

**BC Cancer Data Access Request (DAR)**

**Data Field Extraction Reference Guide**

Revised: 10 August 2023

Welcome to the Data Field Extraction Reference Guide, a tool for navigating the spectrum of available BC Cancer data for your specific data requirements. **Please note that this guide is for reference only** and the submission process has transitioned to our online platform. Instructions for the DAR submission can be found [here](http://www.bccancer.bc.ca/health-professionals/professional-resources/bc-cancer-registry/request-registry-data).

*An asterisk (\*) indicates data fields that BC Cancer considers to be a potential personal identifier and requires a justification to be provided in the DAR for their release to be considered. Data fields requested without appropriate rationales will not be approved for release.*

*Note some fields include both a code and a description. The description will automatically be included on applicable fields.*

Section 1: Demographics/ BC Cancer Registry/ Diagnosis and Mortality

These sections can be used to select data on cases of cancer diagnosed in BC residents. These data can also be linked to data from subsequent sections on cancer treatment and screening.

| **Data Item** | **Description** |
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| **1.1 DEMOGRAPHICS (Address information is more current for cases seen, treated and followed by BC Cancer. Not all cancer cases are seen at BC Cancer)** | |
| \*agency id | A unique identification number assigned to the patient upon initial contact with BC Cancer or the BC Cancer Registry.  Please justify your need for requiring this variable. |
| \*personal health number | The patient’s British Columbia (BC) personal health number.  Please justify your need for requiring this variable. |
| \*birth date | The patient’s date of birth. When the birth day is missing the system automatically sets it to 01. If the birth day and month are missing the system automatically sets the day and month to 0101. |
| *Birth date (day, month, year) Includes a data element indicating when the birth date is partially known.*  Please justify your need for requiring this variable. |
| *Month and Year of birth only* |
| \*name | The patient’s surname, first name, second name, birth surname.  Please justify your need for requiring this variable. |
| \*address | The patient’s last known home address, city, province.  Please justify your need for requiring this variable. |
| \*phone number | The patient’s last known home address phone number.  Please justify your need for requiring this variable. |
| \*postal code | The patient’s last known home address postal code.  Please justify your need for requiring this variable. |
| *First 3 digits (forward sortation area or FSA) of this postal code only*  Please justify your need for requiring this variable. |
| geographical area | The geographical area of the patient’s postal code for their last known BC residence address. |
| Health Authority (HA) |
| Health Service Delivery Area (HSDA) |
| \*Local Health Area (LHA)  Please justify your need for requiring this variable. |
| BC Cancer’s Catchment Centre based on HSDA |
| sex | The patient’s gender: Female or Male |
| **1.2 CANCER DIAGNOSIS (Complete from 1970 to 2 years prior to end of last calendar year)** | |
| **Core Cancer Diagnosis Information (please select this category in the DAR application if data is required). The following information will be provided to you:** | |
| * **Age at Diagnosis**   Calculated age at diagnosis and 5-yr age groups. A flag will indicate if the age at diagnosis is calculated using a partially known birth and/or diagnosis day or month.   * **Diagnosis Date**   The date the patient’s disease was diagnosed. When the month and/or day of diagnosis is missing, the system automatically sets the unknown values to ‘01’. Includes a data element indicating when the diagnosis date is partially known.   * **Diagnostic Geographical Area**   The geographical area of the patient’s BC postal code at time of diagnosis. Includes the HA, HSDA and BC Cancer’s Catchment Centre.   * **Cancer Diagnosis**   The site (topography), histology and behavior of the patient’s distinct primary disease, coded according to the International Classification of Diseases for Oncology 3rd edition (ICD-O-3) as well as laterality.   * **Diagnostic Confirmation**   The most definitive method of confirmation of the patient’s distinct primary disease (eg: histology, autopsy, cytology, radiology, lab, etc)   * **Tumour Group/Subgroup**   The tumour group and tumour subgroup assigned to the patient’s primary disease based on site and histology, regardless of behavior.   * **Incidence Groups**   Cancer diagnosis classified into simple, minor and major incidence groups according to the Canadian Cancer Statistics (CCS) tumour groupings. Includes all invasive disease (behavior code=3) and insitu bladder. Otherwise is blank. Used by BC Cancer and CCS to compile cancer statistics. Details can be found here: [Cancer diagnosis groupings](https://bit.ly/3jueDJS) | |
| \*patient’s location at  diagnosis | The Canadian postal code or the BC Cancer geographic code of the patient’s residence at the time of diagnosis.  Please justify your need for requiring this variable. |
| *First 3 digits (forward sortation area or FSA) of this postal code only*  Please justify your need for requiring this variable. |
| The local health area of the patient’s BC postal code at the time of diagnosis.  Please justify your need for requiring this variable. |
| **1.3 CANCER STAGE** | |
| Cancer Staging System(s) | Staging variables related to the appropriate staging system(s) for the primary disease. (eg: collaborative stage, tnm, other). Available on all referred cases to BC Cancer and in addition, Collaborative Stage is available on referred and non-referred cases from 2010 diagnosis year onwards for breast, cervix, colorectal, lung and prostate cases. |
| Collaborative Site Specific  Prognostic Factors | Site specific prognostic factors for cases with collaborative stage. (Currently collected for non-referred and referred breast, cervix, colorectal, lung and prostate cases diagnosed >=2010). Click on this link for valid entries and descriptions for the site specific prognostic factors. (<http://cancerstaging.org/cstage/Pages/default.aspx>) |
| grade | The histopathological degree of dedifferentiation of malignant neoplasms or the total number of histopathological features translated into a grade. Completeness depends on the tumour group and diagnosis year. Tumour groups listed are those where the grade is ‘known’ for over 60% of referred cases for 2010-2017 diagnosis years.  Breast = 93%; Gastrointestinal = 71%; Genito-urinary = 85%; Lymphoma = 86%; Neural = 64% |
| **1.4 MORTALITY (Complete from 1989 to 6 months prior to current month)** | |
| **Core Mortality Information (please select this category in the DAR application if data is required). The following information will be provided to you** | |
| * **Primary Death Cause**   Primary cause of death. The ICD code (and description) may be any ICD version, dependent on date of death assigned by BC Vital Statistics.   * **Mortality Groups**   If the primary cause of death is cancer, it is classified into simple, minor and major mortality groups according to the Canadian Cancer Statistics (CCS) tumour groupings. Used by BC Cancer and CCS to compile cancer statistics. Details can be found here: [Cancer diagnosis groupings](https://bit.ly/3jueDJS) | |
| \*death date | The date of death. When the day of death is missing the system automatically sets it to 01. If the day and month of death are missing the system automatically sets the day and month to 0101. |
| *Death date (day, month, year) Includes a data element indicating when the*  *death date is partially known.*  Please justify your need for requiring this variable. |
| *Month and Year of death only* |

Section 2: Cancer Treatment Information

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| **2.1 BC CANCER ADMIT INFORMATION** | |
| **Core BC Cancer admit information (please select this category in the DAR application if data is required). The following information will be provided to you:** | |
| * **Location at Admit**   The BC Cancer centre or Community Oncology Network (CON) clinic where the patient was first admitted for a particular primary disease, where applicable.   * **BC Cancer Admit Date**   The date of the initial oncology consult when the patient was admitted to a BC Cancer Centre or Community Oncology Network (CON) clinic for a particular primary disease. Not all patients are seen at a BC Cancer Centre or CON clinic – these cases will have the admit date as blank. | |
| **2.2 RADIATION TREATMENT (Available on cases treated with RT at BC Cancer since 1984)** | |
| **Core Radiation Therapy Treatment Information (please select this category in the DAR application if data is required). The following information will be provided to you:** | |
| * **Treatment Type**   Indicates whether the radiation therapy is internal beam (Brachytherapy) or external beam (Radiotherapy).   * **Course**   The number assigned in sequence to each Radiation Therapy treatment plan (including both radiotherapy (external) and brachytherapy (internal).   * **Start/End Dates**   The date radiotherapy treatment was started and stopped.   * **Intent**   The expected result of the treatment course as indicated by the Radiation Oncologist on the Treatment Prescription form.   * **Plan**   Describes how the radiotherapy fits into the treatment protocol.   * **Facility**   The agency facility where radiotherapy treatment was administered.   * **Treatment Region**   The anatomic site where the patient received radiotherapy treatment.   * **Dose**   The amount of radiation received by the patient.   * **Treatment Complete**   Indicates if the treatment was received as prescribed. | |
| modality | The machine used to administer the radiation beam therapy. |
| technique | The method used to administer the radiation therapy. |
| fractions (radiotherapy) | The total number of individual exposures to radiation that the patient received for each treatment line. |
| insertion number  (brachytherapy) | The sequence number of each of the intracavity insertions or the sequence number of the multiple fractions for Iodine (1-2) or Iridium HDR/LDR (1-20) within each course. |
| **2.3 SURGERY** | |
| **2.3a SURGERY FOR CANCER DIAGNOSES 2002 ONWARDS (Available for all interventions**  **performed in an acute care facility 6 months prior to diagnosis and onwards)** | |
| **Core Surgical Information (please select this category in the DAR application if data is required). The following information will be provided to you:** | |
| * **Procedure Date** * **Type of Procedure** (coded according to the Canadian Classification of Interventions (CCI) * **Surgeon**   Name of surgeon performing the procedure   * **Facility**   Name of facility where procedure was performed   * **Admission/Discharge Dates**   Facility admission and discharge dates related to surgical procedure performed   * **Most Responsible Diagnosis**   Most responsible diagnosis for hospital stay related to surgical procedure performed   * **Geographical Areas (HSDA and HA)**   The Health Service Delivery Area (HSDA) and the Health Authority (HA) of the patient’s residence at the time of surgery | |
| If surgical information is requested, please specify the timeframe for which surgery information is required (eg: all  procedures 1 week prior and within 1 year after diagnosis).  Please specify and justify your need for requiring this timeframe.  ***Note:*** *A list of unique intervention codes associated to the patients in the study cohort will be provided to the research team to select and justify which are to be included in the extract. The requested intervention codes and timeframe will then be reviewed by the Data Request Review Committee for approval. Further justification may be required before the surgical data is approved for release to the research team.* | |
| \*patient’s location at time of surgery | \*The Canadian postal code of the patient’s residence at the time of surgery:  Please justify your need for requiring this variable. |
| *First 3 digits (forward sortation area or FSA) of this postal code only*  Please justify your need for requiring this variable. |
| The local health area of the patient’s residence at the time of surgery:  Please justify your need for requiring this variable. |
| **2.3b SURGERY FOR CANCER DIAGNOSES 1985 – 2016 (Available on cases ‘referred’ to BC**  **Cancer and only includes procedures performed up to 3 months post-admit date)** | |
| **Core Surgical Information (please select this category in the DAR application if data is required). The following information will be provided to you:** | |
| * **Surgical Date**   The date the surgery was performed.   * **Intent**   Indicates the expected result of the surgical treatment.   * **Plan**   Indicates how the surgery fits into the treatment protocol.   * **Surgical Code**   The Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedure (CCP) code used to define the surgery performed. | |
| **2.4 BCCA PHARMACY (Available from January 1995, however 1995 – 1999 is incomplete)** | |
| **Core BCCA Pharmacy Information (please select this category in the DAR application if data is required). The following information will be provided to you:** | |
| * **Prescription Date**   This date represents the best known date the drug treatment was ordered for the patient.  Note: We are not able to determine when the patient receives or takes the drug. This date could represent either the billed, prepared, dispensed, or administered date.  For example, for intravenous (IV) medications, the computer system entry may reflect today’s date (say, Wednesday), but the drug could be prepared next Monday, and be administered on Tuesday. The date may also represent the start date of a series of consecutive or sequential treatments. There could be more variability in the date when patients are prescribed take-home oral medication. An ordered drug may not necessarily be administered or taken.   * **Protocol Code**   The BC Cancer code specifying the name of the protocol for this prescription or predefined mnemonic for swift order entry purposes. May be blank if no code was specified or not applicable.   * **Drug Name**   The generic name of the drug dispensed. The clinical trial name may also be included.   * **Chemotherapy Agent**   Indicates if the drug is on the BC Cancer Benefit Drug list = Y; if it is not, then chemotherapy agent = null.   * **Route**   PO = take-home or oral medication to be administered by a health-care professional or self-administered by the patient  IV = to be given by the intravenous, intraperitoneal, intrapleural, intrathecal, or subcutaneous routes of injection   * **Dose**   The dose of drug dispensed or the unit size of a single unit of the drug.   * **Dispense Unit Quantity**   The quantity of drug dispensed if it is an oral or take-home drug; for intravenous drugs administered it may be the number of vials used in the preparation or it may be the dose. It may be a negative number to indicate that it is a credit. | |
| \*claim id | Prescription number or OSCAR, PANDA or BDM claim number generated by the system.  Please justify your need for requiring this variable. |
| din | A Drug Identification Number (DIN) is a computer-generated (typically) eight digit number assigned by Health Canada to a drug product prior to being marketed in Canada. May also be generated by BC Cancer pharmacy to differentiate between various sources of supply, vial sizes and clinical trials. |
| source | The system from where the information originated (BDM, CERNER, OSCAR, PANDA, VCP, WORx). |
| bill status | Indicates the number of times the line item was filled on the prescription date. If source = OSCAR and the bill status is -1, ignore the line. If source = WORx and the bill status is a negative number, this indicates that this is a credit. Positive values are debits. |

Section 3: Other Requested Data

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| **3.1 PROVINCIAL SCREENING PROGRAMS** | |
| Breast Screening | Includes client demographics, screen exam information, diagnostic follow-up results, cancer diagnosis data and post screen cancer data  Collection start date since 1988  Abnormal screens – 6 months behind  Diagnostic tests – 7 months behind  Post screens – 1 year behind |
| Cervical Screening | Includes client demographics and screen exam information  Collection start date since1986 to within 30 days of screen date |
| Colon Screening | Includes client demographics, screen exam information, diagnostic follow-up results and cancer diagnosis data  Collection start date since 2013 |
| **3.2 OTHER** | |
| Please specify any additional data that are required for your project. If you know the name of the data repository that contains  the information you require and any of the specific data field names, please provide these below. Otherwise provide as much  detail as possible as to what is required. | |