

CANADIAN PARTNERSHIP  
AGAINST CANCER



PARTENARIAT CANADIEN  
CONTRE LE CANCER



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REPORTS

## REPORT SUMMARY:

# Living with Cancer

## A Report on the Patient Experience

**January 2018**

Presents pan-Canadian quantitative and qualitative data on the experiences of individuals and their families living with and beyond cancer.



# Living with cancer

“You have ovarian cancer’...I was absolutely shocked and stunned and sad... there was never any cancer in our family, so cancer was the furthest thing from my mind” *Bonnie*

“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” *Stephen*

“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.” *Charlotte*

## Realizing something is wrong.

IS IT CANCER?

Wait times for a cancer diagnosis are long for some people, which can increase stress and anxiety.

## Hearing “you have cancer”.

WHAT’S NEXT?

People often have unmet needs when they are diagnosed with cancer and during treatment planning.

## Being treated for cancer.

WILL IT WORK?

During treatment, more than half of patients with cancer experience symptoms causing distress.

## Finding a “new normal”.

WHAT WILL LIFE BE LIKE?

People continue to experience physical, emotional and practical challenges one to three years after completing cancer treatment.

AREAS FOR IMPROVEMENT:

Provincial results:

- Women with abnormal breast screen results wait weeks—up to 4 to 8 weeks when a biopsy was not required and up to 11 to 15 weeks when a biopsy was required—for a diagnosis (cancer or benign).
- People with an abnormal fecal test result wait months—up to 3 ½ to 5 months—for a follow-up colonoscopy.



Provincial results:

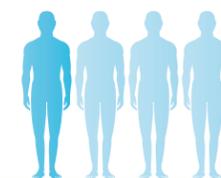
**38% TO 68%** of patients who had anxieties and fears upon diagnosis were not referred to a care provider for help with those concerns.

**12% TO 20%** of patients report that no one discussed different treatments for their cancer with them.

**11% TO 25%** of patients report that their care providers did not consider their travel concerns when planning for treatment.

Of patients who experience symptoms causing distress, they report having moderate to high levels of

Fatigue **35%** Anxiety **20%** Pain **19%** Depression **16%**



**1 in 4** report that they were not satisfied with the emotional support they received during outpatient cancer care—this continues to be the most negatively rated dimension of care.

**8 in 10** report having physical challenges after their treatment ends.

Fatigue is the most difficult to get help for.

**7 in 10** report having emotional challenges after treatment ends.

Worry about cancer returning is the most difficult to get help for.

**4 in 10** report having practical challenges after their treatment ends.

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

**One in three** who seek help for their most difficult post-treatment concerns report waiting too long or being unable to get help.

**Only one in two** who have emotional or practical challenges receive useful information that addresses their needs.

AREAS WE ARE DOING WELL:

## IMPROVED WAIT TIMES

Wait times for a follow-up colonoscopy after an abnormal fecal test result are improving in reporting provinces.



Data source: Provincial breast cancer screening programs, provincial colorectal cancer screening programs.

**OVER 90%** of patients report that they were told of their cancer diagnosis in a sensitive manner, were given enough information about their cancer treatment, or were able to discuss their worries or concerns with their care provider before starting treatment.

Data source: NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

**90%** or more of patients report that they received enough information, communication and education from their care team, or were generally positive about the coordination and continuity of care they received during outpatient cancer care.

Data source: Patient Reported Outcomes Initiative Partners; NRC Health, Ambulatory Oncology Patient Satisfaction Survey.

**97%** of patients/survivors report that they have a care provider in charge of overseeing their follow-up cancer care after completing treatment.

Patients/survivors who are able to visit or speak to their care provider find it easier to get help for their concerns (57%) compared with those who are unable to reach their care provider (19%).

Data source: Canadian Partnership Against Cancer, Experiences of Cancer Patients in Transition study (2016). The study included over 13,000 people who had completed cancer treatment within the past one to three years.

“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*

“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...”

*Charlotte*

## Based on report findings, the following 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.



To read about examples of innovative practices to improve people’s experiences with cancer across Canada and for the full report, visit [systemperformance.ca/report/living-with-cancer-patient-experience/](https://systemperformance.ca/report/living-with-cancer-patient-experience/)