Living with Cancer: A Report on the Patient Experience

January 2018

Technical Appendix

Qualitative data — Qualitative Analysis of Written Comments from the Ambulatory Oncology Satisfaction Survey (AOPSS)

Methods

A descriptive qualitative analysis was developed[1], utilizing data from the AOPSS survey. Permission was obtained from provinces to access their most recent AOPSS data for the purposes of this project. Subsequently, de-identified data files were obtained from seven provinces (British Columbia, Alberta, Saskatchewan, Manitoba, Nova Scotia, Prince Edward Island, Newfoundland). Files contained the written comments from respondents to a final question on the AOPSS survey: *Is there anything else you would like to tell us about your cancer care experience?* (Note: British Columbia's questionnaire asked: *What is the most important change we could make?).*

Analysis: Two questions guided the analysis of the data:

- What is the nature of the comments written by the respondents?
- What are the key messages contained within the written comments?

To determine the nature of comments, an initial assessment was made whether the comments were positive, negative, a mixture of both positive and negative, or neutral. Subsequently an assessment was made regarding the type of commentary within the written statements. The final listing of commentary types emerged from the review of the data (e.g., facts, evaluative, commendation).

To identify the key messages within the written comments, the statements from each province were reviewed separately. Subsequently, the notes were collated to develop a coding category framework which was used to code the respondent comments from each province by the author. Each coded category was then assessed to identify key ideas contained within the statements coded to the category. Finally, key ideas were collated across all provinces to identify significant themes within the total set of written comments.

Limitations: The analysis is based on written comments that cannot be further clarified with respondents. The comments must be handled simply as they appear in the Excel files produced (i.e., typed from questionnaires) at the NRC Health office.

General findings

Sample

The total sample consist of 6,232 written comments from individuals 30+ years of age and 23 comments from individuals between 18 and 29 years. The number of responses from each province is shown in Table 1.

Table 1: Distribution of Sample, by province

Province	Number of written comments
British Columbia	3,638
Alberta	1,106
Saskatchewan	264

[1] Thorne, S. (2000). Data analysis in qualitative research. *Evidence Based Nursing, 3,* 68–70.

Manitoba	468
Nova Scotia	388
Prince Edward Island	158
Newfoundland	233
Total comments	**6,255**

Nature/Type of Written Comments

To understand the nature of the written comments two analysis steps were utilized. In the first instance, the written comments were categorized as containing only positive statements, only negative statements, a mix of both negative and positive statements, or neutral (neither positive or negative).

In the total sample of written comments, 2,647 (42.5%) were completely positive and 1,854 (29.7%) were completely negative. When the mixed comments are added together with each of these categories, 62.3% of the respondents' comments contained positive statements and 49.5% contained negative statements. From the 23 respondents between 18 and 29 years of age, 7 comments were completely positive, 2 were completely negative, and 14 contained both positive and negative comments. In the total sample, 91% contained positive comments and 69.6% contained negative comments.

The second step in determining the nature of the comments, was one of assessing the type of commentary within the written statements. The final list of commentary types was generated from the review and assessment of what respondents had written. Respondents took the opportunity to write about a wide range of specific topics, the content of which will be reported in the following section focusing on key messages.

The written comments ranged in length from a few words to almost two typewritten pages. Some were in the form of one or several phrases or sentences, others were in the form of lists, and others took the style of a letter. In some instances, other family members wrote on behalf of the patient who was unable to complete the survey because of illness (e.g., being at end of life, having dementia) or death.

In terms of the type of commentary shared, respondents wrote facts about their diagnosis and treatment (listing dates and locations of events in their cancer journey), updates about their situation and how they were managing, commendations to staff members and facilities, descriptions about what made their experiences either positive or negative, their appreciation or sense of thankfulness for what had happened, about the survey itself, specific suggestions for change or improvement in care, and comments of an advocacy stance. Many comments made it clear the individual saw cancer as a life threatening illness and a challenge to face and this provided the context for their perspectives. Additionally, individuals often wrote summations that contained a number of insights about their experience. For example:

- Positive example*: I feel that the whole team at the cancer centre were very efficient. The front desk, phlebotomy, pharmacy, chemotherapy nurses, and especially, my doctor and nurse worked very well together so my appointments were well co-ordinated and timely. Any questions I had pertaining to my treatment or side effects were dealt with quickly and thoroughly. My doctor never made me feel rushed and took time to answer any of my questions end explain things to*

me so I could understand everything that was happening. Even the after hours calls through switchboard to the oncologist/hematologist on call were quick and thorough.

- Negative example: *What I question is the degree of ownership or responsibility anyone took for me as a patient as well as how effectively they communicated with each other. Most times I felt no one saw me as a person who was suffering or that they were championing my cause to get treatments under way or questioned why things were not happening in a more timely fashion. I did not feel that anyone really cared that I was sick. I was just another person in the system and they did the best they could to get me on the conveyor belt of the system.*

Key Messages within the Content of Written Comments

Descriptions of the content within the written comments have been organized into broad topic areas of 1) characteristics of a "good" experience, 2) personal care, 3) interaction with health care providers, 4) service delivery, and 5) views about the survey. The topics respondents wrote about were grouped into these broad topic areas at the end of the analysis. Each will be described in detail below outlining the key messages which emerged during the analysis.

It is important to note that the descriptions draw on the total sample of comments and do not pinpoint specific provincial aspects. There was variation in the written comments that reflected some of the local issues various provinces were facing, but these were not drawn into the analysis in a specific manner.

Quantitative data

Section 1: Realizing something is wrong. Is it cancer?

Figure 1.1: Wait times from abnormal fecal test result to follow-up colonoscopy

Definition:	The median and 90th percentile wait time (days) between an abnormal fecal test result and a follow-up colonoscopy required to resolve the diagnosis
Rationale for measurement:	Monitoring and reporting on colorectal cancer diagnosis wait times across Canada can help to reveal where efforts need to be targeted to improve how various parts of the system involved in screening and diagnosing colorectal cancer work together to ensure prompt resolution of abnormal results.
Measurement timeframe:	2013–2014 screening years
Denominator:	Individuals aged 50-74 with an abnormal fecal test result* who went on to receive a colonoscopy within 180 days of the fecal test result * Includes people who had a fecal test within a colorectal cancer screening program
Numerator:	Not applicable
Exclusion criteria:	1) Aged <50 or aged >=75 2) Screens outside of the programmatic colorectal screening 3) Colonoscopies received longer than 180 days after abnormal fecal tests
Data availability:	AB, SK, MB, NS, PE, NL
Stratification:	Province
Data source:	Provincial colorectal cancer screening programs
Data retrieval date:	October–December 2015
Variables details:	Not available
Notes from jurisdictions:	AB: • Multiple databases had been used to capture data on follow-up colonoscopies, such as the National Ambulatory Care Reporting System (NACRS), the Discharge Abstract Database (DAD) and Alberta Claims Database. • The uptake rates were underestimated due to incomplete colonoscopy data, which was caused by delays between the time of colonoscopy and the time the colonoscopy was reported to the databases. In general, reporting delays for NACRS and DAD are at least 1.5 months; some clinics might have longer delay periods. • The available physician claims data in the data warehouse covers until March 31, 2014. PE:

	• Some of the individuals with long waits for colonoscopy had used the Fecal Occult Blood Test (FOBT) kit after a recent colonoscopy. This is not in line with guidelines and results in skewed wait time results.
Methodology notes:	1) The analyses were conducted by provincial colorectal cancer screening programs. Data were provided by provincial cancer registries. 2) Data presented include ages 50–74. 3) Date of abnormal fecal test is the date the result is reported by the laboratory for each individual test; if there is more than one abnormal fecal test, the date of the first test is used. 4) The colonoscopy may have been performed inside or outside of the screening program but only for individuals who had their fecal test performed in the screening program. 5) The target time between an abnormal fecal test result and a follow-up colonoscopy required to resolve the diagnosis is 60 days.
Changes to definition compared to previous years:	Not applicable

Figure 1.2 & 1.3: Wait times from abnormal breast screen to diagnosis without/with biopsy

Definition:	1) The median and 90th percentile wait time (weeks) between an abnormal breast screen result and resolution; 2) Percentage of patients with resolution within the target wait times: • 5 weeks for resolution not requiring a tissue biopsy • 7 weeks for resolution requiring a tissue biopsy
Rationale for measurement:	Monitoring and reporting on breast cancer diagnosis wait times across Canada can help to reveal where efforts need to be targeted to improve how various parts of the system involved in screening and diagnosing breast cancer work together to ensure prompt resolution of abnormal results.
Measurement timeframe:	2013 screening year
Denominator:	Women aged 50–69 participating in an organized breast cancer screening program and who had an abnormal breast screen result (mammogram or clinical breast examination). Two patient groups were analyzed: 1) Patients not requiring a tissue biopsy to resolve the diagnosis 2) Patients requiring a tissue biopsy to resolve the diagnosis
Numerator:	Not applicable
Exclusion criteria:	1) QC and territories 2) Aged <50 or aged >=70 3) Abnormal screens that took longer than 6 months for definitive diagnosis
Data availability:	All provinces, except QC and territories
Stratification:	1) By province 2) Tissue biopsy requirement: requiring a tissue biopsy, not requiring a tissue biopsy
Data source:	Provincial breast cancer screening programs
Data retrieval date:	December 2015
Variables details:	Not available
Notes from jurisdictions:	ON: Women with final result unknown/lost to follow-up were excluded.
Methodology notes:	1) The analyses were conducted by provincial breast cancer screening programs. Data were provided by provincial cancer registries. 2) Data presented include ages 50–69. 3) Tissue biopsy included core (needle) biopsy with or without image guidance and open (excisional) biopsy with or without image guidance. 4) Tissue biopsy did not include fine needle aspiration (FNA).

	5) Time to diagnosis was based on the date of the first pathological biopsy result of breast cancer (excludes FNA and all inconclusive procedures) or the date of the last benign test or pathological biopsy. 6) Definitive diagnosis of cancer was the first core or open surgical biopsy that confirms cancer. In rare occasions, FNA biopsy may also be used as a definitive diagnosis of cancer. Definitive diagnosis of a benign case is the last benign test up to 6 months following an abnormal screen.
Changes to definition compared to previous years:	Not applicable

Hearing "you have cancer." What's next?

Figure 2.1: Percentage of patients who reported they were given their diagnosis in a sensitive manner

Definition:	Percentage of patients who reported that they were given their diagnosis in a sensitive manner
Rationale for measurement:	Having care providers who respond to the needs, preferences and concerns of patients and their families after they hear their diagnosis can improve the patient experience.
Measurement timeframe:	The most recent year of data available for each province: • BC: 2012 • SK, PE: 2013 • AB: 2015 • MB, NS, NL: 2016 • ON, QC: 2015/16 fiscal year
Denominator:	The number of respondents who answered the question "Were you told of your diagnosis in a sensitive manner?"
Numerator:	The number of respondents who provided the following responses to the question: • "Yes, completely" • "Yes, somewhat" • "No"
Exclusion criteria:	• Deceased patients • Patients less than 18 years of age (based on date of birth at time of data extraction for surveying) • Patients with no known fixed address • Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in the facility) including in-situ, benign hematology and/or non-malignant diseases (e.g., myeloproliferative diseases) or those going through a diagnostic assessment process • Patients who received only inpatient services • Patients who have notified the hospital that they wish to be excluded from mailing list
Data availability:	All provinces except NB
Stratification:	Province
Data source:	NRC Health, Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Data retrieval date:	April 2017
Variables details:	The analyses were based on the following question: • Were you told of your diagnosis in a sensitive manner?
Notes from jurisdictions:	AB: Due to small numbers of patients at the Community Cancer Centers (local facilities which offer systemic therapy) 100% of eligible patients attending received a survey. The remaining sample was split based on the proportion of the

	patient population attending at the larger facilities (Associate Cancer Centers and Tertiary Cancer Centers). If a patient attended a Community Cancer Center and a larger facility they received the survey based on the Community Cancer Center attendance. QC: The survey was conducted using a non-proportional stratified sample in order to produce estimates on a regional level. Hence, many regions were oversampled which means that the unweighted data is not representative of the target population.
Methodology notes:	1) Analyses based on unweighted data were conducted and provided by NRC Health for all provinces except QC. 2) QC conducted the analysis and provided weighted provincial results. 3) NB did not participate in the AOPSS.
Changes to definition compared to previous years:	Not applicable

Figure 2.2: Percentage of patients who reported they were not referred to a provider for help with anxieties and fears when diagnosed

Definition:	Percentage of patients who reported they were not referred to a care provider for help with anxieties and fears when diagnosed with cancer
Rationale for measurement:	Being referred to care providers or peer support groups for help with physical, emotional and practical concerns, if needed, after diagnosis can improve the patient experience.
Measurement timeframe:	The most recent year of data available for each province: • BC: 2012 • SK, PE: 2013 • AB: 2015 • MB, NS, NL: 2016 • ON, QC: 2015/16 fiscal year
Denominator:	The number of respondents who answered the question "When you were first told of your illness, were you referred to a care provider who could help you with anxieties and fears?"
Numerator:	The number of respondents who answered "no" to the question.
Exclusion criteria:	• Deceased patients • Patients less than 18 years of age (based on date of birth at time of data extraction for surveying) • Patients with no known fixed address • Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in the facility) including in-situ, benign hematology and/or non-malignant diseases (e.g., myeloproliferative diseases) or those going through a diagnostic assessment process • Patients who received only inpatient services • Patients who have notified the hospital that they wish to be excluded from mailing list • Patients who reported no anxieties or fears
Data availability:	All provinces except NB
Stratification:	Province
Data source:	NRC Health, Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Data retrieval date:	April 2017
Variables details:	The analysis was based on the following question: • Were you referred to a care provider who could help you with anxieties and fears?
Notes from jurisdictions:	AB: Due to small numbers of patients at the Community Cancer Centers (local facilities which offer systemic therapy) 100% of eligible patients attending received a survey. The remaining sample was split based on the proportion of the patient population attending at the larger facilities

	(Associate Cancer Centers and Tertiary Cancer Centers). If a patient attended a Community Cancer Center and a larger facility they received the survey based on the Community Cancer Center attendance. QC: The survey was conducted using a non-proportional stratified sample in order to produce estimates on a regional level. Hence, many regions were oversampled which means that the unweighted data is not representative of the target population.
Methodology notes:	1) Analyses based on unweighted data were conducted and provided by NRC Health for all provinces except QC. 2) QC conducted the analysis and provided weighted provincial results. 3) NB did not participate in the AOPSS.
Changes to definition compared to previous years:	Not applicable.

Figure 2.3: Percentage of patients who reported that no one discussed treatments for their cancer with them

Definition:	Percentage of patients who reported that no one discussed treatments for their cancer with them
Rationale for measurement:	Receiving tailored, understandable information about cancer and treatment options, and having the opportunity to ask questions, can improve the patient experience.
Measurement timeframe:	The most recent year of data available for each province: • BC: 2012 • SK, PE: 2013 • AB: 2015 • MB, NS, NL: 2016 • ON, QC: 2015/16 fiscal year
Denominator:	The number of respondents who answered the question "Did someone discuss different treatments for your cancer with you?"
Numerator:	The number of respondents who answered "no" to the question.
Exclusion criteria:	• Deceased patients • Patients less than 18 years of age (based on date of birth at time of data extraction for surveying) • Patients with no known fixed address • Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in the facility) including in-situ, benign hematology and/or non-malignant diseases (e.g., myeloproliferative diseases) or those going through a diagnostic assessment process • Patients who received only inpatient services • Patients who have notified the hospital that they wish to be excluded from mailing list
Data availability:	All provinces except NB
Stratification:	Province
Data source:	NRC Health, Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Data retrieval date:	April 2017
Variables details:	The analysis was based on the following question: • Did someone discuss different treatments for your cancer with you?
Notes from jurisdictions:	AB: Due to small numbers of patients at the Community Cancer Centers (local facilities which offer systemic therapy) 100% of eligible patients attending received a survey. The remaining sample was split based on the proportion of the patient population attending at the larger facilities (Associate Cancer Centers and Tertiary Cancer Centers). If a patient attended a Community Cancer Center and a larger

	facility they received the survey based on the Community Cancer Center attendance. QC: • The survey was conducted using a non-proportional stratified sample in order to produce estimates on a regional level. Hence, many regions were oversampled which means that the unweighted data is not representative of the target population. • The survey question referred to a discussion with a health care provider rather than "someone" (different from the question asked in other jurisdictions)
Methodology notes:	1) Analyses based on unweighted data were conducted and provided by NRC Health for all provinces except QC. 2) QC conducted the analysis and provided weighted provincial results. 3) NB did not participate in the AOPSS.
Changes to definition compared to previous years:	Not applicable

Figure 2.4: Percentage of patients who reported their care provider did not discuss their worries or concerns with them before beginning treatment

Definition:	Percentage of patients who reported their care provider did not discuss their worries or concerns with them before beginning treatment
Rationale for measurement:	Having care providers who respond to the needs, preferences and concerns of patients and their families after they hear their diagnosis can improve the patient experience.
Measurement timeframe:	The most recent year of data available for each province: • BC: 2012 • SK, PE: 2013 • AB: 2015 • MB, NS, NL: 2016 • ON, QC: 2015/16 fiscal year
Denominator:	The number of respondents who answered the question "If you had any worries or concerns before beginning your treatment, did your care provider discuss them with you?"
Numerator:	The number of respondents who answered "no" to the question.
Exclusion criteria:	• Deceased patients • Patients less than 18 years of age (based on date of birth at time of data extraction for surveying) • Patients with no known fixed address • Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in the facility) including in-situ, benign hematology and/or non-malignant diseases (e.g., myeloproliferative diseases) or those going through a diagnostic assessment process • Patients who received only inpatient services • Patients who have notified the hospital that they wish to be excluded from mailing list • Respondents who reported to have no worries or concerns before beginning treatment
Data availability:	All provinces except QC and NB
Stratification:	Province
Data source:	NRC Health, Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Data retrieval date:	April 2017
Variables details:	The analyses were based on the following question: • If you had any worries or concerns before beginning your treatment, did your care provider discuss them with you?
Notes from jurisdictions:	AB: Due to small numbers of patients at the Community Cancer Centers (local facilities which offer systemic therapy) 100% of eligible patients attending received a survey. The

	remaining sample was split based on the proportion of the patient population attending at the larger facilities (Associate Cancer Centers and Tertiary Cancer Centers). If a patient attended a Community Cancer Center and a larger facility they received the survey based on the Community Cancer Center attendance. QC: QC's version of the AOPSS did not ask this question.
Methodology notes:	1) Analyses based on unweighted data were conducted and provided by NRC Health for all provinces. 2) NB did not participate in the AOPSS and QC did not ask this question.
Changes to definition compared to previous years:	Not applicable

Figure 2.5: Percentage of patients who reported they were not given enough information about therapies for treating their cancer

Definition:	Percentage of patients who reported that they were not given enough information about therapies for treating their cancer
Rationale for measurement:	Receiving tailored, understandable information about cancer and treatment options, and having the opportunity to ask questions, can improve the patient experience.
Measurement timeframe:	The most recent year of data available for each province: • BC: 2012 • SK, PE: 2013 • AB: 2015 • MB, NS, NL: 2016 • ON, QC: 2015/16 fiscal year
Denominator:	The number of respondents who answered the question "Were you given enough information about therapies for treating cancer?"
Numerator:	The number of respondents who answered "no" to the question.
Exclusion criteria:	• Deceased patients • Patients less than 18 years of age (based on date of birth at time of data extraction for surveying) • Patients with no known fixed address • Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in the facility) including in-situ, benign hematology and/or non-malignant diseases (e.g., myeloproliferative diseases) or those going through a diagnostic assessment process • Patients who received only inpatient services • Patients who have notified the hospital that they wish to be excluded from mailing list
Data availability:	All provinces except NB
Stratification:	Province
Data source:	NRC Health, Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Data retrieval date:	April 2017
Variables details:	The analysis was based on the following question: • Were you given enough information about therapies for treating cancer?
Notes from jurisdictions:	Not applicable
Methodology notes:	1) Analyses based on unweighted data were conducted and provided by NRC Health for all provinces except QC. 2) QC conducted the analysis and provided weighted provincial results. 3) NB did not participate in the AOPSS.

Changes to definition compared to previous years:	Not applicable

Figure 2.6: Percentage of patients who reported their care provider did not consider their travel concerns when planning for treatment

Definition:	Percentage of patients who reported that their care provider did not consider their travel concerns when planning for treatment
Rationale for measurement:	Having care providers who respond to the needs, preferences and concerns of patients and their families after they hear their diagnosis can improve the patient experience.
Measurement timeframe:	The most recent year of data available for each province: • BC: 2012 • SK, PE: 2013 • AB: 2015 • MB, NS, NL: 2016 • ON, QC: 2015/16 fiscal year
Denominator:	The number of respondents who answered the question "Did your care providers consider your travel concerns when planning for your treatment?"
Numerator:	The number of respondents who answered "no" to the question.
Exclusion criteria:	• Deceased patients • Patients less than 18 years of age (based on date of birth at time of data extraction for surveying) • Patients with no known fixed address • Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in the facility) including in-situ, benign hematology and/or non-malignant diseases (e.g., myeloproliferative diseases) or those going through a diagnostic assessment process • Patients who received only inpatient services • Patients who have notified the hospital that they wish to be excluded from mailing list • Respondents who reported no travel concerns
Data availability:	All provinces except NB
Stratification:	Province
Data source:	NRC Health, Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Data retrieval date:	April 2017
Variables details:	The analysis was based on the following question: • Did your care providers consider your travel concerns when planning for your treatment?
Notes from jurisdictions:	AB: Due to small numbers of patients at the Community Cancer Centers (local facilities which offer systemic therapy) 100% of eligible patients attending received a survey. The remaining sample was split based on the proportion of the patient population attending at the larger facilities

	(Associate Cancer Centers and Tertiary Cancer Centers). If a patient attended a Community Cancer Center and a larger facility they received the survey based on the Community Cancer Center attendance. QC: The survey was conducted using a non-proportional stratified sample in order to produce estimates on a regional level. Hence, many regions were oversampled which means that the unweighted data is not representative of the target population.
Methodology notes:	1) Analyses based on unweighted data were conducted and provided by NRC Health for all provinces except QC. 2) QC conducted the analysis and provided weighted provincial results. 3) NB did not participate in the AOPSS.
Changes to definition compared to previous years:	Not applicable

Being Treated for Cancer. Will it work?

Figure 3.1: Percentage of patients who reported negative experiences while receiving outpatient cancer care

Definition:	Percentage of patient responses that were negative in each dimension of care (i.e., coordination & continuity of care; emotional support; information, communication & education; physical comfort)
Rationale for measurement:	Ensuring that patients with cancer are well supported and cared for throughout their cancer care journey is a crucial requirement of a high-quality cancer control system. In fact, better patient experience has been linked to improved health outcomes, increased adherence to treatment recommendations and increased use of preventive care. Understanding patients' experience with care can help to identify what's important from the patients' perspective and inform quality improvement initiatives aimed at improving patient experience.
Measurement timeframe:	The most recent year of data available for each province: • BC: 2012 • SK, PE: 2013 • AB: 2015 • MB, NS, NL: 2016 • ON, QC: 2015/16 fiscal year
Denominator:	Total number of responses (positive, neutral or negative) reported by cancer patients in each dimension of care
Numerator:	Number of negative responses reported by cancer patients in each dimension of care
Exclusion criteria:	• Deceased patients • Patients less than 18 years of age (based on date of birth at time of data extraction for surveying) • Patients with no known fixed address • Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in the facility) including in-situ, benign hematology and/or non-malignant diseases (e.g., myeloproliferative diseases) or those going through a diagnostic assessment process • Patients who received only inpatient services • Patients who have notified the hospital that they wish to be excluded from mailing list • No responses or unknown responses
Data availability:	BC, AB, SK, MB, ON, QC, NS (overall only), PE, and NL.
Stratification:	1) Dimension of care: • coordination and continuity of care • emotional support • information, communication & education • physical comfort

	2) Age group: 18–29, 30+, overall (18+)
Data source:	NRC Health, Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Data retrieval date:	September, 2016
Variables details:	The questions on dimension of care varied by province. For each province, relevant questions were identified and included in the analysis.
Notes from jurisdictions:	Not applicable
Methodology notes:	1) Analyses based on unweighted data were conducted and provided by NRC Health for all provinces except QC. 2) QC conducted the analysis and provided unweighted data to be included in the national results. 3) NB did not participate in the AOPSS. 4) Unweighted provincial data were pooled together to calculate the national results: • QC was excluded from *Physical Comfort* due to suppression owing to small numbers. • NS was included in the overall estimates (18+) only as age and gender breakdown was not provided.
Changes to definition compared to previous years:	Not applicable

Figure 3.2: Wait times from ready-to-treat to start of radiation therapy, all cancers

Definition:	1) The median and 90th percentile radiation therapy wait time (days) from ready-to-treat to start of radiation for patients treated for all types of cancer 2) The percentage of radiation therapy cases for which the above wait time was within the current national target (28 days)
Rationale for measurement:	Reporting on radiation therapy wait times is an important step to understanding the health care system's ability to meet the needs of patients with cancer.
Measurement timeframe:	2014 treatment year
Denominator:	All cancer patients receiving radiation therapy in 2014 who have wait time data collected as consistent with the specifications of this indicator.
Numerator:	Not applicable
Exclusion criteria:	Cases with external beam radiation therapy (EBRT) were included. Other types of radiation therapy were excluded.
Data availability:	1) Data for median and 90th percentile: • BC, AB, MB, NB, NL and PE 2) Data for the percentage of wait time within the current national target: • BC, AB, MB, NB, NL, PE, ON (see *Notes from jurisdictions* for details) and QC
Stratification:	Province
Data source:	Provincial cancer agencies and programs
Data retrieval date:	December 2015
Variables details:	Not available
Notes from jurisdictions:	BC: • Brachytherapy was not included. AB: • Data include all cases who had radiation therapy at a Cancer Control Alberta Facility with their first treatment between January 2, 2014–December 31, 2014; it includes those who were living in another province at time of diagnosis but receiving radiation therapy in Alberta. • Tumor group classification for this indicator is based on referral tumor groups. • Brachytherapy was not included. ON: • The percentage of radiation therapy cases for which the wait time was within 14 days (Canadian Association of Radiation Oncologists (CARO) target) were from February to December 2014. NS: • Patients with more than one treated disease may have contributed to more than one wait time.

	• Procedures around specifying ready-to-treat date have not accurately captured the relevant date for prostate and breast patients, so the wait times for these two cancers are not reported.
Methodology notes:	1) For cancers with radiation therapy, all behavior codes were included. 2) There are known discrepancies in the ways in which different provinces measure wait times. One of the key sources of variation is the way the "ready-to-treat" timeframe is defined. Efforts are underway to standardize these definitions. The following outlines the definitions used by the different provinces: • BC: The date at which both oncologist and patient agree that treatment can commence. Being ready-to-treat requires that all diagnostic tests and procedures required to assess the appropriateness of, indications for, and fitness to undergo radiation therapy are complete. • AB: The date when the patient is physically ready to commence treatment. • SK: The date when the patient is ready to receive treatment, taking into account clinical factors and patient preference. In the case of radiation therapy, any preparatory activities (e.g., simulation, treatment planning, dental work) do not delay the ready-to-treat date. • MB: The date when a decision has been made by the radiation oncologist and is agreed to by the patient that radiation therapy is appropriate and should commence AND the patient is medically ready to start treatment AND the patient is willing to start treatment. • ON: The time from when the specialist is confident that the patient is ready to begin treatment to the time the patient receives treatment. • QC: At consultation, the radiation oncologist enters the date at which the patient will be ready-to-treat on a formulary requesting treatment. • NB: The date when any planned delay is over and the patient is ready to begin treatment from both a social/personal and medical perspective. • NS: The date when all pre-treatment investigations and any planned delay are over, and the patient is ready to begin the treatment process from both a social/personal and medical perspective. • PE: The date when all pre-treatment investigations and any planned delay are over, and the patient is

	ready to begin the treatment process from both a social/personal and medical perspective. • NL: The date when all pre-treatment investigations and any planned delay are over, and the patient is ready to begin the treatment process from both a social/personal and medical perspective.
Changes to definition compared to previous years:	Not applicable

Figure 3.3: Wait times from booking date to cancer surgery, by disease site

Definition:	The 90th percentile wait times from booking date to cancer surgery
Rationale for measurement:	Reporting on cancer surgery wait times is an important step to understanding accessibility and the health care system's ability to meet the needs of patients with cancer.
Measurement timeframe:	April 1–September 30, 2016
Denominator:	Cancer patients (18+) with the following surgeries: • all cancer surgeries for proven and suspected cases • all cancer surgery for new and recurrent/metastatic cancers
Numerator:	Not applicable
Exclusion criteria:	Across breast, colorectal, lung and prostate cancer: • biopsies as the sole procedure • patient unavailable days • patients on neo-adjuvant therapy • emergency cases Breast cancer specific exclusion criteria: • breast reconstruction surgery unless done in the same OR episode Colorectal cancer specific exclusion criteria: • closure of ileostomy/colostomy • cancer of the stomach or small intestine
Data availability:	Please refer to Canadian Institute for Health Information's Wait Time Metadata page: https://www.cihi.ca/en/wait-time-metadata
Stratification:	Cancer site: breast, colorectal, lung and prostate
Data source:	Canadian Institute for Health Information
Data retrieval date:	April 2017
Variables details:	Not available
Notes from jurisdictions:	Not applicable
Methodology notes:	Booking date is when the patient and the appropriate physician agree to a service, and the patient is ready to receive it.
Changes to definition compared to previous years:	Not applicable

Figure 3.4: Proportion of patients who reported symptoms of distress

Definition:	Distribution and level of symptoms of distress experienced by patients.
Rationale for measurement:	Routine screening of symptoms is important to identify cancer patients' psychological, social, spiritual, practical or physical concerns that may negatively affect a person's ability to cope with cancer and its treatment. One common self-report tool used to measure patient-reported outcomes is the Edmonton Symptom Assessment System (ESAS-r), which measures nine commonly reported symptoms (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite and lack of well-being and shortness of breath).
Measurement timeframe:	The most recent 3-months of data available for each province: • MB, ON, NS: January–March 2016 • AB, SK, PE, NL: April–June 2016 • QC: May–July 2016
Denominator:	Number of questionnaires completed (no missing responses) for each symptom of distress
Numerator:	Number of questionnaires reporting the level of the following four distress symptoms: • No distress • Low • Moderate • High
Exclusion criteria:	1) Aged <18 2) Benign hematologic diseases
Data availability:	All provinces except BC and NB
Stratification:	Four symptoms of distress: • Pain • Fatigue • Anxiety • Depression Please see *methodology notes* for details.
Data source:	PRO partners
Data retrieval date:	October–November 2016
Variables details:	The questions on symptoms of distress varied by province. For each province, relevant questions were identified and included in the analysis.
Notes from jurisdictions:	MB: • Patients are screened for distress at every physician visit which includes new, on treatment and follow-up appointments. ON:

	• Some methodological differences: (1) CPAC excludes age <18, (2) Cancer Care Ontario also includes hematological cancers. • The denominators vary across symptoms due to skipped questions on paper questionnaires. NS: • The denominator is based on the total number of screens completed by patients from January–March, 2016. The unknown responses are captured in the "No response" column. PE: • Data included initial screens done at first consult, re-screens done at end of treatment and ESAS-r completed at every physician visit (for the IV chemotherapy group that started June 1). NL: • The unknown responses are captured in the "No response" column.
Methodology notes:	1) Data came from partners that participated in the Patient Reported Outcome (PRO) initiative survey 2) Edmonton Symptom Assessment System-revised (ESAS-r), a self-assessment tool, was used to collect common symptoms in cancer patients during their treatment. 3) Respondents scored the degree of symptoms using a scale of 0–10. These responses were grouped into four categories: • No distress: score 0 • Low: scores 1–3 • Moderate: scores 4–6 • High: scores 7–10 4) Each symptom has a small number of no responses that are excluded: pain, 0.4%; fatigue, 0.3%; anxiety, 0.4%; depression, 0.4%.
Changes to definition compared to previous years:	Not applicable

Finding a "new normal." What will life be like?

About the Experiences of Patients with Cancer in Transition Study

In Canada, the availability of consistent, reliable data on what individuals experience in the post-treatment period have 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/survivors across the country.

Specifically, the Transition Study is guided by the following three research questions:

- **Research Question 1:** What is the prevalence and severity of physical, emotional, practical and informational concerns/challenges (i.e. domains) among cancer survivors? What is the unmet level of needs across each of the domains, by disease site, and by socio-demographic characteristics, and across provinces?
- **Research Question 2.** What are the **predictors to overall follow-up cancer care in meeting patients' needs within the system**, in terms of support and aspects of care from the four different health care providers, i.e. access, timeliness, knowledge, etc.?
- **Research Question 3.** What are the predictors of overall care within each domain**? Does having particular supports promote better outcomes, i.e. survivorship care plan, nurse navigator, private insurance, support from family/friends, support from counselling, peer support groups, etc.?**

The results included in this report provides a first look at the findings from adult respondents (aged 30+) with non-metastatic cancers.

Figure 4.2: Care provider in charge of follow-up

Definition:	Distribution of care providers in charge of treatment follow-up
Rationale for measurement:	Having a health care provider in charge after cancer treatment is over is essential to facilitate the transition from specialty oncology care to the broader health care system and to provide person-centred support to patients and families as needs arise
Measurement timeframe:	2016 reporting year
Denominator:	Number of adult cancer patients who responded to the question asking about the main care provider in charge of treatment follow-up (please see *variables details* for more information) To be included in the denominator, patients must be aged 30+ and meet the following qualifying criteria: • Have breast, colorectal, melanoma, prostate or blood cancers (Hodgkin's Lymphoma, Diffuse B-cell Lymphoma, Acute Myelogenous Leukemia, Acute Lymphocytic Leukemia) • Cancer was not metastatic • Last treatment took place 1 to less than 3 years ago
Numerator:	Number of patients who identified as having one of the types of care providers in charge of treatment follow-up: • Primary care provider: family doctor/general practitioner/nurse practitioner • Cancer specialist: oncologist, hematologist, surgeon, or other cancer specialist • Both • No one
Exclusion criteria:	1) Respondents who answered "unsure" 2) Respondents aged <30
Data availability:	All provinces
Stratification:	Not applicable
Data source:	Experiences of Cancer Patients in Transition Study (2016)
Data retrieval date:	March 2017
Variables details:	The analysis was based on the question: • Since completing your cancer treatment, which physician has been in charge of overseeing your follow-up cancer care?
Notes from jurisdictions:	QC: Data presented are weighted.
Methodology notes:	1) The analyses were based on Experiences of Cancer Patients in Transitions Study. Data were provided by IPSOS Reid. 2) Respondents were only allowed to select one response.
Changes to definition compared to previous years:	Not applicable

Figure 4.3: Ease of getting help for post-treatment concerns, by care provider in charge

Definition:	Distribution of level of ease getting help for post-treatment concerns from care provider in charge
Rationale for measurement:	Examining ease of getting help for post-treatment concerns by health care provider in charge (if any) can help to identify enablers of a positive patient experience after treatment is over
Measurement timeframe:	2016 reporting year
Denominator:	Number of respondents who met both of the following criteria: • Had concerns about physical changes, emotional changes or practical challenges post-treatment and sought help for them • Identified the type care provider as in charge for post-treatment To be included in the denominator, patients must be aged 30+ and meet the following qualifying criteria: • Have breast, colorectal, melanoma, prostate or blood cancers (Hodgkin's Lymphoma, Diffuse B-cell Lymphoma, Acute Myelogenous Leukemia, Acute Lymphocytic Leukemia) • Cancer was not metastatic • Last treatment took place 1 to less than 3 years ago
Numerator:	Number of respondent who identified how easy or difficult it was to get help post-treatment. The following breakdown was used: • Very easy/easy • Hard/very hard • Did not get help Please see *methodology notes* for details
Exclusion criteria:	1) Respondents who did not report having concerns about physical changes, emotional changes or practical challenges 2) Respondents who reported 'no' to seeking help for physical changes, emotional changes or practical challenges 3) Respondents who did not response to the questions listed in *variable details* section below 4) Respondents who checked "unsure" for the provider in charge question 5) Respondents aged <30
Data availability:	All provinces
Stratification:	Ease of getting help for post-treatment concerns was stratified by care provider in charge as follows: • Primary care provider: Family doctor, general practitioner, nurse practitioner

	• Cancer specialist: oncologist, hematologist, surgeon or other cancer specialist • Both • No one
Data source:	Experiences of Cancer Patients in Transition Study (2016)
Data retrieval date:	March 2017
Variables details:	The analyses were based on the following questions: • Since completing your cancer treatment, which physician has been in charge of overseeing your follow-up cancer care? • How easy was it to get help for the concern? There were several related questions for each of dimension of concern: o Physical changes o Emotional changes o Practical challenges
Notes from jurisdictions:	Not applicable
Methodology notes:	1) The analyses were based on Experiences of Cancer Patients in Transitions Study and data were provided by IPSOS Reid. 2) Ease of getting help is defined by the most difficult experience the respondent had amongst his or her physical/emotional/practical concern(s) and is quantified as very easy, easy, hard, very hard and didn't get any help. If a respondent sought help and didn't get any help, this was considered the most difficult experience. 3) Then, the responses were further grouped into three categories: • Very easy/easy • Hard/very hard • Did not get help (includes responses "did not get any help" and "hard—no help") 4) Respondents who reported having at least one type of concerns and sought help were included in the analyses.
Changes to definition compared to previous years:	Not applicable

Figure 4.4: Ease of getting help for post-treatment concerns, by difficulty asking questions to doctors

Definition:	Distribution of level of ease of getting help for post-treatment concerns by difficulty asking doctors questions
Rationale for measurement:	Examining ease of getting help for post-treatment concerns by difficulty to ask questions can help to identify potential barriers to a positive patient experience after treatment is over
Measurement timeframe:	2016 reporting year
Denominator:	Number of respondents who met both of the following criteria: • Had concerns about physical changes, emotional changes or practical challenges post-treatment and sought help for them • Identified the ease of asking doctors about the concerns To be included in the denominator, patients must be aged 30+ and meet the following qualifying criteria: • Have breast, colorectal, melanoma, prostate or blood cancers (Hodgkin's Lymphoma, Diffuse B-cell Lymphoma, Acute Myelogenous Leukemia, Acute Lymphocytic Leukemia) • Cancer was not metastatic • Last treatment took place 1 to less than 3 years ago
Numerator:	Number of respondent who identified how easy or difficult it was to get help for post-treatment concerns. The following breakdown was used: • Very easy/easy • Hard/very hard • Did not get help (includes responses "did not get any help" and "hard—no help") Please see *methodology notes* for details
Exclusion criteria:	1) Respondents who did not report having concerns about physical changes, emotional changes or practical challenges 2) Respondents who reported 'no' to seeking help for physical changes, emotional changes or practical challenges 3) Respondents who did not response to all relevant questions 4) Respondents aged <30
Data availability:	All provinces
Stratification:	Ease if getting help was stratified by level of difficulty asking doctors questions about their concerns: • Easy : very easy or easy

	• Neutral • Hard: hard or very hard
Data source:	Experiences of Cancer Patients in Transition Study (2016)
Data retrieval date:	March 2017
Variables details:	The analyses were based on the following questions: • How easy or hard do you find asking doctors questions about your concerns related to follow-up cancer care? • How easy was it to get help for the concern? There were several related questions for each of dimension of concern: o Physical changes o Emotional changes o Practical challenges
Notes from jurisdictions:	Not applicable
Methodology notes:	1) The analyses were based on Experiences of Cancer Patients in Transitions Study and data were provided by IPSOS Reid. 2) Ease of getting help is defined by the most difficult experience the respondent had amongst his or her physical/emotional/practical concern(s) and is quantified as very easy, easy, hard, very hard and didn't get any help. If a respondent sought help and didn't get any help, this was considered the most difficult experience. Then, the responses were further grouped into three categories: • Very easy/easy • Hard/very hard • Did not get help
Changes to definition compared to previous years:	Not applicable

Figure 4.5: Reasons for not seeking help for physical, emotional or practical concerns after completing treatment

Definition:	Prevalence of reasons for not seeking help for physical changes, emotional changes or practical challenges after completing treatment. Each dimension of concern is considered separately.
Rationale for measurement:	Reporting on reasons for not seeking help for post-treatment concerns can help to reveal where efforts need to be targeted to encourage active participation of patients/survivors in post-treatment care
Measurement timeframe:	2016 reporting year
Denominator:	The number of respondents who did not seek help for each dimension of concern (physical changes, emotional changes and practical challenges) after completing treatment To be included in the denominator, patients must be aged 30+ and meet the following qualifying criteria: • Have breast, colorectal, melanoma, prostate or blood cancers (Hodgkin's Lymphoma, Diffuse B-cell Lymphoma, Acute Myelogenous Leukemia, Acute Lymphocytic Leukemia) • Cancer was not metastatic • Last treatment took place: 1 to less than 3 years ago
Numerator:	Number of responses in each of the following reasons including: • I didn't want to ask • I didn't know services were available to help me • Someone told me it was normal and I didn't think anything could be done about it • I was embarrassed Notes: • Respondent were allowed to select multiple reasons for not seeking help. • The indicator included most common reasons for not seeking help. More response options were available, including o I didn't know I could ask o I didn't know where to go o Other
Exclusion criteria:	1) Respondents who reported that they did not have concern for each dimension of concern 2) Respondents who reported that they sought help for all of their concerns 3) Respondents aged < 30
Data availability:	All provinces

Stratification:	Reasons for not getting help for concerns were categorized by the nature of the concern: physical, emotional or practical.
Data source:	Experiences of Cancer Patients in Transition Study (2016)
Data retrieval date:	March 2017
Variables details:	The analyses were based on the following questions: • If you did not seek help for at least one physical concerns, which of the following describes why not? • If you did not seek help for at least one emotional concerns, which of the following describes why not? • If you did not seek help for at least one practical concerns, which of the following describes why not?
Notes from jurisdictions:	Not applicable
Methodology notes:	1) The analyses were based on Experiences of Cancer Patients in Transitions Study and data were provided by IPSOS Reid. 2) This is a prevalence indicator. In other words, the percentages are the total number of times a given response was selected and a respondent could have selected more than one response for each question. 3) Only the top three reasons identified for each dimensions were reported. 4) Each dimension of concern is considered separately.
Changes to definition compared to previous years:	Not applicable

Figure 4.6: Percentage of patients who reported receiving useful information for their emotional or practical concerns

Definition:	Distribution of degree of getting useful information for their emotional concerns or practical challenges
Rationale for measurement:	Ensuring that patients/survivors receive useful information that address their post-treatment concerns is a crucial element of person-centred care. Reporting on this metric can help identify areas where quality efforts could be targeted to provide patient-centered information.
Measurement timeframe:	2016 reporting year
Denominator:	The number of respondents who reported having emotional concerns or practical challenges To be included in the denominator, patients must be aged 30+ and meet the following qualifying criteria: • Have breast, colorectal, melanoma, prostate or blood cancers (Hodgkin's Lymphoma, Diffuse B-cell Lymphoma, Acute Myelogenous Leukemia, Acute Lymphocytic Leukemia) • Cancer was not metastatic • Last treatment took place 1 to less than 3 years ago
Numerator:	The number of respondents who reported the degree of getting useful information for their emotional concerns or practical challenges (separately). The responses were based on the Likert Scale; for each question, the respondents provided the degree of usefulness of information they received: • Strongly agree • Somewhat agree • Neither agree nor disagree • Somewhat disagree • Strongly disagree
Exclusion criteria:	1) Respondents who reported that they did not have concerns 2) Respondents who did not answer to relevant questions (see *variables details* below). 3) Respondents aged <30 Note: The above criteria were applied to emotional concerns and practical challenges separately.
Data availability:	All provinces
Stratification:	Dimensions of concern: • Emotional changes • Practical challenges
Data source:	Experiences of Cancer Patients in Transition Study (2016)
Data retrieval date:	March 2017

Variables details:	The analyses were based on the following questions: • Do you agree or disagree with the statement: I received useful information about my emotional concerns. • Do you agree or disagree with the statement: I received useful information about my practical concerns.
Notes from jurisdictions:	Not applicable
Methodology notes:	1) The analyses were based on Experiences of Cancer Patients in Transitions Study and data were provided by IPSOS Reid. 2) Each dimension of concern (emotional, practical) was considered separately.
Changes to definition compared to previous years:	Not applicable