Prostate Cancer Control in Canada:
A System Performance Spotlight Report

November 2015

Technical Appendix

1. Burden and Outcomes

Age-standardized incidence rates

Definition: The incidence rate that would have occurred if the age distribution in the population of interest was the same as that of the standard, where incidence rate is defined as the number of prostate cancer cases (in men aged 35 and older) newly diagnosed during a specific time period, per 100,000 men at risk.
Numerator: Number of prostate cancer cases (men aged ≥ 35)
Denominator: Total male population aged ≥ 35 during the given time period
Age standardization: Direct method using the 2011 Canadian Census population
Data sources: Statistics Canada, Canadian Cancer Registry
Measurement timeframe:
For overall trends, Canada: 1992 to 2011; by province: 3-year combined (2008 – 2010); by age group, Canada: 3-year average (2008 – 2010).
Stratification variables: Year, province, age group (35 to 49, 50 to 64, 65 to 79, 80+)
General notes:

1. World Health Organization, International Classification of Diseases for Oncology, Third Edition (ICD-O-3) and the International Agency for Research on Cancer (IARC) rules for determining multiple primaries sites were used: prostate (ICD-O-3: C61.9).
2. Population estimates provided by the Demography Division, Statistics Canada.
3. Joinpoint Regression Program 4.1.1 for Windows was used to analyze linear trends across years. The software takes trend data and fits the simplest joinpoint (piecewise linear) model that the data allow. The program starts with the minimum number of joinpoints (e.g. 0 joinpoints, which is a straight line) and tests whether more joinpoints are statistically significant and must be added to the model (up to a user-specified maximum number). This enables the user to test whether an apparent change in trend is statistically significant. The tests of significance use a Monte Carlo Permutation method. Annual Percent Change (APC) was reported to characterize trends in cancer rates over time. APC assumes that cancer rates are changing at a constant percentage of the rate of the previous year. The minimum and maximum number of joinpoints used in this analysis were 0 and 4 respectively. For further details, refer to the Joinpoint Regression Program documentation (http://surveillance.cancer.gov/joinpoint/).

Age-standardized mortality rates

Definition: The mortality rate that would have occurred if the age distribution in the population of interest was the same as that of the standard, where mortality rate is defined as the number of deaths due to prostate cancer (in men aged 35 and older) during a given time period, per 100,000 men at risk.
Numerator: Number of deaths from prostate cancer (men aged ≥ 35)
Denominator: Total male population aged ≥ 35 during the given time period
Age standardization: Direct method using the 2011 Canadian Census population
Data sources: Statistics Canada, Canadian Vital Statistics death database
Measurement timeframe: For overall trends, Canada: 1992 to 2011; by province: 3-year combined (2009 – 2011); by age group, Canada: 3-year combined (2009 – 2011).
Stratification variables: Year, province, age group (35 to 49, 50 to 64, 65 to 79, 80+)

General notes:

1. Up to the year 1999, causes of death were coded according to World Health Organization (WHO), International Classification of Diseases, Ninth Revision (ICD-9): prostate (ICD-9: 185). After the year 1999, causes of death were coded according to the World Health Organization (WHO), International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10): prostate (ICD-10: C61).
2. Population estimates provided by the Demography Division, Statistics Canada.
3. Joinpoint Regression Program 4.1.1 for Windows was used to analyze linear trends across years. The software takes trend data and fits the simplest joinpoint model that the data allow. The program starts with the minimum number of joinpoints (e.g. 0 joinpoints, which is a straight line) and tests whether more joinpoints are statistically significant and must be added to the model (up to that maximum number). This enables the user to test whether an apparent change in trend is statistically significant. The tests of significance use a Monte Carlo Permutation method. Annual Percent Change (APC) was reported to characterize trends in cancer rates over time. APC assumes that cancer rates are changing at a constant percentage of the rate of the previous year. The minimum and maximum number of joinpoints used in this analysis were 0 and 4 respectively. For further details, refer to the Joinpoint Regression Program documentation (http://surveillance.cancer.gov/joinpoint/).

PSA testing (self-reported)

Definition: Percentage of men aged 35 or older reporting at least one Prostate-Specific Antigen (PSA) test in the past one year, two years or ever for asymptomatic reasons. 'Asymptomatic' is defined as respondents who indicated going for a PSA test for any of the following reasons: family history, regular check-up/routine screening, age, or race. PSA testing received for the following reasons were excluded: follow-up of problem, follow-up of prostate cancer treatment, other.
Numerator: Number of men aged ≥ 35 reporting having had at least one PSA test in the past year, past two years, or ever
Denominator: Total number of men aged ≥ 35 in the past year, past two years, or ever
Data source: Statistics Canada, Canadian Community Health Survey
Measurement timeframe: 2010 – 2013 combined
CCHS variables:

1. Have you ever had a prostate specific antigen test for prostate cancer, that is, a PSA blood test?
2. When was the last time?
3. Why did you have it? (Mark all that apply): family history, regular check-up/routine screening, age, race, follow-up of problem, follow-up of prostate cancer treatment, other.

Stratification variables: Province/territory, age group (35 to 49, 50 to 64, 65 to 79, 80+)
Provinces/territories with data available: NS (2010, 2011, 2012), PE (2010), NL (2010), YT (2010, 2013), NT (2010, 2011, 2012, 2013), ON (2011, 2012), NU (2011), QC (2013).
General notes: CCHS data is based on a representative sample which is then extrapolated to the overall population.

DRE (self-reported)

Definition: Percentage of men aged 35 or older reporting at least one Digital Rectal Examination (DRE) in the past one year, two years or ever (note: this indicator is not included in detail in the report).
Numerator: Number of men aged ≥ 35 reporting having had at least one DRE in the past year, past 2 years or ever
Denominator: Total number of men aged ≥ 35 in the past year, past 2 years or ever
Data source: Statistics Canada, Canadian Community Health Survey
Measurement timeframe: 2010 – 2013 combined
CCHS variables:

1. A Digital Rectal Exam is an exam in which a gloved finger is inserted into the rectum in order to feel the prostate gland. Have you ever had this exam?
2. When was the last time?

Stratification variables: Province/territory, age group (35 to 49, 50 to 64, 65 to 79, 80+)
Provinces/territories with data available: NS (2010, 2011, 2012), PE (2010), NL (2010), YT (2010, 2013), NT (2010, 2011, 2012, 2013), ON (2011, 2012), NU (2011), QC (2013).
General notes: CCHS data is based on a representative sample which is then extrapolated to the overall population.

2. Diagnosis

Age-standardized incidence rates by risk category

Definition: The incidence rate in each risk category that would have occurred if the age distribution in the population of interest was the same as that of the standard, where incidence rate is defined as the number of non-metastatic prostate cancer cases (men aged 35 and older) newly diagnosed during a specific time period, per 100,000 men.
This indicator was estimated by multiplying the age-standardized incidence rates in 2010 by the proportion of cases in each risk category in 2012.
Risk category numerator: Of the denominator, the total number of prostate cancer cases (men aged ≥ 35) in a defined risk category (low-, intermediate-, or high-risk based on GUROC)
Risk category denominator: Total male population aged ≥ 35 diagnosed with prostate cancer in 2012
Age-standardized incidence rates: Refer to 'Age-standardized incidence rates' under the '1. Burden and outcomes' section
Data source: Provincial cancer agencies (risk categories) and Statistics Canada, Canadian Cancer Registry (age standardized incidence)
Measurement timeframe: Risk category data from 2012 diagnosis year and age-standardized incidence rates from 2010
Stratification variables: Province, age at diagnosis (35-49, 50-64, 65-79, 80+)
Provinces/territories submitting data: BC, AB, SK, MB, NB, NS, PE, NL
General notes:
Consensus Risk Categories as follows:

I. Low-risk; must have ***ALL*** of the following:
   - PSA ≤ 10ng/ml
   - Biopsy Gleason Score ≤ 6
   - Clinical Stage T1-T2a

II. Intermediate-risk; must have **all of the following if not low risk**:
   - PSA ≤ 20ng/ml
   - Biopsy Gleason Score =7
   - Clinical Stage T1/T2

III. High-risk; must have **ANY** of the following:
   - PSA > 20ng/ml
   - Biopsy Gleason Score = 8-10
   - Clinical Stage T3a-T4

1. Inclusions: Provincial residents only, cases with clinical stage if stage is needed to classify the risk
2. Exclusions: M1 cases
3. CS Extension – Clinical Extension used to extract data for Stage
4. CS Site-Specific Factor 8 (SSF8) used to extract data for Biopsy Gleason Score
5. CS Site-Specific Factor 1 (SSF1) used to extract data for PSA Value
6. Stage T2NOS is treated as T2c
7. Valid Biopsy Gleason Score – see indicator 1 below for definition
8. Valid PSA Value – see indicator 2 below for definition
9. **Valid Clinical Stage: cases with clinical stage, exclude cases with error, T0, TX

10. High-risk can be determined if either the PSA Value, Biopsy Gleason Score, or Clinical Stage is present. However, low-risk and intermediate-risk requires that PSA Value, Biopsy Gleason Score, and Clinical Stage are all present.

Age-standardized incidence rates by stage

Definition: The incidence rate in each stage category that would have occurred if the age distribution in the population of interest was the same as that of the standard, where incidence rate is defined as the number of prostate cancer cases (men aged 35 and older) newly diagnosed during a specific time period, per 100,000 men.
Numerator: Of the denominator, the total number of prostate cancer cases (men aged ≥ 35) newly diagnosed in 2010, by stage at diagnosis
Denominator: Total male population aged ≥ 35 in 2010
Age standardization: Direct method using the 2011 Canadian Census population
Measurement timeframe: 2010 diagnosis year
Stratification variables: Province, stage (stage I, II, III, IV, Unknown, Blank)
Data sources: Statistics Canada, Canadian Cancer Registry; Provincial cancer agencies (BC and SK)
Provinces/territories with data available: BC, AB, SK, MB, ON, NB, NS, PE and NL
General notes:

1. Stage data are not available for Quebec in 2010.
2. The "Unknown" category refers to cases with unknown staging.
3. The "Blank" category refers to cases when the Collaborative Staging (CS) algorithm was not run or resulted in error.
4. Population estimates provided by the Demography Division, Statistics Canada.
5. World Health Organization, International Classification of Diseases for Oncology, Third Edition (ICD-O-3) and the International Agency for Research on Cancer (IARC) rules for determining multiple primaries sites were used: prostate (ICD-O-3: C61.9).
6. American Joint Committee on Cancer 7 edition (AJCC 7) was used to classify cancer staging.

3. Treatment

a. Wait Times

Wait times for radiation therapy

Definition:

1. Median and 90th percentile radiation therapy wait time from ready-to-treat to start of radiation therapy, measured in days
2. The percentage of cases treated with radiation therapy within 4 weeks from ready-to-treat

The population includes prostate cancer cases (men aged 35 and older) receiving radiation therapy in 2013 that have wait time data collected.

Measures:

1. Wait time
    a. Median wait time (days)
    b. 90th percentile wait time (days)
2. Percentage of patients starting treatment within target timeframe (4 weeks after being deemed 'ready-to-treat')

Numerator: Of the denominator, the total number of prostate cancer cases (men aged ≥ 35) starting radiation therapy within 4 weeks of being 'ready-to-treat'

Denominator: Total number of prostate cancer cases receiving radiation therapy within 2013

Data source: Provincial cancer agencies

Measurement timeframe: 2013 treatment year

Stratification variables: Province, risk category* (low, intermediate, high)

*Refer to 'Age-standardized incidence rates by risk category' under '2. Diagnosis' section for detail.

Provinces submitting data: BC, AB, SK, MB, ON, NB, NS, PE, NL

Province specific notes: AB: For 2013, data included all cases who had radiation therapy at a Cancer Control Alberta Facility with their first treatment between Jan 1, 2013 - Dec 31, 2013; 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. Data by risk category were not available since risk category could not be assigned for more than 55% of patients. **SK:** For 2013, data were reported by treatment site, any RT treatment modality was included. **NS:** For 2013, wait time were computed using the same rules for producing wait time for NS Department of Health and Wellness. As such, wait time were based on patient first courses of treatment in the period of interest. Data by risk category were not available due to incomplete disease information for 2013 cases. **PE:** For 2013, data were based on new treatment starts within the timeframe of 2013. Individual cancer patients could have more than one treatment start in the timeframe and could therefore be counted more than once.

General notes:

1. All behaviour codes are included.
2. Radiation therapy to the primary site only.
3. Disease Site and Morphology Codes: In order to identify prostate cancer, the provinces used whatever disease site and morphology codes they typically use within their provincial registry for reporting incident cases by disease site.
4. There are known discrepancies in the ways in which different provinces measure wait times. One of the key sources of variation is how "ready-to-treat" is defined. Efforts are underway to standardize

these definitions. The following section outlines the definitions used by the different provinces, collected in 2013:

Provincial definitions:

AB: The date when the patient is physically ready to commence treatment. **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. **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. **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. **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. **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. Nova Scotia did not have a ready to treat date until February 2010; a proxy date was used prior to this time. **ON:** The time from when the specialist is confident that the patient is ready to begin treatment to the time the patient receives treatment. **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. **QC:** At consultation, the radiation oncologist enters the date at which the patient will be ready to treat on a formulary requesting 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.

Wait times for surgery

Definition: Median and 90th percentile surgery wait times for prostate cancer (men aged 35 and older), measured in days
Measures: a. Median wait time (days); b. 90th percentile wait time (days)
Data source: Canadian Institute of Health Information (CIHI)
Measurement timeframe: 2014 treatment year
Stratification variables: Province
Provinces/territories with data available: BC, AB, SK, ON, QC, NB, NS, PE and NL
Province-specific notes: AB: Includes biopsies as the sole procedures; includes patient unavailable days; includes neo-adjuvant therapy. **SK:** Includes radical prostatectomy cases only. **ON:** Includes endoscopic cases. **QC:** Start date is the date the surgeon signs the surgical request. **PE:** Includes emergency cases; includes days when the patient was unavailable. **NL:** Excludes suspected cases.

b. Patterns of Care

Prostate cancer cases receiving primary treatment

Definition: Proportion of prostate cancer cases (men aged 35 and older) that received primary treatment by type of treatment

Numerator: Of the denominator, the total number of prostate cancer cases (men aged ≥ 35) receiving primary treatment *within one year* of diagnosis by type:

- Surgery only (radical prostatectomy)
- Radiation therapy only (External Beam Radiation Therapy and/or Brachytherapy)
- Surgery with adjuvant radiation therapy (adjuvant radiation therapy within one-year post-surgery)
- *No record of treatment

Denominator: Total number of prostate cancer cases newly diagnosed in 2010

Data source: Provincial cancer agencies

Measurement timeframe: 2010 diagnosis year

Stratification variables: Risk category (low, intermediate, high), age group (35≤ age ≤ 75, 75+)

Provinces submitting data: BC, AB, SK, MB, NS, PE

Province-specific notes: AB: No record of treatment includes 185 cases of surgeries that were not radical prostatectomy and 271 cases on hormone treatment. **SK:** Cases that were diagnosed with Stage Mx were placed into the "Unable to Classify" category.

General notes:

1. *No record of treatment was calculated as follows: a) For the cases that were referred to a radiation oncologist: # of no record of treatment = # of prostate cancer cases that were referred to a radiation oncologist – (# of cases that had surgery only + # of cases that had radiation therapy only + # of cases that had surgery with adjuvant radiation therapy); b) For the cases that were not referred to a radiation oncologist: # of no record of treatment = # of prostate cancer cases that were not referred to a radiation oncologist - # of cases that had surgery only.
2. Surgery with adjuvant radiation therapy include the cases receiving surgery within one year of diagnosis and had adjuvant radiation therapy within one year post-surgery.
3. Radiation therapy to the primary site only.
4. Only provincial residents are included.

Prostate cancer cases receiving radiation therapy

Definition: Proportion of prostate cancer cases (men aged 35 and older) that received radiation therapy by type of radiation

Numerator: Of the denominator, the total number of prostate cancer cases receiving radiation therapy by type:

- External Beam Radiation Therapy (EBRT) only
- Brachytherapy only
- Both EBRT and Brachytherapy

Denominator: Total number of prostate cancer cases newly diagnosed in 2010

Data source: Provincial cancer agencies

Measurement timeframe: 2010 diagnosis year

Stratification variables: Risk category (low, intermediate, high), age group (35 ≤age ≤ 75, 75+)

Provinces submitting data: BC, AB, SK, MB, NS, PE

Province-specific notes: N/A

c. Radical Prostatectomy

Radical Prostatectomy

Definition: Proportion of prostate cancer cases that underwent radical prostatectomy in 2013 – 2014 by type of surgery

Numerator: Of the denominator, the total number of prostate cancer cases that underwent radical prostatectomy in 2013 - 2014 by type of surgical approach:

- Open
- Robotic laparoscopic
- Non-robotic laparoscopic

Denominator: Total number of prostate cancer cases in 2013 - 2014 that underwent a radical prostatectomy procedure

Data source: Canadian Institute of Health Information (CIHI)

Measurement timeframe: 2013 - 2014

Stratification variables: Province

Provinces submitting data: All

Province-specific notes: N/A

General notes:

1. Results shown by province pertain to the location of surgery, not the province of patient residence.
2. The denominator consists of all records for male patients of all ages whose discharge record contains a treatment for prostate cancer in the measurement timeframe.

   Inclusion criteria:

   i. Discharged from acute care
      - ANALYTICAL_INST_TYPE_CODE in ("1")

   ii. Discharge must have a valid male gender recorded
      - Gender in ("M")

   iii. Has a most responsible diagnosis = C61

   iv. Has no past history of prostate cancer (Z85.4)

   v. Has a surgery (one of 1.QT.91) on the index procedure

Intervention CCI Code	Intervention CCI Description
1.QT.91	Excision radical, prostate
1.QT.91.PB; 1.QT.91.PK	Excision radical, prostate—Open Surgery
1.QT.91.DA; 1.QT.91.BQ	Excision radical, prostate—Laparoscopic Surgery
1.QT.91.BQ	Excision radical, prostate—Robotic Assistance (2009–2011)
7.SF.14	Excision radical, prostate—Robotic Assistance (2012)

   Exclusion criteria:

   i. Duplicate records are removed from the analysis. These are identified as discharges with identical values in the following data elements:
      INST_CODE HEALTH_CARD_ENCRPT_NUM ADMISSION_DATE ADMISSION_TIME DISCHARGE_DATE DISCHARGE_TIME HEALTH_CARD_PROV_CODE BIRTHDATE GENDER POSTAL_CODE MR_DIAG_ICD10_CODE PRINC_INTERV_CCI_CODE

   ii. Newborns, Stillbirths and Cadaveric Donors

- If ENTRY_CODE not in ("S," "N")
- If ADMISSION_CATEGORY not in ("R")

iii. Discharges with an invalid encrypted health care number

- HEALTH_CARD_ENCRYPT_NUM = "0000000000"

iv. All identified procedures with a status attribute code "A" (abandoned)

- STATUS_ATTRIBUTE not in ("A")

3. Volumes are calculated using a methodology similar to that used in CIHI's report *The Delivery of Radical Prostatectomy to Treat Men With Prostate Cancer*, with small modifications to allow for annual production, as follows:
   a) The annual Quick Stats tables in the CIHI report include only inpatient records from the DAD, whereas the report included inpatient and day surgery records from the DAD, NACRS and AACRS;
   b) The annual Quick Stats tables count discharges, whereas the report counts episodes;
   c) The annual Quick Stats tables use the variable *SUBMITTING_PROV_CODE* to determine the location of surgery, whereas the report uses Organization ID (OI) data to determine the location of surgery.

   Due to these modifications, the 2 related products are not directly comparable.

4. Person-Centred Perspective

a. Patient Satisfaction with Care

Patient satisfaction with care – all dimensions

Definition: Provincial percentage of negative experience ratings among prostate cancer patients (aged 50 and older) across the following dimensions of care: Access to Care; Coordination and Continuity of Care; Emotional Support; Information, Communication & Education; Physical Comfort; Overall Quality of Care

Data source: National Research Corporation Canada's Ambulatory Oncology Patient Satisfaction Survey (AOPSS) results (self-reported data: see Inclusion/Exclusion criteria below) –provided to the Canadian Partnership Against Cancer with permission from provincial cancer agencies (or equivalent).

Measurement timeframe: 2011 – 2013

(**BC**: June-Dec 2012 **AB:** Feb-Aug 2012 **SK:** Apr-June 2011 **MB:** June-Oct 2011 **ON:** Apr-Sept 2012 **NS:** June-Sept 2012 **PE:** Nov12-Jan13 2013)

Stratification variables: Province

Provinces submitting data: BC, AB, SK, MB, ON, NS, PE

Province-specific notes: see Inclusion/Exclusion Criteria below

General notes:

1. For the AOPSS sample population, prostate cancer patients were selected using question #74 (What was the primary type of cancer you were being treated for in the past 6 months?), response k (Prostate/testicular) only.
2. Only included surveys in which respondents identified being age 50 years or older [1]. This makes it likely that the vast majority of respondents whose data are included here were diagnosed with prostate cancer. Due to differences in the way data were collected in MB and BC, results for these two provinces only included men definitively diagnosed with prostate cancer (i.e., the question on the patient's primary type of cancer included a response category with only prostate cancer).

[1] Data on age-related cancer incidence from Canada and the United Kingdom show that 98% of men with prostate cancer are at least 50 years old, while just 10% of those with testicular cancer are over 50. Given that the incidence rate of testicular cancer is relatively low compared to prostate cancer, the actual number of testicular cancer cases over 50 years old would be very small.
References: Statistics Canada. Canadian Cancer Registry, 2008; UK Cancer Research. Prostate Cancer Incidence Statistics: By Age [Internet]. London (England): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/uk-prostate-cancer-incidence-statistics#age; UK Cancer Research. Testicular Cancer Incidence Statistics: By Age [Internet]. London (England): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/testis/incidence/.

Patient satisfaction with care – emotional support dimension

Definition: Provincial percentage of negative experience ratings among prostate cancer patients (aged 50 and older) for 8 survey questions on emotional support:

1) Was told of diagnosis in a sensitive manner;
2) Upon diagnosis, referred to other provider for help with anxiety/fear;
3) Given enough info on possible emotional changes;
4) Given enough info on possible sexual activity changes;
5) Given enough info on possible relationship changes;
6) Care provider(s) went out of way to help patient feel better;
7) Got as much help as wanted on figuring out extra costs for care; and
8) In the past 6 months, referred to other providers for help with anxiety/fear.

Data source: National Research Corporation Canada's Ambulatory Oncology Patient Satisfaction Survey (AOPSS) results (self-reported data: see Inclusion/Exclusion criteria below) – provided to the Canadian Partnership Against Cancer with permission from provincial cancer agencies (or equivalent).

Measurement timeframe: 2011 – 2013

(**BC**: June-Dec 2012 **AB:** Feb-Aug 2012 **SK:** Apr-June 2011 **MB:** June-Oct 2011 **ON:** Apr-Sept 2012 **NS:** June-Sept 2012 **PE:** Nov12-Jan13 2013)

Stratification variables: Province

Provinces submitting data: BC, AB, SK, MB, ON, NS, PE

Province-specific notes: see Inclusion/Exclusion Criteria below

General notes:

1. For the AOPSS sample population, prostate cancer patients were selected using question #74 (What was the primary type of cancer you were being treated for in the past 6 months?), response k (Prostate/testicular) only.
2. Only included surveys in which respondents identified being age 50 years or older [1]. This makes it likely that the vast majority of respondents whose data are included here were diagnosed with prostate cancer. Due to differences in the way data were collected in MB and BC, results for these two provinces only included men definitively diagnosed with prostate cancer (i.e., the question on the patient's primary type of cancer included a response category with only prostate cancer).

[1] Data on age-related cancer incidence from Canada and the United Kingdom show that 98% of men with prostate cancer are at least 50 years old, while just 10% of those with testicular cancer are over 50. Given that the incidence rate of testicular cancer is relatively low compared to prostate cancer, the actual number of testicular cancer cases over 50 years old would be very small.
References: Statistics Canada. Canadian Cancer Registry, 2008; UK Cancer Research. Prostate Cancer Incidence Statistics: By Age [Internet]. London (England): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/uk-prostate-cancer-incidence-statistics#age; UK Cancer Research. Testicular Cancer Incidence Statistics: By Age [Internet]. London (England): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/testis/incidence/.

Patient satisfaction with care – information, communication, & education dimension

Definition: Provincial percentage of negative ratings among prostate cancer patients (aged 50 and older) for 10 survey questions on information, communication, & education:

1) Wait for first consultation appointment explained;
2) Different cancer treatments discussed;
3) Given enough info on cancer treatments;
4) Comfortable talking with staff about clinical trials/new treatments;
5) Given enough info on possible changes to physical appearance;
6) Given enough info about nutritional needs;
7) Given enough info on possible changes to work/usual activities;
8) Given enough info on possible changes to energy/fatigue level;
9) Care provider explained why tests needed; and
10) Staff explained test results understandably.

Data source: National Research Corporation Canada's Ambulatory Oncology Patient Satisfaction Survey (AOPSS) results (self-reported data: see Inclusion/Exclusion criteria below) – provided to the Canadian Partnership Against Cancer with permission from provincial cancer agencies (or equivalent).

Measurement timeframe: 2011 – 2013

(**BC**: June-Dec 2012 **AB:** Feb-Aug 2012 **SK:** Apr-June 2011 **MB:** June-Oct 2011 **ON:** Apr-Sept 2012 **NS:** June-Sept 2012 **PE:** Nov12-Jan13 2013)

Stratification variables: Province

Provinces submitting data: BC, AB, SK, MB, ON, NS, PE

Province-specific notes: see Inclusion/Exclusion Criteria below

General notes:

1. For the AOPSS sample population, prostate cancer patients were selected using question #74 (What was the primary type of cancer you were being treated for in the past 6 months?), response k (Prostate/testicular) only.
2. Only included surveys in which respondents identified being age 50 years or older [1]. This makes it likely that the vast majority of respondents whose data are included here were diagnosed with prostate cancer. Due to differences in the way data were collected in MB and BC, results for these two provinces only included men definitively diagnosed with prostate cancer (i.e., the question on the patient's primary type of cancer included a response category with only prostate cancer).

[1] Data on age-related cancer incidence from Canada and the United Kingdom show that 98% of men with prostate cancer are at least 50 years old, while just 10% of those with testicular cancer are over 50. Given that the incidence rate of testicular cancer is relatively low compared to prostate cancer, the actual number of testicular cancer cases over 50 years old would be very small.
References: Statistics Canada. Canadian Cancer Registry, 2008; UK Cancer Research. Prostate Cancer Incidence Statistics: By Age [Internet]. London (England): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/prostate/incidence/uk-prostate-cancer-incidence-statistics#age; UK Cancer Research. Testicular Cancer Incidence Statistics: By Age [Internet]. London (England): UK Cancer Research; 2014 [updated 2014 Jul 5; cited 2014 Oct 6]. Available from: http://www.cancerresearchuk.org/cancer-info/cancerstats/types/testis/incidence/.

Patient satisfaction with care – inclusion and exclusion criteria

National Research Corporation Canada
Ambulatory Oncology Patient Satisfaction Survey – Jurisdiction Group
Inclusion and Exclusion Criteria – October, 2013

The criteria have been used by jurisdictions going to field as of June 1st, 2012. While more refined criteria in terms of cancer diagnosis and/or specific type of treatment may be desired, it is recognized that data collection and the time it takes to code more specific details may not be available in all jurisdictions by the point in time when data is submitted to NRC for the purpose sampling. As such, the criteria as stated are more general than specific.

1. The table below highlights where sampling criteria for jurisdictions varies from the criteria outlined above. This will be confirmed by the jurisdiction upon data submission to NRC.

2. Following fielding of the survey by a number of jurisdictions, NRC will conduct an analysis to determine if detectable differences in sampling are of such a nature that they may affect comparability of data between jurisdictions.

3. Depending on the findings of the analysis, it will be determined if there is a specific population within the patient group that is (or is not) included in some jurisdictions that is affecting the benchmark in some way. If so, it may be possible to calculate comparative benchmarks that include or exclude this particular patient population.

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 haematology and/or non-malignant cancers (for example 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.

Inclusion Criteria:

- Patients who have received active treatment in an ambulatory setting in the past 3 months
- Patients with a confirmed diagnosis of Cancer (include those patients with diseases identified as invasive, with a 3 in the 5th position of the ICD-O-3 histology code (malignant, primary site)

- Have undergone active outpatient treatment in the past 3 months
- Are 18 years or older (based on date of birth at time of data extraction for surveying)

Jurisdiction	Deviations from the standard Inclusion/Exclusion criteria	Data elements in addition to those required as per NRC Implementation Manual
Alberta	Inclusion Those who have been on treatment for **6 months.**	• Can identify patients who received chemo and RT treatments however surgery is not captured until approximately a year after diagnosis so the vast majority of patients will not have surgical information. • Will identify patients who received IV and/or oral chemo at the tertiary centres. However at the Associate and Community cancer centres, unable to determine the type of systemic treatment received. This will result in the inclusion of patients who received hormones and immunotherapy as well as those who received chemotherapy. • Alberta will use the ICD code for invasive cancer as used by the other provinces. • Will use age at diagnosis as prescribed on the Implementation Manual
Nova Scotia Surveyed Point in Time Summer 2012	Exclusion Exclude in-situ bladder There is a further restriction that some registries (NS would be one) may be able to apply. There is a flag set on each case where 'ambiguous' terms appear on the pathology report. The histology could still be classified as /3 (invasive), but if this flag were set, we would prefer not to approach the patient.	Oral Chemotherapy patients: Our problem is in identifying these patients. We don't specifically include them or exclude them. Because of limitations to our IT system, we have developed an algorithm for selecting patients that are most likely to be receiving chemotherapy based on visits to medical oncologists so oral chemo patients could be part of that algorithm. Certainly oral chemo is increasing and they may have different issues or not identify themselves as chemotherapy patients in the survey.
Quebec Continuous quarterly sample since January 2012	As per criteria above with following deviations: - Patients surveyed in the last 365 days - Patients who were not in active treatment in an ambulatory settings in the last 6 months - patients who have not received a confirmed cancer diagnosis (even if they received treatment in your facilities) [different wording from above] - Patients who have received active treatment in an ambulatory setting in the past **SIX** months	

Jurisdiction	Deviations from the standard Inclusion/Exclusion criteria	Data elements in addition to those required as per NRC Implementation Manual
Ontario Quarterly sample point in time (Q1 and Q2 only) since 2012	As per criteria above - Patients who have received active treatment **<u>for a confirmed cancer diagnosis</u>** in an ambulatory setting in the past 3 months - Patients with a confirmed diagnosis of Cancer (includes malignant hematology cases)	
Saskatchewan Sample point in time every 1 – 2 years	<u>Exclusions:</u> - Patients who are on injections (determined by a comprehensive drug master list from Care Services) - Patients who have restrictions in Ceres/Eureka/CMS - Patients with specific chemo/radiation events <u>Inclusions:</u> - Patients who have a specific COPS institution as a scheduled event - Haematology patients (as there is no way currently to exclude those patients) - have undergone active outpatient treatment in the past **<u>six</u>** months.	<u>Oral Chemotherapy patients:</u> Oral chemo patients included in sample size. Patients not receiving IV chemo are not excluded from the serious side effects and care that they should receive and expect during their cancer care service. Many cancer patients are on oral chemo, such as our brain, GI, pancreatic cancer patients that require the same information, education, support, follow up and side effects management as do the IV chemotherapy patients.
Manitoba	As per criteria above	
Prince Edward Island	As per criteria above	
British Columbia Treatment start and/or end dates between 1st submission Treatment Date (start and/or end) between 15 June 2012 and 15 September 2012	<u>Inclusions:</u> - All patients who meet the criteria for Radiation Therapy and IV Chemotherapy. - A random sample of patients who meet the criteria for Oral Chemotherapy. – BC patients only – BCCA Referred Radiation Therapy Cases – BCCA Referred and Non-Referred Chemotherapy Cases – Invasive cases only – Alive – Age > 18 at time of data retrieval	See table below*

Jurisdiction	Deviations from the standard Inclusion/Exclusion criteria	Data elements in addition to those required as per NRC Implementation Manual
(extraction date 22 October 2012) 2nd submission Treatment Date (start and/or end) between 16 September and 15 December 2012 (extraction date 21 January 2012)	– On active outpatient treatment (IV chemo, oral chemo and radiation (including brachytherapy)) – Treatment start and/or end dates between [defined dates] <u>Exclusions</u>***:*** – Patients known to be deceased – Patients < 18 years of age at time of data retrieval – Patients with no known fixed address (no address.addr_type = H, or address_type=H with no viable entry in 'address_1' and/or 'city' fields) – Patients who do not have a confirmed cancer diagnosis (even if they have received treatment in our facility)..e.g. last character of patient_type = '_P' for 'pending' (pending diagnosis or pending death information) – Patients who are not on active treatment in an ambulatory setting in the past 90 days – Patients who received only inpatient services – Patients where unable to determine if treatment was for a distinct primary disease record meeting above survey criteria (e.g. chemotherapy meeting survey criteria but no tumour group attached to treatment record so can't match to a disease record meeting survey criteria) – Patients where treatment (chemotherapy) facility is unknown – Patients identified thru Jimmy Pattison Surrey. (The rationale remains that they are not a formalized program within the BCCA delivery of oncology services).	

*Data elements in addition to those required as per NRC Implementation Manual
British Columbia

NRCPicker Field	BCCA Field	Specifications
Salutation	n/a	Include field but leave blank (optional)
Fname	warehouse.cancer.fst_name	
Lname	warehouse.cancer.surname	
ADDR1	cais.address.address_1	Where cais.address.addr_type = 'H' (and cais.address.city OR cais.address.post_code OR cais.address.province_code determined to be 'BC') Exclude records where no viable mailing address (eg. '-', or 'No Fixed Address', etc)
ADDR2	cais.address.address_2	Where cais.address.addr_type = 'H' (and cais.address.city OR cais.address.post_code OR cais.address.province_code determined to be 'BC')
City	cais.address.city	Where cais.address.addr_type = 'H' (and cais.address.city OR cais.address.post_code OR cais.address.province_code determined to be 'BC') Exclude records where no viable BC mailing city (eg. 'blank', 'San Francisco', 'Toronto', etc)
Postal Code	cais.address.post_code	Where cais.address.addr_type = 'H' and cais.address.city OR cais.address.post_code OR cais.address.province_code determined to be 'BC') Cais.address.postal_code Like V* OR '' OR IS Null Include records where cais.address.post_code = blank/null if viable BC cais.address.address_1 and cais.address.city fields (as can look up post code)
Province	cais.address.province	Province = BC Derived field Flagged to 'BC' where below derived field 'curr_home_addr_BC' = 'Y'
Gender	warehouse.cancer.sex	F = Female, M = Male
DOB	warehouse.cancer.birth_date	Calculate age at data retrieval to select records where age ≥18 yo (algorithm based on DOB and date of retrieval date; for survey volumes used 28May2012). Format mmddyyyy (include leading zeros if applicable).
VisitType	n/a	oncology = 04 (must include leading zero)
Facilitynum	warehouse.radiation.treat_facility 'pharmacy dataset'.hospital_id	Unique number that identifies your facility (up to 10 characters) – appears on survey letters to patients above patient name….as per Implementation Manual.
MRN	warehouse.radiation.agency_id or 'pharmacy dataset'.agency_id	Warehouse.radiation and/or 'pharmacy dataset' BCCA agency_id's.

NRCPicker Field	BCCA Field	Specifications
SiteName	lookup.description	Facility name as it should appear on the survey (up to 42 characters)…as per Implementation Manual Where radiation.treat_facility,'pharmacy dataset'.hospital_id = lookup.code (lookup table 018 – hlth facility/sor).
VisitDate	warehouse.radiation.start_date and/or end_date and/or 'pharmacy dataset'.prescription_date	Date of radiation treatment (RT and/or BT) Date the chemotherapy prescription was entered into the various pharmacy computer systems (patient may not have received the drug on this date) Note: where patient received more than one treatment just use one of the treatment end dates. Date used by NRC to know the patient falls into the encounter period we are surveying. Format mmddyyyy (include leading zeros if applicable).
Language Code	n/a	01 = English Language survey is produced in.
Additional	Additional_IV_chemo_meets_survey_criteria	Y = Yes Text Format, Field Size = 1
Additional	Additional_Oral_chemo_meets_survey_criteria	Y = Yes Text Format, Field Size = 1
Additional	Additional_Radiation_RT_meets_survey_criteria	Y = Yes Text Format, Field Size = 1
Additional	Additional_Radiation_BT_meets_survey_criteria	Y = Yes Text Format, Field Size = 1
Additional	Facility.curr_hlth_auth	Include exact same field name but leave blank as NRC has script written to populate treatment facility HA.
Additional	Facility.curr_desc_hlth_auth	Include exact same field name but leave blank as NRC has script written to populate treatment facility HA description.
Additional	Facility.curr_hsda	Include exact same field name but leave blank as NRC has script written to populate treatment facility HSDA.
Additional	Facility.curr_desc_hsda	Include exact same field name but leave blank as NRC has script written to populate treatment facility HSDA description.

b. Palliative Radiation

Palliative Radiation

Definition: Percentage of prostate cancer cases (men aged 35 and older) receiving radiation therapy within one year prior to death
Numerator: Of the denominator, total number of cases receiving radiation therapy within one year prior to death
Denominator: Total number of deaths with the cause of prostate cancer in 2011
Data source: Provincial cancer agencies
Measurement timeframe: 2011 year of death
Stratification variables: N/A
Provinces submitting data: AB, BC, PE, NS, SK, MB
Province-specific notes: AB: Radiation therapy data was from EMR database, hence not including out-of-province treatment.
General notes:

1. Cause of death identified from Vital Statistics death database.
2. Only provincial residents included.
3. Denominator includes prostate cancer deaths of *all* ages

c. Place of Death

Place of death

Definition: Percentage of cancer deaths occurring in hospital, private home, or other
Numerator:

1. By province: Number of prostate cancer deaths in hospital, private home, or other;
2. Canada: Number of prostate, breast, lung, and colorectal cancer deaths in hospital, private home, or other

Denominator:

1. Number of prostate cancer deaths in the given province;
2. Number of prostate, breast, lung, or colorectal cancer deaths in Canada

Data source: Vital Statistics death database
Measurement timeframe: 2011
Stratification variables: Province, disease site (prostate, breast, lung, colorectal)
General notes:
1. "Other" includes other specified locality and other health care facilities. Unknown localities are excluded.

d. Prostate Cancer Focus Groups: Interview Guides (September 22, 2014)

Notes for facilitators:

- Questions should be posed in plain language (i.e., not all patients may be familiar with the term 'active surveillance').
- Listed below are examples of specific questions to consider that cover the themes of interest for CPAC's report on prostate cancer. It is understood that all aspects within each question may not

be covered. If time permits, other areas can be discussed but at a minimum the themes below should be explored.

- Feel free to use prompts, such as … tell me more; and then what happened; can you expand on that; what did you expect.
- Advise the participants against using the name(s) of their health care team members – all names will be removed from the transcripts.

A. For Patients/Survivors

1. Your joining us today indicates that you have all been affected by prostate cancer. Think back and tell me what it was like for you in the beginning when you were first given the diagnosis of prostate cancer.
    - *What started your cancer journey? Did you have a PSA test? Were you tested on a regular basis (i.e., annual physicals)? Importance of PSA testing in your diagnosis?*
    - *Who told you of your diagnosis (GP, referring physician)?*
    - *How was your diagnosis explained to you? How did you feel?*
    - *Was there a wait for your diagnosis?*
    - *Were you told all you wanted to know about your condition at that time?*

2. Tell us about your experiences as you and your doctor discussed your treatment options, they may have included radiation, surgery, ADT, chemotherapy, or active surveillance.
    - *Were you involved in deciding which treatment to have? Who influenced your decision? Were family members and/or caregivers involved? How did you decide on the treatment modality/regimen? Were decision aids used? Did you have the chance to talk to different types of doctors to help you reach an informed decision (e.g., radiation oncologists and urologist's consults)? Was the option of active surveillance discussed with you?*
    - *Did you understand your treatment plan? Where did you have the treatment?*
    - *Were you offered to join a clinical trial?*
    - *Were you given enough information and supporting documents about what to expect regarding the side effects of treatment?*

3. Adjusting to life after treatment may have been challenging. Can you tell us about any challenges that you may have experienced?
    - *Were you given a follow-up plan? Were you involved in making a plan? Who does your follow-up? Was there follow-up with primary care physicians post-treatment? Who initiated this follow-up?*
    - *Emotional burden that prostate cancer treatment had on your partner and family members*
    - *Where do you seek care? Were support services to effectively manage pain, fatigue and other symptoms you may have experienced provided to you? Did you have access to sexual help clinics/counselling?*

4. Reflecting on your experiences during diagnosis, treatment, and your care, who did you find was the most helpful (or not helpful), and what were some of the most helpful (or not helpful) resources that you utilized.
    - *What was helpful?*

5. If you could change one thing that would have improved your experience, or your family's experience, what would that be?
    - *Did you have or were you given the right amount of information? Too much? Too little?*
    - *What could be done to improve your experience? What should be a priority for future efforts?*

6. If someone came to you and said they just learned they had prostate cancer, what advice would you offer? Why?

B. For Family Members

1. Your joining us today indicates that you have all been affected by prostate cancer. Think back and tell me what it was like for you in the beginning when your loved one was first given the diagnosis of prostate cancer.
    - *How were you told of the diagnosis? Were you there when your loved one was given the diagnosis?*
    - *How did you feel?*
    - *Were you told all you wanted to know at that time? Were you comfortable with asking for information and help?*

2. Tell us about your experiences as you and your loved one discussed treatment options with his doctor. Treatment may have included radiation, surgery, ADT, chemotherapy, or active surveillance.
    - *Were you involved in deciding which treatment your loved one had? How did you decide on the treatment? Did you have the chance to talk to different types of doctors to help you reach an informed decision (e.g., radiation oncologists and urologist's consults)?*
    - *Was the option of active surveillance discussed with you? If the patient was on active surveillance or watchful waiting, did you have concerns with the patient/family member delaying treatment?*
    - *Did you seek out information on treatment options, side effects and research about the disease? Did you know what to expect after treatment? Such as, when and where to seek help after?*
    - *Were there side effects related to his treatment? How did you support your loved one in dealing with them? How was your life/relationship affected? Follow-up on physical and emotional impact.*
    - *Did the treating physician offer support to you? If not, where did you go for support?*
    - *Were you provided with support in administering medications and other care?*
    - *Did you and your loved one talk about end-of-life care planning? Did the health care team talk about this at all?*

3. Adjusting to life after his treatment may have been challenging. Can you tell us about any challenges that your loved one and your family may have experienced?
    - *How did your family's life change after his treatment was complete?*
    - *Did your relationship change?*
    - *Physical, emotional, practical (financial, transportation, employment) impact*
    - *Did you have enough information?*

- *Did you feel supported? Did you need help? (i.e. touch on emotional burden)*
- *Did you know where to go for help?*
- *Are you aware of any support services available to you? Did you access them?*
- *Were you referred to support groups consisting of other care givers/family members with similar experiences?*
- *Were you involved in making sure follow-up care was done?*

4. Reflecting on your experience as a caregiver through this cancer journey during diagnosis, treatment, and care, who did you find was the most helpful (or not helpful), and what were some of the most helpful (or not helpful) resources that you utilized?

5. If you could change one thing that would have improved your experience, or your family's experience, what would that be?
    - *Did you have or were you given the right amount of information? Too much? Too little? Was there appropriate information provided to you along the disease course (diagnosis, treatment, support)? Would you have wanted more information?*
    - *What could be done to improve your experience? What should be a priority for future efforts*

6. If someone came to you and said they just learned their partner has prostate cancer, **what advice would you offer**? Why?

7. Anything else you want to share that we did not yet touch upon?

5. Research

a. Cancer Research Investment

Cancer research investment for the four most common cancers

Definition: The percentage distribution of cancer research investment across the four most common cancers (breast, prostate, lung, colorectal) in 2012. Within each disease site, distributions are shown alongside the percentage of new cancer cases in 2010 and cancer deaths in 2011. An 'other' category is also included to show the remaining distribution of cancer research investment.

Numerator:

1. Investment: Amount of site-specific research investment (in dollars) for breast, prostate, lung, colorectal, or other cancers;
2. New cases: Number of site-specific cases for breast, prostate, lung, colorectal, or other cancers;
3. Deaths: Number of site-specific deaths from breast, prostate, lung, colorectal, or other cancers.

Denominator:

1. Investment: Total amount of site-specific cancer research investment (in dollars);
2. New cases: Total number of site-specific cases;
3. Deaths: Total number of site-specific deaths.

Data source:

1. Investment: Canadian Cancer Research Alliance, Canadian Cancer Research Survey;
2. New cases: Statistics Canada (CANSIM Table 103-0553), Canadian Cancer Registry;
3. Deaths: Statistics Canada (CANSIM Table 102-0552), Vital Statistics Death Database.

Measurement timeframe: 2012 (cancer research investment), 2010 (new cancer cases), 2011 (cancer deaths)

Stratification variables: disease site (breast, prostate, lung, colorectal, other)

General notes: N/A

Prostate cancer research investment across areas of research for the top five funders

Definition: The percentage of investment in prostate cancer research by the top five funders* across the following five areas of research: Biology; Etiology; Prevention; Early Detection, Diagnosis & Prognosis; Treatment; Cancer Control, Survivorship & Outcomes; and Scientific Model Systems.

Numerator: Amount of prostate cancer research investment contributed by the top five funders (in dollars) for a given area of research

Denominator: Total amount of prostate cancer research investment contributed by the top five funders (in dollars)

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

Measurement timeframe: 2005, 2012

Stratification variables: Year (2005 vs. 2012)

Provinces submitting data: All

General notes:

1. Research areas are based on Common Scientific Outline Codes.
2. *In 2012, the top five funders were the Canadian Institutes of Health Research, Prostate Cancer Canada, Ontario Institute for Cancer Research, The Terry Fox Foundation, and Canadian Cancer Society. In 2010, the top five funders were the Canadian Institutes of Health Research, Canada

Foundation for Innovation, Canadian Cancer Society, Terry Fox Foundation, and Prostate Cancer Canada.

Per capita investment (male population) in prostate cancer research

Definition: The amount of per capita investment (in Canadian dollars) for prostate cancer research in each province
Numerator: Total amount of prostate investment (in Canadian dollars) from a given province in a given year
Denominator: The total male population (all ages) from a given province in a given year
Data source: Canadian Cancer Research Alliance, Canadian Cancer Research Survey
Measurement timeframe: 2005, 2012
Stratification variables: Province, year (2005 vs. 2012)
Provinces submitting data: All
General notes:

1. The male population includes males of all ages.

b. Clinical Trial Participation

Adult clinical trial participation by disease site

Definition: The ratio of the total number of adult patients (aged 19 and older) newly enrolled in cancer-related therapeutic trials or clinical research studies in 2013 to the projected number of new cancer cases (all ages) in 2013
Numerator: Number of cancer patients (aged ≥19) newly enrolled in cancer-related therapeutic clinical trials or clinical research at provincial cancer centres in 2013. For patients enrolled in multiple clinical trials, all occurrences are counted.
Denominator: Projected number of new invasive cancer cases (all ages) in 2013
Data source: Provincial cancer agencies or equivalent (numerator); Canadian Cancer Society, Canadian Cancer Statistics 2013 (denominator).
Measurement timeframe: 2013 enrolment year
Stratification variables: Disease site: Breast (female); 2. Prostate; 3. Colorectal; 4. Lung; 5. All invasive cancers (the numerator includes all invasive cancers; the denominator consists of all invasive cancers including in-situ bladder cancer cases).
Provinces submitting data: BC, AB, SK, MB, NB, NS, PE, NL
Province-specific notes: AB: For 2013, the total number of accruals for cancer patients (aged ≥19) included newly enrolled patients in cancer-related therapeutic trials or clinical research who were in the Alberta Cancer Clinical Trials (ACCT) database. If a patient had multiple clinical trial accruals in the given year, a patient would be counted for each accrual. The ACCT database also includes patients who were living outside of Alberta, as long as they were on a clinical trial in Alberta. The ACCT database includes both females and males in the Breast Tumour Group and may include clinical trials for non-melanoma skin patients.
General notes:

1. "All cancers" may include non-melanoma skin patients.
2. Incident cases are estimated for 2013, obtained from the Canadian Cancer Statistics.

Adult clinical trial participation for prostate cancer

Definition: The ratio of the total number of prostate cancer patients (aged 19 and older) newly enrolled in cancer-related therapeutic trials or clinical research studies in 2013 to the projected number of new prostate cancer cases (all ages) in 2013

Numerator: Number of prostate cancer patients (aged ≥19) newly enrolled in prostate cancer-related therapeutic clinical trials or clinical research at provincial cancer centres in 2013. For patients enrolled in multiple clinical trials, all occurrences are counted.

Denominator: Projected number of new invasive prostate cancer cases (all ages) in 2013

Data source: Provincial cancer agencies or equivalent (numerator); Canadian Cancer Society, Canadian Cancer Statistics 2013 (denominator).

Measurement timeframe: 2013 enrolment year

Stratification variables: Province

Provinces submitting data: SK, MB, BC, NB, AB, NS, PE, NL

Province-specific notes: AB: For 2013, the total number of accruals for cancer patients (aged ≥19) included newly enrolled patients in cancer-related therapeutic trials or clinical research who were on the Alberta Cancer Clinical Trials (ACCT) database. If a patient went on multiple clinical trial accruals in the given year, a patient would be counted for each accrual. The ACCT database also includes patients who were living outside of Alberta, as long as they were on a clinical trial in Alberta.

General notes:

1. Incident cases are estimated for 2013, obtained from the Canadian Cancer Statistics.