

Living with Cancer

A Report on the
Patient Experience

January 2018



Cancer is a human experience

Living with cancer is about dealing with the unknown. It is about trying to grasp the news and starting to understand its life-changing effect. It is about wondering if the treatment is working and whether the side effects will go away soon. It is about questioning whether anything else can be done to overcome this illness. And it is about figuring out what life will be like when treatment is over, while having hope for the future. Sometimes, it is about learning to let go of the possibility of cure.

Support from health care providers—and from the health system in general—is crucial in helping people have the best possible experience throughout their cancer journey.

Cancer is an unexpected and life-changing event during which individuals and families have to learn new skills, gather information and understand options to adapt to physical, emotional and day-to-day changes.¹ How people experience this journey and its impact will vary from one person to the next depending on personal factors, including²⁻⁵

- Place of residence
- Income and work stability
- Gender identity, sex and age
- Immigrant status
- Education and health literacy
- Culture and traditions

People need the help of the health care system to navigate each stage of the cancer journey in a way that aligns with their background, priorities and values. In a high-quality system, people are more likely to have the best possible experience when cancer care services are supported by the following pillars:⁶

Pillars of a positive experience and what they mean

I AM A UNIQUE INDIVIDUAL

To be seen as an individual with unique preferences and a broader life beyond my disease (family, work and culture).

I AM RESPECTED

To receive consistently delivered care that considers my time and preferences.



I AM EMPOWERED

To participate actively in my care by receiving tailored information that facilitates decision making and promotes self-care.

I AM SUPPORTED

To receive support for physical, emotional and practical needs in a way that alleviates my concerns and is culturally sensitive.

This is the first national report that presents indicator and survey data to illustrate the experience of those individuals and families living with and beyond cancer. The report is organized in a way that reflects not how the system is structured but how patients themselves experience their journey: from **realizing something is wrong, to hearing “you have cancer” and wondering what’s next, to being treated for cancer and hoping it works, through to finding a “new normal” after treatment is over and beyond.**

A person-centred approach to cancer care integrates these pillars to fully embrace people as partners in care.

To best support people with cancer and their families—from the moment they start wondering if they have cancer to post-treatment care—it is essential to treat them as individuals with a reality that extends beyond being a cancer patient.^{6,7} A health care system guided by a person-centred approach recognizes this and establishes a partnership among everyone involved—health care providers, patients and loved ones.

In Canada’s cancer control system, shifting toward person-centred care means

- 1. Expanding from “episodes of care” to an extended care continuum.** Throughout the course of diagnosis, treatment and follow-up care, living with cancer is a continuous experience for patients and families. Delivering integrated care that coordinates services across all phases of the cancer journey—while being considerate of travel concerns, barriers to accessing services and cultural preferences—is an essential element of person-centred care.
- 2. Recognizing that the patient experience is a dimension of quality and empowering patients to be co-designers of care services.** The patient experience is recognized internationally as one of the foundations of high-quality care.⁸ Providing a positive patient experience should therefore be top of mind during the design, planning and delivery of cancer care services. Patients and families have fundamental knowledge about what their cancer experience is like and what is

needed to improve their quality of life. The health care system should therefore look for opportunities to involve patients when identifying, implementing and evaluating improvement to health care services.^{3,9}

- 3. Aligning patients’ and clinicians’ concepts of what a positive experience is.** A gap often exists between what patients and their families want and what health care providers think they want.⁷ A relationship between the person with cancer and the clinicians who provide care should be based on reciprocity, active listening and sharing of the knowledge and preferences of everybody involved. It is crucial that clinicians hold discussions that encourage patients to express their personal needs and preferences, paying particular attention to the complex needs of individuals in low-income, Indigenous, immigrant and rural groups, among others. This enables a personalized approach to care to create the best possible experience, as defined by all individuals concerned.¹⁰

This report presents pan-Canadian qualitative and quantitative data on person-centred care, including

- data on wait times and patient-reported outcomes,
- results from the Ambulatory Oncology Patient Satisfaction Survey, including qualitative analysis of over 6,000 patient comments,
- results from the Experiences of Cancer Patients in Transition Study, a national survey examining the experiences of over 13,000 people with cancer as they transition from cancer treatment to the broader health care system,
- examples of initiatives implemented in certain jurisdictions to improve the patient experience that could be more broadly adopted.

This report also includes the patient perspectives of **Bonnie, Charlotte** and **Stephen**, who share their personal experiences through the milestones of the cancer journey.

For more information about the qualitative and quantitative data included in this report, please see the Technical Appendix at systemperformance.ca



Living the cancer experience

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“Things did not settle down. I went to my family doctor and said, ‘This is not right. It’s been four to six weeks and this fever is coming and going. I think I need a complete work-up.’”

Stephen

“I was absolutely shocked and stunned and sad. I really can’t explain how I felt because there was never any cancer in our family, so cancer was the furthest thing from my mind.”

Bonnie

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STEPHEN'S STORY

“Before I was diagnosed with cancer my outlook on life was pretty free and optimistic...”

Stephen, at age 62, had an active and stable life in Charlottetown, working full-time and being involved in the lives of his children. “Before I was diagnosed with cancer my outlook on life was pretty free and optimistic. My plans were pretty much set to prepare for retirement while working full time and being actively involved with my community [through my] involvement in rowing and the lives of my young people.”



BONNIE'S STORY

“I never smoked and only drank socially. I really enjoyed my business career...”

In 2008, Bonnie was turning a page in her life. She moved to Newfoundland from the US and was starting a new relationship with her boyfriend, Charlie. “I am, by nature, a very positive person, and I have been blessed with a loving, caring family and many lifelong friends. In late 2008, I moved home to Newfoundland for a fresh start. I was 52, happy to be home, healthy, just starting a new relationship and was high on life. Exercise and good food were always important to me. I never smoked and only drank socially. I really enjoyed my business career and I always felt that my contributions were valued.”



CHARLOTTE'S STORY

“I loved being busy and always working to advance all aspects of my life.”

For Charlotte, an avid soccer player, life in 2013 was busy, given her role as a company vice president in Alberta and spending time with her young family—including her husband and three-year-old daughter. “I was a relatively active person, an overall healthy eater and a generally positive person who loved my family and my career. I loved being busy and always working to advance all aspects of my life but looking back, I was probably trying to cram too much into each day at the risk of my own health needs more than I should have—in this day and age, too many of us are.”

List of indicators

While this report focuses on cancer experiences that culminate in survivorship—here defined as being in remission one to three years after treatment—sometimes those with advanced cancer must embark on end-of-life care. The publication *Palliative and end-of-life care: A cancer system performance report* is dedicated to that particular phase of the cancer experience. For more information, please visit systemperformance.ca.

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Realizing something is wrong





Is it cancer?

This section describes factors that contribute to a positive experience for patients and their families from the time cancer is suspected to diagnosis, using personal stories and indicators.

Almost everyone has their own story about how they or a loved one found out they might have cancer.

Some people find an unexplained lump or have other symptoms. For other people, a routine cancer screening test finds something that needs further investigation. Once cancer is suspected, waiting for a diagnosis can be emotionally difficult. People may feel uncertain, stressed and anxious as they visit multiple care providers and services and wait for test results to find out if they have cancer.¹¹

Pillars of a positive experience within a person-centred approach to care

				
PILLARS OF A POSITIVE EXPERIENCE	I AM A UNIQUE INDIVIDUAL Being seen as an individual with unique needs, preferences and concerns about the possibility of cancer.	I AM RESPECTED Receiving care that is timely and considerate of patients' needs and preferences from the many care providers and services responsible for screening for and diagnosing cancer.	I AM EMPOWERED Receiving tailored information about what to expect leading up to the diagnosis.	I AM SUPPORTED Receiving support for physical, emotional and practical concerns while waiting for a diagnosis.
ASSOCIATED INFORMATION/ DATA	<ul style="list-style-type: none"> • Stephen's, Bonnie's and Charlotte's stories 	<ul style="list-style-type: none"> • People's perceptions of wait times (AOPSS – qualitative) • Wait time from an abnormal breast screen to resolution (provincial breast cancer screening programs) • Wait time from an abnormal fecal test to follow-up colonoscopy (provincial colorectal cancer screening programs) 	—	—



“I went to my family doctor and said, ‘This is not right.’”

After travelling back from Costa Rica, Stephen developed a high fever. He went to his family doctor and was told he likely had a bladder infection. Two courses of antibiotics later, “things did not settle down. I went to my family doctor and said ‘This is not right. It’s been four to six weeks and this fever is coming and going. I think I need a complete work-up.’”

Stephen’s doctor was concerned about Stephen’s blood results. “They booked an appointment with the oncologist right away, but I experienced acute back pain and my urine turned pale. I knew I was in trouble and I went to the emergency department...They scheduled a CAT scan for Sunday morning [the next day]...after the scan, [a doctor] came in and said that the ureter is blocked by a tumour and it is cancer.”



“To be quite honest, I thought, well, I’m 54 years of age, so this must be the start of menopause...”

When Bonnie was living in Florida in 2007, she started experiencing lower abdominal pain. She went to a gynecologist who “carried out all kinds of tests. [The gynecologist] came back and told me that I had fibroids and that unless they were causing me a great deal of pain that I should just leave them.”

Three years later in Newfoundland, Bonnie started experiencing other symptoms: “Bloating that didn’t go away, a little tiny bit of pain up through my rectum when I sat down, and I had gained about 10 pounds. I went to see my GP and she did the regular internal and said she felt something that she thought may be a cyst. She sent me for blood work and an internal ultrasound. Following the internal ultrasound, within a few days I was booked for an MRI...To be quite honest, I thought, well, I’m 54 years of age, so this must be the start of menopause because everyone told me that bloating is a sign of menopause.”



“...at this point we were not panicking...there was no mention of cancer.”

In the spring of 2013, Charlotte was playing soccer when “all of a sudden I was disoriented, and I didn’t know what was happening...And then I blacked out.” At the hospital, numerous tests were performed but they all came back normal. Given her persistent headache and fatigue she underwent several other tests to check for heart conditions and epilepsy, but again these tests came back with normal results. She then underwent a CT scan and “they saw something. [My family doctor] then ordered an MRI for the next day on an urgent basis...And the next thing I knew...I was preparing for surgery [in September 2013].”

“But at this point we were not panicking...there was no mention of cancer. The surgery would be done to get as much as possible of the mass...They believed I would have 10–15 years before it might grow again.”

Some people describe waiting too long for their cancer diagnosis.

A qualitative analysis of written comments from the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) showed that some patients thought wait times were too long for a number of events or intervals along the cancer journey, including

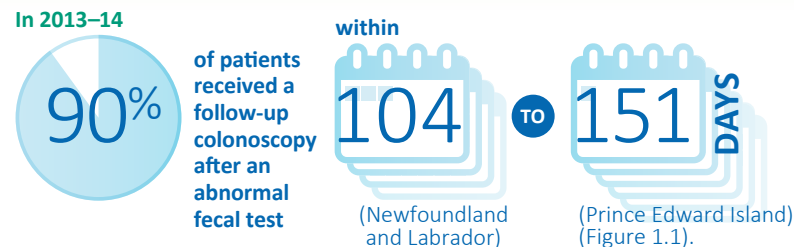
- from reporting a symptom to having their family doctor do tests,
- getting an appointment for diagnostic tests,
- receiving the results after a test has been done,
- having an appointment scheduled with a specialist, and
- hearing the cancer diagnosis.



Some survey respondents emphasized how waiting increased anxiety. Waiting for the initial diagnosis was described as one of the periods of highest anxiety, filled with concerns about the cancer spreading. Individuals said they thought their cancer may have spread beyond what was curable in the time it took to be diagnosed. They described numerous challenges in convincing

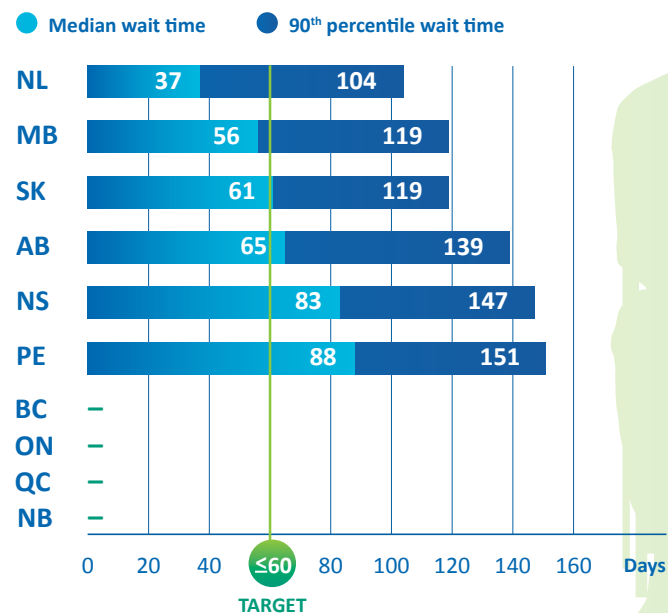
their primary care provider to investigate a symptom or to act on the basis of test results. In other instances, test results and referral forms to see specialists were lost or not acted on. Some respondents expressed frustration and disbelief that it took so long to see a specialist.

While wait times are improving, people continue to wait months for a follow-up colonoscopy after an abnormal fecal test result.



- Wait times in 2013–14 were shorter than in 2011–12 for provinces that reported data for the two periods (Saskatchewan, Manitoba, Prince Edward Island and Newfoundland and Labrador).

FIGURE 1.1
Wait times from abnormal fecal test result to follow-up colonoscopy, by province – 2013–14 screening years combined



“—” Data not available. See the Technical Appendix for more details. Data include screening tests conducted in 2013 and 2014 for people aged 50–74 and colonoscopies performed within 180 days of abnormal fecal test results. During this time period, provinces were in different stages of implementation of colorectal cancer screening programs with significant variation in available data. Results should be interpreted cautiously within this context. The Canadian Association of Gastroenterology recommends that a colonoscopy be completed within 60 days of an abnormal fecal test. Data source: Provincial colorectal cancer screening programs.

Women with abnormal breast screen results continue to wait many weeks for a diagnosis.

When a tissue biopsy was not required,

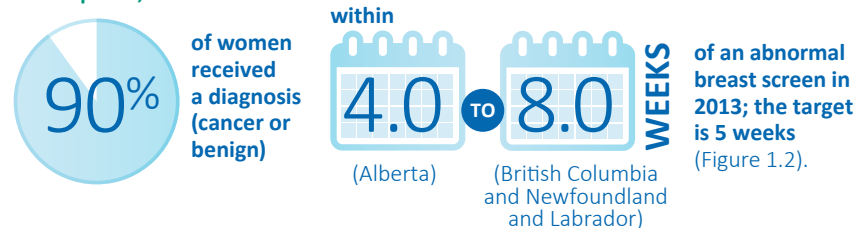
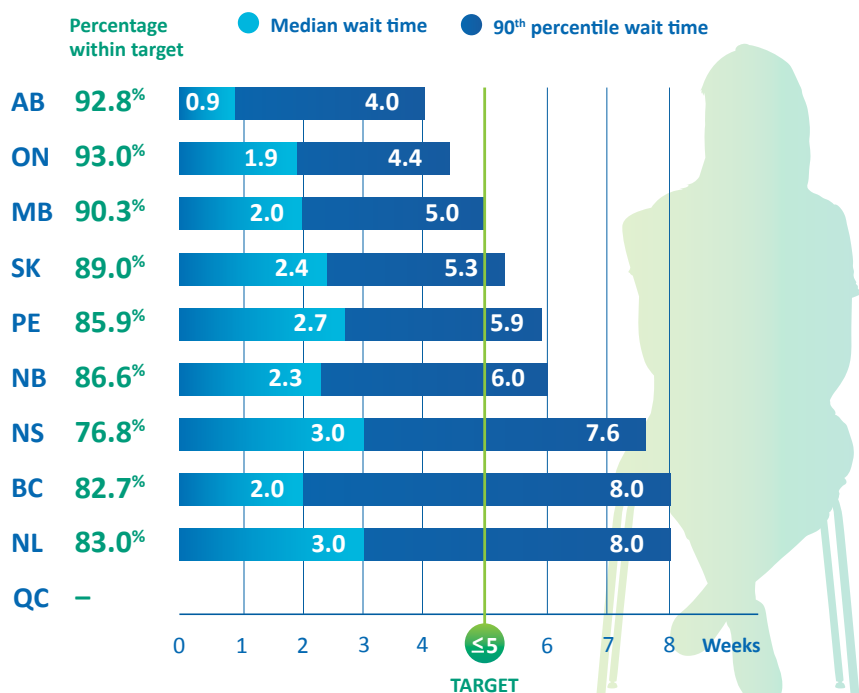


FIGURE 1.2
Wait times from abnormal breast screen to diagnosis without biopsy, by province – 2013 screening year

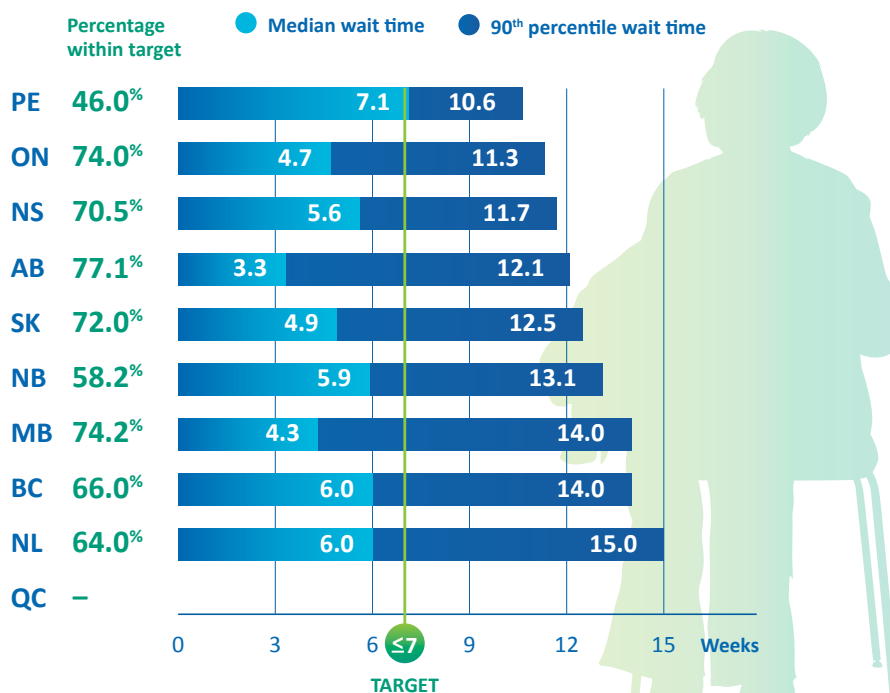


“—” Data not available.
Data include women aged 50–69 who were screened for breast cancer within a cancer screening program. Women who were screened outside of such programs (i.e., opportunistic screening) are not included. Cases where resolution of an abnormal breast screen took more than six months were excluded.
ON: Women with final result unknown/lost to follow-up were excluded.
Data source: Provincial breast cancer screening programs.

When a tissue biopsy was required,



FIGURE 1.3
Wait times from abnormal breast screen to diagnosis with biopsy, by province – 2013 screening year



“—” Data not available.
Data include women aged 50–69 who were screened for breast cancer within a cancer screening program. Women who were screened outside of such programs (i.e., opportunistic screening) are not included. Cases where resolution of an abnormal breast 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.

What are the main challenges people experience when they realize something is wrong?

Many people continue to wait several weeks to months to find out if they have cancer. Waiting for a diagnosis is described as one of the periods of highest anxiety, with some patients reporting that wait times are too long for a number of events, including getting an appointment for a diagnostic test and receiving results after a test has been done.



Examples of innovative practices to improve people's experiences with cancer

One-stop diagnostic clinics have been opened across Canada and internationally so that people with a suspicion of cancer can receive a faster diagnosis. For example:

- As part of its IN SIXTY initiative, CancerCare Manitoba has implemented Regional Cancer Program Hubs that consist of multidisciplinary teams that work with nurse navigators to ensure people have timely and coordinated access to referrals, testing, diagnosis and treatment.¹²
- Cancer Care Ontario has implemented lung/thoracic, colorectal and prostate cancer diagnostic assessment programs across Ontario.¹³ These programs consist of multidisciplinary care teams, including a patient navigator, that provide
 - one place for all diagnostic services,
 - streamlined coordination of diagnostic tests and consultations, and
 - relevant, timely support and information for individuals going through the process.
- The National Health Service in England launched the Accelerate, Coordinate, Evaluate (ACE) Programme in 2017 to enable faster cancer diagnosis.¹⁶ The program is supported by Cancer Research UK and Macmillan Cancer Support and includes
 - over 50 projects exploring innovative approaches to allow timely diagnosis, such as interventions to improve screening uptake for vulnerable groups, to streamline diagnosis and to enhance roles for primary care professionals who are not general practitioners, and
 - six pilot projects testing one-stop diagnostic pathways for patients with non-specific but concerning symptoms.

The diagnostic assessment programs reduce the time to diagnosis, which likely reduces anxiety and stress associated with waiting for a diagnosis.^{14,15}

Hearing “you have cancer”

What’s next?

This section describes factors that contribute to a positive experience for individuals and their families during diagnosis and treatment planning, using personal stories and indicators.

After waiting—sometimes days, sometimes months—for test results (e.g., from an imaging procedure or a biopsy), some people will hear “you have cancer.”

Being diagnosed with cancer can be an overwhelming, life-changing experience that brings a range of emotions: fear, uncertainty, denial, anger, guilt, stress, anxiety, loneliness, isolation, sadness, depression, hope and adjustment.¹⁷ Those diagnosed with cancer and their loved ones may have many questions: “What is cancer?” “Am I going to die?” “How do I cope?” People diagnosed with cancer may need to undergo more tests and investigations to learn more about their disease and will need to start preparing to undergo treatment.

Pillars of a positive experience within a person-centred approach to care

PILLARS OF A POSITIVE EXPERIENCE				
ASSOCIATED INFORMATION/ DATA	I AM A UNIQUE INDIVIDUAL	I AM RESPECTED	I AM EMPOWERED	I AM SUPPORTED
Being seen as an individual, not just a diagnosis.	Having care providers who respond to the needs, preferences and concerns of patients and their families after they hear their diagnosis.	Receiving tailored, understandable information about cancer and treatment options, and having the opportunity to ask questions.	Being referred to care providers or peer support groups for help with physical, emotional or practical concerns, if needed, after diagnosis.	
<ul style="list-style-type: none"> • Stephen’s, Bonnie’s and Charlotte’s stories 	<ul style="list-style-type: none"> • Patients’ experiences with being told their diagnosis sensitively (AOPSS – quantitative) • Patients’ experiences with being able to discuss their worries and concerns with their care providers (AOPSS – quantitative) • Patients’ experiences with their care providers considering their travel concerns when planning treatment (AOPSS – quantitative) 	<ul style="list-style-type: none"> • Patients’ experiences discussing treatments for their cancer with their care providers (AOPSS – quantitative) • Patients’ experiences with being given enough information about cancer treatments (AOPSS – quantitative and qualitative) 	<ul style="list-style-type: none"> • Patients’ experiences being referred to care providers for help with anxieties and fears after diagnosis (AOPSS – quantitative) 	



BONNIE'S STORY

“You have ovarian cancer’... I was absolutely shocked and stunned and sad.”

Bonnie was diagnosed with Stage III ovarian cancer when she was 54. “April 7, 2010, was the date I received my diagnosis and I don’t think I’ll ever forget it...[My doctor] called me into the office...and when I walked in she said to me, ‘You have ovarian cancer. We don’t know how far along it is, or what stage it is, but it is ovarian cancer.’ And I just, I really just about collapsed in her office. All I remember was walking around the office, saying ‘Am I going to die?’ because it was the first thing I associated with cancer...”

“I was absolutely shocked and stunned and sad. I really can’t explain how I felt because there was never any cancer in our family, so cancer was the furthest thing from my mind. I think before that time, I don’t know if I even said the ‘cancer’ word, to be honest. So it was such a total shock for me. Also, my parents were in their 80s, and I had to go and tell them that I had cancer. I certainly wasn’t looking forward to doing that.”



STEPHEN'S STORY

“The hard part is telling people about the diagnosis...”

After several tests, Stephen was diagnosed with Stage III follicular lymphoma at age 62. “The first message about the cancer was devastating.” After the initial shock, Stephen describes positively the moment he was told he had cancer: “In the emergency department, when the doctor told me my diagnosis, he did not lord it over me. He crouched down and was at eye level with me...He was so respectful.”

Reflecting back on his cancer journey, Stephen says, “The hard part is telling people about the diagnosis. I found that hard. All react differently. Some will say, ‘I know a friend and he’s not dead;’ well, that is not helpful. Others will just cry and that is not helpful. So just getting it out and telling people, communicating about it, that was hard.”

Most people report being told of their cancer diagnosis sensitively.

Based on quantitative responses to the Ambulatory Oncology Patient Satisfaction Survey (AOPSS)

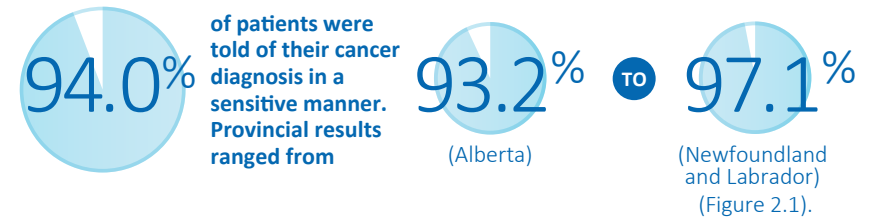
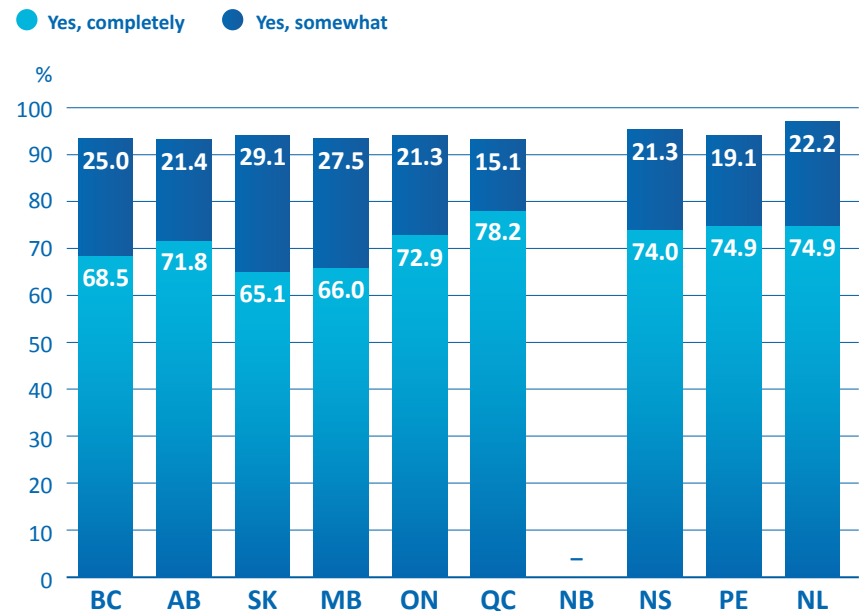


FIGURE 2.1
Percentage of patients who reported they were given their diagnosis in a sensitive manner, by province – most recent year of data*



*Province-specific data are for the most recent year available. BC: 2012; SK, PE: 2013; AB: 2015; MB, NL, NS: 2016; ON, QC: 2015/16 fiscal year.
 “-” Data not available.
 QC: Data were weighted.
 Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

More than half of people report that they are not referred to a care provider for help with their anxieties and fears when they are diagnosed.

CHARLOTTE’S STORY



“People need to know the reality and have access to information, but they also should have support.”

After the surgery to remove the brain tumour, Charlotte went to her first appointment at a cancer centre. Charlotte described her experience when she found out she had cancer: “The doctor came into the room and immediately began talking about radiation treatment and about a clinical trial. We said, ‘What do you mean? We thought surgery went well.’ And he said, ‘You have cancer.’ This was the first we had heard about it. Then he said, ‘You have Stage III anaplastic astrocytoma.’

“We said we needed time, time alone. We were so shocked! They gave us 10 minutes...But we were just so shocked! And we did not feel comfortable at all with the situation. We felt let down—why had we not been told anything after surgery? Why were we kept in the dark? Why were we not told officially about the cancer there?...I did not like the idea that they had been talking about what to do with me and my treatment and I did not know, that we did not know.

“At the beginning I felt I was dropped. There was not a lot of communication back in my home town...We walked into that first appointment at the cancer centre without any preparation...I found [the appointment] was blunt, formal, just black and white. There was no room for feelings or supporting. It was shocking news... People need time to process it, even though they will vary in their responses and reactions. People need to know the reality and have access to information, but they also should have support.”

Based on quantitative responses to the AOPSS, 68.1% of patients reported that they had anxieties or fears when first told they had cancer.

Of patients who had anxieties and fears

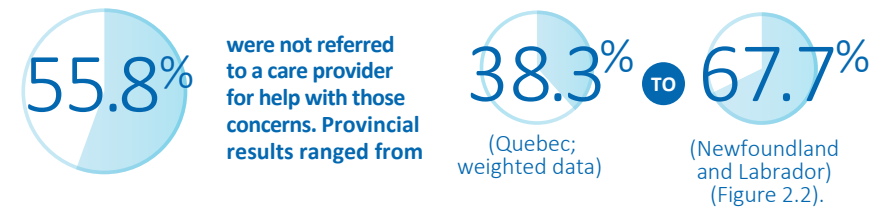
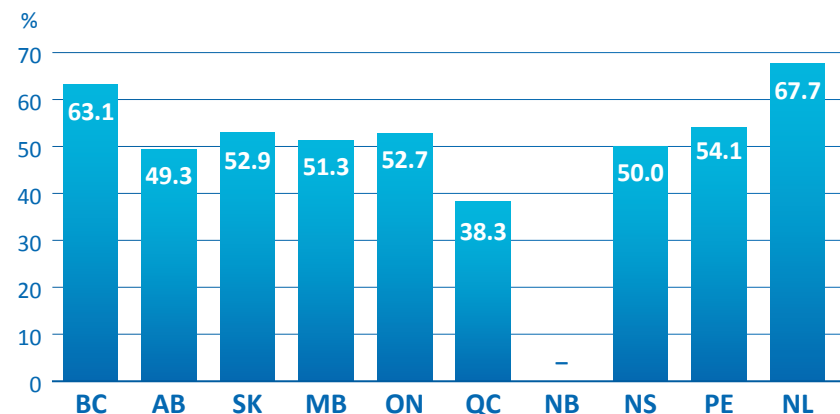


FIGURE 2.2

Percentage of patients who reported they were not referred to a provider for help with anxieties and fears when diagnosed, by province – most recent year of data*



*Province-specific data are for the most recent year available. BC, 2012; SK, PE, 2013; AB, 2015; MB, NL, NS, 2016; ON, QC, 2015/16 fiscal year.
 “-” Data not available.
 QC: Data were weighted.
 Data include only patients who reported having anxieties and fears when diagnosed.
 Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

Some patients report that no one discusses treatment options with them.

Based on quantitative responses to the AOPSS, between

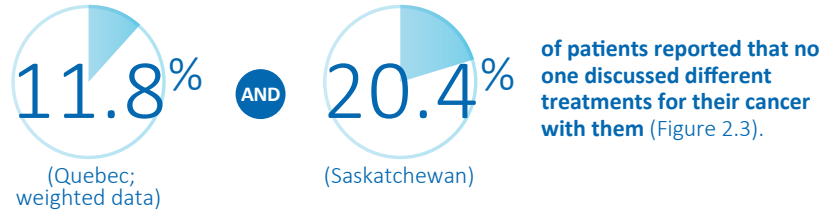
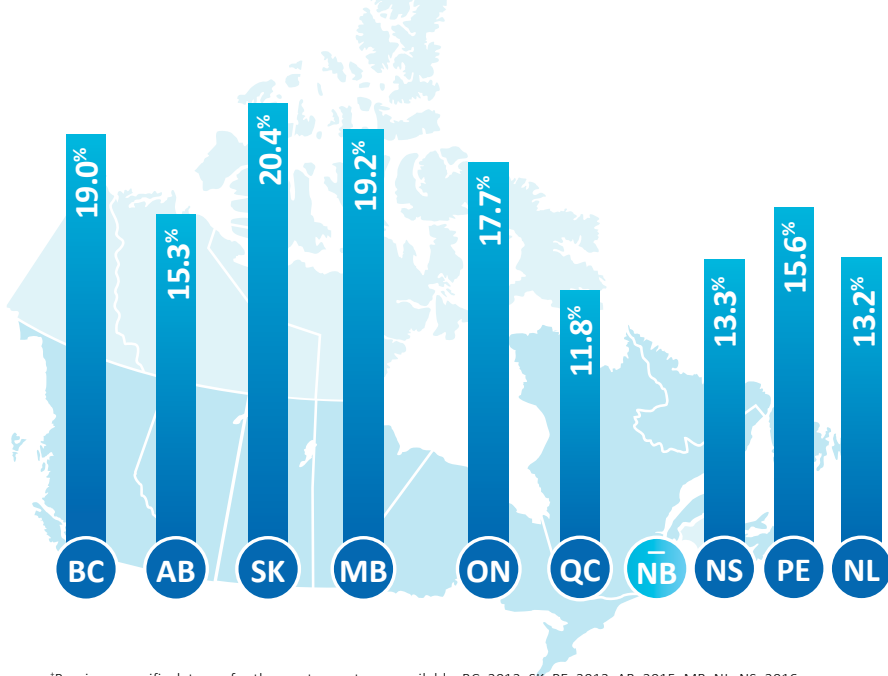


FIGURE 2.3

Percentage of patients who reported that no one discussed treatments for their cancer with them – most recent year of data*



*Province-specific data are for the most recent year available. BC: 2012; SK, PE: 2013; AB: 2015; MB, NL, NS: 2016; ON, QC: 2015/16 fiscal year.
 “—” Data not available.
 QC: Data were weighted. The survey question refers to a discussion with a health care provider rather than “someone.”
 Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

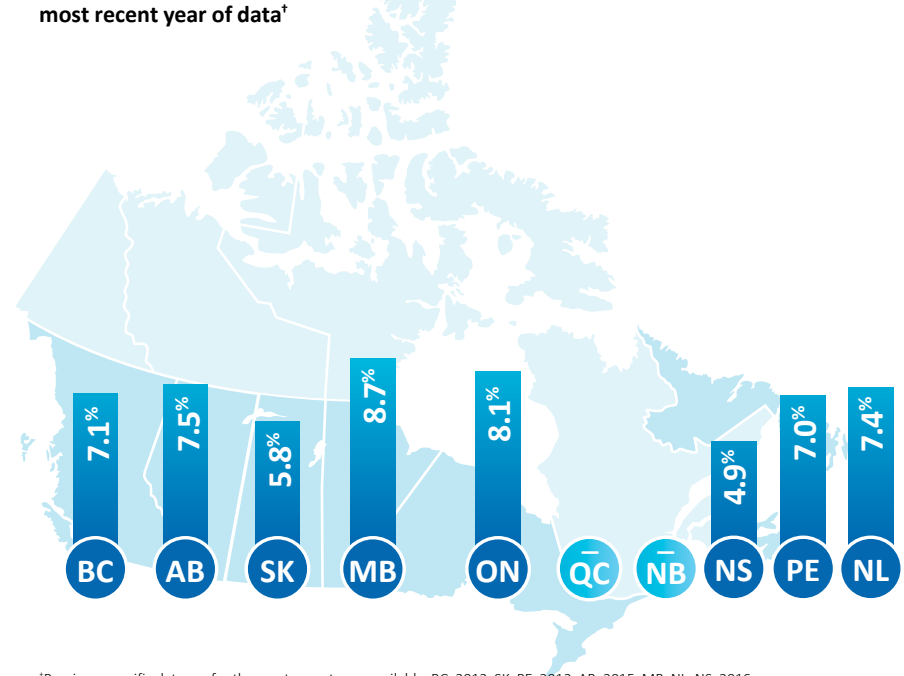
For patients who have worries or concerns before beginning treatment, most report that they are able to discuss them with their care providers.

Based on quantitative responses to the AOPSS, 79.6% of patients reported that they had worries or concerns before starting treatments.



FIGURE 2.4

Percentage of patients who reported their care provider did not discuss their worries or concerns with them before beginning treatment – most recent year of data*



*Province-specific data are for the most recent year available. BC: 2012; SK, PE: 2013; AB: 2015; MB, NL, NS: 2016; ON, QC: 2015/16 fiscal year.
 “—” Data not available.
 Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

Most patients say they are given enough information about cancer treatments, though some describe needing more information to make an informed decision.

Based on quantitative responses to the AOPSS, only

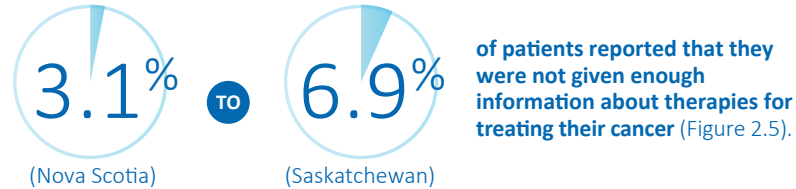
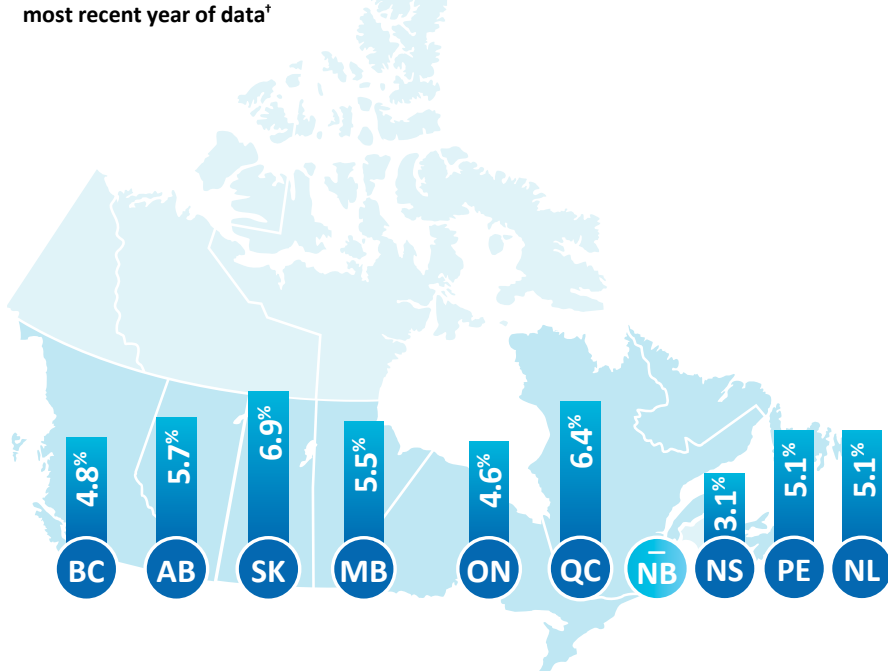


FIGURE 2.5

Percentage of patients who reported they were not given enough information about therapies for treating their cancer – most recent year of data[†]



[†]Province-specific data are for the most recent year available. BC: 2012; SK, PE: 2013; AB: 2015; MB, NL, NS: 2016; ON, QC: 2015/16 fiscal year.
 “—” Data not available.
 QC: Data were weighted.
 Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

- An analysis of written comments from the AOPSS shows that some survey respondents felt they were not told very much about their situation or that they did not fully understand what was said. They did not always see statistics and generalities as useful.
- Some patients felt they did not have enough information to make what they thought was an informed decision about their treatment and felt they could not have talked about it with their oncologist. Others wanted more information about treatment options than they were given, while others wanted more open discussion specifically about alternative medicines. Respondents who wanted to talk about alternative treatments said they found that physicians were not always open to talking about those treatments or to hearing that the patient wished to pursue a course of action other than what the doctors proposed.

“Once I got the diagnosis, I basically put my head down and just went forward with whatever they told me to do, although I had many questions for the doctors all the time.”

Bonnie



Some patients who have to travel for tests or treatments report that their care providers do not consider their travel concerns when planning their treatment.

Based on quantitative responses to the AOPSS, 69.0% of patients reported that they had to travel for tests or treatments.

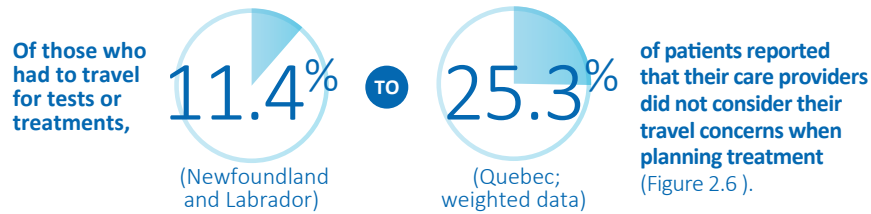
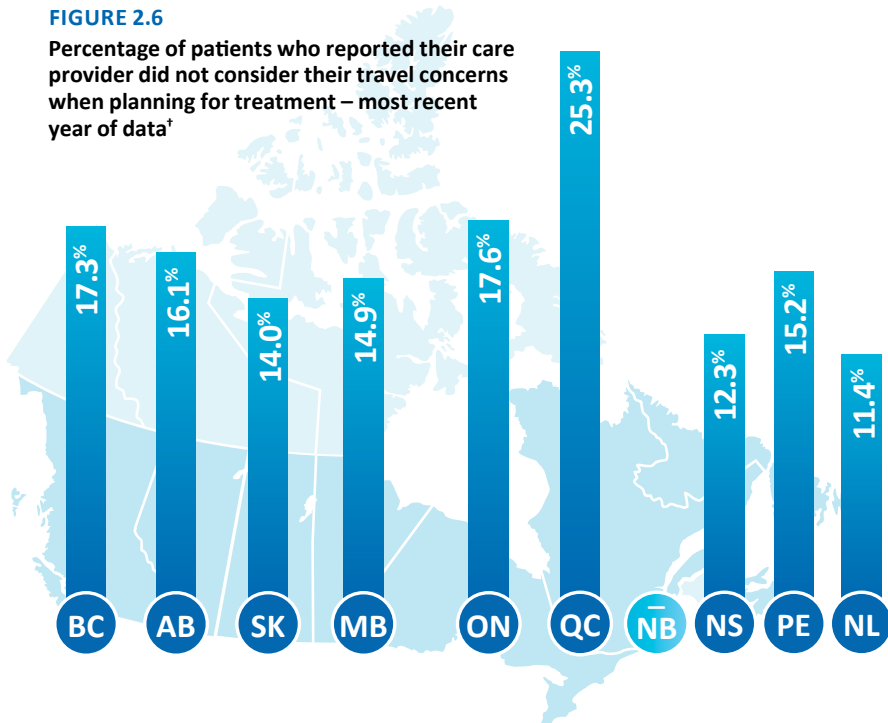


FIGURE 2.6
Percentage of patients who reported their care provider did not consider their travel concerns when planning for treatment – most recent year of data*



*Province-specific data are for the most recent year available. BC, 2012; SK, PE, 2013; AB, MB, NL, NS, 2016; ON, QC, 2015/16 fiscal year.
 “—” Data not available.
 QC: Data were weighted. The survey question refers to a discussion with a health care provider rather than “someone.”
 Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

CHARLOTTE'S STORY



“I did a bunch of research...I looked at radiation, tumours, drugs, treatment, how to care for ourselves, how to be strong and how to be successful.”

To treat Charlotte’s Stage III anaplastic astrocytoma, her doctor proposed that she participate in a clinical trial. Charlotte described her process for determining what treatment was the right option for her. It would mean travelling from Medicine Hat to Calgary every week for six weeks for radiation therapy.

“How would I manage that? And then treatment would be chemotherapy for one year. I did not know what that meant or what to expect. So I organized my two sisters and my sister-in-law and gave them each an area to research...I did a bunch of research myself as well. I looked at radiation, tumours, drugs, treatment, how to care for ourselves, how to be strong and how to be successful. And on Monday they came back and we got sort of a consensus. And that increased our confidence, on the part of my husband and I. So we agreed to do the trial.”

STEPHEN'S STORY



“Just tell me what you are going to do.’ And we have not moved off that plan and it has worked perfectly.”

When it came to planning for treatment, Stephen told his oncologist, “This is the way I want it to go. I do not want to know numbers or possible outcomes. Just tell me what I got, the treatments you are going to give me, when they are not working, and what you are going to do for me. Cover stuff in that order—the rest is noise to me. Just tell me what you are going to do. And we have not moved off that plan and it has worked perfectly.”

What are the main challenges people experience when they hear “you have cancer?”

The majority of people report that they are told of their cancer diagnosis in a sensitive manner, with most experiencing anxieties or fears at this time. Many people, however, are not referred to a care provider for help with those concerns. In addition, some people report that their care providers are not discussing treatments for their cancer with them and are not considering their travel concerns when planning their treatment.

Examples of innovative practices to improve people’s experiences with cancer

Across the country, navigators are helping people with cancer, and their families, navigate the cancer care system. Navigators help people to get answers about their diagnosis, to connect with the right care providers and to access available resources. Navigators provide a familiar face for people who often need to see numerous physicians and other health care professionals throughout their cancer journey.¹⁸ For example,

- In Alberta, nurse navigators have been integrated in all 17 cancer centres across the province. Navigators help patients diagnosed with cancer navigate the multiple tests, appointments, treatments and services they need.¹⁹
- In Quebec, pivot nurses in oncology (PNOs) are integrated in health care teams in hospitals.²⁰ PNOs act as resource people for patients and their families from the moment of diagnosis and along the entire care continuum, assess and manage needs, teach and provide information, provide support and coordinate services.²¹⁻²³
- In New Brunswick, pediatric oncology nurse navigators help children and teens and their families navigate the health care and community support systems from the time of diagnosis to recovery. Navigators provide patients and their families with information about treatments and their effects, provide educational materials about the cancer, assist with travel and accommodations, and link families to local resources.^{24,25}
- In Nova Scotia, navigators provide education, emotional support and logistical assistance as individuals and families deal with the challenges of cancer. An evaluation of the program suggests that navigators have helped people deal with the emotional turmoil, need for information and logistical challenges associated with cancer and that they have improved the quality and consistency of care.²⁶
- In Prince Edward Island, navigators support and guide cancer patients and their families from diagnosis and treatment to continuing care. Navigators provide education materials and information on support services based on a patient’s psychological, emotional or financial needs.^{27,28}

Some provinces have patient navigators who help address people’s language and cultural needs. For example,

- Cancer Care Ontario has an Aboriginal Patient Navigator Program that provides support and advocacy for First Nations, Inuit and Métis people. For example, Aboriginal Patient Navigators at the Juravinski Cancer Centre help people communicate with their care team, arrange language and cultural translation services and access cancer services, among other things.²⁹
- The BC Cancer Agency has a Chinese Peer Navigator Program. The peer navigators are people who have had cancer who provide the Chinese-speaking population with conversational support and help them find resources or services.³⁰

Being treated for cancer

Will it work?

This section describes factors that contribute to a positive experience for people with cancer and their families during cancer treatment using personal stories and indicators.

An individual with cancer is a whole person and treatment is not “one size fits all.”

The treatment journey can be different from one person to the next. While some people undergo a long treatment phase with multiple therapies, others experience a relatively short treatment phase that may involve only surgery or radiation. When undergoing treatment, individuals and families can feel overwhelmed with stress and anxiety around making informed decisions about care, while at the same time dealing with changes to their normal routine.

Pillars of a positive experience within a person-centred approach to care

				
PILLARS OF A POSITIVE EXPERIENCE	I AM A UNIQUE INDIVIDUAL Receiving care that considers the impact of treatment on family and broader life.	I AM RESPECTED Receiving prompt care from providers who are familiar with medical history, and being told who is in charge of care during treatment and after.	I AM EMPOWERED Having access to tailored information on emotional changes and treatment side effects and being taught how to manage them.	I AM SUPPORTED Having a care team during treatment that is aware of, and responsive to, physical, emotional and practical needs.
ASSOCIATED INFORMATION/ DATA	<ul style="list-style-type: none"> • Challenges with finances and travel during treatment (AOPSS – qualitative) • Charlotte’s story 	<ul style="list-style-type: none"> • Radiation therapy and surgery wait times (provincial cancer agencies and programs; Canadian Institute for Health Information) • Coordination and continuity of services during treatment (AOPSS – quantitative and qualitative) • Charlotte’s story 	<ul style="list-style-type: none"> • Information, communication and education (AOPSS – quantitative and qualitative) • Stephen’s and Charlotte’s stories 	<ul style="list-style-type: none"> • Patient-reported symptoms of distress (Patient-Reported Outcome Partners; AOPSS – qualitative) • Emotional support and physical comfort during treatment (AOPSS – quantitative and qualitative) • Bonnie’s, Stephen’s and Charlotte’s stories

In addition to different treatment pathways, many personal factors can influence the cancer experience:³¹⁻³⁴

- age and sex
- where a person lives (e.g., large urban centre versus rural or remote community)
- existence and severity of other chronic illnesses and conditions
- support system (e.g., family and friends) and how well established in the country the person is (e.g., recent immigrant)
- work stability and income
- education level and how well the person understands health information
- cultural beliefs about cancer and treatment



Cancer care is not just about treating the disease. Many people with cancer experience a range of symptoms that make their treatment journey more difficult. Routine screening for physical, emotional and practical concerns can help identify the unique needs and challenges individuals have during treatment.³⁵ And the early integration of palliative care during treatment can help prevent and relieve suffering—for both patients and their families—ensuring optimal quality of life.³⁶ Additionally, having a care plan in place at the end of treatment and knowing what to expect next are important in helping people prepare for life after treatment.³⁷

Integrating Palliative Care During Treatment

Early integration of palliative care during treatment not only improves quality of life—better symptom control, reduced anxiety and pain, and more support for emotional, psychosocial and spiritual needs—but also leads to greater satisfaction with care.³⁶ The best possible patient experience means all people with cancer have equitable access to high-quality person-centred palliative care regardless of where they live, their age and the type of cancer they have.

The Canadian Partnership Against Cancer's *Palliative and end-of-life care: A cancer system performance report* details the importance of early integration of palliative care. For more information, please visit systemperformance.ca.





STEPHEN'S STORY

“I generally felt I had control over how I was being cared for...I felt empowered to get to the end.”

After Stephen was diagnosed with cancer, he was told he would need to be treated with chemotherapy.

“It was done all very quickly. From the diagnosis on Monday to the chemotherapy starting on Wednesday; really from the emergency visit to the chemo was all just 12 days. I think they treated me pretty well to get all that done in that time frame—so much was happening.”

“I generally felt I had control over how I was being cared for—not the treatment, because you have no control over that. But I felt empowered to get to the end.”



BONNIE'S STORY

“They put me on really heavy chemotherapy because they really didn’t know where the cancer had started.”

Less than three weeks after receiving her diagnosis, Bonnie underwent a six-hour total hysterectomy. Following surgery, she endured a stronger-than-typical dose of chemotherapy.

“Six weeks after the surgery, I began my first of 18 sessions of chemotherapy. They put me on really heavy chemotherapy because they really didn’t know where the cancer had started. So they said they would give me as strong a chemotherapy as they could.”



CHARLOTTE'S STORY

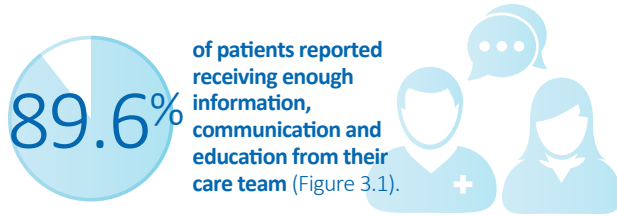
“When you are on treatment you are just working to get through it all. People need to be treated as whole persons.”

After completing a year of chemotherapy, the oncologist offered Charlotte another year of it. Charlotte decided this was her best option, “even though I had side effects and that was not helping improve things regarding my work, function and left-sided disability.” Reflecting on her journey, she considers cancer treatment a “full-time job.”

“When you are on treatment you are just working to get through it all. People need to be treated as whole persons. You are more than a disease. You are more than prescriptions and test results.”

Most people are receiving enough information, communication and education from their health care team, but some want more information on possible changes that will affect their lives.

Based on quantitative data from the Ambulatory Oncology Patient Satisfaction Survey (AOPSS)

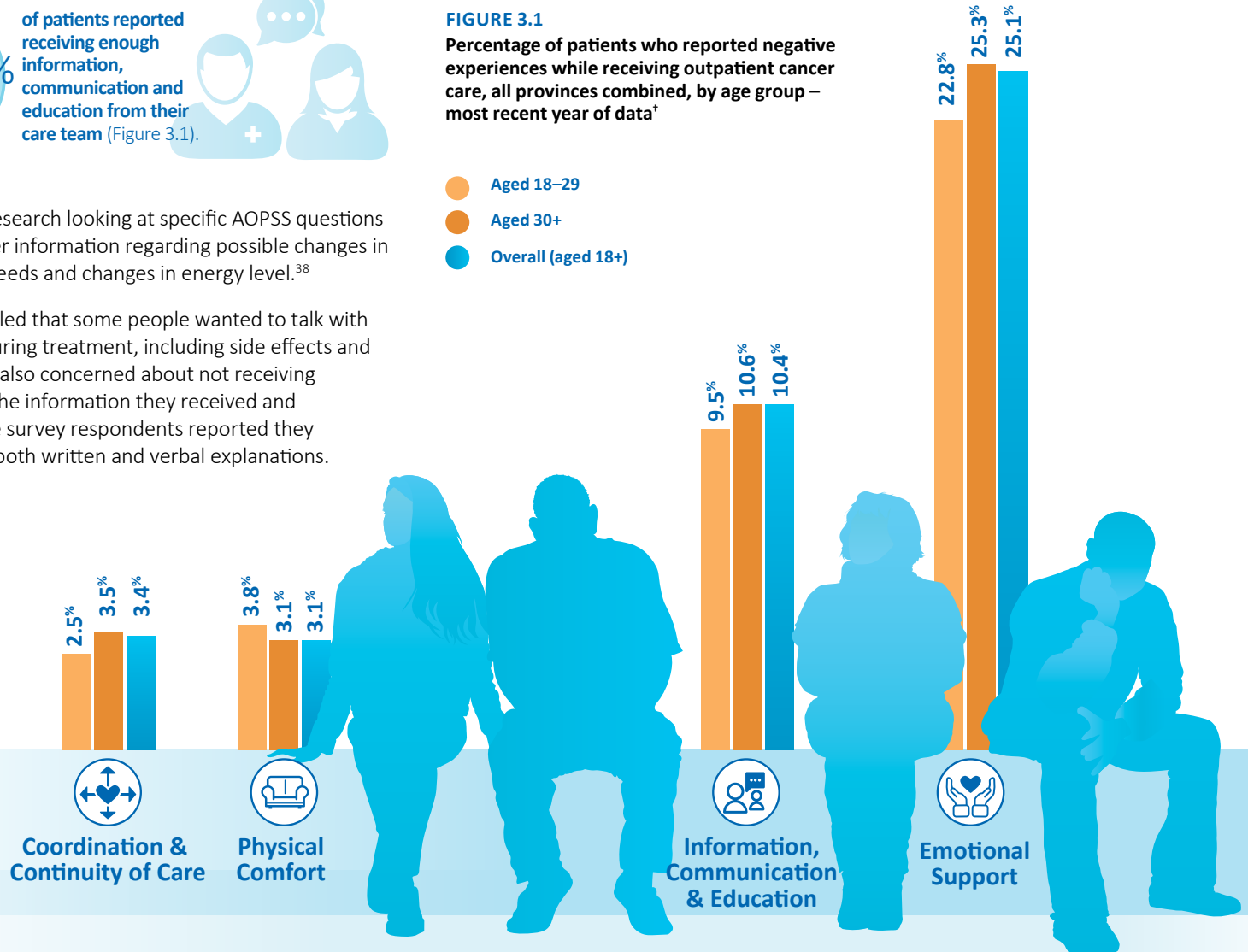


While this is a positive finding, other research looking at specific AOPSS questions found that respondents wanted further information regarding possible changes in work and usual activities, nutritional needs and changes in energy level.³⁸

Written comments in the AOPSS revealed that some people wanted to talk with doctors more about what to expect during treatment, including side effects and how to best manage them. They were also concerned about not receiving information at all, not understanding the information they received and wanting additional explanations. Some survey respondents reported they would prefer that care teams provide both written and verbal explanations.

FIGURE 3.1
Percentage of patients who reported negative experiences while receiving outpatient cancer care, all provinces combined, by age group – most recent year of data[†]

- Aged 18–29
- Aged 30+
- Overall (aged 18+)



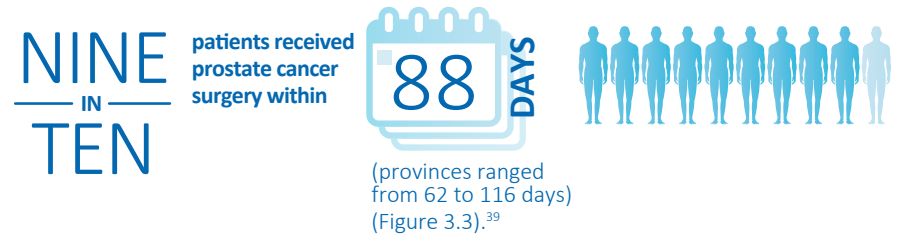
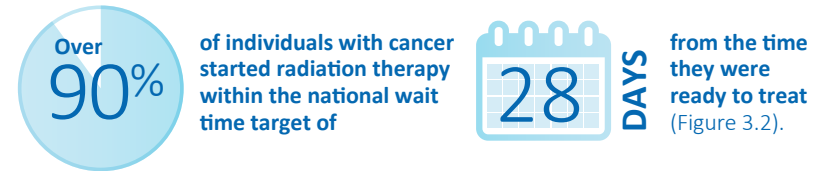
[†]Province-specific data are for the most recent year available. BC: 2012; PE, SK: 2013; AB: 2015; MB, NL, NS: 2016; ON, QC: 2015/16 fiscal year. QC: Excluded for physical comfort because of suppression owing to small numbers. Data for aged 18-29 and aged 30+ includes all provinces except NS and NB. Data for overall includes all provinces except NB. Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

People feel wait times for—and during—treatment are too long for a disease like cancer.

Delays in care can provoke feelings of anxiety, fear and frustration.

As shown in the AOPSS qualitative data, some respondents were frustrated that it took so long to see a specialist or to start treatment. Once treatment had begun, some described instances of lengthy registration processes at cancer centres, waiting too long to see a doctor for a scheduled appointment, lack of timely scheduling of future appointments and delays in care because test results were not available. People “found the waiting to be anxiety provoking” and were often afraid that their cancer had advanced while they were waiting.

People are receiving radiation therapy quickly but wait times for surgery vary significantly depending on the type of cancer.

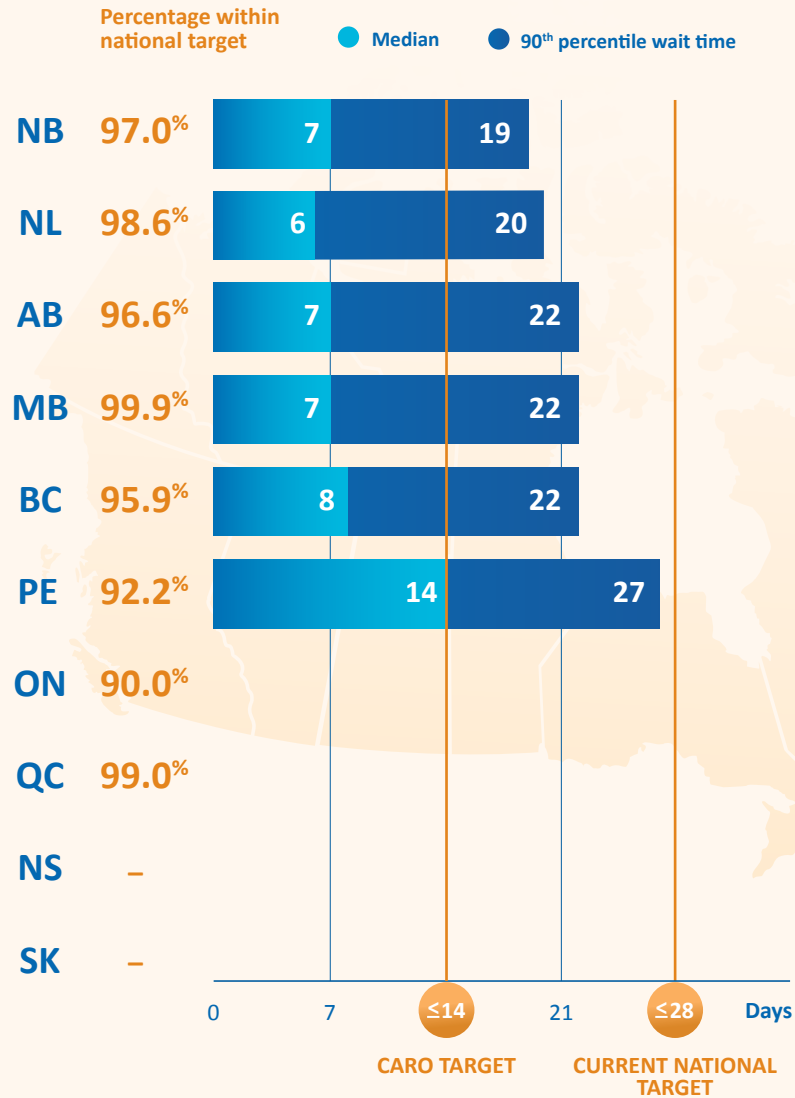


Many prostate cancers are slow growing, so treatment may be considered less urgent than for other cancers and watchful waiting may be undertaken. Given that, the longer wait times reported for prostate cancer treatment (both radiation therapy and surgery) are not unexpected.



FIGURE 3.2

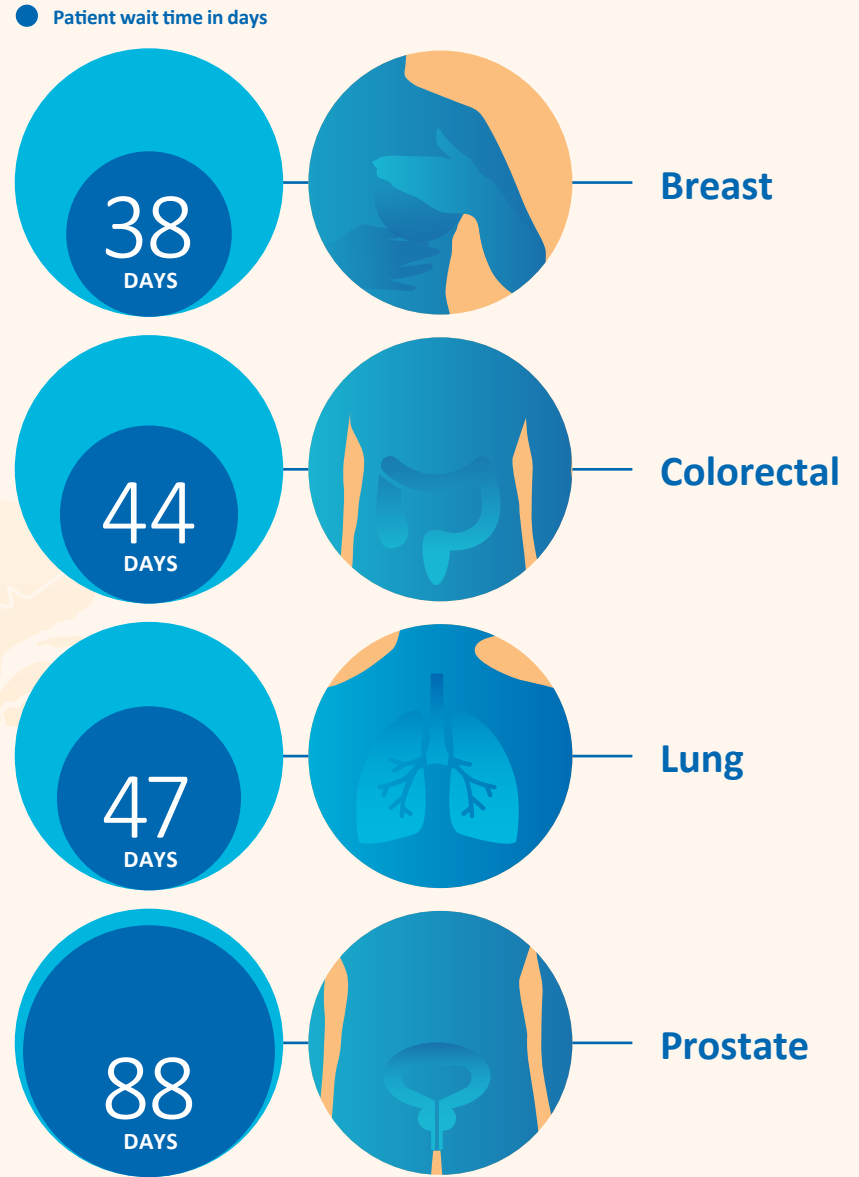
Wait times from ready-to-treat to start of radiation therapy, all cancers, by province – 2014 treatment year



“—” 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.
 National target: 90% of patients receive radiation therapy within 28 days of being ready to treat.
 Canadian Association of Radiation Oncologists (CARO) target: 90% of patients receive radiation therapy within 14 days of being ready to treat.
 Data source: Provincial cancer agencies and programs.

FIGURE 3.3

Wait times from booking date to cancer surgery, by disease site — 2016 treatment year



The Canadian Institute for Health Information defines wait time as the number of days that patients waited between the booking date and the date of cancer surgery. Booking date is when the patient and the appropriate physician agree to a service, and the patient is ready to receive it.
 Data source: Canadian Institute for Health Information.

STEPHEN'S STORY

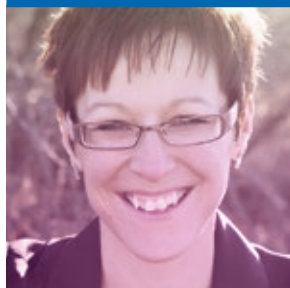


“Just give me the steroid and Benadryl and the name of a doctor in Halifax and I am going.”

For Stephen, “with every dose of chemotherapy the side effects are a little different.” Luckily, nurses told him what to expect during treatment so he was not surprised by these side effects.

However, after the third cycle of chemotherapy he experienced an extended rash, which almost prevented him from attending his son’s graduation. Stephen did not want to miss it, so he told his oncologist “‘just give me the steroid and Benadryl and the name of a doctor in Halifax and I am going.’ And all the pictures of the graduation have me with a really red face. But I got there.”

CHARLOTTE'S STORY



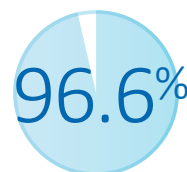
“We were given a big binder, all the papers and pamphlets, on the first or second appointment.”

Charlotte was given a lot of information at the cancer centre at the start of treatment, but struggled to understand the material provided.

“We were given a big binder, all the papers and pamphlets, on the first or second appointment. But it was all so overwhelming. And there was no rhyme or reason to the material. I had to research a lot online.”

Most people are generally positive about the coordination and continuity of care they receive; however, some desire more consistency in staff.

The AOPSS quantitative data showed that



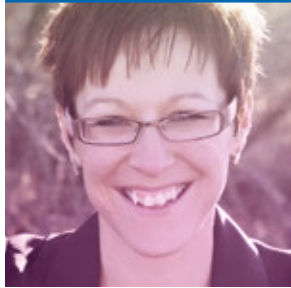
of patients were generally positive about the coordination and continuity of care they received (positive and neutral rating) (Figure 3.1).



However, other research done using the AOPSS found that respondents reported that they didn’t always know the next step in their care nor did they feel providers were always familiar with their medical history.³⁸

Written comments in the AOPSS revealed that people wanted to see the same doctor at each cancer centre visit. They felt this would allow for relationship building with their doctor and allow for providers to know them as a person. Some respondents had “seen a different doctor every time,” meaning they had to repeat their stories for each new care provider. The constant changing of physicians left some individuals wondering if anyone was overseeing their overall treatment or really knew what was happening to them. Some stated fears of “falling through the cracks” and the negative impact this could have on their care.

CHARLOTTE'S STORY



“We had to recalibrate the whole team. It was tough on me.”

Charlotte had a troubling experience with her care team in the middle of treatment. Her primary care provider, whom she had come to trust, moved away, which resulted in having to convene a new team.

“We had to recalibrate the whole team. It was tough on me. One time a new nurse came into my room and said my MRI showed changes. Well that is the worst thing a cancer patient can hear, that there are changes. Then she said, ‘Oh no, wrong chart.’ Had I had my own consistent team I expect that would never have happened.”

STEPHEN'S STORY

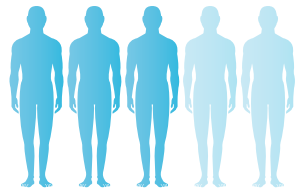


Stephen felt his care was handled well by his doctors, but emotional concerns were still a challenge for him.

“Now I was handled in an expeditious way, and that was phenomenal, don't get me wrong, but it felt like a roller coaster ride emotionally.”



People are receiving care for their physical comfort, but individuals and their families need more information about—and better access to—services to manage symptoms of distress.



THREE
IN
FIVE

people with cancer who visited a cancer centre were screened for distress (i.e., fatigue, anxiety, pain and depression). Of those, more than half reported physical and emotional symptoms of distress (Figure 3.4).

35.2%

reported moderate to high levels of fatigue.

20.4%

reported moderate to high levels of anxiety.

19.0%

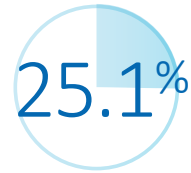
reported moderate to high levels of pain.

15.7%

reported moderate to high levels of depression.

Among AOPSS respondents (as shown in the quantitative data),

across Canada, emotional support was the most negatively rated dimension of care:



IN
CONTRAST



of respondents gave physical comfort a negative rating (Figure 3.1).

Among men with prostate cancer, over half reported they had not been referred to another provider for help with their anxieties and fears.⁴⁰

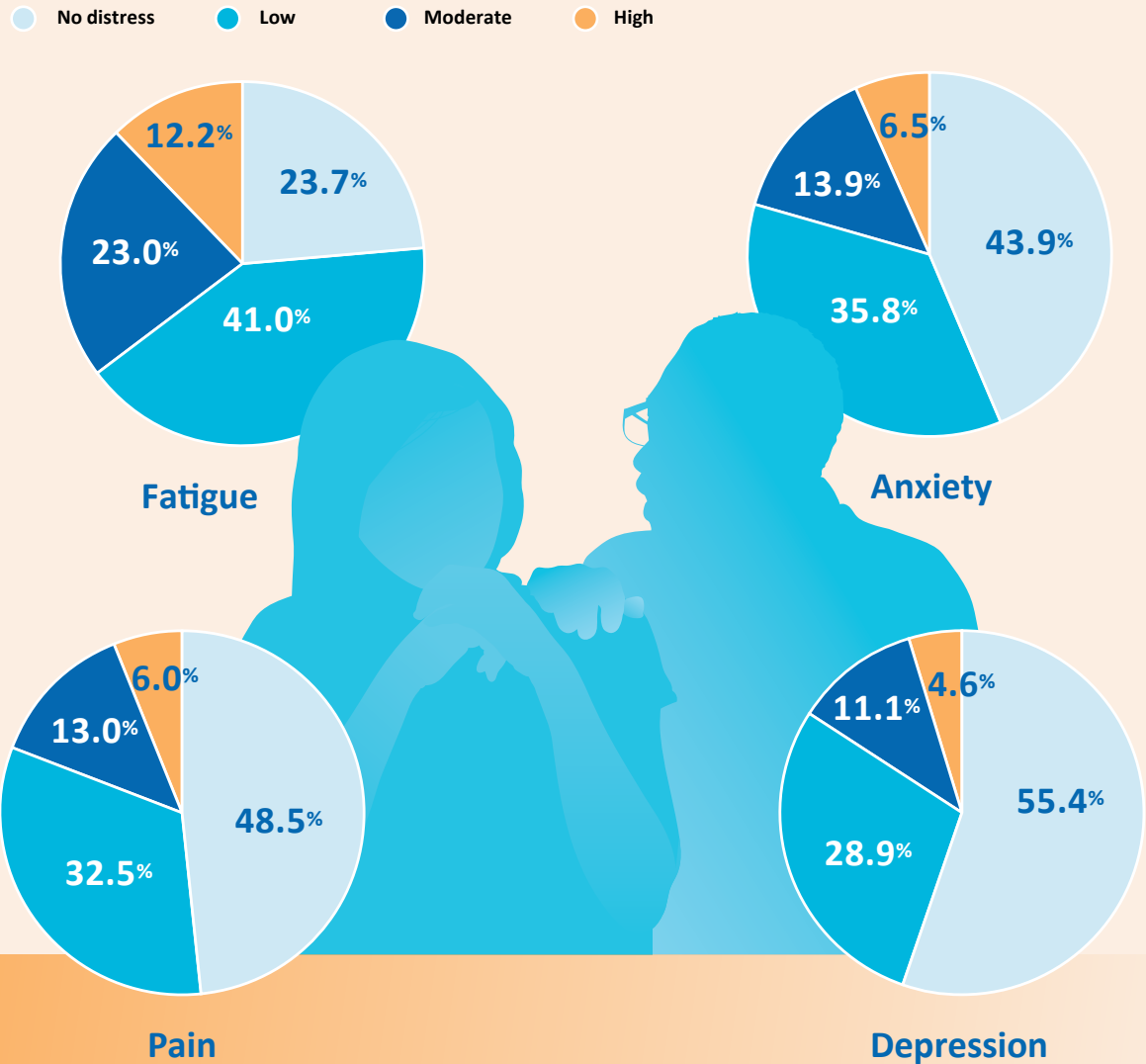
In the written responses to the AOPSS, some people described feeling “very alone” and “isolated” during treatment and cancer being “a lot to deal with” without professional support. They expressed the desire for someone who could talk more about their psychosocial, emotional and spiritual concerns than was possible in the routine course of care. Some people voiced the need for emotional and spiritual support services to be “significantly increased” and for a counsellor to be a part of the care team. Support for families was cited as being absent and “help with the patient’s emotions and how to navigate their own emotions” was needed. While most people were not accessing services to meet their psychosocial, emotional and spiritual needs during treatment, those who did reported they got “a lot out of counselling.”

“I really think those who have been through a cancer experience understand the side effects better than the health professionals and can explain it. They can identify with the side effects and talk about it better. My ex was my best coach. She had had cancer in the past and she told me in language I could understand all about the side effects.”

Stephen

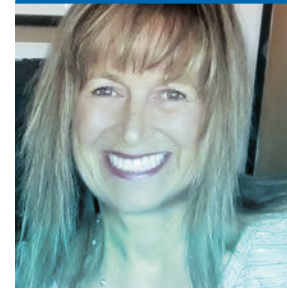
FIGURE 3.4

Proportion of patients who reported symptoms of distress, provinces combined – most recent three months of data in 2016*



*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. The Edmonton Symptom Assessment System-revised asks patients to describe how they feel on a scale of 0–10. 0 indicates no symptoms (i.e., no pain, anxiety, fatigue or 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, which are excluded: pain, 0.4%; fatigue, 0.3%; anxiety, 0.4%; depression, 0.4%. ON: Denominators vary across symptoms owing to skipped questions on paper questionnaires. NL: Patients who indicated they had no symptoms (score of 0) and who did not answer could not be separated. The number of people likely to have given no response was therefore estimated based on the overall average of other provinces and excluded. Data source: PRO partners.

BONNIE'S STORY

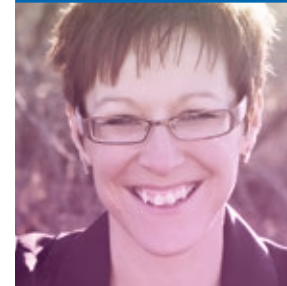


Bonnie was left with residual scar tissue and pain in the area where the chemotherapy port was inserted. She also experienced side effects from chemotherapy that resulted in emotional challenges.

“I went through my chemo, and of course the emotions that go along with having to lose your hair, your eyebrows and everything.”

“I tried to stay positive about everything as much as I could. There’s times, you know, you get down...you just can’t help it...there are your quiet, alone times, and there’s anxiety periods for sure.”

CHARLOTTE'S STORY



Charlotte’s main caregiver was her husband. He also experienced emotional challenges while Charlotte was receiving treatment for over two years.

“My husband had to continue to work full time while caring for me and our daughter. On top of this he was constantly reminded I was sick and that my disease could eventually kill me—there was no way to predict this and no way to ignore it. This wore on him and his anxiety and stress levels went through the roof.”

Challenges related to arranging travel, accommodation and financial constraints are burdensome for people affected by cancer.

CHARLOTTE'S STORY



“I spent as little time as possible away from home.”

Charlotte had to travel from Medicine Hat to Calgary for six weeks for radiation treatment.

“My husband would stay with our three-year-old daughter through the week. And a different family member would come with me each week to Calgary. I was in Calgary from Monday to Friday. And the team was so good to organize my appointments for late afternoon on Monday and early mornings on Fridays, so I could get home on the weekends. I spent as little time as possible away from home.”

In their written comments on the AOPSS, some respondents described travelling for treatment and having to arrange accommodations near the treatment centre as “very difficult financially and logistically” and as significant sources of distress.

These problems disrupted their family lives and everyday routines and caused financial strain (e.g., parking costs, loss of income and medications paid for out of pocket). However, people expressed gratitude when cancer centre staff were able to accommodate their schedule and allowed them to spend as much time as possible outside the facility.



What are the main challenges people experience while being treated for cancer?

Some patients want more information on what to expect when they undergo treatment for their cancer and possible changes that will affect their life. In addition, most people report experiencing symptoms of distress during treatment, including fatigue, anxiety, pain and depression. Many would like more information about—and better access to—support services that address their and their families’ psychosocial, emotional and spiritual concerns.

Examples of innovative practices to improve people’s experiences with cancer

- **Publicly available cancer surgery wait time information**

All provinces (except Alberta and Prince Edward Island) report cancer surgery wait times for specific disease sites and/or by region on their provincial websites.⁴¹⁻⁴⁸ Furthermore, British Columbia and Nova Scotia provide cancer surgery wait time information by disease site, hospital and surgeon.

- **Support groups**

Cancer Chat Canada provides access to online support groups led by professional facilitators for people across Canada affected by cancer, including patients, survivors and family members.⁴⁹ The sense of community and the shared experiences provide emotional support and a place to safely discuss personal topics.

- **Patient education**

- **In-person education sessions**

In Nova Scotia, in-person education sessions are offered twice per month to meet the needs of adults with cancer and to improve the patient experience.⁵⁰ The five symptom management sessions focus on fatigue, anxiety and worry, sadness and depression, pain, and brain fog. Prince Edward Island (PEI) patients have an opportunity to join Nova Scotia’s in-person sessions via telehealth.

PEI offers a weekly Oncology Patient Orientation Program for people with cancer and their caregivers.⁵¹ The program provides information

about the logistics of the cancer facility and processes, along with education on the psychological and practical aspects of cancer treatment, home life and wellness.

- **Informational videos**

Cancer agencies in Alberta, Saskatchewan and Manitoba collaboratively developed a video series, “Living well with cancer-related fatigue,” to help people with cancer identify and address symptoms of cancer-related fatigue.⁵²

- **Awareness campaigns**

- **British Columbia’s Emotional Support Transformational Project—Get Your Province Together!⁵³**

Six cancer centres and 33 hospitals in BC worked together alongside individuals and families to improve emotional support for people with cancer. Focus groups were held with patients, families and staff to understand the reasons for lower satisfaction scores and to create strategies for improvement. The top four strategies have been implemented.

The project’s evaluation showed a 300% increase in Cancer Chat Canada use, a 44% improvement in perception of emotional support by people with cancer and a significant improvement in the awareness of emotional support resources by staff, patients and families.

Finding a “new normal”

What will life be like?

Cancer is not over when it is over: even though treatment is complete, people still need the support of the health care system.⁵⁷ This section describes factors that contribute to a positive experience for individuals and their families after cancer treatment ends, using different data sources.

After completing cancer treatment, people experience various changes, some of which can persist for years and even become a permanent part of their lives.

When treatment is over, individuals and families often have to face a reality that looks very different from life before cancer. People who have had cancer may experience numerous difficulties after treatment, including physical challenges such as prolonged fatigue; emotional challenges, including fear of cancer returning; and practical concerns, such as going back to work or school.^{54,55} Individuals experience these issues in different ways and the intensity of the challenges can vary from one person to the next. Sometimes, people feel as if they were left on their own to deal with challenges after treatment, without a clear idea of who in the health care system is responsible for their follow-up or how to reach out for help.⁵⁶

Pillars of a positive experience within a person-centred approach to care



PILLARS OF A POSITIVE EXPERIENCE

I AM A UNIQUE INDIVIDUAL

Being seen as an individual who has specific challenges and priorities while finding a new normal.



I AM RESPECTED

Receiving coordinated care across health care professionals in a way that ensures follow-up and facilitates the transition from specialist to survivorship care.



I AM EMPOWERED

Being able to ask for and get information that teaches how to cope with changes after treatment or that guides to useful resources.



I AM SUPPORTED

Receiving support for both the temporary and permanent physical, emotional and practical changes that arise while adjusting to life after cancer.

ASSOCIATED INFORMATION/ DATA

- Charlotte’s and Stephen’s stories
- Prevalence and severity of physical, emotional and practical challenges (Transition Study)
- Challenges when returning to work (patient stories, Transition Study, AOPSS – qualitative)
- Care provider in charge of follow-up care (Transition Study)
- Charlotte’s story
- Percentage of patients who receive useful information about concerns (Transition Study)
- Ease/difficulty of asking doctors questions (Transition Study)
- Reasons for not seeking help for concerns (Transition Study)
- Ease of getting help for concerns (AOPSS – qualitative)
- Self-reported wait times for patients who sought help for most difficult concern (Transition Study)



STEPHEN'S STORY

“I get aches and pains, off and on, and you can’t help but worry about them. What do they mean?”

Despite a challenging diagnosis, Stephen has been in remission since 2015. “I was told I was in remission one year after my diagnosis. I was told that a lot of people do not do well with this, but that I was one of the good ones.” After “staring death in the eye,” Stephen has adopted a direct and pragmatic outlook on life. But he feels anxious about cancer returning—which is a concern most people experience after achieving remission.

“I get aches and pains, off and on, and you can’t help but worry about them. What do they mean? Is it the cancer back again? You find you worry about these little things, about a number of them.”



CHARLOTTE'S STORY

“...It really helps to be directed as to where to go and to supports in the hospital or beside it.”

Charlotte worked hard to stay healthy and strong throughout two years of cancer treatment, and felt positive at the last round of chemotherapy in November 2015, when she was told the tumour had not grown since surgery.

Yet life became harder in many ways because there was no discussion of what to expect next. “I found it was all harder after treatment stopped. So much more of what you are dealing with is mental, emotional and dealing with day-to-day living. It really helps to be directed as to where to go and to supports in the hospital or beside it. For me there was nothing. No transition appointment. There was no closure.”

What is the Transition Study?

In Canada, the availability of consistent, reliable data on what individuals experience in the post-treatment period has been limited. To fill this information gap and better understand the challenges related to cancer survivorship, the Canadian Partnership Against Cancer collaborated with all 10 provinces to conduct the Experiences of Cancer Patients in Transition Study.

Over 13,000 people who had completed cancer treatment within the past one to three years participated in the national survey to share their experiences as they transitioned from specialty oncology care to the broader health care system. As the first national survey of its kind, the Transition Study provides a foundation of information about the various difficulties, information requirements, and met and unmet needs of cancer patients and survivors across the country.

This section provides a first look at the findings from adult respondents (aged 30+) with non-metastatic cancers.

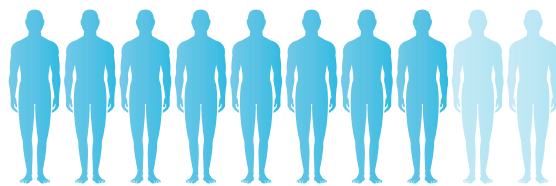


People continue to experience diverse physical, emotional and practical challenges after completing cancer treatment.

The end of treatment does not mean that individuals stop having concerns or challenges.⁵⁸



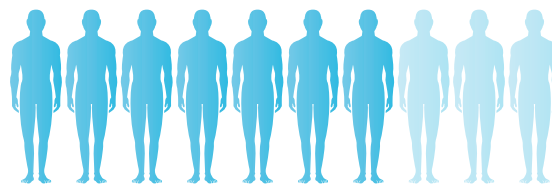
FIGURE 4.1
Prevalence and severity of physical, emotional and practical concerns after completing cancer treatment – 2016 reporting year



EIGHT
IN
TEN patients had physical challenges after their treatment ended. Increased fatigue and changes in sexual function and fertility were their biggest concerns.



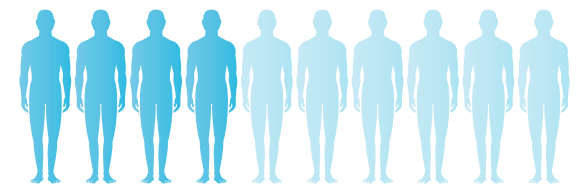
Fatigue was the most difficult physical concern to get help for, especially among patients with hematological cancers.



SEVEN
IN
TEN patients reported having emotional concern after treatment ended. Worry about cancer returning, depression and changes in sexual intimacy were their biggest concerns.



Worry about cancer returning was the most difficult emotional concern to get help for.



FOUR
IN
TEN patients reported having practical challenges after their treatment ended. Returning to work or school and difficulty getting life insurance were their biggest concerns.



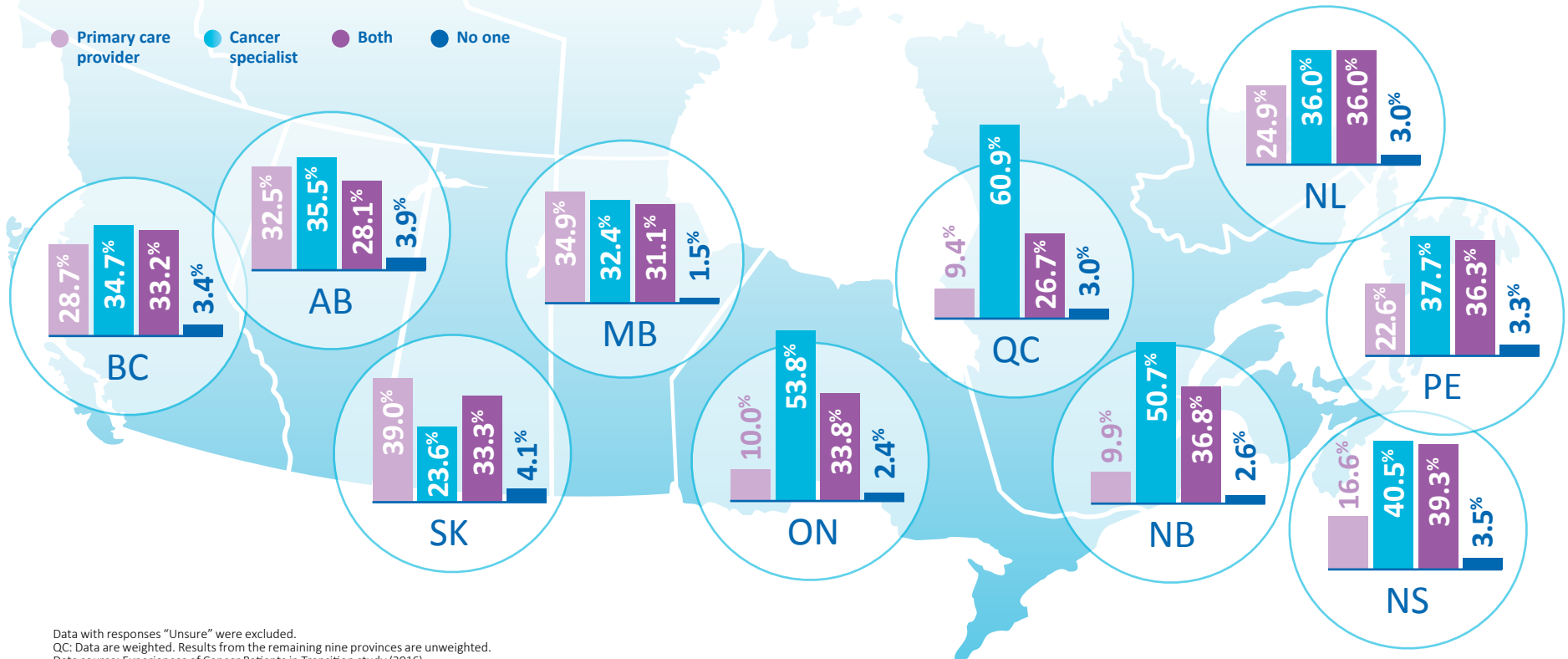
Financial problems such as paying health care bills and getting life insurance were the most difficult practical concerns to get help for.

Individuals who have a care provider in charge of their cancer care follow-up find it easier to get help for their concerns than those without someone in charge after treatment.

- **42.4%** of participants identified their specialist (oncologist, hematologist, surgeon or other) as the care provider in charge of their follow-up care.
- **31.9%** reported both specialists and primary care providers (family doctor, nurse or general practitioner) as being in charge of their follow-up.
- **22.4%** identified a primary care provider as the one in charge.
- **3.3%** reported that no one was in charge of their care after treatment.

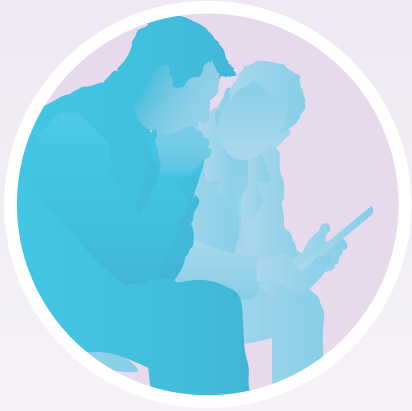
Transition Study data showed that most people had a cancer specialist (alone or with a primary care provider) in charge of follow-up care after treatment (Figure 4.2).

FIGURE 4.2
Care provider in charge of follow-up, by province – 2016 reporting year



Data with responses "Unsure" were excluded.
 QC: Data are weighted. Results from the remaining nine provinces are unweighted.
 Data source: Experiences of Cancer Patients in Transition study (2016).

The data show a positive link between having someone in charge of follow-up care and getting help for concerns after treatment.



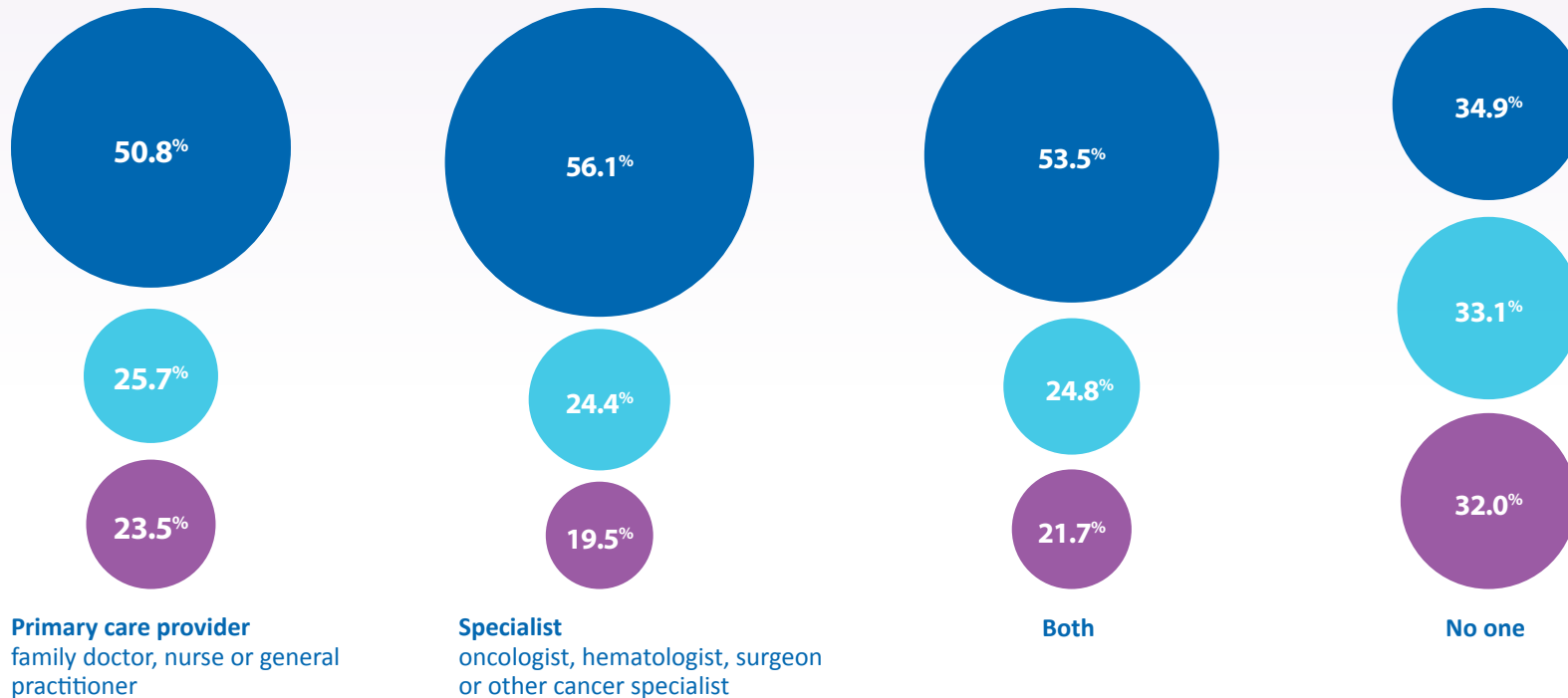
Of patients/survivors with a care provider in charge, 50.8–56.1% found it easy or very easy to find help for their concerns. Of those without someone in charge, 34.9% found it easy (Figure 4.3).

“When I got out, I went to my family doctor and I said, ‘You are my quarterback outside the hospital and I want an appointment to see you once a month, even if it is just to say hi.’ Seeing someone regularly, who really cares for you, is so helpful.”

Stephen

FIGURE 4.3
Ease of getting help for post-treatment concerns, by care provider in charge – 2016 reporting year

● Very easy/easy ● Hard/very hard ● Did not get help



Data source: Experiences of Cancer Patients in Transition Study (2016).

The easier it is for people to ask their care providers questions, the better their experience is after treatment.

After treatment, some individuals and families deal with an altered reality and day-to-day life. Some may feel uncertain about what to do and may have more questions than they have answers.⁵⁹ Qualitative data from the Ambulatory Oncology Patient Satisfaction Survey (AOPSS) showed that most individuals needed someone they could talk to about their concerns “at length” after treatment and that they needed more information that addressed their challenges. In some cases, people ended up going to the emergency department to find help for their problems, but staff there may not be familiar enough with cancer care to help them.

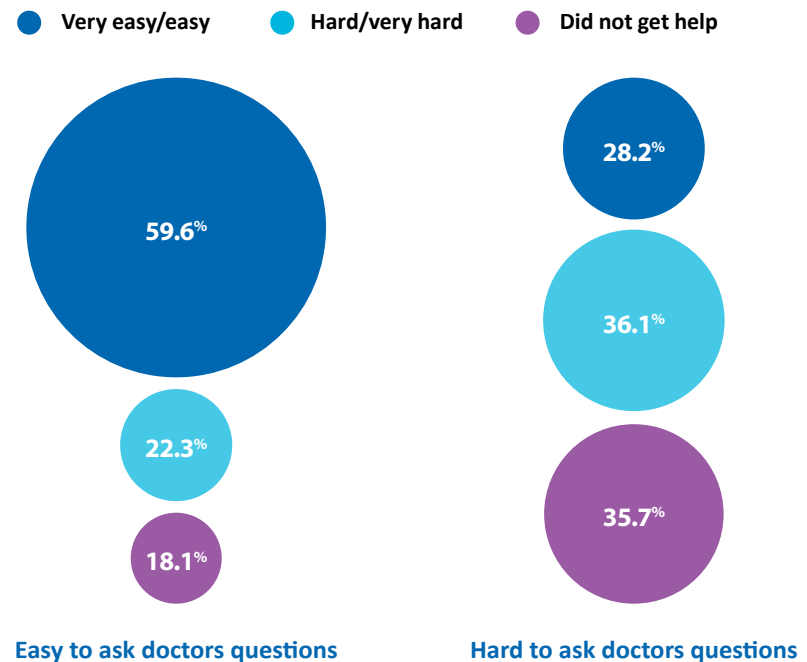
If they are not addressed, these concerns can affect the daily function and quality of life of individuals and families who are going through the adjustment process.

Data from the Transition Study showed that the easier it was for patients/survivors to ask their doctors questions, the easier it was to get help for their physical, emotional and practical concerns. One-third of patients/survivors who had a hard time asking questions of doctors found it very hard to get help or did not get help at all (Figure 4.4).

Primary care practitioners and other health care professionals in cancer or community care centres—in addition to doctors—can help individuals address their emotional, physical or practical concerns.

For example, participants in the Transition Study who were able to visit or speak to other health care providers in cancer centres found it easy or very easy to get help for their concerns (56.6%), compared with those who were unable to reach other care providers (19.1%).

FIGURE 4.4
Ease of getting help for post-treatment concerns, by difficulty asking questions to doctors – 2016 reporting year



Data on the “neither easy nor hard to ask doctors questions” category are not shown.
Data source: Experiences of Cancer Patients in Transition study (2016).

“The team is a huge factor—as long as they are ready to work with me and I am a member of that team. If I am not a partner, then it won’t be as good. The patient is a partner, or needs to be. It is not just all about them, the team. You all need to work together and allow the patient to adjust their role as the situation calls for it.”

Charlotte

6 out of 10 individuals look for help to alleviate their concerns after treatment; sometimes, they cannot find it.

Over one-third of people who seek help for their most difficult concerns report waiting too long or being unable to get help.

Most people are concerned about side effects and unexpected complications after treatment. Written comments in the AOPSS revealed that some people felt their concerns were dismissed or brushed off, and they became more distressed when their difficulties remained unaddressed.

The Transition Study asked patients/survivors about the physical, emotional or practical concern they had the most difficulty getting help for and how long they had to wait to get help. Depending on the nature of the concern (emotional, physical or practical), respondents answered the following:

- 32–37% found help within 3 months.
- 19–21% found help in 3–12 months.
- 8–13% waited a year or more to get help.
- 34–36% were not able to get help.

Some people do not seek help for their problems, mostly because they think nothing can be done. Some do not want to ask a health care provider for help. As a result, their concerns after treatment remain unaddressed.

The Transition Study revealed that patients/survivors did not reach out for help mainly because someone had told them their concerns were normal and they thought nothing could be done about them, because they did not want to ask, or because they did not know services were available (Figure 4.5).

FIGURE 4.5
Reasons for not seeking help for physical, emotional or practical concerns after completing treatment — 2016 reporting year



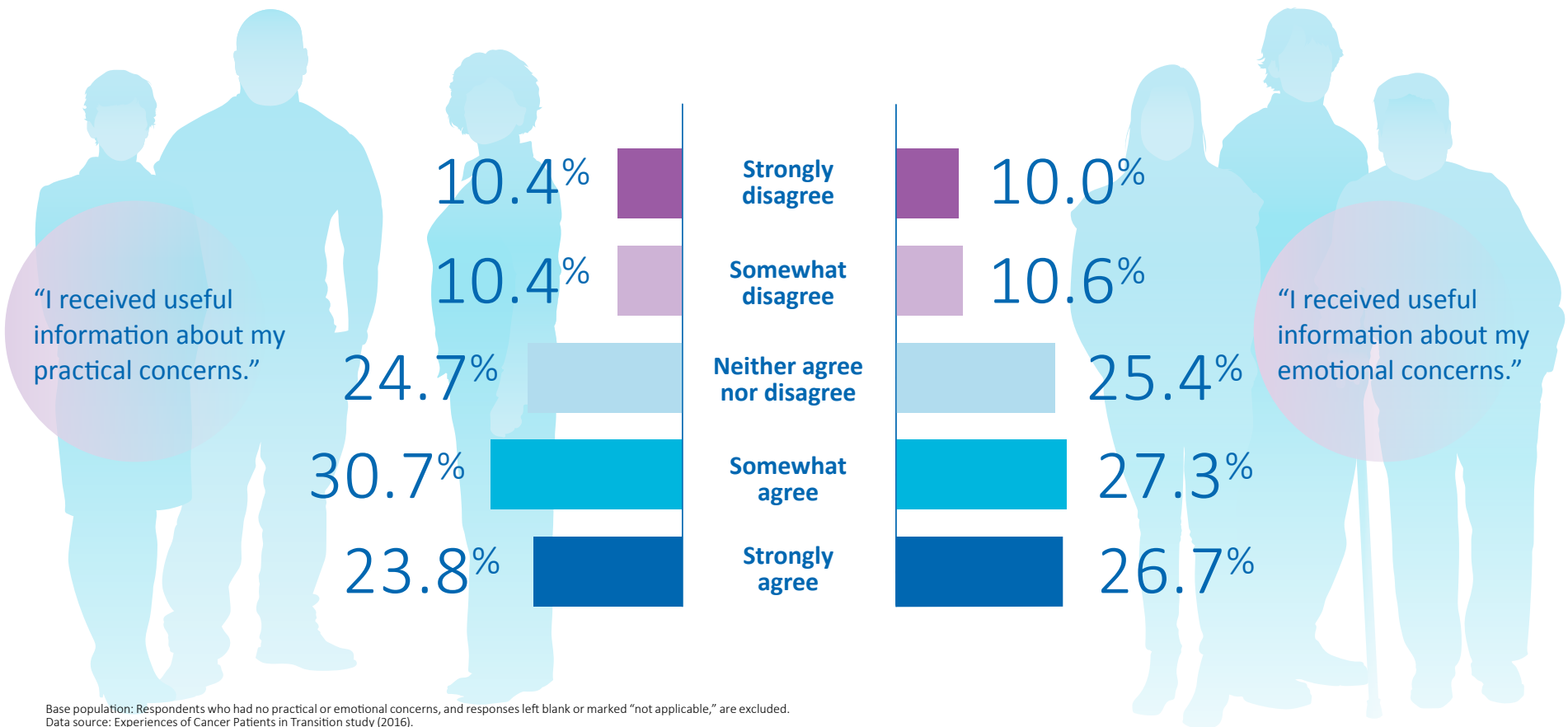
Percentages reflect total number of times a certain response was selected regardless of whether a respondent checked off one or more responses. Base population excludes respondents who had no concerns and those who sought help for their concerns. Data source: Experiences of Cancer Patients in Transition study (2016).

Receiving useful information to address concerns and getting help for practical needs are essential elements of a positive experience after treatment.

Only half of the people with emotional or practical challenges receive useful information that addresses their needs.

FIGURE 4.6
Percentage of patients who reported receiving useful information for their emotional or practical concerns – 2016 reporting year

The Transition Study showed that most patients/survivors agreed that they received useful information about their physical needs (74.9%). But when asked whether they received useful information about their emotional or practical concerns, only half agreed they received information to address those concerns (Figure 4.6).

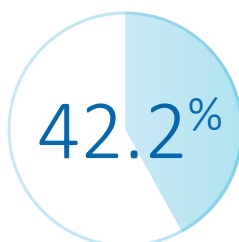


Base population: Respondents who had no practical or emotional concerns, and responses left blank or marked “not applicable,” are excluded.
Data source: Experiences of Cancer Patients in Transition study (2016).

Almost half of individuals aged 30 to 64 are concerned about returning to work or school after treatment. Over half do not seek help for this concern.

Cognitive limitations, trouble coping, fatigue, depression and anxiety can get in the way of returning to work or school. In some cases, people find themselves not being able to keep up with work the way they want to.⁶⁰ Written comments in the AOPSS survey revealed that most respondents who expressed concern about returning to work immediately after ending treatment were not entirely convinced health care professionals understood what they were experiencing or knew how to support them as they dealt with these challenges.

Data from the Transition Study revealed that



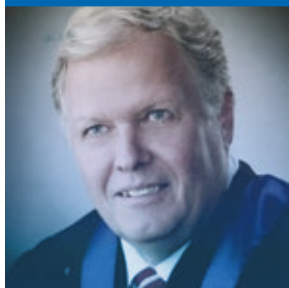
of participants (aged 30 to 64) were concerned about going back to work or school one to three years after ending treatment.

19.3% reported it was a big concern.

12.2% reported it was a moderate concern.

10.8% reported it was a small concern.

STEPHEN'S STORY

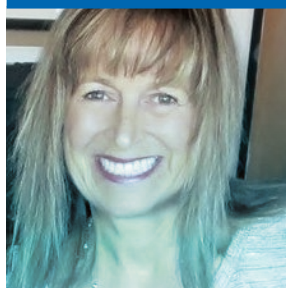


After treatment, Stephen returned to work part time and adapted to the permanent changes in his life.

“Currently I am working about 60% of the time

and am working on a contract basis. The work situation was challenging as my previous employer laid me off as soon as he heard I was ill. So that meant I did not have any income. And I did not have any sick time coverage as the sick time could not be carried over from the previous 15 years. This was not a good situation. Now I am doing part-time contracts and it is working out.”

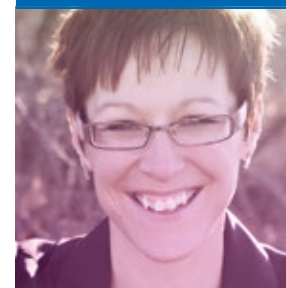
BONNIE'S STORY



For Bonnie, going back to work after chemotherapy was over was one of her biggest challenges. Her permanent fatigue made her reconsider her decision to return to work.

“I worked for probably seven or eight months and I just couldn't do it anymore because I had no quality of life. I would go to work in the morning, I'd come home, and I'd be totally exhausted. The doctors decided that it was best for me and for my health—and because I had a recurring type of ovarian cancer—that I finish work and try to concentrate more on taking care of myself. So that's what I did. I was broken-hearted, as I really didn't want to give up work, but the exhaustion and fatigue I was feeling didn't allow me to continue working.”

CHARLOTTE'S STORY



After completing the final round of chemotherapy, Charlotte and her family decided it was best for her not to return to work in the foreseeable future. Her former role as VP

involved a lot of traveling and stressful situations that could affect her recovery.

“I have grieved the loss of my work. It was so hard to give it up. I had to face the reality that my brain and body could not do what they once could, I was not able to do what I once excelled at doing. I just could not keep up and deliver as I wanted to do. It was just too much stress with the side effects and it would help not to be in the kinds of situations work created.”



Most individuals live with the uncertainty of cancer returning.⁶¹ For some, cancer does come back.

Sometimes, cancer returns. When that happens, patients, survivors and their loved ones often feel discouraged, hopeless and even more uncertain about the future. Finding strategies to cope, maintaining emotional well-being and regaining a sense of control are essential.

BONNIE'S STORY

After treatment was over, Bonnie remained cancer-free for four years. She and her partner were planning their wedding when she found out her cancer was back. "I was having my yearly CT scans and in 2014, they discovered that I had a recurrence of my cancer." This time, she received a more aggressive, second-line chemotherapy treatment. As a result, she and her partner decided to postpone their wedding to focus completely on her treatment and well-being.

"While I was going through that, I tried to stay as healthy as I could, eat as healthy as I could. I did a lot of juicing. I started yoga. I tried to walk as much as I could. More so after the second time."

Bonnie and Charlie married in August 2016.

Integrating palliative care is important

Palliative care is shifting from care of the dying to a broader focus on integrated care, with palliative care provided to anyone with a life-threatening illness with the intent of providing comfort and improving quality of life.⁶²

Recurrent cancer is being seen more frequently—sometimes years after initial treatment. A recurrent cancer often requires a full assessment and proven management strategies to preserve quality of life and relieve emotional distress for individuals and family members. In an integrated model of care, palliative care can provide relief by addressing emotional and physical effects that persist after treatment is over or that may arise after a cancer recurrence.

What are the main challenges people experience while finding a new normal?

Most patients with non-metastatic cancers continue to experience physical, emotional and practical challenges one to three years after completing cancer treatment. Some report having difficulty asking doctors questions or talking to other care providers in cancer centres and community settings, which can be a barrier to getting help for their concerns. Although most people receive useful information about their physical concerns, many report that they are not receiving useful information that can help address their emotional or practical concerns.



Examples of innovative practices to improve people’s experiences with cancer

Health care provider education and training on cancer survivorship

- The McGill University Health Centre developed **Caring for Cancer Survivors in Family Medicine**, an educational workshop for primary care providers in Montreal. The program is accredited by the College of Family Physicians of Canada and is focused on improving the care that patients receive after active treatment ends. This educational intervention has demonstrated increased primary care practitioner confidence and knowledge about late effects of cancer treatment (e.g., physical and psychosocial challenges, sexual dysfunction and pain management).^{64,65}

In-person and online information programs for patients

- Nova Scotia, Newfoundland and Labrador and Saskatchewan implemented the **Cancer Transitions: Moving Beyond Treatment** program. It is a six to seven week in-person program designed to support and empower cancer survivors as they transition from disease-oriented treatment to life beyond treatment. It provides support and information about exercise, nutrition, emotional health, well-being and local services available to assist with coping during the transition.⁶⁶⁻⁶⁸

-
- Manitoba developed the **Moving Forward After Cancer Treatment Program**.⁶⁹ This program helps patients transition to follow-up care at the end of curative therapy by developing standardized care plans, implementing transition appointments and providing cancer-specific follow-up care resources.⁶⁹
 - McGill University, the BCCA and the de Souza Institute partnered with the Canadian Partnership Against Cancer to develop **Cancer and Work** (cancerandwork.ca). It is a website that provides interactive resources for cancer survivors, health care providers and employers. Available resources include information and tools to support returning to, staying or leaving work and to manage challenges after returning to work.⁷⁰

Cancer survivorship registries

- The **Patient Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship (PROFILES)** registry collects patient-reported outcomes annually in the Netherlands. The data are linked with patients' clinical data available through cancer registries. This unique data linkage makes it possible to interpret outcomes in relation to medical and demographic characteristics and provides a unique monitoring system for outcome assessment.⁷¹

The recently released **Pan-Canadian Framework for Cancer Survivorship Research**, developed by the Canadian Cancer Research Alliance in collaboration with over 30 federal agencies, can help to build and expand survivorship research infrastructure across the country to accomplish this aim and to identify opportunities to advance person-centred care in Canada.⁶³



STEPHEN'S STORY

“Connecting to friends and being grounded in the inevitability that we all will need to face life’s challenges.”

“Upon reflection after this experience, life is fragile and I need to find ways to live my life fully; look for alternative ways to earn an income. Connecting to friends and being grounded in the inevitability that we all will need to face life’s challenges. Some we will be able to overcome; others will require us to consider our contributions and live the rest of our lives with hope and dignity. There are people around you who really care!”



BONNIE'S STORY

“I don’t know if anyone who has received a cancer diagnosis will ever feel ‘normal’ again.”

“In addition to getting married in 2016, I also turned 60 and celebrated my birthday with over 100 friends and family members. I try to stay as active as I can. I walk, go to yoga and line-dancing and have recently begun to enjoy painting. I don’t know if anyone who has received a cancer diagnosis will ever feel ‘normal’ again. The fear of it coming back is there every day for me, as I was told by my doctor that I have a recurring type of ovarian cancer...I did already have one recurrence in 2014—four years after my initial diagnosis. A cancer diagnosis does indeed change your life forever.”



CHARLOTTE'S STORY

“When my cancer recurs in the future, we hope with confidence that there will be better options for me.”

“I am a stronger person now. We are a stronger family, and we have sorted out our priorities in our lives. This type of tumour has tentacles and they spread throughout so recurrence is highly likely but it takes time for them to grow to a size that they can see them. We choose not to let this fact rule our lives but in all honesty, it does still come to mind in some of the oddest moments. When my cancer recurs in the future, we hope with confidence that there will be better options for me. I remind myself daily, yes I have lost parts of me, I can’t do all the things I used to be able to do, but I choose to embrace all that can still be—I choose to be the best wife, mother, friend and person I can be not in spite of my cancer but because of it.”

Conclusion

There are no breaks during the cancer journey.

From the moment people start wondering if they have cancer to post-treatment care, the cancer experience is a continuous one for everyone involved. Providing person-centred care during each stage of the journey will ensure that patients and families are seen as unique individuals, receive coordinated care that is considerate of their time and preferences, have access to useful information that promotes self-care, and have their various needs met as they arise. The Canadian Partnership Against Cancer will continue to work with patients, families and health care partners across Canada to spread innovation and promote better quality of care for all.



The way ahead: What system changes are needed to catalyze a shift from disease-centred to person-centred cancer care?



Clinicians should have access to real-time data that informs their clinical decisions, to help ensure patients' physical, emotional and practical needs are being met from cancer suspicion through to survivorship.



Health system administrators should adopt existing evidence-based, validated tools to collect data on patient-reported outcome and experience measures from cancer suspicion to survivorship.



These tools should be adapted by **hospitals and other health care facilities** to address the local real-time information needs of their clinicians.



Provincial and territorial governments should work with national health data partners (such as the Canadian Institute for Health Information and Canada Health Infoway) to ensure the infrastructure is in place to create and maintain a national database of information on patient-reported outcome and experience measures to facilitate system performance monitoring, quality improvement, and research.

In time, these changes will have the following impact:

People with cancer will have the time and support to communicate their physical, emotional and practical needs, and to be active participants in their care before diagnosis, during treatment and after treatment.

Clinicians will receive real-time feedback about their patients' needs, allowing them to have conversations with patients about their care, address their concerns and offer person-centred support.

Health systems and facilities will have a suite of tools and data that help identify unmet needs of patients with cancer and their families. With this information they can efficiently distribute resources to address gaps in cancer care services.

Health services researchers will be able to conduct studies to identify innovative ways to improve the patient experience of cancer care.

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