapy included if available but may not be complete.

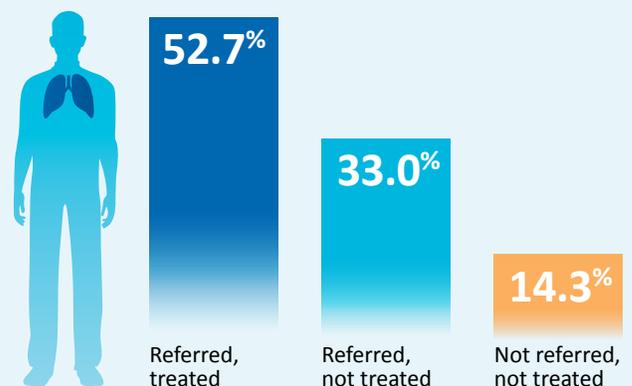
Data included chemotherapy started within 120 days following surgery.
 Data source: Provincial cancer agencies and programs.

Given the variety of treatments available (including post-operative chemotherapy), multidisciplinary evaluation is recommended for locally advanced NSCLC cases.²⁷ A 2008 chart review in four Canadian provinces examined factors that influence adjuvant chemotherapy use among patients with locally advanced NSCLC (Figure 2.9):

- 33.0% of patients were referred but not treated. The main reasons were patient choice, comorbidities and complications, which are all valid, patient-centred reasons.
- 14.3% of patients were not referred to a specialist and were not treated with adjuvant chemotherapy. In most cases, the reason for non-referral was not clearly documented. This result highlights the need to improve monitoring and understanding of treatment planning decisions.

FIGURE 2.9

Referral and treatment status from chart review results: use of chemotherapy following resection for patients diagnosed with Stage II or IIIA non-small cell lung cancer — 2008



N=112
 Data include AB, SK, MB and PE.
 Referral is by surgeon who performed the resection to a medical oncologist.
 Data source: Canadian Partnership Against Cancer, 2008 chart review; Provincial cancer agencies and programs.

FUTURE STATE

If all patients with NSCLC (Stage II or IIIA) were referred to a specialist after surgery,

630
more
patients

could be made aware of their chemotherapy options each year.

Clinical Trial Participation

BACKGROUND

Clinical trials are the foundation for the consolidation of effective, high-quality cancer treatments. Trials evaluate the safety and efficacy of emerging treatments, paving the way for improved best practices. Evidence shows that local centres participating in clinical trials are more likely to follow evidence-based treatment guidelines and thus improve patient outcomes than centres that do not host clinical trials.^{31,32} Finally, if the trial or regimen is successful, patients in the treatment group can benefit from a breakthrough treatment.

In synergy, these benefits improve treatment quality at both the individual and system level and can provide better care options for present and future generations. An effective, high-quality cancer system ensures the availability of clinical trials for a broad range of cancers and stimulates participation among eligible patients.

All eligible patients receive enough guidance to decide whether to join a clinical trial and to fully understand its implications.

All eligible cancer patients are aware of and have the opportunity to participate in clinical trials.

Clinical trials are available for a larger proportion of cancer patients with a broader range of cancers across broader geographic areas.

Effective
clinical trial
participation

CURRENT STATE

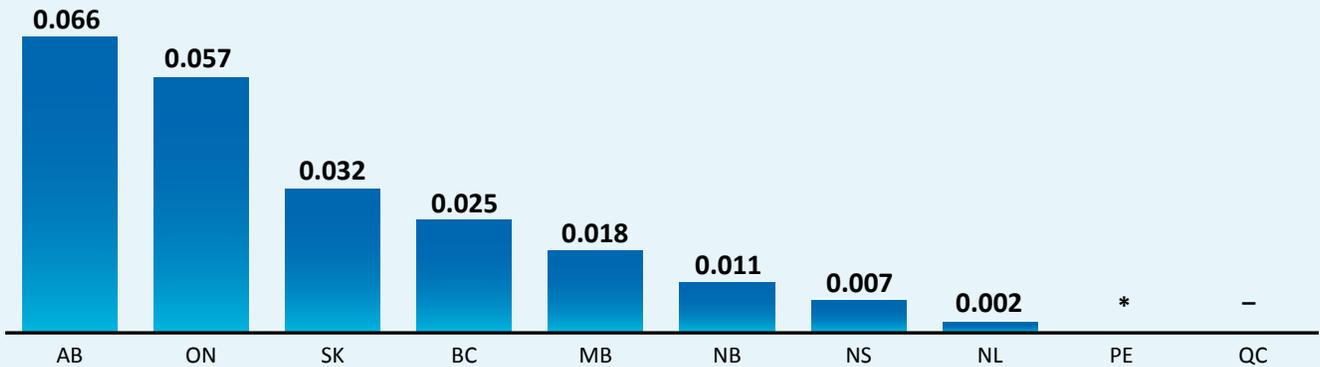
Across Canada, fewer than seven out of 100 adult cancer patients participate in clinical trials.

The ratio of adult patients enrolled in clinical trials to the number of new cancer cases ranged from 0.002 in Newfoundland and Labrador to 0.066 in Alberta (Figure 2.10). These rates can be interpreted as fewer than one participant in 100 cancer patients and about seven participants per 100 patients, respectively.^c

Although the number of cancer clinical trials has increased across Canada, there is still room for improvement in clinical trial availability and patient participation. The United Kingdom had the highest reported rate of trial participation, with 12% of adults with cancer participating.³³ In contrast, fewer than 5% of adult cancer patients participate in trials in the United States, as estimated by the National Cancer Institute.

^c As a proxy for the actual clinical trial participation rate, the results of this indicator can be cautiously interpreted as percentages to aid data interpretation.

FIGURE 2.10
Ratio of adult patients enrolled in clinical trials to number of incident cases, by province, all cancers — 2014 enrolment year



* Suppressed owing to small numbers.

"—" Data not available.

The Canadian Cancer Society's (CCS) projected 2014 cancer incident cases were used for this indicator. CCS projections are derived from statistical models incorporating data obtained from the Canadian Cancer Registry, National Cancer Incidence Reporting System, Canadian Vital Statistics' Death Database, and population life tables, censuses and forecasts.

The 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 or could be recurrent cases. AB: Includes non-intervention cases.

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

FUTURE STATE

If we reached the same clinical trial participation rate as the United Kingdom (12%),

10,600
additional
adult cancer
patients

would participate in clinical trials each year, which could result in more and better treatment options.

Calculation estimates exclude QC (data not available). Detailed calculation methodology is contained in the Technical Appendix available at systemperformance.ca. Data source: Provincial cancer agencies and programs; Canadian Cancer Society, Canadian Cancer Statistics.

CALL TO ACTION

A cancer diagnosis is a life-changing event for patients and their families. To ensure they receive the right patient-centred care at the right place and time, it is important to identify and systematically address ineffectiveness across the cancer care continuum, from screening to long-term and end-of-life care.

Equally important is strengthening our reporting infrastructure at the system level. Provincial and national efforts to standardize information provided in medical charts, including data on interdisciplinary consultations, patient referrals and the patient's involvement in treatment planning and execution, would improve the monitoring of evidence-based practices and patient-centred care.

Patients and medical staff should be informed about clinical research opportunities earlier in the clinical trial recruitment process to focus on alleviating concerns and increasing the likelihood of participation. Overall, increased awareness among everyone involved, whether an investigator or a participant, is key to expanding the Canadian clinical trial landscape.



MAXIMIZING DATA IMPACT

What additional data and measurements are needed to tell a more comprehensive story about quality?

- **Consistent, standardized information on the provision of interdisciplinary consultations and referrals** (including reasons for non-referral) before and after treatment is required. Currently, the only mechanism to collect this information is chart reviews, which are inefficient and time-consuming. Standardized, systematic data collection in cancer registries would improve accountability and monitoring of evidence-based practices over time.
- **Comprehensive data on details of treatment** (e.g., treatment intent—curative or palliative; chemotherapy delivery—intravenous or oral) would allow for development of more accurate indicators of treatment patterns relative to guidelines and other evidence-based recommendations.
- Measurement of **patients' met and unmet informational needs during treatment** is required.
- Collecting **data on the number of patients eligible for existing clinical trials**—instead of incident cases—would provide more accurate information about the current state of cancer clinical trial participation in Canada. For this report, participation in clinical trials is estimated based on number of patients registered in clinical trials over the number of incident cases, which is a proxy measure.

Equity

Are we narrowing the gap in cancer outcomes between at-risk populations and others?

In an equitable cancer control system, all Canadians have equal access to effective cancer prevention and care throughout the cancer journey, regardless of their place of residence, income, education, age or gender, and whether they are immigrants or Canadian born, including First Nations, Inuit and Métis people.



BACKGROUND

Two of the five fundamental health care pillars outlined in the *Canada Health Act* are **universality** and **accessibility**.

Accessibility means providing health services whenever necessary; universality means the same level of care is available to all residents of Canada.³⁴ In a truly universal and accessible health care system, all individuals have equitable access to health care that allows everyone to attain the best possible outcomes.

To ensure people across Canada have equitable access to our cancer control system, we have to properly identify and systematically address potential barriers that may prevent at-risk groups from accessing cancer care services, reducing their chances of achieving better outcomes and a positive experience. By overcoming potential barriers to care, an equitable cancer system can ultimately reduce gaps in cancer outcomes and quality of life across at-risk populations.

Although numerous communities face barriers to accessing cancer services, this chapter focuses on three categories for which we have data on disparities in health care access and outcomes across Canada: Income (income quintile), place of residence (rural-very remote, rural-remote, rural or urban) and immigrant status (Canadian born or otherwise) when possible.

This chapter focuses on three categories for which we have data on disparities in health care access and outcomes across Canada:



Income

- Smoking prevalence by household income quintile
- Adult overweight and obesity by household income quintile
- Self-reported cervical cancer screening rates by household income quintile
- Lung and colorectal cancer incidence by neighbourhood income quintile
- Lung and colorectal cancer mortality by neighbourhood income quintile
- Lung, colorectal, breast and prostate cancer five-year survival by neighbourhood income quintile



Place of residence

- Adult overweight and obesity by place of residence
- Mastectomy versus breast-conserving surgery by place of residence
- Mastectomy versus breast-conserving surgery by travel time to nearest radiation treatment facility



Immigrant status

- Self-reported cervical cancer screening rates by immigrant status
- Self-reported cervical cancer screening rates by language spoken at home

For indicators based on the Canadian Community Health Survey (CCHS), *immigrant status* and *income* are assigned based on information self-reported by individuals surveyed. For all other data sources, income and immigrant status were ecologically defined at the area or neighbourhood level. Place of residence was adapted from Statistics Canada's census metropolitan area (CMA), census agglomeration (CA) and metropolitan influenced zones (MIZ).

CURRENT STATE

Cancer prevention practices vary across populations.

Some populations are more likely to develop behaviours that increase their risk of getting cancer.

People with lower incomes and lower education levels tend to have a higher cancer burden than advantaged populations. Numerous factors could account for these disparities, including higher risk factors for getting cancer such as smoking and having an unbalanced diet. For instance, tobacco use is responsible for 85% of new lung cancer cases in Canada—and at-risk populations are more likely to smoke.

In 2011,

- 24.9% of individuals (aged 12 or older) in low-income households reported smoking, compared with 15.2% in high-income households.
- 19.3% of urban residents reported smoking, compared with 24.0% of rural residents (aged 12 or older) living in very remote areas.
- 46.9% of women (aged 18 or older) in low-income households are overweight or obese, compared with 38.8% in high-income households. The relationship is reversed for men: 65.9% of men in high-income households are overweight or obese, compared with 51.1% in low-income households.
- 60.7% of rural individuals (aged 18 or older) living in very remote rural areas are overweight or obese, compared with 50.7% of urban residents.

Cancer screening participation varies across populations.

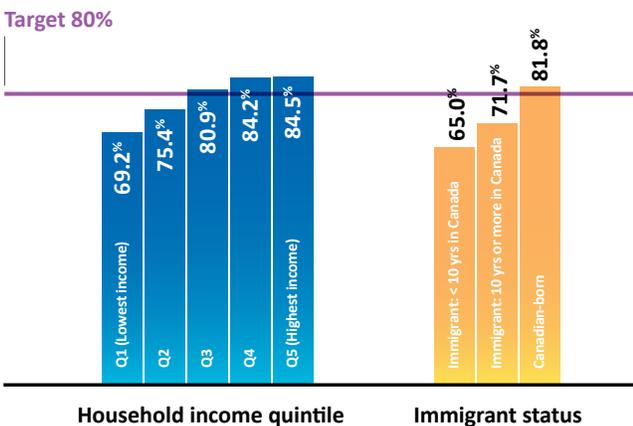
Screening is a fundamental cancer control tool that decreases mortality by reducing the proportion of patients diagnosed with late-stage disease. Screening also promotes timely access to treatment.¹¹ For example, Pap test screening is available through cervical screening programs and is universally covered for all Canadian women aged 21–69 who have ever been sexually active.¹⁷ The target is that 80% of eligible women in Canada will participate in cervical screening. In 2012, this target was met only for Canadian-born women and women in middle- and high-income households (Figure 3.1).

- 84.5% of women aged 21–69 from high-income households had had a Pap test in the past three years, compared with 69.2% from low-income households.
- 81.8% of Canadian-born women aged 21–69 had had a Pap test in the past three years, compared with 65% of recent immigrants.

Language can be an additional barrier to screening for Canadian immigrants. Women aged 21–69 who speak neither English nor French at home are more likely to never have had a Pap test (26.2%) than those who speak an official language (8%) (Figure 3.2).

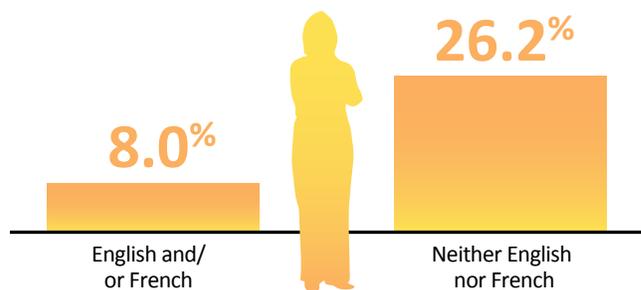
Canadian immigrants can feel apprehensive about cancer screening if prevention and early detection programs are not the norm in their home countries. Therefore, it is vital for immigrants to have access to additional screening information that is culturally sensitive and addresses language barriers.³⁵

FIGURE 3.1
Percentage of women[†] aged 21–69 reporting at least one Pap test in the past three years, by household income quintile and immigrant status, Canada — 2012 reporting year



[†] Age-standardized to 2011 standard population. The territories are excluded from income analysis in the Canadian Community Health Survey. Data source: Statistics Canada, Canadian Community Health Survey.

FIGURE 3.2
Percentage of women[†] aged 21–69 reporting never having a Pap test, by language spoken at home, Canada — 2012 reporting year



[†] Age-standardized to 2011 standard population. Data source: Statistics Canada, Canadian Community Health Survey.

Access to cancer treatment may be affected by where patients live.

Evidence shows that not all individuals have access to the cancer treatments and care services that are best suited to their needs. Even if a patient is in great need of care, age and geography can sometimes hinder timely access to appropriate treatment and end-of-life care.³⁶

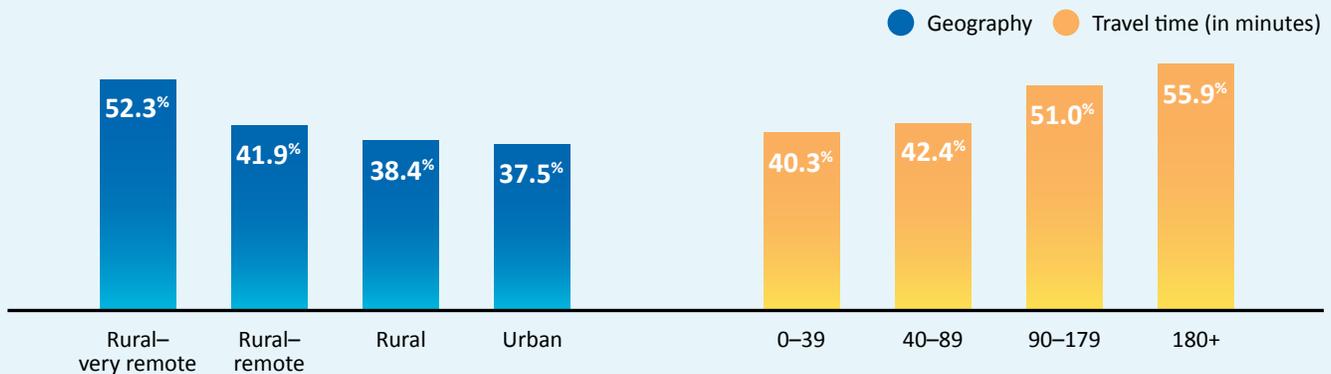
For example, breast-conserving therapy is a less invasive, but equally effective, procedure compared with mastectomy for the treatment of early-stage breast cancer. However, it requires radiation therapy after surgery, which for many patients in rural and remote communities translates into long travel times and extended time off work to go to radiation therapy appointments.^{37,38}

Between 2007 and 2012,

- 55.9% of women with breast cancer who lived three hours away from a treatment centre had a mastectomy, compared with 40.3% who lived less than half an hour away (Figure 3.3).
- 52.3% of women who lived in remote areas had a mastectomy, compared with 37.5% who lived in urban areas (Figure 3.3).



FIGURE 3.3
Percentage of breast cancer resections that are mastectomies, by geography and travel time to nearest radiation treatment facility, Canada — 2007/08 to 2011/12 combined



Mastectomy rates include women who receive mastectomy first and women who receive breast-conserving surgery first followed by mastectomy within 1 year. QC is excluded from the travel time analysis. Data for AB are for 2007/08 to 2009/10.

Data source: Hospital Morbidity Database, Canadian Institute for Health Information, National Ambulatory Care Reporting System, Canadian Institute for Health Information, Fichier des hospitalisations MED-ÉCHO, Ministère de la Santé et des Services Sociaux du Québec, Alberta Ambulatory Care Reporting System.

FUTURE STATE

If all women had access to breast-conserving surgery instead of mastectomy, regardless of where they live,

160
more women

could benefit from this less-invasive but equally effective treatment each year.



Data source: Canadian Partnership Against Cancer, Canadian Institute for Health Information.

CURRENT STATE

Cancer outcomes differ across at-risk groups.

In 2012, 70 people per 100,000 population at the lowest income level died of lung cancer, compared with 43 per 100,000 at the highest income level.

Individuals at the lowest income level are 1.66 times more likely to be diagnosed with lung cancer (Figure 3.4) and 1.62 times more likely to die from it (Figure 3.5) than those at the highest income level.^d

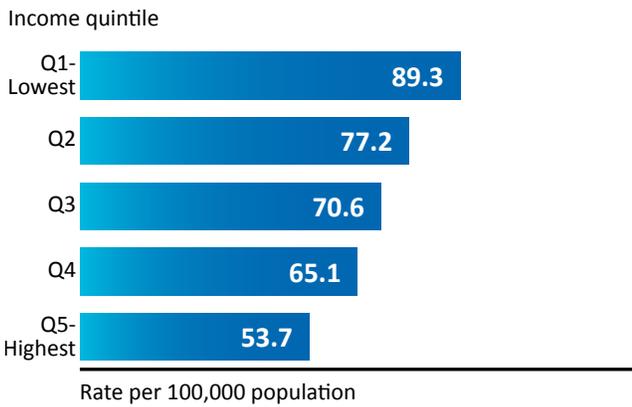
^d Estimate based on incidence rates.



Lowest income:

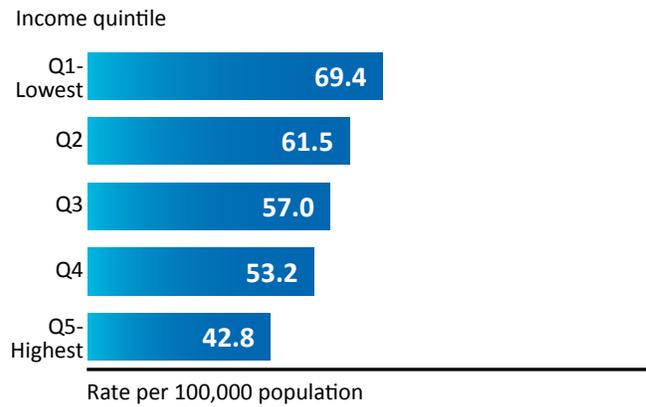
1.66 times more likely to be diagnosed with lung cancer
1.62 times more likely to die from it

FIGURE 3.4
Incidence rates[†] for lung cancer by neighbourhood income, both sexes combined, urban and rural combined, Canada — 2012 diagnosis year



[†] Age-standardized to 2011 Canadian population. Territories were excluded. QC: Incidence cases in 2012 were copied from 2010. Data source: Statistics Canada, Canadian Cancer Registry.

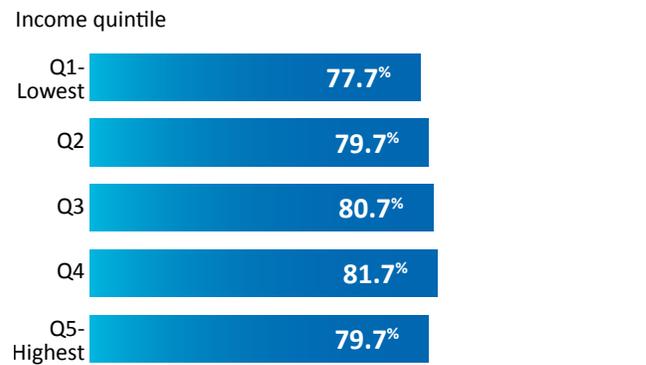
FIGURE 3.5
Mortality rates[†] for lung cancer by neighbourhood income, both sexes combined, urban and rural combined, Canada — 2012 death year



[†] Age-standardized to 2011 Canadian population. Territories were excluded. Data source: Statistics Canada, Vital Statistics Death Database.

Such a difference across income levels is balanced out when the number of lung cancer deaths is compared with the number of lung cancer cases (Figure 3.6). This indicates that most of the observed differences between lower and higher income populations in lung cancer mortality is likely a result of the incidence (number of new cases across income quintiles).

FIGURE 3.6
Fatality ratio for lung cancer by neighbourhood income, both sexes combined, urban and rural combined, Canada — 2012 diagnosis and death years

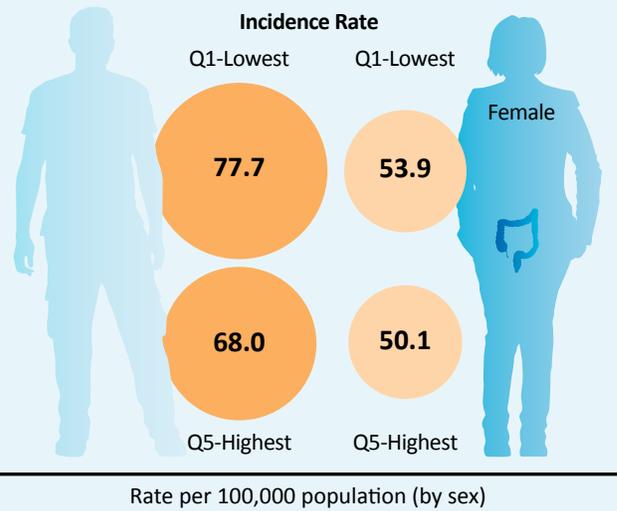
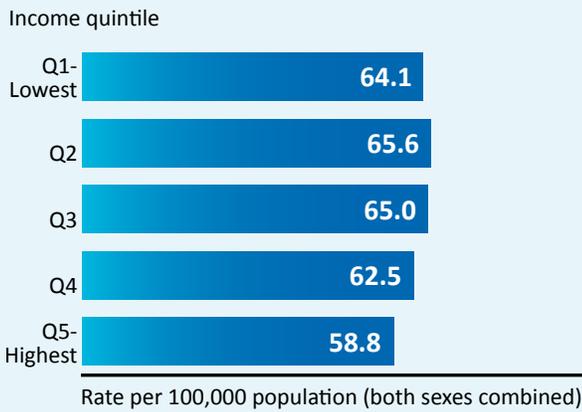


Territories were excluded. QC Incidence cases in 2012 were copied from 2010. Data source: Statistics Canada, Canadian Cancer Registry, Vital Statistics Death Database.

Although there is no distinct pattern across income gradients, Canadians at the lowest income level are more likely to be diagnosed with colorectal cancer than Canadians at the highest income level (Figure 3.7).



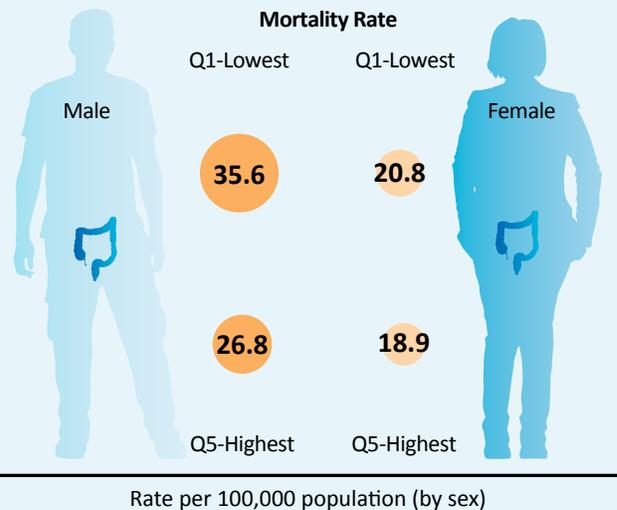
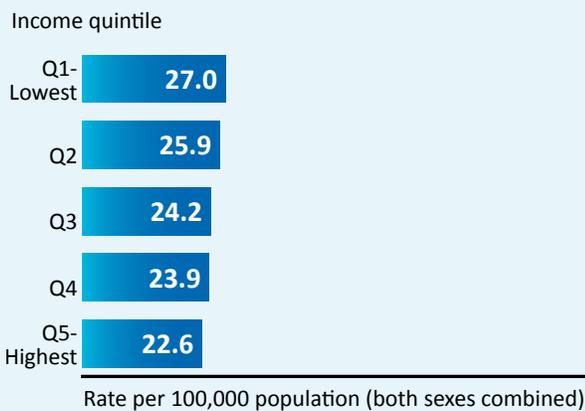
FIGURE 3.7
Incidence rates[†] for colorectal cancer by neighbourhood income, urban and rural combined, Canada — 2012 diagnosis year



[†] Age-standardized to 2011 Canadian population. Territories were excluded. QC: Incidence cases in 2012 were copied from 2010. Data source: Statistics Canada, Canadian Cancer Registry.

There is a difference in the annual colorectal cancer mortality rate between low-income individuals (27 per 100,000 people) and high-income individuals (23 per 100,000 people) (Figure 3.8).

FIGURE 3.8
Mortality rates[†] for colorectal cancer by neighbourhood income, urban and rural combined, Canada — 2012 death year



[†] Age-standardized to 2011 Canadian population. Territories were excluded. Data source: Statistics Canada, Vital Statistics Death Database.

Although the lowest-income populations are more likely to get lung and colorectal cancer, the opposite is true for breast cancer.

- In 2012, 119 women per 100,000 at the lowest income level were diagnosed with breast cancer, compared with 133 per 100,000 at the highest income level.
- Higher participation in breast cancer screening can help to explain the positive association between income level and breast cancer cases.³⁹ In 2012, 80.5% of eligible women in high-income households reported having had a screening mammogram, compared with only 62.3% at the lowest income level. More screening increases the chances of cancer detection. Despite the higher incidence rate, women at high income levels are as likely to die of breast cancer as women in low income levels (data not shown).
- In a given year, about 25 women per 100,000 from any income level die of breast cancer.

For lung, colorectal and breast cancer, as income increases, so does cancer survival.

Although several underlying factors can influence cancer outcomes, studies have demonstrated that low socioeconomic status is consistently associated with poor cancer survival (Figure 3.9).^{40,41}

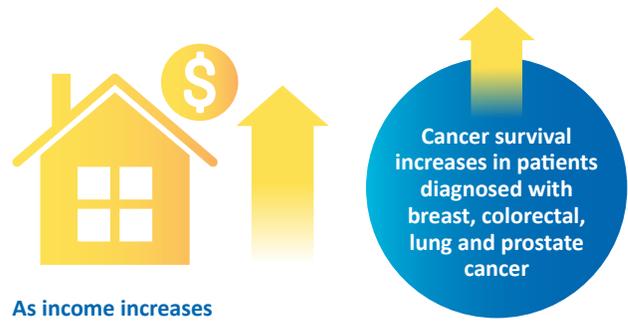
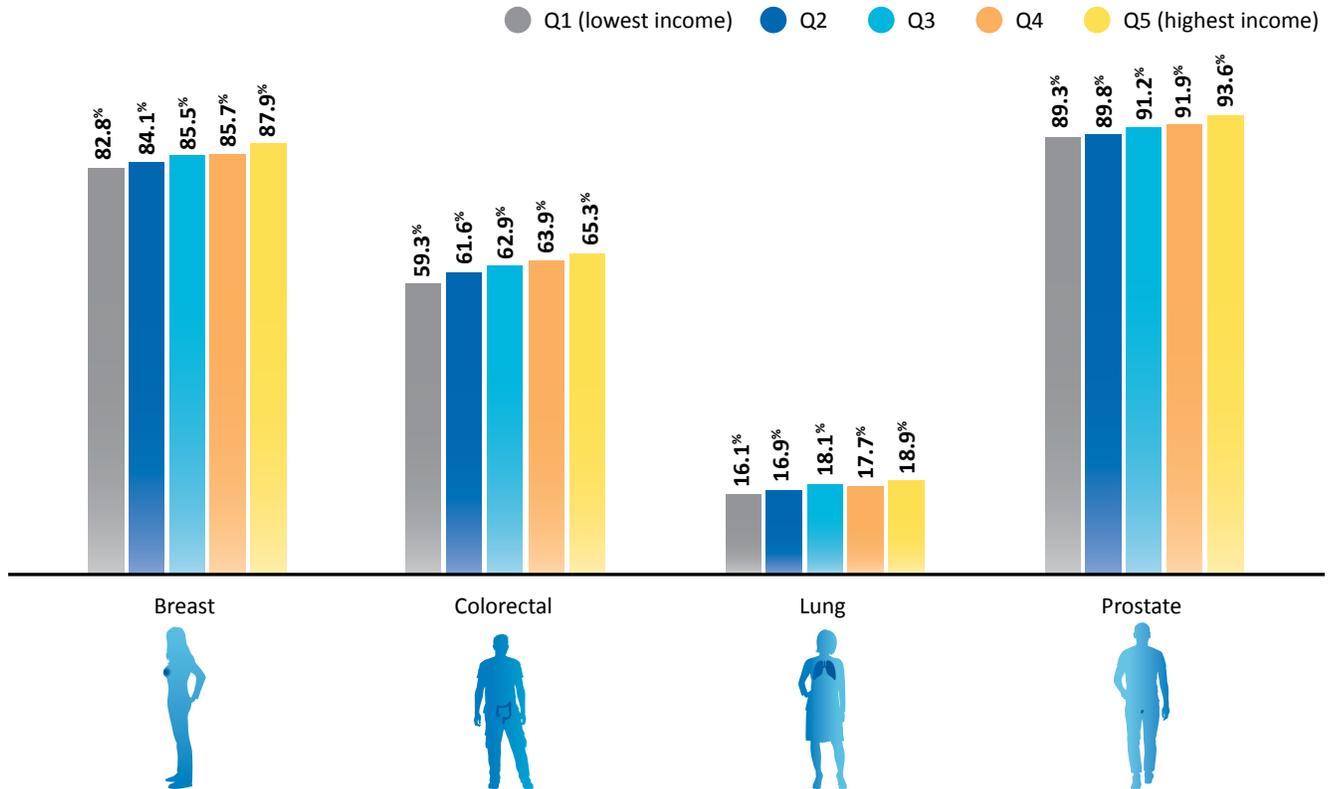


FIGURE 3.9
Five-year net survival* by patient income quintile for four cancers — 2004–09 diagnosis years



* Age-standardized using the International Cancer Survival Standard weights. NL, NT, NU and YK were not included in analysis by income quintile. Data source: CONCORD-2, Provincial cancer agencies and programs.

FUTURE STATE

If our cancer system could ensure that all Canadians had the same five-year survival chances that high-income populations have, five years after diagnosis we could have

550

more breast
cancer
survivors



340

more lung
cancer
survivors



550

more colorectal
cancer
survivors



Detailed calculation methodology is contained in the Technical Appendix available at systemperformance.ca.

Data source: CONCORD-2, Provincial cancer agencies and programs.

MAXIMIZING DATA IMPACT

What additional data and measurements are needed to tell a more comprehensive story about equity?

- We need to promote efforts to **link cancer outcomes and demographic data** (e.g., income, education, immigrant status, place of residence) at the individual level. This information will enable clear demonstration of associations between socioeconomic status and cancer outcomes. Until very recently, we were unable to link an individual's socioeconomic information with their cancer outcomes. Instead, we have to make assumptions at the ecological level, using neighbourhood income level and immigrant density as proxies for individual socioeconomic status. Individual linkages are only now becoming possible through the Social Data Linkage Environment at Statistics Canada.
- To achieve an equitable cancer control system for all, it is important to **investigate disparities among all Canadians**, without leaving anyone behind. As of 2017, jurisdictions are limited in their ability to consistently identify First Nations, Métis and Inuit patients in cancer registries or health care records.⁴² Since 2011, multiple provinces have collaborated with the Partnership within the First Nations, Inuit and Métis Action Plan on Cancer Control to develop culturally appropriate strategies that enhance cancer data collection among Indigenous peoples. Progress is being made.
- Obtaining **information on inequities in access** to cancer care and related outcomes in Indigenous communities is a critical step toward creating an equitable cancer system.

CALL TO ACTION

Cancer disparities in Canada are real. If we work on addressing barriers to care, we can ensure that all Canadians from coast to coast to coast, regardless of background, place of residence or income, receive the necessary support to prevent cancer, to participate in screening programs and to have appropriate access to cancer treatment and care options that help them improve their outcomes.

Seamlessness

Is our health care system centred on the needs of patients and their families?

Patient experiences can be described as seamless when cancer control service providers work together to create an integrated, person-centred system. This in turn allows patients and their families to easily understand, access and navigate the range of services they need to receive the best possible care by the right provider at the right time.

BACKGROUND

The current health care system is shifting from a model designed to deliver disease-centred care into one that is **focused on person-centred care.**

A seamless cancer care system requires that the various service providers involved work together to deliver the care that the person receiving service actually needs. Doing this involves integrating cancer services from diagnosis through treatment, recovery, survivorship, and palliative and end-of life care, with patients and their families as the central focus. To achieve this integration and embed the person-centred perspective into cancer care, the system must identify and incorporate the needs and preferences of individual patients and their families, and it must plan and deliver care based on those needs while removing any barriers impeding access to services. Person-centred care is one of the most critical elements in Canada's cancer control strategy.

Four factors are key to supporting a seamless patient experience:

1



System design elements, including coordination of services, the smooth transition of patients between sectors and providers, alignment of services with patient need for minimal disruption and reasonable wait times, and equitable resource allocation and service access.

2



Communication between patient and health care providers to make providers aware of patient preferences, to provide information that is meaningful for the patient at appropriate times, and to offer support for decision making and navigating the cancer care continuum.

3



Communication among health care providers that ensures effective mechanisms for sharing comprehensive information during referrals and treatment that reflects patient needs.

4



Education and training to help care providers engage patients effectively at the right time and place and ensure symptom burdens (e.g., physical and psychosocial concerns) are identified and addressed.

This chapter focuses on indicators that are influenced by all four of the enablers above:

Breast cancer
diagnosis
wait times

Colorectal cancer
diagnosis
wait times

Radiation
therapy
wait times

Screening
for
distress

Place
of
death

Canadians may wait over three months for a cancer diagnosis following an abnormal screen.

BACKGROUND

Waiting for a cancer diagnosis to be confirmed as positive or negative after an abnormal screening result can be stressful for patients and their families. Even though diagnostic intervals of a few weeks may not necessarily affect overall outcomes, including survival, shorter wait times can reduce anxiety, bring about relief with a benign diagnosis, and enable timely treatment for those who do have cancer.

CURRENT STATE

Most provinces have not achieved wait time targets for diagnosis after an abnormal screening mammogram.

- 90% of women who did not have a biopsy following an abnormal screening result received a diagnosis (positive or negative) within four to eight weeks, depending on the province. Three of nine provinces met the five-week target (Figure 4.1).
- Approximately 15% of women had a biopsy following abnormal screening results. Of these women, 90% waited 10 to 15 weeks for a diagnosis, depending on the province. No province met the seven-week target (Figure 4.2).
- While the percentage of women diagnosed within the target timeframes has increased since 2009 (data not shown), wait times until final diagnosis remain long, particularly for women who require tissue biopsy.⁴³

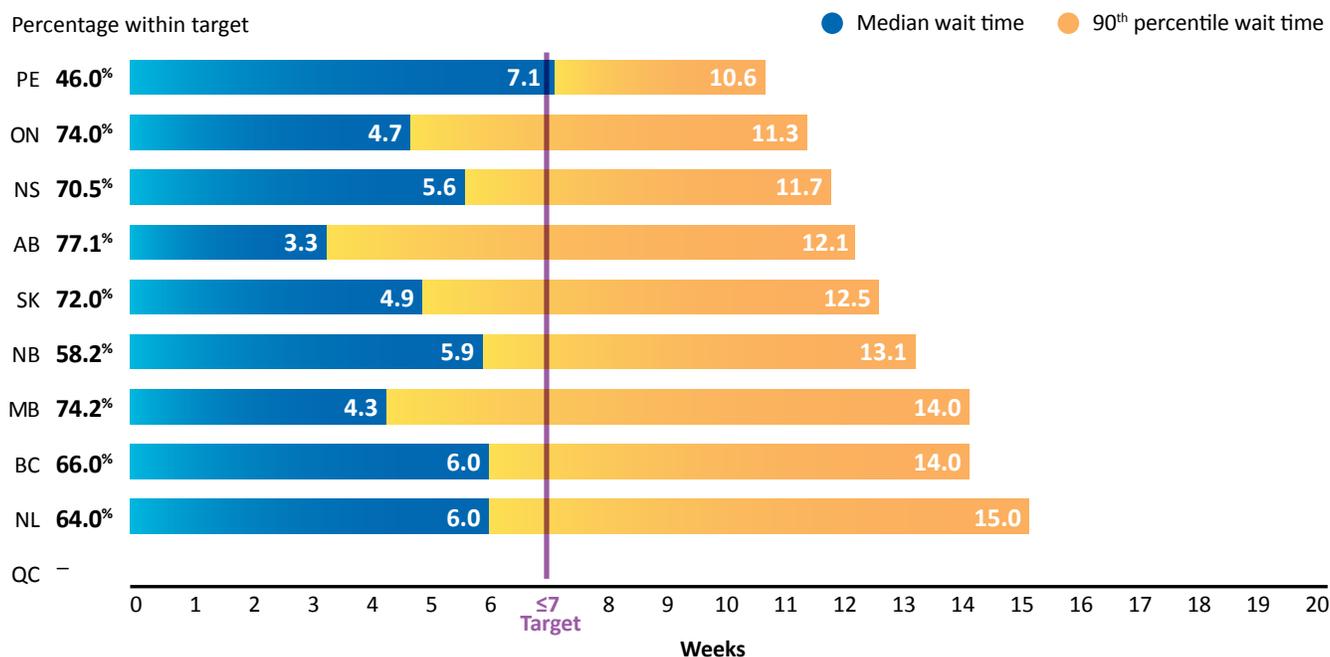
FIGURE 4.1

Median and 90th percentile wait times for resolution of abnormal breast screen without tissue biopsy for asymptomatic women aged 50–69, by province — 2013 screening year



“—” Data not available.
 Cases where resolution of an abnormal screen took more than six months were excluded.
 ON: Women with final result unknown/lost to follow-up were excluded.
 Data source: Provincial breast cancer screening programs.

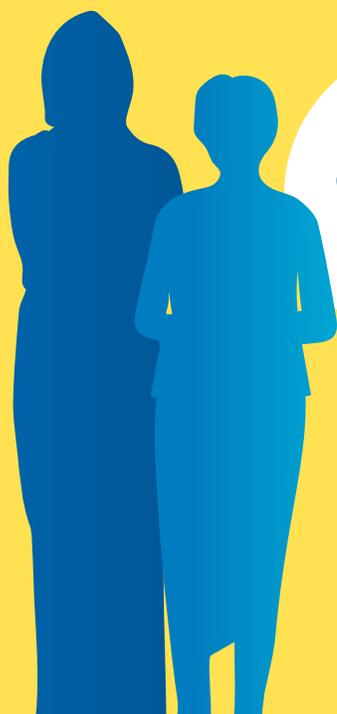
FIGURE 4.2
Median and 90th percentile wait times for resolution of abnormal breast screen with tissue biopsy for asymptomatic women aged 50–69, by province — 2013 screening year



“—” Data not available.
Cases where resolution of an abnormal screen took more than six months were excluded.
ON: Women with final result unknown/lost to follow-up were excluded.
Data source: Provincial breast cancer screening programs.

FUTURE STATE

It is important that patients receive seamless and timely care throughout their cancer journey. If all provinces could achieve the wait time targets for abnormal breast screen resolution, every year



3,200
more
women

could receive
faster diagnosis
when no tissue
biopsy is needed.

4,000
more
women

who need a tissue
biopsy could receive
faster diagnosis.

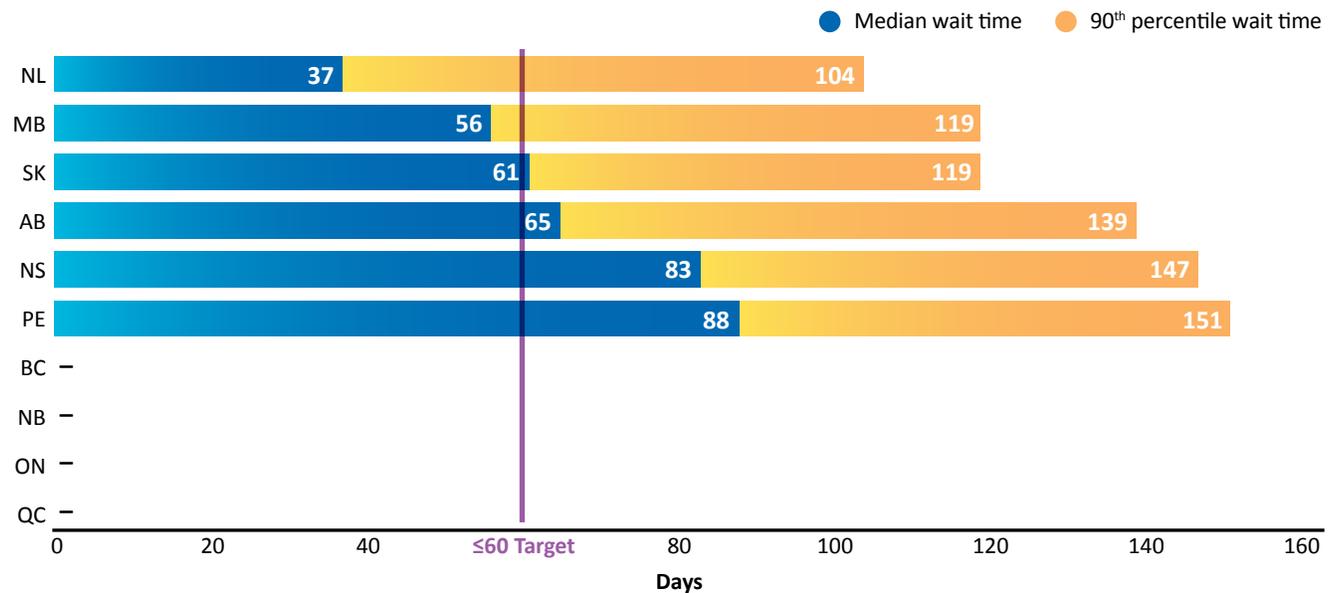
Detailed calculation methodology is contained in the Technical Appendix available at systemperformance.ca.
Data source: Provincial and territorial breast cancer screening programs.

Wait times for follow-up colonoscopy after an abnormal screening fecal test result are decreasing, but no province has met the 90th percentile target of 60 days.

- From 2011–12 to 2013–14, 90th percentile wait times decreased for the four provinces that reported data for both periods.
- Wait times remain longer than the target, however: 90% of patients waited 104 to 151 days for a follow-up colonoscopy after an abnormal screening fecal test result, depending on the province. No reporting province achieved 90th percentile wait times below the 60-day target (Figure 4.3).
- While all provinces have developed or are developing organized colorectal cancer screening programs, several are still in the early stages of implementation.

FIGURE 4.3

Median and 90th percentile wait times from abnormal fecal test result to follow-up colonoscopy, by province — 2013–14 screening years combined



“—” Data not available.

Data include colonoscopies performed within 180 days of abnormal fecal test results.

Target: The Canadian Association of Gastroenterology recommends that colonoscopy be completed within 60 days of an abnormal fecal test.

Data source: National Colorectal Cancer Screening Network.

Cancer patients are receiving **radiation therapy** quickly.

BACKGROUND

Timely access to cancer treatment is crucial for effective cancer control and improved outcomes. Prolonged delay between patients being ready for treatment and the actual start of treatment can also lead to anxiety for patients and families.

CURRENT STATE

All reporting provinces have met the national wait time target for radiation therapy.

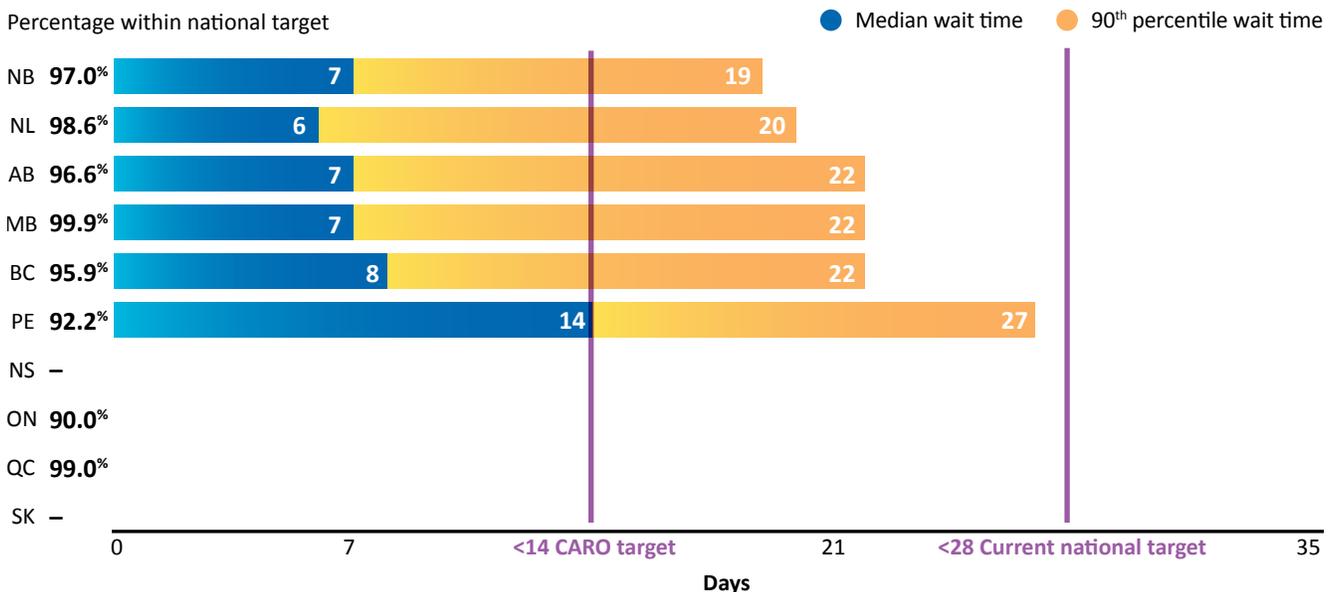
As a result of concerted efforts by federal, provincial and territorial governments, the vast majority of Canadians who require radiation therapy receive it within the wait time target.

- Over 90% of cancer patients started radiation therapy within the national wait time target of 28 days from the time they were ready to treat (Figure 4.4).

- Of the four most common disease sites—breast, colorectal, lung and prostate—prostate cancer patients continue to have the longest 90th percentile radiation therapy wait times. Prostate cancer is most often a slow-developing disease so the delay may signal that health care providers are triaging cases to ensure shorter waits for people with faster-developing cancers (Figure 4.5).

FIGURE 4.4

Median and 90th percentile wait times for radiation therapy, all cancers, by province — 2014 treatment year



“—” Data not available.

BC, AB: Brachytherapy was not included for the 2014 treatment year but was included in previous years.

ON: Data include percentage of patients treated with radiation therapy within 14 days (CARO target), February–December 2014.

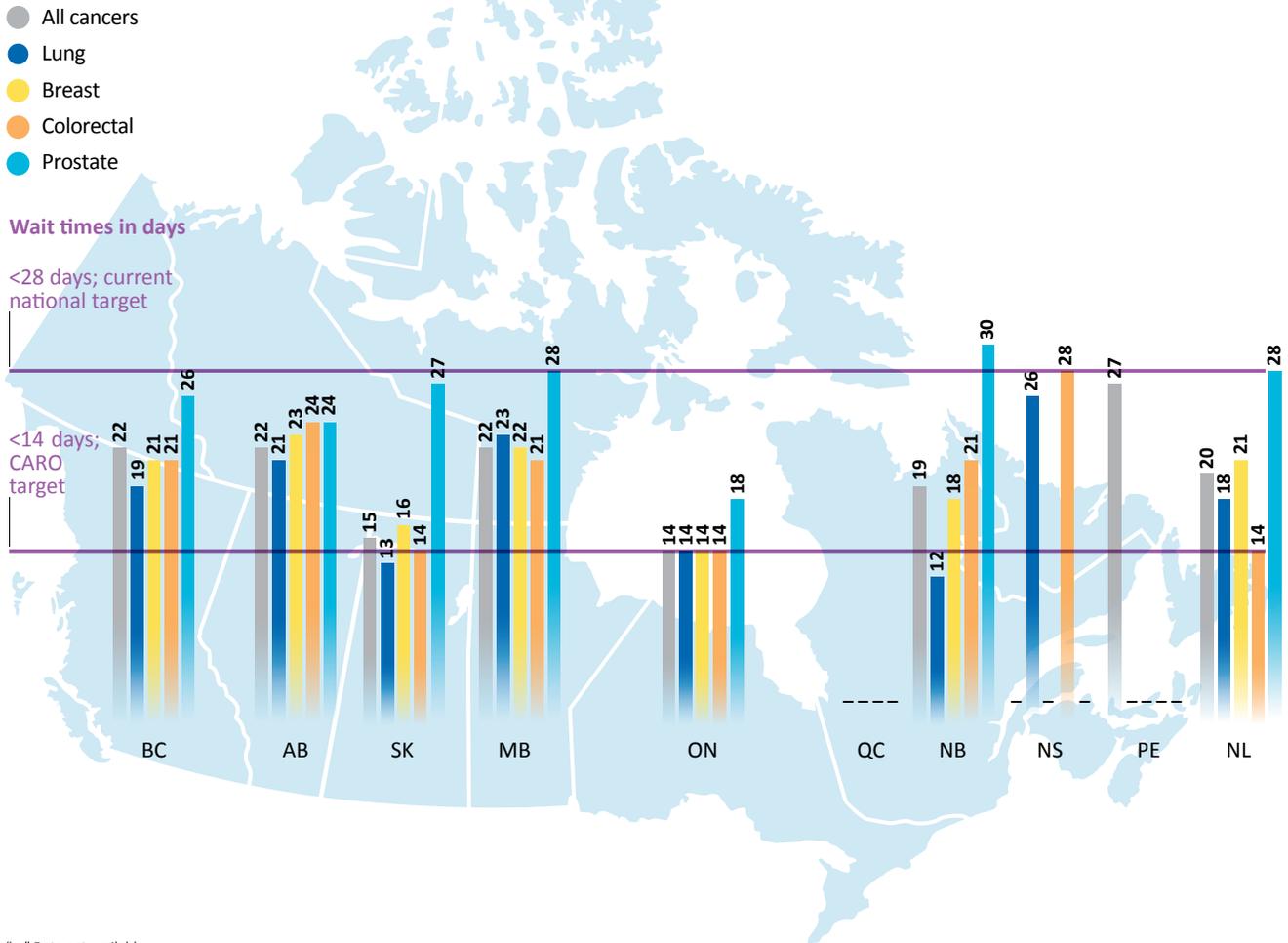
Current national target is that 90% of patients receive radiation therapy within 28 days of being ready to treat.

Canadian Association of Radiation Oncologists (CARO) target is that 90% of patients receive radiation therapy within 14 days of being ready to treat.

The Canadian Institute for Health Information defines ready-to-treat as the time when the referring physician makes the referral to start radiation therapy. Considerable effort has gone into developing and adopting standardized definitions for this term, but interprovincial variations may persist.

Data source: Provincial cancer agencies and programs.

FIGURE 4.5
90th percentile wait times for radiation therapy, by disease site and by province — 2014 treatment year



“-” Data not available.
 SK, ON: Data are from 2013 treatment year.
 BC, AB: Brachytherapy was not included for the 2014 treatment year but was included in previous submissions.
 Current national target is that 90% of patients receive radiation therapy within 28 days of being ready to treat.
 Canadian Association of Radiation Oncologists (CARO) target is that 90% of patients receive radiation therapy within 14 days of being ready to treat.
 The Canadian Institute for Health Information defines ready-to-treat as the time when the referring physician makes the referral to start radiation therapy. Considerable effort has gone into developing and adopting standardized definitions for this term, but interprovincial variations may persist.
 Data source: Provincial cancer agencies and programs.

FUTURE STATE



Because the cancer care system is now meeting the radiation therapy needs of cancer patients across the country, we will no longer report on this indicator annually.

Patients are reporting pain, fatigue, depression and anxiety.

We will soon be able to measure the extent to which the system is addressing these symptoms.

BACKGROUND

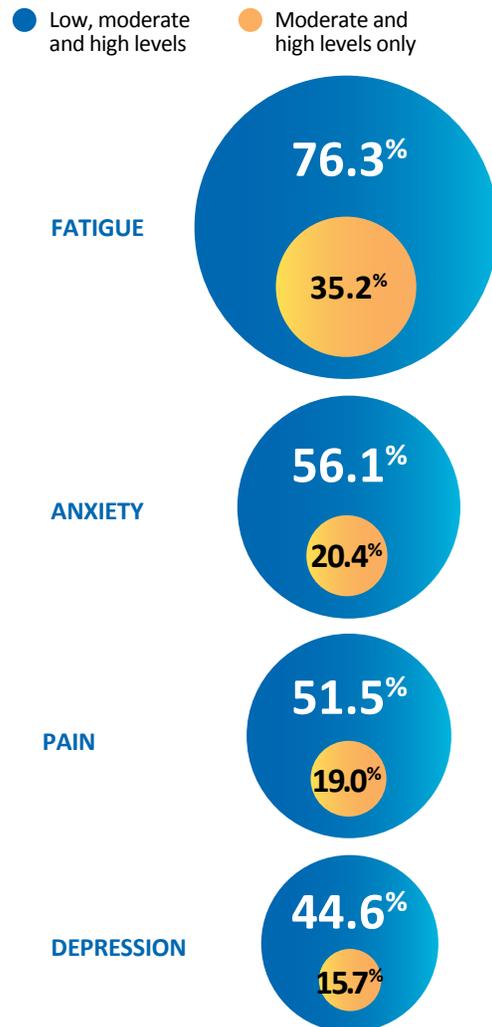
Delivery of effective cancer care is not just about disease-specific treatment—most people with cancer experience symptoms that make their cancer experience even more difficult. Routine screening for symptoms is important to identify psychological, social, spiritual, practical or physical concerns that may negatively affect a person's ability to cope with cancer and its treatment. The Edmonton Symptom Assessment System (ESAS) is one commonly used tool to measure patient-reported symptoms. Many clinical sites collect ESAS measures, although the frequency of screening varies across provinces (Figure 4.6).

Routine measurement of patient-reported outcomes is not by itself sufficient for addressing patients' needs. To have a positive impact on patient well-being, measurement must be accompanied by adequate follow-up and intervention (e.g., further assessment, change in care plans, physical and psychosocial intervention, referral to other practitioners and ongoing monitoring of symptoms).^{44,45} These steps can help improve patients' quality of life and satisfaction with care.

CURRENT STATE

At least half of all screened patients report symptoms of distress during or after their cancer treatment. Follow-up data are not yet available to help identify whether these patients are receiving appropriate support to address their distress.

- From 2007 to 2015, there was more than a threefold increase in the number of provinces reporting province-wide implementation of standardized tools to screen for distress in cancer centres.
- More than 80% of patient surveys reported symptom distress (data not shown). Of these, the severity of symptoms reported were as follows:



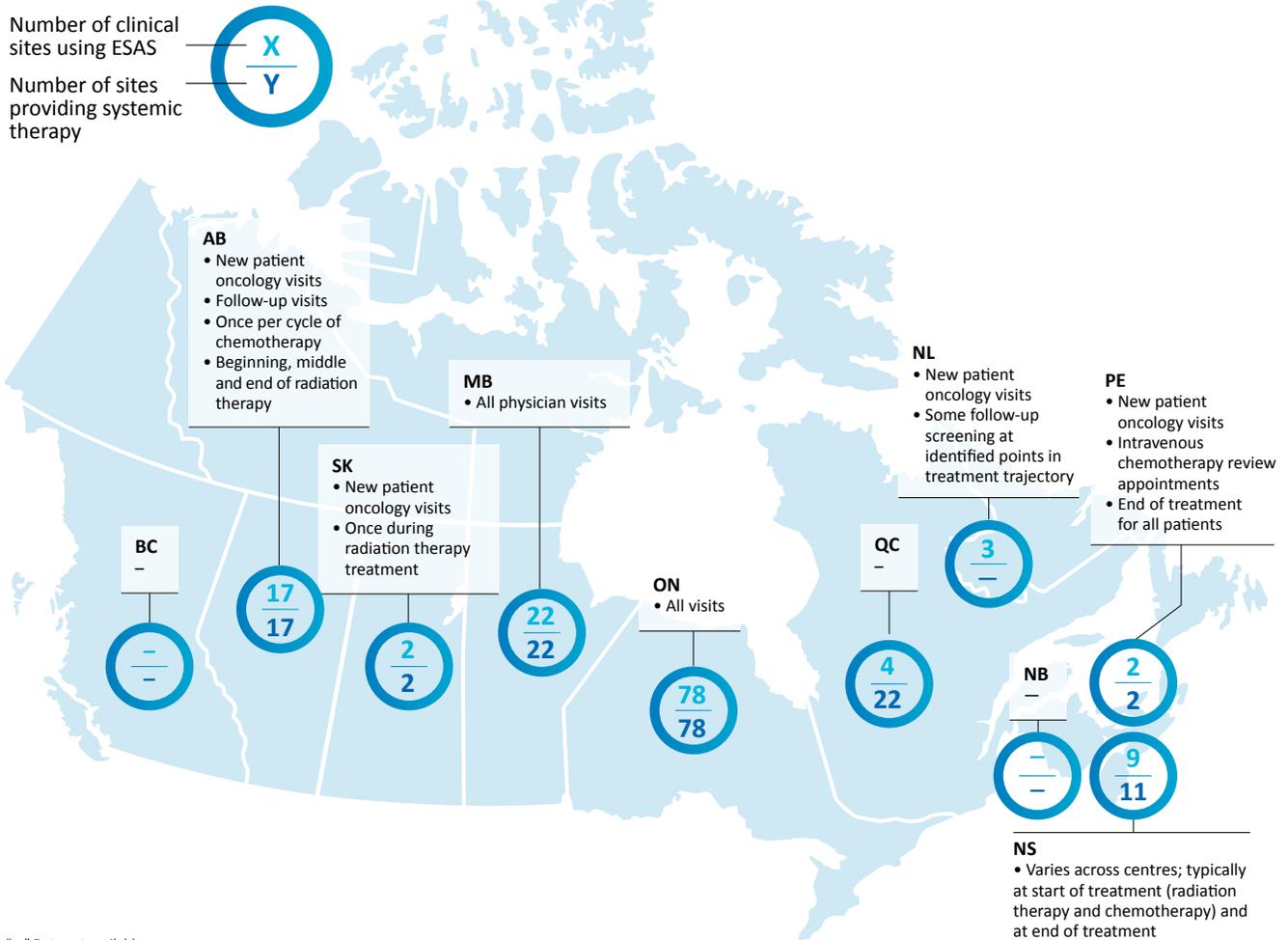
The most recent three months of data available varied by province: MB, NS and ON: January–March 2016; PE, SK, AB and NL: April–June 2016; QC: May–July 2016. Data include AB, SK, MB, ON, QC, NS, PE and NL.

The ESAS-r asks patients to describe how they are feeling on a scale of 0–10. Scores of 0 indicate no symptoms (e.g., no pain, no anxiety, no fatigue, no depression). Symptom distress refers to low, moderate or high levels of distress (i.e., scores of 1–10). Low = scores 1–3; Moderate = scores 4–6; High = scores 7–10.

Each symptom has a small number of no responses that were excluded: fatigue, 0.3%; anxiety, 0.4%; pain, 0.4%; depression, 0.4%.

Data source: Patient-Reported Outcome Initiative partners.

FIGURE 4.6
Current state of Patient-Reported Outcome Initiative implementation, all cancer types, by province — as of January 2017



FUTURE STATE

Improving measurement of patient-reported outcomes enables patients to guide the delivery of their care. If all patients were screened for symptoms at various points in the cancer journey, the system could better identify their distress and customize interventions that address specific—and changing—patient needs.

If patients were screened more frequently throughout their time in the cancer care system as well as during follow-up care, we would be better able to identify the extent to which an intervention has made a positive impact on the patient’s quality of life over time.

Two-thirds of patients die in hospital, even though many would prefer to die at home.

BACKGROUND

Studies suggest that given the choice, most patients with terminal cancer would prefer to die at home or in a home-like setting, such as a hospice, if they are well supported and in the presence of loved ones.^{46,47} While some hospitalizations near the end of life are necessary and some patients would prefer to die in the hospital, of seven developed countries, Canada had the highest proportion of cancer patients who died in hospital, indicating that end-of-life care may be more hospital-centric in Canada.⁴⁸ This finding highlights the disparity between available end-of-life care settings and patient and family preference.

CURRENT STATE

- Although the majority of cancer patients still die in hospital, the percentage decreased from 71.6% in 2008 to 66.8% in 2012 (Figure 4.7).
- Slightly more cancer patients are dying outside of hospital settings (e.g., in hospice or with home care). The percentage of those who died in a private home has remained relatively constant, ranging from 11.8% in 2008 to 13.4% in 2012 (Figure 4.7).
- Provinces vary in how they categorize location of death on death certificates and how they classify different settings (e.g., designation of hospital-based hospices or palliative care units). 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 (which are home-like settings), not in acute-care beds.

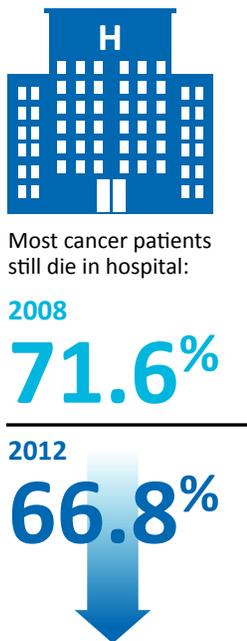
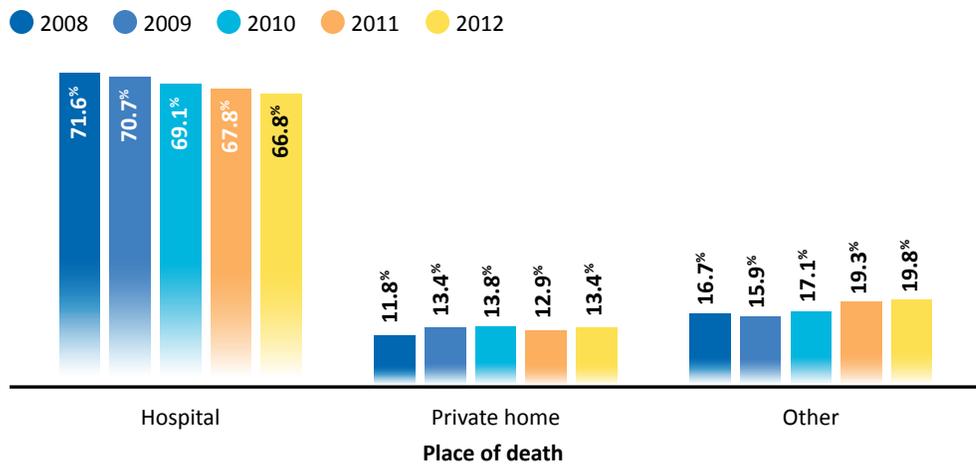
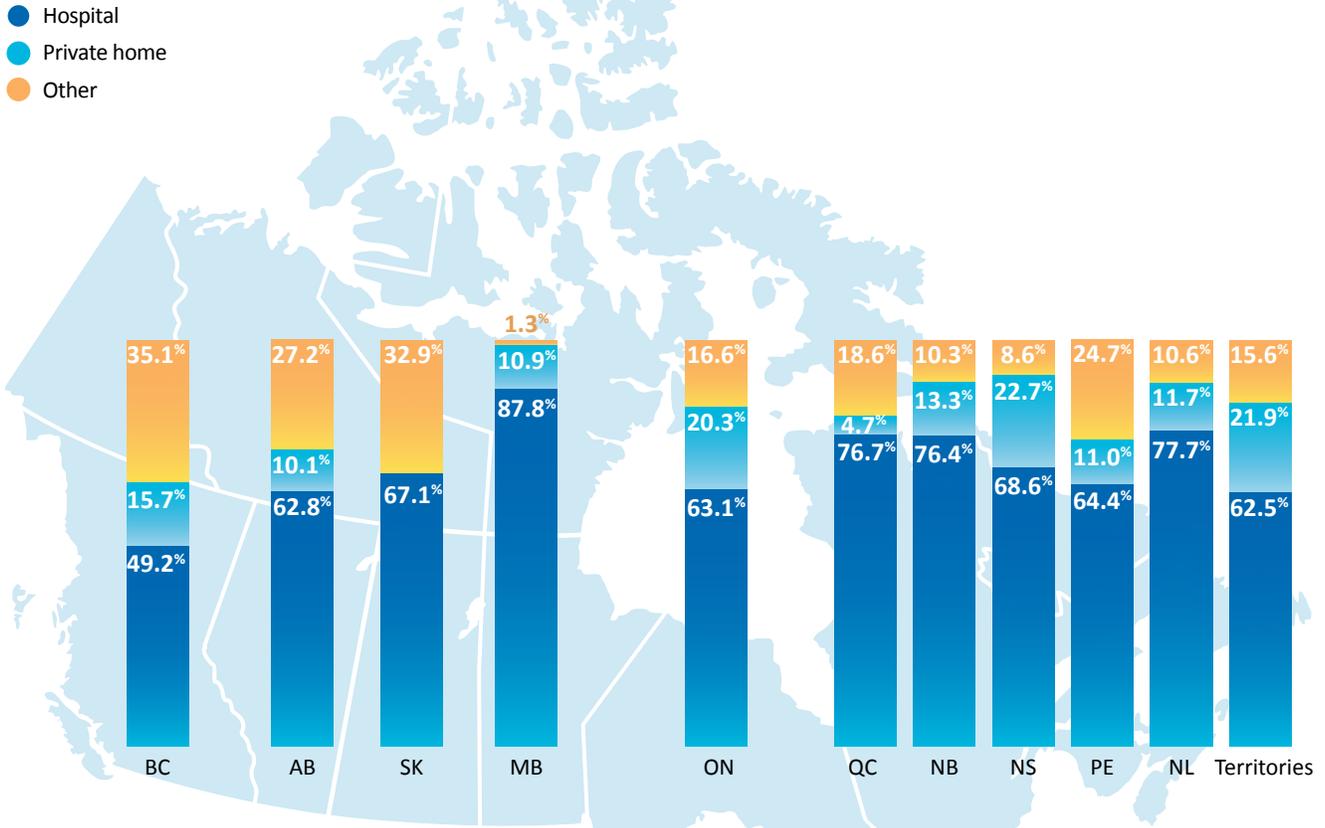


FIGURE 4.7
Percentage of cancer patient deaths by location, Canada — 2008–12 death years



Data include all provinces and territories.
 Definition of hospital varies across provinces. Hospices can be classified as “Other” or “Hospital” depending on province.
 “Other” includes other specified locations, other health care facilities and unknown locations.
 Data source: Statistics Canada, Vital Statistics Death Database.

FIGURE 4.8
Percentage of cancer patient deaths by location, by province/territory — 2012 death year



"Other" includes other specified locations, other health care facilities and unknown locations.
 SK: Due to small numbers, deaths in private homes were combined in "Other."
 Territories include NU, NT and YK.
 Definition of hospital varies across provinces. QC: "Hospital" includes residential and long-term care centres.
 MB: Designated palliative care units were included in "Hospital." In other provinces this type of bed may be considered part of long-term care ("Other"). As a result, percentages of hospital deaths for QC and MB may appear higher relative to other provinces but do not necessarily indicate an actual difference in delivery of services.
 Hospices can be classified as "Other" or "Hospital" depending on province.
 The way palliative care beds are designated in hospitals varies across provinces. The resulting variation in reporting deaths that occurred in hospital is unknown.
 Coding on death certificates varies by province.
 Data source: Statistics Canada, Vital Statistics Death Database.

FUTURE STATE

If every province could reach the same proportion of in-hospital deaths as the province with the lowest proportion of in-hospital deaths (49.2%),

9,500
fewer patients

may die in hospital each year.

If every province could reach the same proportion of in-home deaths as the province with the highest proportion of in-home deaths (22.7%),

600
more patients

may die at home each year.

Detailed calculation methodology is contained in the Technical Appendix available at systemperformance.ca.
 Data source: Statistics Canada, Vital Statistics Death Database.

CALL TO ACTION

Efforts to design and transform the system from the perspectives of patients and their families will allow gaps in the care continuum to be closed so that people can follow a simpler and more understandable path when navigating the system.

Early integration of palliative care into patients' cancer care has been associated with multiple benefits, including improved disease outcomes, quality of life, and satisfaction with care for patients and caregivers, as well as increased likelihood of death at home rather than in hospital.^{49,50} Place of death, although a crude measure, addresses one important aspect of end-of-life care and may contribute to better planning for and quality of end-of-life care for cancer patients.

By identifying the preferences of patients and their families throughout the cancer pathway, the system can ensure that preferences can be managed and addressed to allow patients to have a high quality of life for as long as possible.

MAXIMIZING DATA IMPACT

What additional data and measurements are needed to tell a more comprehensive story about seamlessness?

- **Measures of patient experiences that are more meaningful for patients and their families:**
 - Measure diagnostic and treatment intervals in ways that are more meaningful for patients and caregivers (e.g., from abnormal screen to start of treatment, from first diagnostic test to resolution, from specialist referral date to date seen).
 - Gather data on the extent to which appointments are organized to minimize burden and anxiety for patients and caregivers (e.g., single appointment for all tests when possible, convenient scheduling, transportation to appointments).
- **Data on the needs and preferences of patients and families throughout the care pathway:**
 - Increase the use of data-gathering tools across cancer services and gather longitudinal data.
 - Use ESAS (and other tools) more frequently throughout a patient's cancer journey to understand whether symptoms improve over time or with intervention.
 - Collect information on whether appropriate referrals are made among patients who have higher levels of distress.
 - Impose more consistency across jurisdictions when defining place of death. The Canadian Institute for Health Information uses data based on consistent definitions of institution type but does not include data on deaths at home, whereas Statistics Canada uses death certificate data so includes deaths at home but has a broader and often inconsistent definition of "hospital."
 - Advance care plans, including health care directives, often include questions on where patients prefer to die. Routinely collect data from the plans and link the data to registries to allow for better comparison of patient preferences and the settings used and services delivered.

Sustainability

Are we providing cancer control services in a way that balances resource use and patient benefits?

A sustainable health care system is one that meets the health care needs of the population—from disease prevention to end-of-life care—in a way that optimizes the balance between resource use and patient outcomes. Achieving this balance will help ensure future generations of Canadians continue to benefit from our universal health care system.



BACKGROUND

The sustainability of our health care system is of critical importance: **the average annual number of new cancer cases is expected to increase by 40% in the next 15 years**, which will put considerable strain on Canada's health care resources.⁵¹

The increase in new cancer cases is driven primarily by Canada's growing and aging population—Canadians aged 65 or older will represent close to a quarter of the population by 2032.^{1,51}

Five key elements can support sustainable health care:⁵²

1

Effective disease prevention and health promotion strategies and policies.

2

Effective health system structures, processes and approaches that support value-based care.

3

Funding models that promote desired behaviours.

4

Innovations and technologies that can improve quality of care.

5

Optimal training, alignment and support of human resources.

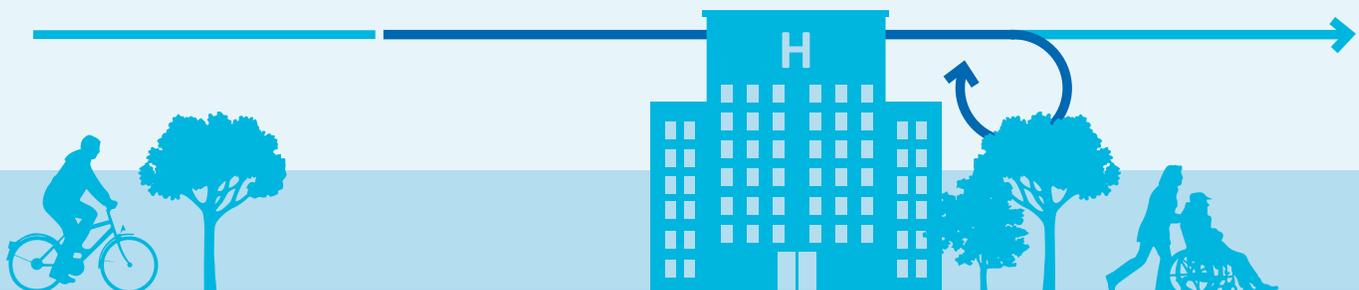
This chapter focuses on:

Prevention

- Smoking prevalence
- Human papillomavirus vaccination uptake

Value-based care

- Self-reported breast cancer screening mammograms performed on average risk women aged 40–49
- Palliative radiation therapy for bone metastases in cancer patients
- Intensive care use in the last two weeks of life
- Breast cancer mastectomies performed as day surgery



At least **one-third** of cancers can be prevented.

BACKGROUND

Many types of cancer can be prevented through a combination of eliminating tobacco use, improving nutrition, limiting alcohol consumption, participating in regular physical activity and maintaining a healthy body weight.⁵³ Other factors that can increase a person's risk of developing cancer include certain infections (e.g., human papillomavirus), environmental exposures (e.g., second-hand smoke) and occupational risks (e.g., nightshift work).⁵⁴ Prevention is an essential long-term strategy for reducing the burden of cancer on Canadians, which in turn will reduce the demand for health care services. The risk of cancer in the population can be reduced through the development of policies that promote healthier lifestyles and create healthier environments where people live, work and play.

CURRENT STATE

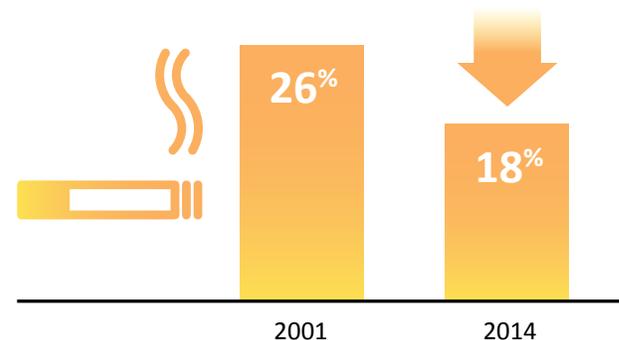
Smoking rates have declined.

Smoking causes 30% of all cancer deaths and up to 85% of lung cancer cases.^{51,55} Smoking remains the most preventable cause of disease and premature death in Canada. Controlling tobacco use is a key cancer prevention mechanism. The Government of Canada has set a new target of reducing smoking prevalence to 5% by 2035.⁵⁶

- The good news:
 - Smoking (daily or occasional) has declined from 26% in 2001 to 18% in 2014 (Figure 5.1).
 - In 2014, 18% of Canadians who recently smoked reported quitting in the past two years.
- But there is still room for improvement:
 - None of the provinces or territories had self-reported smoking rates lower than the previous 12% target⁵⁷ —smoking prevalence ranged from 14.3% in British Columbia to 61.7% in Nunavut in 2014. Prevalence was highest in the three territories (data not shown).

⁵⁷ The Federal Tobacco Control Strategy set a target of reducing overall smoking prevalence in Canada to 12%.

FIGURE 5.1
Percentage of Canadians[†] who reported smoking daily or occasionally — 2001 vs. 2014



[†] Includes individuals aged 12 and older.
Data source: Statistics Canada, Canadian Community Health Survey.

FUTURE STATE

If Canada could achieve the 5% target smoking rate by 2035, every year (on average between 2016 and 2035)

- approximately **1,600** fewer people may be diagnosed with lung cancer
- approximately **1,000** fewer people may die from lung cancer
- approximately **23,000** quality-adjusted life years could be gained
- approximately **\$34 million[†]** in lung cancer treatment-related costs could be saved

[†] Based on 2016 Canadian dollars.
Detailed calculation methodology is contained in the Technical Appendix available at systemperformance.ca.
Data source: Canadian Partnership Against Cancer, OncoSim.

CURRENT STATE

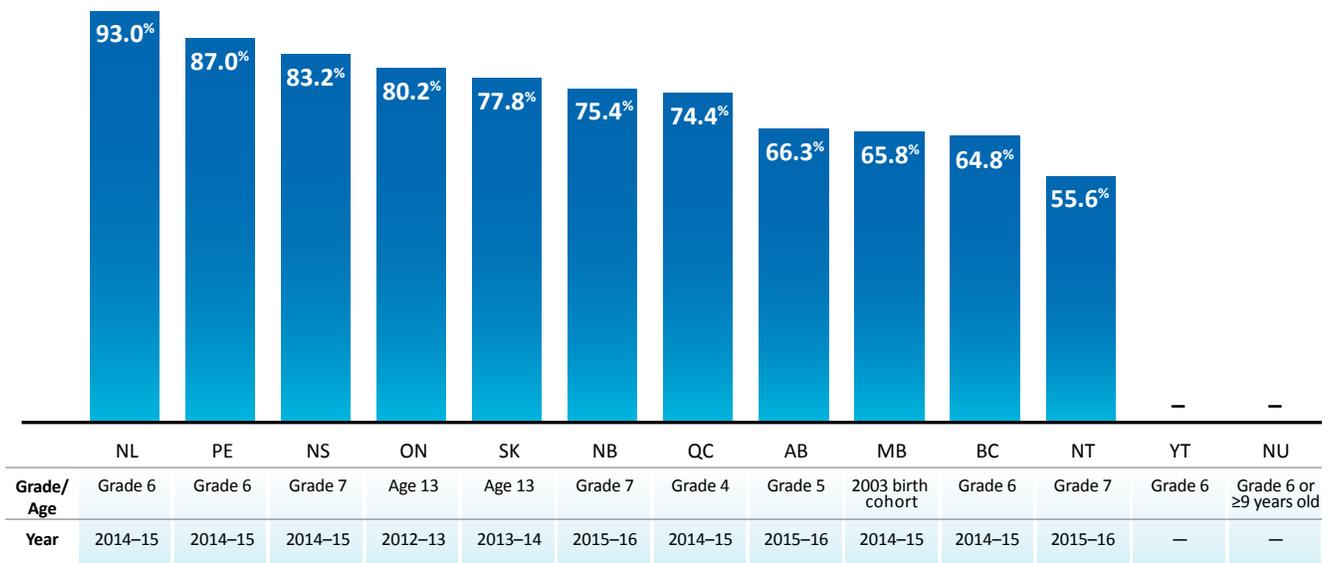
HPV vaccination uptake rates vary based on where people live.

High-risk human papillomavirus (HPV) types 16 and 18 cause about 70% of cervical cancers, as well as other cancers, including anal cancer, penile cancer and oral cavity and oropharyngeal cancers.⁵⁸⁻⁶⁰ Three HPV vaccines (HPV-2, HPV-4 and HPV-9) were approved for use in Canada as of 2017 and all protect against these high-risk strains of HPV.⁶¹ All provinces have implemented school-based HPV immunization programs for girls, and several provinces (Alberta, Manitoba, Ontario, Quebec, Nova Scotia and Prince Edward Island) have announced or implemented school-based programs for boys.⁶² Continued efforts to increase HPV vaccination uptake will play a critical role in reducing the burden of cervical and several other cancers.

- HPV vaccination uptake varied considerably across the country (Figure 5.2), ranging from 55.6% in the Northwest Territories to 93.0% in Newfoundland and Labrador. The age or grade of girls being vaccinated also varied across provinces.

FIGURE 5.2

Percentage of girls who received a full course[†] of HPV vaccination from school-based HPV immunization programs



[†]As of 2015/16 school year, full course of vaccination for school-based programs is 3 doses in AB and NU and 2 doses in all other provinces/territories. As of 2015, the National Advisory Committee on Immunization (NACI) recommends a 2-dose or 3-dose schedule for HPV-2 or HPV-4 because evidence suggests a 2-dose schedule provides protective efficacy similar to a 3-dose schedule.^{61,63} Studies are still examining the efficacy of a 2-dose schedule for HPV-9, so NACI recommends a 3-dose schedule for this vaccine.⁶¹

“—” Data not available.

ON: Full course of vaccination for school-based programs is 2 doses. Data are not available for the 2-dose schedule, so data on 3-dose schedule are presented.

NB: 2-dose schedule has been implemented for grade 7 girls starting in school year 2015/16.

NT: Vaccination occurs in grades 4–6. Vaccination uptake listed is for grade 7 girls.

SK, ON: HPV vaccination is offered in grade 6 and grade 8, respectively, but immunization information is not recorded by grade. Vaccination uptake is assessed at age 13.

Data source: Provincial/territorial immunization programs.

CURRENT STATE

In addition to tobacco control and HPV vaccination, efforts to promote fruit and vegetable consumption and physical activity and to reduce alcohol consumption, second-hand smoke exposure and overweight/obesity rates can all help to prevent some cancers.

The Canadian Community Health Survey indicates that in 2014,

60% 

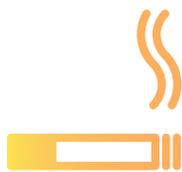
of Canadian adults reported eating fruit and vegetables fewer than five times per day—up 6 percentage points since 2009.

80% 

of Canadian adults reported drinking alcohol in the past year—rates have remained similar since 2009.

79% 

of Canadian adults did not report engaging in active transportation—walking or biking to and from school or work (2013).

14% 

of Canadians reported second-hand smoke exposure in public—down 6 percentage points since 2003.

53% 

of Canadian adults reported being overweight or obese—rates have remained similar since 2007.

CALL TO ACTION

A world with less cancer is possible and it starts with prevention. Developing policies that create environments enabling people to lead healthier lives can help to reduce the burden of preventable cancers, which in turn will reduce the demand for limited health care resources.

MAXIMIZING DATA IMPACT

What additional data and measurements are needed to tell a more comprehensive story about sustainable prevention initiatives?

- **Consistent, standardized data on HPV vaccination** of girls and boys across Canada. As of 2017, provinces and territories collected and reported data on HPV vaccination differently. And only three provinces—Alberta, Nova Scotia and Prince Edward Island—have implemented school-based vaccination programs for boys (Manitoba, Quebec and Ontario have announced that they will begin vaccinating boys in school-based programs).
 - Standardized data collection and reporting would make it easier to compare uptake rates and to more accurately assess prevention and health promotion efforts and the impact of vaccination on subsequent cancer outcomes.
- **Data on the projected impact of cancer prevention and health promotion efforts on the burden of cancer** (e.g., incidence, mortality) will allow us to estimate the subsequent effect on the health care system (e.g., cost savings). Gathering these data requires building on the capabilities of OncoSim, a micro-simulation modelling tool managed by the Partnership.
- **Measures of the prevalence of unhealthy behaviours** (e.g., smoking, alcohol consumption, obesity) **after a cancer diagnosis** will enable study of their effect on prognosis, outcomes and quality of life.

An estimated **770,000 tests and treatments** comprising nine cancer control practices that may be of limited value are performed annually.

BACKGROUND

Not all cancers can be prevented. It is essential that people who develop cancer receive high-value care—care that provides the best outcomes with the most efficient use of resources. The concept of high-value care is especially important given the substantial increase in new cancer cases expected in the next 15 years, primarily as a result of Canada’s growing and aging population.⁵¹

CURRENT STATE

A 2016 report by the Partnership measured the evidence-based use of certain interventions in cancer care across Canada, particularly those highlighted by Choosing Wisely Canada, a national campaign to identify low-value, unnecessary or harmful services that are frequently used in Canada.⁶⁴ Based on indicator findings related to the nine cancer control practices examined in the report, in one year there were more than 770,000 instances of practices being used that could be of low value and may expose patients to unnecessary harm.

Over 700,000 screening tests for breast and cervical cancer are performed outside the recommended age ranges each year.

Although screening has multiple benefits (i.e., reduced incidence and mortality rates for cervical cancer^{2,3} and mortality from breast cancer⁶⁶⁻⁶⁹), evidence suggests that there are also potential harms, namely false positive results, over-diagnosis and subsequent over-treatment.

As part of Choosing Wisely Canada, the College of Family Physicians of Canada and the Canadian Medical Association recommended that physicians and patients should question two cancer screening practices:

- 1 Do not screen women with Pap smears (tests) if under 21 years of age or over 69 years of age.
- 2 Do not routinely do screening mammography for average risk women aged 40–49.⁶⁵



Self-reported breast cancer screening mammography performed on average risk women aged 40–49

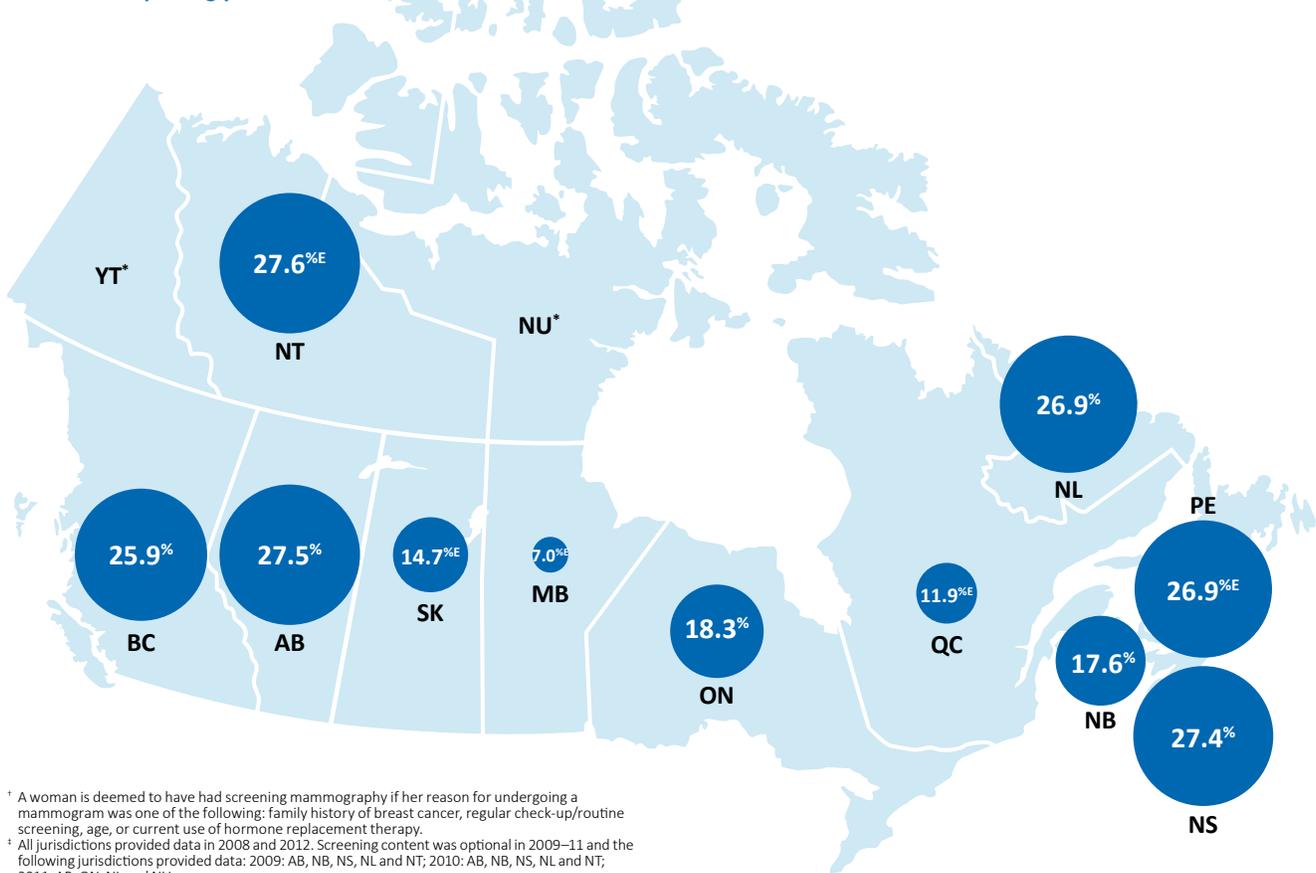
The Canadian Task Force for Preventive Health Care, the World Health Organization and Choosing Wisely Canada recommend not routinely screening women aged 40–49 with mammography.^{65,70,71} The benefits of screening mammography (i.e., on mortality) are lower and the risk of false positives is higher for that age group than for older women.⁶⁵ It is important to note, however, that screening mammograms are appropriate and beneficial for some women in their 40s (e.g., those at high risk of developing breast cancer).

- Of all screening mammograms performed in the previous year,⁶ 20.8% were done on women aged 40–49 (2008–12 data).
- Provincial rates ranged from 7.0% in Manitoba to 27.6% in the Northwest Territories (Figure 5.3).

This indicator does not distinguish between women at higher-than-average risk and women of average risk. Because of this, for some women captured in these results, screening may be appropriate.

FIGURE 5.3

Percentage of all screening[†] mammograms in the past year that were reported by women aged 40–49, by province/territory — 2008–12 reporting years combined[‡]



† A woman is deemed to have had screening mammography if her reason for undergoing a mammogram was one of the following: family history of breast cancer, regular check-up/routine screening, age, or current use of hormone replacement therapy.

‡ All jurisdictions provided data in 2008 and 2012. Screening content was optional in 2009–11 and the following jurisdictions provided data: 2009: AB, NB, NS, NL and NT; 2010: AB, NB, NS, NL and NT; 2011: AB, ON, NL and NU.

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

* Suppressed owing to small numbers.

Women aged ≥ 40 were included in the denominator for this indicator.

Data source: Statistics Canada, Canadian Community Health Survey.

These results mean that more than **450,000** mammograms are performed on Canadian women aged 40–49 each year.

Over 17,000 cancer patients receive treatments that may be of limited value each year.

A Tri-Society Task Force (representing the Canadian Society of Surgical Oncology, the Canadian Association of Medical Oncologists and the Canadian Association of Radiation Oncology), convened by the Partnership, developed a list of oncology practices that should be questioned because they may be unnecessary or harmful but are frequently used in Canada.^{72,73} Baseline measures of current practice patterns are available for five of the treatment-related recommendations:

- 1 Do not recommend more than a single fraction of palliative radiation for an uncomplicated painful bone metastasis.
- 2 Do not initiate whole-breast radiation therapy in 25 fractions as part of breast-conservation therapy in women age 50 or older with early-stage invasive breast cancer without considering shorter treatment schedules.
- 3 Do not initiate management in patients with low-risk prostate cancer (T1/T2, PSA < 10 ng/ml and Gleason score < 7) without first discussing active surveillance.
- 4 Do not routinely use extensive locoregional therapy in most cancer cases where there is metastatic disease and minimal symptoms attributable to the primary tumour (e.g., colorectal cancer).
- 5 Avoid chemotherapy and instead focus on symptom relief and palliative care in patients with advanced cancer unlikely to benefit from chemotherapy (e.g., performance status 3 or 4).

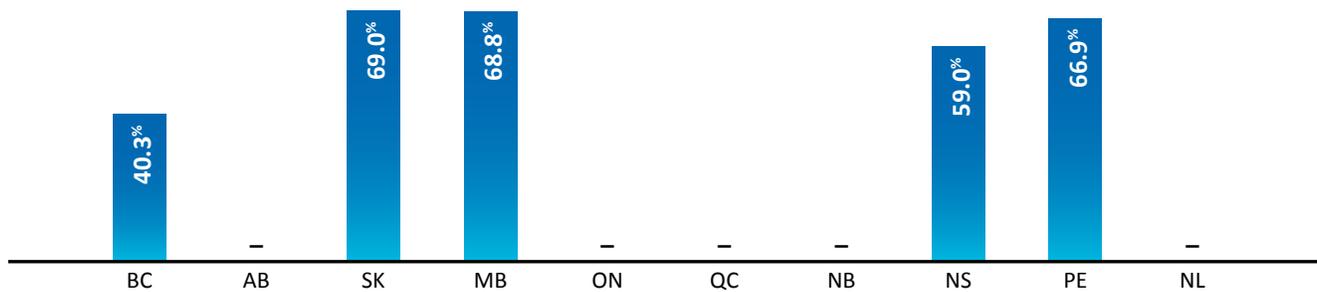
PALLIATIVE RADIATION THERAPY FOR BONE METASTASES IN CANCER PATIENTS

External beam radiation therapy is often effective for cancer patients who have painful bone metastases.^{74,75} A single fraction of radiation (i.e., one dose) to a previously unirradiated, uncomplicated peripheral bone metastasis has been shown to offer equivalent pain relief and morbidity, but a higher incidence of re-treatment at a later date, than multiple fractions of radiation.⁷⁴⁻⁷⁶

In 2013, between 40.3% (British Columbia) and 69.0% (Saskatchewan) of cancer patients received more than one fraction of radiation to the bone (five provinces submitted data) (Figure 5.4).

FIGURE 5.4

Percentage of cancer patients receiving palliative radiation therapy to the bone who received more than one fraction, by province — 2013 treatment year



“—” Data not available.
 MB: Data reflect number of planned fractions rather than number of fractions actually delivered.
 Data source: Provincial cancer agencies and programs.

Extrapolating these findings to the entire country reveals that over **11,000 individuals in one year may have received multiple-fraction regimens to manage their bone metastases**. Given that single-fraction and multi-fraction regimens provide equivalent pain relief and morbidity, the additional use of resources with multi-fraction regimens may provide limited clinical benefit to some patients.

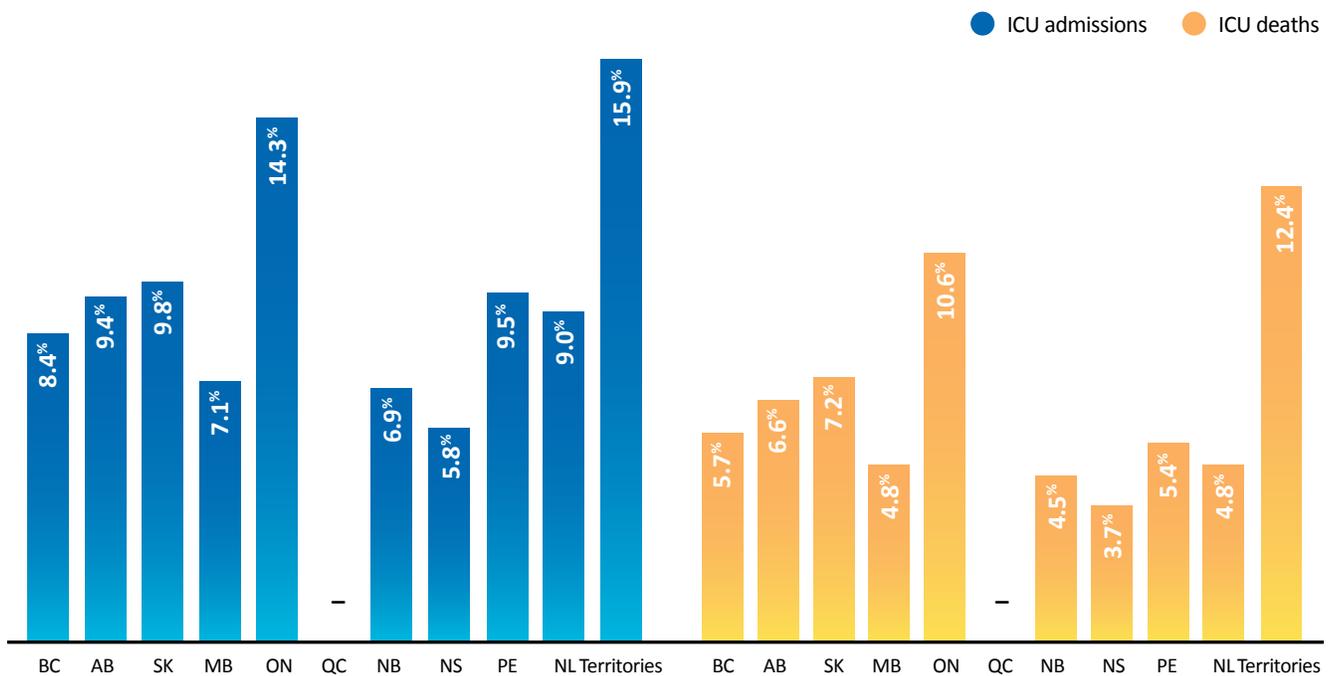
Over 2,000 cancer patients near the end of life receive care in an intensive care unit each year—not an optimal setting for addressing their palliative care needs.

People dying of cancer deserve care that helps alleviate physical symptoms and addresses emotional and psychosocial needs in a setting that is supportive, comfortable and minimally disruptive. While some cancer patients may have complications that require the life-sustaining therapies offered by critical care units, such units are not always the ideal setting for quality end-of-life care, which includes supportive care and symptom control.⁷⁷

- From April 2011 to March 2015, between 5.8% (Nova Scotia) and 15.9% (territories) of cancer patients were admitted to an intensive care unit (ICU) in their last two weeks of life (Figure 5.5).
- Of cancer patients admitted to an acute-care hospital, between 3.7% (Nova Scotia) and 12.4% (territories) died in an ICU (Figure 5.5).

FIGURE 5.5

Percentage of cancer patients admitted to an intensive care unit in the last 14 days of life and dying in an ICU, by province/territories — 2011/12 to 2014/15 fiscal years combined



"—" Data not available.

Territories include NU, NT and YK.

Data on ICU admission include only facilities that report ICU data. Deaths in ICU include all cancer patients regardless of when they were admitted to an ICU.

Data source: Canadian Institute for Health Information, Discharge Abstract Database.

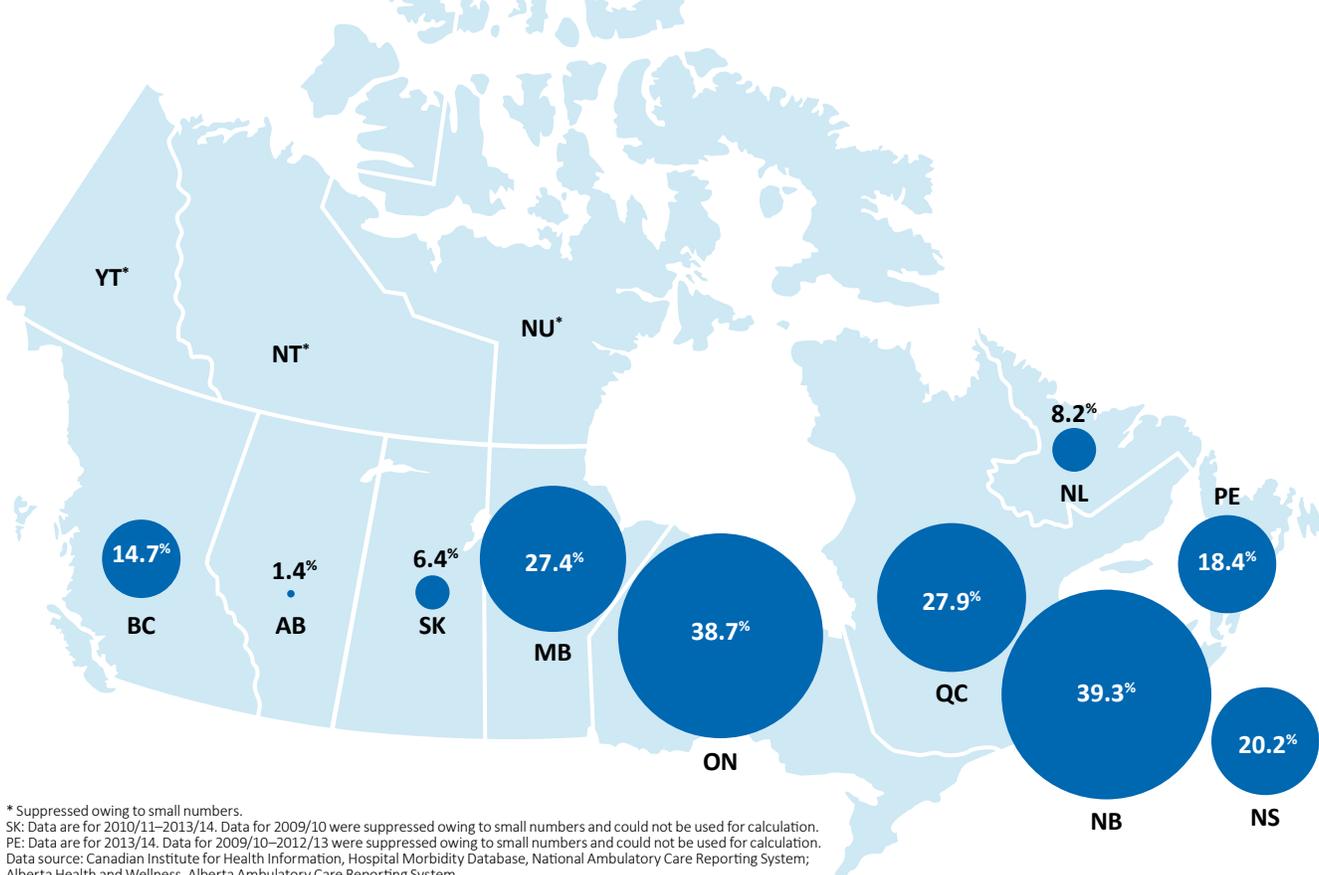
While the use of ICUs at the end of life for cancer patients is relatively low, **provincial variation still exists**. Given that variation, it is likely that a portion of ICU visits are of limited value and that some patients may benefit more from palliative care in a different setting.

Over 5,000 inpatient mastectomies are performed each year even though the procedure can generally be safely performed as day surgery.

Mastectomy is one of the standard treatments for women with resectable breast cancer.⁷⁸ Although this procedure is relatively invasive, mastectomy can now be safely performed as day surgery.⁷⁹ Given that patient outcomes are favourable, shifting from inpatient to day surgery for women undergoing mastectomy would yield a reduction in system costs and free up inpatient capacity for other uses. It would also allow more women to recover at home and benefit from the psychological boost of early discharge (assuming adequate system resources are in place).

- Between April 2009 and March 2014, 1.4% (Alberta) to 39.3% (New Brunswick) of mastectomies were performed as day surgery (Figure 5.6).
- In eight of the nine reporting provinces, the percentage of mastectomies performed as day surgery increased from 2008–10 to 2011–13 (data not shown).

FIGURE 5.6
Percentage of breast cancer mastectomies done as day surgery, by province/territories — 2009/10 to 2013/14 fiscal years combined



There was a **38 percentage point difference** between the provinces with the lowest and highest rates of day surgery mastectomy. The variation suggests that a portion of inpatient hospitalizations for mastectomy may not be necessary and could be shifted to day surgery, when appropriate, in many provinces.

FUTURE STATE

If we could reduce use of breast and cervical cancer screening outside of the recommended age ranges by 15%,

9,000
false positive
results

may be avoided each year.

Data source: Statistics Canada, Canadian Community Health Survey; literature (false positive rate); provincial fee schedules.

If we could reduce use of the five cancer treatment practices considered potentially low-value by Choosing Wisely Canada by 15%,

3,000
treatments

and treatment-related side effects may be avoided each year.

4,500
hours of linear
accelerator
capacity

could be freed up for radiation therapy each year.

Data source: Canadian Partnership Against Cancer, OncoSim; Provincial cancer agencies and programs; literature; Statistics Canada, socioeconomic database.

Detailed calculation methodology is contained in the Technical Appendix available at systemperformance.ca.

CALL TO ACTION

The delivery of high-value cancer care that is supported by evidence has the potential to improve patient outcomes and quality of life while helping to maintain the sustainability of Canada's health care system. Continued measurement and reporting of potentially low-value cancer control practices across Canada can help identify opportunities for benchmarking and can inform future strategies to encourage evidence-based practices that maximize clinical benefit while ensuring optimal use of system resources.

MAXIMIZING DATA IMPACT

What additional data and measurements are needed to tell a more comprehensive story about sustainable high-value treatment?

- **Data on risk factors that would warrant breast cancer screening for women outside the recommended age range.** Routine use of screening mammography is not recommended for average-risk women aged 40–49. Data from the Canadian Community Health Survey and breast cancer screening programs do not distinguish between women at higher-than-average risk (e.g., those with a family history of breast cancer, with high breast density or who are on hormone replacement therapy) and those of average risk.
- More complete **data on practice patterns associated with all 15 Choosing Wisely Canada cancer-related recommendations.** Baseline measures are provided for only seven of the 15 recommendations because of limitations in or lack of data (see *Quality and Sustainability in Cancer Control* for more information on the recommendations that could not be measured). For the seven recommendations reported on, data were not available for all jurisdictions. Data for the missing provinces and territories are needed to provide a truly pan-Canadian view of adherence to the Choosing Wisely Canada recommendations.
- **Data on management options other than surgery, radiation therapy and chemotherapy.** For example, active surveillance is a recommended management option for men with low-risk prostate cancer. As of 2017, cancer registries do not include data on this practice so “no record of treatment” is used as a proxy.
- Consistently collected and standardized **data on the intent of therapy** (e.g., palliative or curative) will help to assess the appropriateness of treatment.
- **Data on patients' need for hospital services.** For example, data on intensive care use at the end of life include a subset of cancer patients who were not near the end of life, but who experienced complications that required the life-sustaining therapies offered by ICUs.

Maximizing Data Impact

In collaboration with provincial cancer agencies and programs and other key partners, the Partnership is currently able to meaningfully analyze and report on a wide range of cancer control indicators.

While data on cancer system performance have highlighted variations in practice patterns across the country and have resulted in some system-level changes, there are still opportunities to broaden the scope and improve the availability of health and cancer system data. To maximize the impact of data, efforts could be focused on the following areas:

- 1 improving the quality and comparability of the data collected,
- 2 collecting new data on under-measured aspects of cancer control and expanding data collection to populations and jurisdictions for which data are not currently available,
- 3 linking existing data sources to enhance relevance.

1. Improving the quality and comparability of the data collected

While we are currently able to report on a wide array of indicators, there are still many areas where data quality and comparability across jurisdictions could be enhanced.

Standardizing indicator definitions and data collection presents an opportunity to improve the accuracy and comparability of cancer system performance data across Canada. Here are a few examples:

- Having consistent, standardized data on HPV vaccination of girls and boys across Canada could allow for more comparable measures of program uptake and impact. As of 2017, jurisdictions collected and reported on HPV vaccination uptake data differently (e.g., the denominator or the target vaccination population is not defined consistently).
- Improving consistency across jurisdictions when defining and collecting data on place of death presents an opportunity to better assess end-of-life care. There is provincial variation in the interpretation of place of death categories (e.g., hospital, private home, other). For example, a hospice can be categorized as an “other health care facility” or as an “other specified locality,” but it could also be located in an acute-care hospital and therefore designated as a hospital setting.
- As of 2017, adult clinical trial participation was calculated based on the ratio of adult cancer patients enrolled in clinical trials at provincial cancer centres to the estimated number of new cancer cases (i.e., incidence projections). However, more meaningful participation rates could be derived from using the number of patients eligible for clinical trials as the denominator rather than incidence projections, leading to a more precise snapshot of the current state of cancer clinical trial participation in Canada.
- Increasingly, clinicians are encouraged to present and discuss complex cases in multi-specialist and/or interdisciplinary consultations. Despite this increase, a systematic and standardized approach to data collection and reporting is still required in order to improve accountability and monitoring of evidence-based practices over time. In 2017, the only way to extract information from these interdisciplinary consultations, including information on reasons for non-referral or on treatment plans, is to conduct resource-intensive chart reviews. A consistent approach for collecting data on inter-specialty referrals and consultations would provide a more complete picture of quality indicators.

Improving consistency across jurisdictions when defining and collecting data on place of death presents an opportunity to better assess end-of-life care.



2. Collecting new data on under-measured domains and under-represented populations and jurisdictions

There is a paucity of routinely collected national data on the cancer journey for under-served populations, particularly First Nations, Inuit and Métis people. Data on the territories are also limited, particularly for cancer diagnosis and treatment, and several jurisdictions are not yet able to report performance data on key aspects of cancer control. In addition, better data on person-centred care is needed, particularly on the current state of palliative and end-of-life care in Canada.

Jurisdictions across the country are not always able to consistently identify First Nations, Inuit and Métis cancer patients in cancer registries or health records. The Partnership has actively engaged with several provincial partners to develop safe and culturally appropriate strategies that enhance cancer data collection in Indigenous populations. While there has already been some progress in linking Indigenous status to registry data, data are still not yet available at the national level. Obtaining information on inequities in access to cancer care in Indigenous communities and building a system to capture this information is a critical step toward achieving an equitable cancer system.

In the 2010s, there has been an emphasis on transforming the health system from delivering disease-centred care to a more person-centred model. In support of this shift, there are numerous opportunities to collect new data while also leveraging existing datasets. For example, as of 2017, treatment indicators were focused on guideline concordance, which does not capture whether patients' preferences were factored into their treatment plan or whether patients were informed of different treatment options—important components of person-centred care. To support quality care and a seamless patient experience, it is important to measure and collect data on patients' met and unmet needs (e.g., informational, psychosocial) during treatment. These new data will facilitate the identification of opportunities to provide better patient-centred care.

Other ways to improve person-centred care include the following:

- introducing patient wait time intervals that more meaningfully reflect patient experiences (e.g., time from symptom suspicion to resolution of diagnosis to start of treatment, rather than “ready to treat,” which is more clinician focused),
- collecting longitudinal Edmonton Symptom Assessment System data, which would allow for trend analyses of symptom prevalence and intensity,
- collecting data on follow-up interventions (e.g., change in care plans, physical or psychosocial intervention, referral to a provider) for patients who have higher levels of distress.

To strive toward achieving a truly pan-Canadian view of the cancer control system, it is essential to gather data from all jurisdictions across Canada. In the Partnership's reporting of practice patterns associated with Choosing Wisely Canada's cancer-related recommendations, for example, limited or absent data resulted in an inability to report on eight of 15 recommendations. Of the seven recommendations reported on, data were not available in all jurisdictions. It is therefore important to work with all jurisdictions to collect these data and make them available.

In addition, for the indicators presented throughout this report, often little or no information was available from the territories. In 2017, British Columbia processes cancer data for Yukon, Alberta processes cancer data for the Northwest Territories and Ontario processes cancer data for Nunavut. As a next step, an assessment and further engagement with key provincial and territorial stakeholders is necessary to determine the scope of data that are being captured. This knowledge can set the stage for future work to improve data collection in the territories.

To achieve a high-quality, equitable, seamless and sustainable system for all and to ensure that needs are being met, it is important to collect a complete set of data from all provinces and territories, to measure and analyze variations across the country—including those relevant to the patient experience, and to examine disparities in populations across Canada to ensure we are not leaving anyone behind. Empowered with data, we can better understand the needs of specific populations and determine the best mechanisms to help people navigate their cancer care journey.

3. Linking existing data sources

Throughout this report, the analysis and interpretation of cancer control indicators have been at the aggregate or ecological level.

Neighbourhood income level is often used as a proxy for an individual's socioeconomic status. Limitations in analysis at the ecologic level include the fact that it masks individual or contextual effects and assumes homogeneity across a particular region or group. Until very recently, we were not able to link individual socioeconomic information with cancer outcomes. Statistics Canada's new Social Data Linkage Environment will allow for the linkage of cancer care outcomes with demographic data at the individual level and should enable clear demonstration of the association between socioeconomic status and cancer outcomes.

At the Partnership, efforts are ongoing to work closely with jurisdictions to develop data sharing agreements and to establish standards for data collection, such as through the Coordinated Data Development Initiative (CDDI). The CDDI aims to identify a core set of treatment data elements that can be reported to the Canadian Cancer Registry. This effort includes seeking provincial alignment on common data definitions, testing the feasibility of obtaining

treatment data and feeding it into the national registry. As part of ongoing work, the CDDI has funded five treatment data linkage projects to be delivered by the BC Cancer Agency, Statistics Canada, Eastern Health – Newfoundland and Labrador, Cancer Care Nova Scotia and Health PEI. These projects will link provincial cancer datasets to administrative and staging data, Drug Information System data and the Radiation Therapy Electronic Medical Record system, enabling provinces to better analyze radiation, surgery and chemotherapy data and to determine whether treatment aligns with recommended clinical guidelines.

The ongoing political challenge associated with expanding and increasing data linkages should be recognized. Privacy and sensitivity of data often present additional barriers to accessing and linking existing datasets. It is essential to achieve a better balance between safeguarding the privacy of personal information while providing access to data for the purposes of quality improvement in cancer care.

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What do the results in this report suggest can be done to improve cancer control in Canada?

QUALITY

- **Identify and systematically address inefficiencies across the cancer care continuum**—from screening to long-term and end-of-life care. Doing so can ensure that patients receive the right patient-centred care at the right place and time.
- **Strengthen the reporting infrastructure at the system level.** Provincial and national standardization of information provided in medical charts, including data on interdisciplinary consultations, patient referrals and the patient's involvement in treatment planning and execution, would improve the monitoring of evidence-based practices and patient-centred care.
- **Educate patients and medical staff about research procedures earlier in the clinical trial recruitment process** to focus on alleviating concerns and thus increasing the likelihood of participation. Overall, increased awareness among all those involved, whether investigators or participants, is paramount to improve the Canadian clinical trial landscape.

EQUITY

- **Address barriers to cancer control services** to ensure that all Canadians from coast to coast to coast, regardless of background, place of residence or income, receive the necessary support to prevent cancer, to participate in screening programs and to have appropriate access to cancer treatment and care options that help them improve their outcomes.

SEAMLESSNESS

- **Redesign and transform the system from the perspectives of patients and their families** to allow gaps in the care continuum to be closed so that people can follow a simpler and more understandable path when navigating the system.
- **Integrate palliative care earlier in patients' cancer care.** Doing so can help improve disease outcomes, quality of life and care satisfaction for patients and caregivers, as well as increase the likelihood of home death. Place of death, although a crude measure, addresses one important aspect of end-of-life care and may contribute to better planning for and quality of end-of-life care for cancer patients.
- **Identify patient needs and preferences throughout the cancer pathway** so that the system can manage and address these preferences and ensure that patients and caregivers have a high quality of life for as long as possible.

SUSTAINABILITY

- **Develop policies that create environments enabling people to lead healthier lives** (e.g., that increase the likelihood of people engaging in behaviours that reduce their risk of developing cancer). Creating healthier environments can help to reduce the burden of preventable cancers, which in turn will reduce the demand for limited health care resources.
- **Continue to measure and report on potentially low-value cancer control practices across Canada.** Gathering data on these practices can help identify opportunities for benchmarking and can inform future strategies to encourage use of evidence-based practices that maximize clinical benefit. The delivery of high-value cancer care that is supported by evidence has the potential to improve patient outcomes and quality of life while helping to maintain the sustainability of Canada's health care system.



Conclusion

Improving the quality, equity, seamlessness and sustainability of cancer control, and maximizing the impact of population and cancer data, have been identified as major themes for future work with national, provincial and territorial partners.

Efforts in these areas will help the cancer control community to secure a future where fewer people get cancer, fewer people die from cancer and more people living with cancer have a better quality of life. To measure progress, the Partnership's System Performance Initiative will continue to monitor and report on cancer system performance to inform cancer control planning, to inform system and practice improvements, and to promote the exchange and uptake of best practices across the country.



Summary of Indicator Results

Indicator	Page #	BC	AB	SK	MB	ON	QC	NB	NS	PE	NL	YT	NT	NU	Data source
Quality															
Screening history for women (21–69 years) diagnosed with invasive cervical cancer — 2011–13	8	See Quality chapter for details.													
Programmatic breast cancer screening abnormal call rate (%), subsequent screens — 2011–12 screening years	9	6.4	6.1	4.0	4.2	7.1	9.2	8.9	5.1	11.9	6.3	—	4.9	—	BCSP
Programmatic invasive breast cancer detection rate (per 1,000 screens), subsequent screens — 2012 screening year	9	3.9	2.9	3.9	4.2	3.5	4.4	2.9	3.5	4.6	3.4	—	*	—	BCSP
Removal and examination of 12 or more lymph nodes in colon resections (%) — 2009–12 diagnosis years	13	—	83.0	74.2	82.3	—	—	77.8	76.4	70.7	81.9	—	—	—	PCA
Preoperative radiation therapy for Stage II or III rectal cancer (%) — 2009–12 diagnosis years	15	—	46.7	—	50.4	—	—	43.0	41.5	—	41.6	—	—	—	PCA
Post-operative chemotherapy for Stage II or IIIA non-small cell lung cancer (%) — 2012 diagnosis year	16	See Quality chapter for details.													PCA
Adult clinical trial participation (ratio) — 2014 enrolment year	18	0.025	0.066	0.032	0.018	0.057	—	0.011	0.007	*	0.002	—	—	—	PCA, CCS
Equity															
Women (21–69 years) reporting at least one Pap test in the past three years, by household income quintile and immigrant status (%) — 2012 reporting year	22	See Equity chapter for details.													CCHS
Women who reported never having had a Pap test, by language spoken at home (%) — 2012 reporting year	22	See Equity chapter for details.													CCHS
Breast cancer resections that are mastectomies, by geography and travel time to nearest radiation facility (%) — 2007/08 to 2011/12 combined	23	See Equity chapter for details.													CIHI
Lung cancer incidence rate by neighbourhood income quintile — 2012 diagnosis year	24	See Equity chapter for details.													CCR
Lung cancer mortality rate by neighbourhood income quintile — 2012 death year	24	See Equity chapter for details.													VSD
Fatality ratio for lung cancer by neighbourhood income — 2012 diagnosis and death years	24	See Equity chapter for details.													CCR, VSD
Colorectal cancer incidence rate by neighbourhood income quintile and sex — 2012 diagnosis year	25	See Equity chapter for details.													CCR
Colorectal cancer mortality rate by neighbourhood income quintile and sex — 2012 death year	25	See Equity chapter for details.													VSD
Breast, colorectal and lung cancer five-year net survival by income quintile — 2004–09 diagnosis years	26	See Equity chapter for details.													CCR

Top third

Middle third

Bottom third

“—” Data not available.

*Suppressed owing to small numbers.

Data sources:

BCSP: Provincial breast cancer screening programs

CCHS: Statistics Canada, Canadian Community Health Survey

CCR: Statistics Canada, Canadian Cancer Registry

CCS: Canadian Cancer Society, Canadian Cancer Statistics

CIHI: Canadian Institute for Health Information

PCA: Provincial cancer agencies and programs

VSD: Statistics Canada, Vital Statistics Death Database

Indicator	Page #	BC	AB	SK	MB	ON	QC	NB	NS	PE	NL	YT	NT	NU	Data source
Seamlessness															
Breast cancer diagnosis wait time (weeks), 90 th percentile (no biopsy) — 2013 screening year	30	8.0	4.0	5.3	5.0	4.4	—	6.0	7.6	5.9	8.0	—	—	—	BCSP
Breast cancer diagnosis wait time (weeks), 90 th percentile (biopsy) — 2013 screening year	30	14.0	12.1	12.5	14.0	11.3	—	13.1	11.7	10.6	15.0	—	—	—	BCSP
Colorectal cancer diagnosis wait time (days) — first-round screening tests in 2013 and 2014	32	—	139	119	119	—	—	—	147	151	104	—	—	—	NCCSN
Radiation therapy wait time, 90 th percentile (days) — 2014 treatment year	33	22	22	15 [†]	22	14 [†]	—	19	—	27	20	—	—	—	PCA
Screening for distress — 2016 reporting year	35	See Seamlessness chapter for details.													PRO partners
Place of death within hospital (%) — 2012 death year	37	49.2	62.8	67.1	87.8	63.1	76.7	76.4	68.6	64.4	77.7	—	62.5	—	VSD
Sustainability															
Smoking prevalence (%) — 2014 reporting year	42	14.3	19.1	20.6	16.2	17.4	19.5	20.8	22.1	19.7	21.6	26.1	33.4	61.7	CCHS
Human papillomavirus vaccination uptake — full course (%) — 2012/13, 2013/14, 2014/15 or 2015/16 school year	43	64.8	66.3	77.8	65.8	80.2	74.4	75.4	83.2	87.0	93.0	—	55.6	—	Immunization programs
Breast cancer screening mammograms performed on average-risk women aged 40–49 (%) — 2008–12 reporting years combined	46	25.9	27.5	14.7	7.0	18.3	11.9	17.6	27.4	26.9	26.9	*	27.6	*	CCHS
Palliative radiation therapy for bone metastases — multiple fractions (%) — 2013 treatment year	47	40.3	—	69.0	68.8	—	—	—	59.0	66.9	—	—	—	—	PCA
Intensive care use in the last 2 weeks of life — admissions (%) — 2011/12 to 2014/15 fiscal years combined	48	8.4	9.4	9.8	7.1	14.3	—	6.9	5.8	9.5	9.0	—	15.9	—	CIHI
Breast cancer mastectomies as day surgery (%) — 2009/10 to 2013/14 fiscal years combined	49	14.7	1.4	6.4	27.4	38.7	27.9	39.3	20.2	18.4	8.2	—	*	—	CIHI

Top third

Middle third

Bottom third

“—” Data not available.

*Suppressed owing to small numbers.

[†] 2013 treatment year

Data sources:

BCSP: Provincial breast cancer screening programs

CCHS: Statistics Canada, Canadian Community Health Survey

CIHI: Canadian Institute for Health Information

Immunization programs: Provincial/territorial immunization programs

NCCSN: National Colorectal Cancer Screening Network

PCA: Provincial cancer agencies and programs

PRO partners: Patient-Reported Outcomes Initiative partners

VSD: Statistics Canada, Vital Statistics Death Database

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About the System Performance Initiative

The Partnership's System Performance Initiative is a national effort to identify aspects of the cancer control system that need to be measured or are under-measured, to define performance indicators and to report findings in an integrated manner that allows for synthesis of results and interpretation of patterns. Such knowledge is intended to aid policy makers, health planners, administrators, researchers and clinicians in identifying best practices and pursuing opportunities for quality improvement in cancer control across Canada.

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