

Mapping Canadian Provincial Data Assets to Conduct Real-World Studies on Cancer Drugs Cange Value Collaboration Data Working Group

CanREValue Collaboration Data Working Group Interim Report 2019

Appendix



Appendix Section I: Provincial Data Holdings

British Columbia (BC):

Data Holder	Database Name	Data Range	Update Frequency	Notes
	BC Systemic Therapy Program	1985(?) to date	Real-time to quarterly	Data from community sites received at least quarterly
DC Company	BCC Radiotherapy Database	1985 to date	Real-time	
BC Cancer	BCC Surgery Database	1985 to date	Real-time (varies)	Some delay; abstracted from patient notes
(BCC)	BCC CAIS Scheduling Database	1985 to date	Real-time	For appointments at regional cancer centres only; not yet validated for research
	BC Cancer Registry	1969 to last year	Annual	
	PopData Consolidation File/ MSP Registration	1986 to last year	Annual	
	MSP Payment Information File	1985/86 to last year	Annual	
	PharmaNet	1996 to present	Annual	
BC Ministry of Health, accessed via Population Data BC (PopData)	Home and Community Care	1990 to 2012	Annual	Health authorities stopped contributing data between 04/05 and 11/12 as they moved to a new reporting system. Recent data can be requested directly from the Ministry of Health but the structure may vary from the previous data.
	Discharge Abstract Database	1985/86 to last year	Annual	Includes same-day surgery
	National Ambulatory Care Reporting System	2012/13 to last year	Annual	Includes data on emergency department visits only. Includes 29 sites and covers ~60% of ED visits in province. Smaller, rural EDs do not contribute data. CACS groups are not available.
BC Vital Statistics Agency (accessed via Pop Data)	Vital Statistics Deaths file	1985 to last year	Annual	

Legend: BC = British Columbia; BCC = BC Cancer; CAIS = Cancer Agency Information System; PopData = Population data BC; MSP = Medical Services Plan;



Alberta (AB):

Data Holder	Database Name	Data Range	Update Frequency	Notes
Alberta Health Services (AHS)	ARIA (Oncology-Specific Clinical Information System)	2008 to date	Daily	
	Alberta Cancer Registry	1982 to date	Annually	
	Pharmaceutical Information Network	Apr 2008 to date	Weekly	
	Alberta Blue Cross Claims	Apr 1994 to date	Monthly and Annually	
	Population Registry	April 1993 to date	Annually	
	Practitioner Claims	Apr 1994 to date	Weekly	
	Diagnostic Imaging	Jan 2011 to date	Daily (7 days latency)	
	National Ambulatory Care Reporting System	Apr 2010 to date	Monthly	
	Discharge Abstract Database	Apr 2002 to date	Monthly	
	Alberta Continuing Care Information System	Jan 2007 to date		
Service Alberta	Vital Statistics – Death Registry	2000 to date	Annually	
	Vital Statistics – Birth Registry	1983 to date	Annually	



Saskatchewan (SK):

Data Holder	Database Name	Data Range	Update Frequency	Notes
Saskatchewan Cancer Agency (SCA)	Saskatchewan Cancer Registry	1972 - present	Live database	Approximate 1-year lag e.g. cases up to Dec 31, 2016 would be available in mid-2017
()	Pharmacy Oncology Database RX3000 BDM	(RX3000) Jan 1, 2003 – Fall 2018 (BDM) After Fall 2018	Live database	Pharmacy is switching to a new system in fall 2018. Data fields available in the new system could potentially be different from the 2003-2008 data. Plans to capture more fields in new system (BDM), such as drug protocol codes.
	Clinical Management System: ARIA MO (Medical Oncology)	2007 - present	Live database	Earlier years of 2007/2008 may be incomplete;
	Clinical Management System: ARIA RO (Radiation Oncology)	2009 – present	Live database	
Saskatchewan Ministry of Health	Physician Claims - MSB	1970 - present	Monthly	Physician billing data goes back to 1970, however it gets sparse the further we go back. Data from 1990-91 and on is easily accessible, anything older requires extra resources
	Discharge Abstract Database	2002 – present	Monthly	Hospital data is available that goes back to 1970, however data going further back in time gets more and more sparse
	National Ambulatory Care Reporting System	2002 - present	Monthly	*The level of reporting to NACRS has been inconsistent throughout the years. Potential gaps in data, and only certain hospitals reporting to NACRS.
	Continuing Care Reporting System	2002 – present	N/A	Minimal reporting. Data from this database may not be suitable for analysis. Access to submission extracts to CIHI, however Ministry of Health does not have received back the CIHI data. Currently as of Jan 1 2019, Ministry does not have access to this data

Legend: MSB = Medical Services Branch



Manitoba (MB):

Data Holder	Database Name	Data Range	Update Frequency	Notes
CancerCare Manitoba	ARIA† (Electronic Patient record) – Medical Oncology (ARIA-MO)			
(ССМВ)	 Oncology Drug Program database Home Care Drug Program database 	1997 to present 2017 to present	Ongoing/on request	
	Manitoba Cancer Registry and Treatment	1956 to 2017 Treatment: 1984 to 2017	Annual	14 months lag Stage was collected since 2004; In 2010 AJCC 6 th was changed to AJCC 7 th ; In 2005, ICD9 was changed to CCI which resulted in some missing treatment data.
	ARIA† (Electronic Patient record) – Radiation Oncology (ARIA – RO)	1997 to present	Ongoing/on request	
Manitoba Health, Seniors and Active	Manitoba Health Insurance Registry	1970 to present	Annual	6 months lag
Living	Medical Claims	1970 to present	Annual	6 months lag
	Drug Program Information Network	1995 to present	Annual	3 months lag
	Discharge Abstract Database	2004/5 to 2016/17	Annual	8 months lag after fiscal year ends
	National Ambulatory Care Reporting System	April 1 st 2014 to March 31 st to 2018	Annual	Data is missing for many data elements
Manitoba Vital Statistics	Vital Statistics Mortality	1970 to 2017	Annual	Delayed but date of death received through Manitoba Health Insurance Registry data

[†]ARIA is a registered trademark of Varian Medical Systems, Inc.

Legend: AJCC = American Join committee on Cancer; ICD = International Classification of Disease; CCI = Canadian Classification of Health Interventions;

Ontario (ON)¹:

Data Holder	Database Name	Data Range	Update Frequency	Notes
Cancer Care	New Drug Funding Program	CCO: 1997-to date	CCO: Live	CCO: lag of 1 month for utilization data to
Ontario	(NDFP)	ICES: Mar,1995 to Aug, 2017	ICES: Annual	end of last fiscal year (Mar of prior year)
(CCO)		CCO: Apr,1997 to date	CCO: Monthly	CCO: 2 months lag;
	Activity Level Reporting System	ICES: Apr,1995 to Aug 2016	ICES: Annual	Systemic therapy data comprehensive as of April 2014 (includes treatment provided in hospital, not covered under the NDFP)
	Ontorio Con con Donistro	CCO: ~1995 onwards	CCO: depends	OCR contains multiple databases and the
	Ontario Cancer Registry	ICES: Jan, 1964 to Oct, 2017	ICES: annual	update varies at CCO.
	Compute as Management	CCO: Jan 2007 – Sept 2017		
	Symptom Management	ICES: Jan 2007 – Sept 2017	ICES: Annual	
Ministry of	Registered Persons Database	CCO: 1851- to Apr, 2017	CCO: Quarterly	CCO: lag in data
Health	Registered Persons Database	ICES: Apr, 1991 to Mar, 2017	ICES: ~ 2 months	
		CCO: 1999 to May, 2017	CCO: Monthly	CCO: 2 months lag
	Ontario Health Insurance Plan	ICES: Jul, 1991 to 2 months	ICES: Bi-monthly	ICES: 2 months lag
		ago		
		CCO: 1998 to May, 2017	CCO: Monthly	CCO: 2 months lag
	Ontario Drug Benefit (ODB)	ICES: Apr, 1990 to Apr, 2017	ICES: Monthly	Captures publicly covered ODB-eligible outpatient community /retail pharmacy dispensing records
	Home Care Database	ICES: Apr, 1994 – Jun, 2017	ICES: Quarterly	
	Discharge Abstract Database	CCO: 2006 - Mar, 2017	CCO: Monthly	CCO: 2 months lag for actual episode;
	Discharge Abstract Database	ICES: Apr, 1988 to Mar, 2017	ICES: Annual	
		CCO: 2006 - Mar, 2017	CCO: Monthly	CCO: 2 months lag for actual episode;
				recommended for analytic use;
	National Ambulatory Care	ICES:	ICES: Annual	
	Reporting System	ED: Jul 2000-Mar 2017		Missing information on day surgery;
		Dialysis/Cancer Clinic Visits:		
		Apr 2003-Mar 2017		
	Continuing Care Reporting System	ICES: Jul, 1996 to May 2017	ICES: Annual	

Legend: CCO = Cancer Care Ontario; ICES = Institute for Clinical Evaluative Sciences. ED = Emergency Department;

¹ Information on ICES is obtained from the ICES data dictionary. https://datadictionary.ices.on.ca/

Québec (QB):

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Value-based d	lecisions from	Real	World	Evidence	

Data Holder	Database Name	Data Range	Update Frequency	Notes
	Fichier d'inscription des personnes assurées (FIPA)	1969-present	Quarterly	Includes month and year of death
	Services rémunérés à l'acte (SMOD)	Pre-1980-present	Quarterly	
Régie de	Fichier d'admissibilité au régime général d'assurance médicaments	Pre-1980-present	Quarterly	
l'assurance	Services pharmaceutiques (SMED)	Pre-1980-present	Quarterly	
maladie du Québec (RAMQ)	Maintenance et exploitation des données pour l'étude de la clientèle hospitalière (MED-ECHO)	1976-present	Annual	Available in November for the FY ending the previous March; includes date of deaths in-hospital; Health Ministry data held at RAMQ;
	Banque de données communes des urgences (BDCU)	2013-present	Real-time	Health Ministry data held at RAMQ;
	Système d'information sur la clientèle et les services des CSSS - mission CLSC	2012-present	Real-time	Health Ministry data held at RAMQ;
Ministère de la Santé et des	Performance hospitalière (APR- DRG)	1995-present	Annual	Available in February for the FY ending the previous March
Services sociaux	Fichier des tumeurs (FitQ)	1984-2010	Annual	Based on Med-Echo data
du Québec	Registre québécois du cancer (RQC)	2013/14-present	Annual	These data are not yet available
Institut de la statistique du Québec	Fichier des décès	Pre-1980-present	Annual	INESSS has 2005-2015

Legend: INESSS = Institut national d'excellence en santé et services sociaux

New Brunswick (NB):

Data Holder	Database Name	Data Range	Update Frequency	Notes
	NB Cancer Treatment Access Repository	2012 –2017	Annual	
	Clinical oncology data	? - 2018	TBD	Data collection on chemotherapy administered to ambulatory patients in NB oncology clinics/hospitals is currently underway
	Citizen Database	1970—2018	Annual	
NB Department of	NB Cancer Registry	1992—2017	Annual	First diagnosis of a particular tumor site. Availability of updated years of data can be delayed
Health	NB Physician Billing Database	2000—2018	Annual	
	NB Drug Plans Claims Database	1995—2017	Annual	Captures data on drugs dispensed through retail pharmacies and publicly funded by the NB public drug plans
	Drug Information System Database	2017 to present	Annual	Captures oral data on drugs prescribed through pharmacies regardless of the method of payment.
	NB long term care database	2008—2017	Annual	
	Discharge Abstract Database	1999 2017	Annual	

Legend: TBD = To be determined;

Nova Scotia (NS):

Data Holder	Database Name	Data Range	Update Frequency	Notes
	NS Cancer Registry	Early 1970s to present	TBD	
	Oncology Patient		TBD	Contains physician visits and radiotherapy treatments
NC Donartment	Information System (OPIS)	Late 1990 to present	IBU	
NS Department of Health and	Hospital Pharmacy	TBD	TBD	
Wellness	Imaging System	Late 1000 to present	TBD	Imaging Studies Only; province wide such data would only
vveiiiiess	Imaging System	System Late 1990 to present		be available since mid 2000s (since PACS was introduced)
	Insured Patient Registry		TBD	
	(MSI)	Late 1990 to present	IBU	
Health Data	Discharge Abstract		TBD	Good for diagnosis codes, hospital units, and procedures
Nova Scotia	Database	1995 and onwards	ושט	
	Seniors Pharamacare	TBD	TBD	
	MSI Physician's Billing	1997 and onwards	TBD	
	Drug information system	2017 and onwards	TBD	No intravenous chemo

Legend: TBD = To be determined; MSI = Medical Services Insurance; PACs = Picture Archiving and Communication System;



Newfoundland and Labrador (NL):

Data Holder	Database Name	Data Range	Update Frequency	Notes
	ARIA Medical Oncology (ARIA MO)	2014-Present	Live system	
NL Cancer Care	ARIA Radiation Oncology (ARIA RO)	2010-Present	Live system	
	Oncolog (Cancer Registry)	1960s onward		
Program (Accessed through Eastern	Provincial Systemic Therapy Database	TBD	Live System	A composite database that collects systemic therapy data from multiple systems including ARIA and Meditech.
Health)	Oncology Patient Information System (OPIS)	2005-2014	Legacy system	Replaced/upgraded by ARIA MO system in 2014. ARIA MO has a more comprehensive capture.
NL Centre for	Pharmacy Network	May 2017-present	Live system	Partial data exists from November 2009-May 2017
Health Information	NL Prescription Drug Program Database (NLPDP)	Mid 2000s-Present	Live system	Information in NLPDP may only be reliable from 2010 onward due to incompleteness of data.
	Medical Care Plan Billing	2006-March 2017	TBD	
Eastern Health, Central Health, Western Health and Labrador Grenfell Health	Meditech	Data Availability depends on the database	Live system	
CIHI	Discharge Abstract Database	2006-March 2018	TBD	

Legend: ARIA MO = ARIA Medical Oncology; ARIA RO = ARIA Radiation Oncology; CIHI = Canadian Institute for Health Information; TBD = To be determined;

Prince Edward Island (PEI):

Data Holder	Database Name	Data Range	Update Frequency	Notes
	PEI Cancer Registry (Oncolog)	1969 – present	Daily	
	Drug Information System	2009 – present	Daily	3 months lag to capture cancelled prescriptions; Data available on request.
PEI Cancer	ARIA	2006 – present	Daily	Usually 2 months lag; Data available on request.
Treatment	Claims Processing System – Medicare	~1995 - present	TBD	Data available on request.
Center	PharmaCare	2000 to TBD	TBD	Oral drug through pharamacare
	Clinical Information System	2008 – present	Daily	IV drugs administered in hospital
	Discharge Abstract Database	~1995 - present	TBD	Data available on request.
	National Ambulatory Care Reporting System	TBD	TBD	Only available for 1 of 4 hospitals

Legend: TBD = To be determined;

Appendix Section II: Provincial Data elements

British Columbia (BC):

Variables to identify disease of interest:

Variables	Description	Database	Notes
Topography – Site	ICD-O code for typographic point of origin	BCCR	ICD-O-3 for 2001 onward
Morphology – Histology	ICD-O code for cell type	BCCR	ICD-O-3; up to three histology codes per record
Behaviour code	ICD-O code indicating malignancy	BCCR	5th digit of histology
Date of diagnosis	The date the patient's disease was	BCCR	The earliest diagnosis date of class IV/V cytology, positive
	diagnosed		pathology, autopsy report or in the absence of the former,
			clinical diagnosis. Potentially identifiable; need to justify full date
			vs. MM/YY

Abbreviation: BCCR = BC Cancer Registry; ICD-O-3 = International Classification of Disease for Oncology third version;

Variables to identify treatment of interest:

unables to identify treatment of interest.				
Variables	Description	Database	Notes	
Drug Identifier – Protocol Code	BC Cancer systemic therapy protocol code	BC STPD	Incomplete in ~20% of records (but improves in recent years)	
Drug Identifier – Drug name;	Generic drug name and/or Health Canada Drug Identification Number (DIN)	BC STPD		
Intent of treatment	Adjuvant, curative, or palliative	BC STPD	Can use protocol codes to identify intent;	
Line of therapy	Line of therapy such as first-line setting	TBD	Approximated using in-house algorithm;	
Treatment Date	Date of treatment for particular drug	TBD	Treatment date is not available. Assumed to be dispensing date	
Prescription Date	Drug dispensing date	BC STPD		
Route	Route of drug administration – IV or oral	BC STPD		

Abbreviation: BC STPD = BC Systemic Therapy Program database; TBD = To be determined; IV = intravenous;

Variables to identify baseline characteristics:

Variables	Description	Databases	Notes
Provincial Patient Identifier	BC Personal Health Number	BCCR, PopData, MSP Claims, PharmaCare, PharmaNet, DAD, SDS, NACRS	BCCR can be used to translate PHN to BC Cancer identifier, for linkage to other BC Cancer databases. Unencrypted PHN is not provided to researchers.
Gender	Patient's gender;	BCCR	
Date of birth	Patients' date of birth	BCCR, PopData	



Rural/urban residence	Rural or urban residence	BCCR, PopData	Researcher-calculated using postal code or Statistical Area Classification (SAC).
Neighbourhood-Level Income	Socioeconomic quintile or decile	PopData	Based on PCCF but PopData provides variable directly (i.e. can be requested without full postal code)
Regional Health Authority	Health Authority (HA) of residence	BCCR (at diagnosis) PopData (by year)	There are 5 HA's in BC. Can also request Health Services Delivery Area (HSDA - 16 in the province) or Local Health Area (LHA - 89 in the province) for more detailed regional analysis
Charlson's Score	Comorbidity Scores	DAD	Researcher-calculated using DAD
Adjusted clinical groups (ACG)	Comorbidity Scores	DAD MSP Claims NACRS	Johns Hopkins ADG software licensed through PopData. Can be researcher-calculated (e.g. for custom date range) or available annually by request from PopData
Eastern Cooperative Oncology Group – Performance Status	Performance status: ECOG- PS	BCCR	ECOG-PS at admission to BC Cancer only. High rates of missing data
Palliative Performance status	Performance Status: PPS	N/A	

Abbreviation: PHN = Personal Health Number; BCCR = BC Cancer Registry; DAD = Discharge Abstract Database; SDS = Same Day Surgery; PopData = Population Data BC Consolidation File (includes MSP registration, demographics); NACRS = National Ambulatory Care Reporting System; N/A = Not Available; MSP = Medical Services Plan;

Variables to identify surgical and radiotherapy treatments:

Variables	Description	Databases	Notes
Radiation - Course	Radiation therapy course number (in sequence). One record per course of therapy.	BCC Radiotherapy	Includes brachytherapy
Radiation – Dose, fractions	Total dose, total number of fractions (or number of radioactive sources for brachytherapy)	BCC Radiotherapy	
Radiation - Intent	Expected result of treatment course	BCC Radiotherapy	Values include radical, palliative, adjuvant, or unknown
Radiation – start date, end date	Start date and end date for course of therapy.	BCC Radiotherapy BCC Scheduling	Specific visits can potentially be identified using Scheduling (appointment) data, but it is more challenging
Surgical resection code	Intervention code	DAD/SDS BCC Surgery	BCC Surgery data is from patient charts and is often incomplete. DAD/SDS is more correct and complete. CCI codes available in DAD/SDS database from 01/02 onward. CCP codes in BCC Surgery database
Surgical resection date	Procedure date	DAD/SDS BCC Surgery	

Abbreviation: BCC = BC Cancer; DAD = Discharge Abstract Database; SDS = Same Day Surgery; CCI = Canadian Classification of Health Interventions; CCP = Canadian Classification of diagnostic, therapeutic, and surgical procedure (CCP);

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of death	BCCR BC Vital Statistics	Potentially identifiable; need to justify full date vs. MM/YY of death
ED Visit - Date of registration ¹	Date of registration to emergency department	NACRS	NACRS available for ER visits only, from 2012/13 onwards.
ED Visit - Main Problem ¹	Most clinically significant diagnosis, condition, problem or circumstance	NACRS	Includes data on emergency department visits only. Includes 29 sites and covers ~60% of ED visits in
ED Visit - Visit disposition code ¹	Type of separation from the ambulatory care service	NACRS	province. Smaller, rural EDs do not contribute data. Comprehensive Ambulatory Classification System groups are not available.
Hospital Visit - Date of admission ²	Date of admission to inpatient	DAD	
Hospital Visit - Diagnosis codes or procedure codes ²	ICD diagnosis code and type (most-responsible diagnosis)	DAD	ICD-9 (up to 2000/01), ICD-10 (2001/02 onward).
Hospital Visit - Discharge disposition ²	Status of the patient upon leaving the hospital	DAD	

Abbreviation: ED = Emergency department; BCCR = BC Cancer Registry; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ICD = International Classification of Disease;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost	Total cost of dispensed drug	BC STPD	Total cost of dispensed drug. Not on the checklist; available by special request
Drug - reimbursed cost	Total cost of dispensed drug	BC STPD	Same as total cost
Drug (IV) – administration cost	Cost to administer IV drug at the cancer clinic	N/A	No data on ambulatory care; can be estimated with dispensing date (BC STPD) and unit cost per visit
Drug (oral) - total cost	Total cost of dispensed drug	BC STPD	Use 'Route' variable to distinguish between IV and oral; Costs of dispensing/compounding are not included
Drug – dispensing fees	Total cost of drug dispensing fee to a drug program	N/A	
Drug – compounding fees	Total cost of drug confounding fee to a drug program	N/A	
Physician Fee item	MSP fee item	MSP Claims	Only available for physicians paid through fee-for-service. No shadow billing for alternative payment systems (including oncology services); Records of services for cancer care are limited.
Physician fee item paid	Amount paid for fee item	MSP Claims	



			Value-based decisions from Real World Evidence
Outpatient laboratory and	MSP fee item	MSP Claims	Only available for labs/imaging centres paid fee-for-service.
imaging services fee item			Hospital-based services are not included.
Outpatient laboratory and	Amount paid for fee item	MSP Claims	
imaging services fee item paid			
ED cost/resource intensity	Resource intensity weights	NACRS	Comprehensive Ambulatory Classification System groupers are not
weight			available for the BC NACRS data
Hospitalization cost/resource	Resource intensity weights	DAD	
intensity weight			
Home care – care unit cost	Care unit cost	N/A	
Complex continuing care	Cost of complex continuing	N/A	
	care		
Drug name – DIN	Health Canada Drug	BC PharmaNet	BC PharmaNet includes all dispensed outpatient prescription
	Identification Number (DIN)		drugs. BC PharmaCare includes only those outpatient prescription
Prescription date	Dispensing date	BC PharmaNet	drugs covered publicly. BC's PharmaCare plan has income-based
Dose	Total dose	BC PharmaNet	deductibles and co-pay. BC also has PharmaCare programs for
Dispensed quantity; Days	Quantity dispensed; days'	BC PharmaNet	specific patient populations, including the Palliative Care Benefits
supplied	supply dispensed		Program. The PharmaCare fields are also available in the
Ingredient cost	Drug cost	BC PharmaNet	PharmaNet database.
Service Fee	Pharmacist dispensing fee	BC PharmaNet	Dispensed quantity, days' supply, and costs all can be broken
Total Cost	Total Cost	BC PharmaNet	down by total amount and PharmaCare accepted amount
		1	I

Abbreviation: IV = Intravenous; BC STPD = BC Systemic Therapy Program database; MSP = Medical Services Plan; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ED = Emergency department; N/A = Not Available;

Variables to identify budget impact

Variables	Description	Database	Notes
Dispensed quantity	Total amount dispensed; Number of doses dispensed;	BC STPD	Total amount dispensed (oral). Not the same as days supplied
Dose	Dose of IV drugs received	BC STPD	Dose of drug dispensed or unit size of a single unit of the drug
Body surface area	Patient's body surface area at treatment	N/A	
Height	Patient's height at treatment	N/A	
Weigh	Patient's weight at treatment	N/A	

Abbreviation: BC STPD = BC Systemic Therapy Program Database; N/A = Not Available;

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
ESAS	Edmonton Symptom Assessment Score	N/A	

Abbreviation: N/A = Not Available;



Alberta (AB):

Variables to identify disease of interest:

Variables	Description	Database	Notes
Topography – Site	Anatomical location of the primary site	ACR	ICD-O
Morphology – Histology	Cell type's malignancy	ACR	ICD-O
Behaviour code	Ability of tumor to invade and metastasize	ACR	0 to 3
Date of diagnosis	Year of Cancer Diagnosis	ACR	

Abbreviation: ACR = Alberta Cancer Registry; ICD-O-3 = International Classification of Disease for Oncology third version;

Variables to identify treatment of interest:

Variables	Description	Database	Notes
Drug Identifier – Drug	Identifier for the prescribed product	PIN	Largely available (protocol names)
name/code/regimen/DIN	dentiner for the prescribed product	FIIN	Dispensing records for the entire province are available
Prescription Indication	Indication the prescription is being prescribed for	PIN	
Intent of treatment	Adjuvant, curative, or palliative	PIN	Somewhat missing
Line of therapy	Line of therapy such as first-line setting	PIN	Somewhat missing
Dates of treatment	Dispensing or chemo administration date	PIN	
Dispensing date	Date of dispensing event		
Route of administration	Primary method of drug administration	PIN	

Abbreviation: DIN = Drug information system; Pharmaceutical Information Network = PIN

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Patient Identifier	ACR	
Gender	Patient's sex	ACR	
Date of birth	Patient's date of birth	ACR	Only MM/YY.
Rural/urban residence	Urban or Rural residence	ACR	Need to justify full postal code vs. forward sortation area (3-digit).
			Variable sourced from Postal Code Translation File (PCTF)
Neighbourhood- Level Income	Socioeconomic categories	ACR	
Regional Health Authority	Regional Health Authority	ACR	Only one health authority in AB.
Charlson's Score	Comorbidity Scores	DAD	
Adjusted clinical groups (ACG)	Comorbidity Scores	DAD	
Eastern Cooperative Oncology Group –	Performance status:	Performance status:	
Performance Status	ECOG-PS	N/A	

14 | Page

Alberta: Real-world Data Elements

Palliative Performance status	Performance Status: PPS	N/A	

Abbreviation: ACR = Alberta Cancer Registry; DAD = Discharge Abstract Database; N/A = Not Available;

Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Receiving a course of radiation treatment	EMR	
Radiation - Intent	Expected result of treatment course	EMR	Messy and not always user friendly.
Radiation – start date	Start date of the radiation treatment	EMR	
Surgical resection code	Intervention code	DAD/NACRS	
Surgical resection date	Procedural date	DAD/NACRS	

Abbreviation: EMR = Electronic Medical Record; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System;

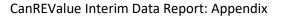
Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of Death	ACR Vital Statistics	
ED Visit - Date of registration	Date of registration to emergency department	NACRS	
ED Visit - Main Problem	Most clinically significant diagnosis, condition, problem or circumstance	NACRS	
ED Visit - Visit disposition code	Type of separation from the ambulatory care service	NACRS	
Hospital Visit - Date of admission	Date of admission to inpatient	DAD	
Hospital Visit - Diagnosis codes or procedure codes ²	ICD diagnosis code and type (most-responsible diagnosis)	DAD	
Hospital Visit - Discharge disposition	Status of the patient upon leaving the hospital	DAD	

Abbreviation: ACR = Alberta Cancer Registry; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ED = Emergency department; ICD = International Classification of Disease;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost			
Drug - reimbursed cost			
Drug (IV) – administration cost			
Drug (oral) - total cost			
Drug – dispensing fees			
Drug – compounding fees			
Physician Fee item			





		Value-based decisions from Real World Evidence
Physician fee item paid		
Outpatient laboratory and imaging services fee item		
Outpatient laboratory and imaging services fee item paid		
ED cost/resource intensity weight		
Hospitalization cost/resource intensity weight		
Home care – care unit cost		

Abbreviation: IV = Intravenous;

Variables to identify budget impact

Variables	Description	Database	Notes
Total Amount dispensed	Amount of medication to be dispensed to the patient	PIN	Total amount dispensed, but quite messy
Dosage	Dose of IV drug received	PIN	
Body surface area	Patient's body surface area at treatment	N/A	
Height	Patient's height at treatment	N/A	
Weigh	Patient's weight at treatment	N/A	

Abbreviation: Pharmaceutical Information Network = PIN; N/A = Not Available;

Variables to identify patient reported outcomes:

	Variables	Description	Database	Notes
I	ESAS	Edmonton Symptom Assessment Score	TBD	Available after 2006

Abbreviation: TBD = To be determined;

Note: The variables to identify cost in Alberta will be iteratively updated after completing a real-world analysis in Alberta.



Saskatchewan (SK):

Variables to identify disease of interest:

Variables	Description	Database	Notes
Topography – Site	The topography code indicates the site of origin (not extension) of a tumor, the primary site of the tumor. The code is represented by a four digit alphanumeric characters. Coded using ICD-O Third Edition	SCR	
Morphology – Histology	The morphology code indicates the type of cell (histology) the tumor arose from. The code is represented by a four digit numeric characters (histology) along with a one digit numeric character (behavior).	SCR	
Behaviour code	There are four types of cell behavior when it comes to cancer staging. The behavior is depended on the cell growth.	SCR	
Date of diagnosis	Date of confirmed cancer diagnosis. Based on cancer registry coding definitions.	SCR	

Abbreviation: SCR = Saskatchewan Cancer Registry; ICD-O-3 = International Classification of Disease for Oncology third version;

Variables to identify treatment of interest:

Variables	Description	Database	Notes
Drug Identifier – Drug name/code/regimen/DIN	Name of anti-cancer drug or supportive drug.	SCA Pharmacy	
Treatment Indication	Identifies specific indication for use	TBD	Can be approximated using in-house algorithm
Intent of treatment	Adjuvant, curative, or palliative	SCA Pharmacy (BDM)	Intent is only recorded for radiotherapy. Starting in 2019, intent will be recorded in the new pharmacy system (BDM)
Line of therapy	Line of therapy such as first- line setting	TBD	Can be approximated using in-house algorithm;
Dates of treatment	Date of treatment administration of anti-cancer drugs. Only applicable to IV drugs.	SCA Pharmacy CMS (ARIA MO)	From SCA Pharmacy database, an estimated treatment date is recorded in the database; IV hang date. Using scheduling appointments (ARIA MO), it is possible to obtain dates (2009 onward) of chemotherapy treatments occurring at SCA clinics (inpatient hospital chemotherapy excluded)
Dispensing date	Dispensing date	SCA Pharmacy	Available for IV, oral take-home, and supportive drugs dispensed by the SCA.
Route of administration	Primary method of drug administration	SCA Pharmacy	

Abbreviation: DIN = Drug Identification Number; IV = Intravenous; SCA = Saskatchewan Cancer Agency; CMS = Clinical management system; TBD = To be determined;

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient ID	Saskatchewan Health Services Number (HSN)	SCR, MSB, SCA Pharmacy, CMS (ARIA MO/RO), DAD, NACRS, CCRS	Used to link patients across multiple databases
Gender	Patient's sex	SCR, SCA Pharmacy	
Date of birth	Patient's date of birth	SCR, SCA Pharmacy, CMS (ARIA MO)	
Rural/urban residence	Urban or Rural residence	SCR	Can be derived from postal codes. Two postal codes are available (postal code at time of diagnosis, and postal code of most recent address on record).
Neighbourhood- Level Income	Socioeconomic categories	SCR	Calculated through PCCF+. SCA has access to the PCCF+ macro from Statistics Canada.
Regional Health Authority	Regional Health Authority	SCR	In Dec 2017, the Saskatchewan regional heath authorities amalgamated into one. RHA is recorded prior to amalgamation. Can be generated from PCCF+ macro.
Charlson's Score	Comorbidity Scores	DAD	Not recorded directly in any dataset. Must be calculated during analysis phase.
Adjusted clinical groups (ACG)	Comorbidity Scores	DAD, NACRS MSB	Currently, SCA does not have a Johns Hopkins ACG software. No foreseeable obstacles in obtaining the license if required.
Eastern Cooperative Oncology Group – Performance Status	Performance status: ECOG-PS	SCR	
Palliative Performance status	Performance Status: PPS	TBD	Work is in place to start recording scores in 2019.

Abbreviation: SCR = Saskatchewan Cancer Registry; SCA = Saskatchewan Cancer Agency; CMS = Clinical Management System; MSB = Medical Services Billing; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; TBD = To be determined;

Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Receiving a course of radiation treatment	CMS (ARIA RO) SCR	Radiation use flags are available in SCR data. From ARIA RO, radiation use can be determined from radiotherapy treatment dates
Radiation Use - Course	Radiotherapy Course Number and Name	CMS (ARIA RO)	



Radiation - Dose/minutes per fraction	Total dose, total number of fractions	CMS (ARIA RO)	Actual total dose, planned total dose, planned total fractions, and total delivered fractions.
Radiation - Intent	Planned intent of radiation treatment	CMS (ARIA RO)	Captured in radiotherapy course data.
Radiation - visit date	Radiation treatment dates	CMS (ARIA RO)	Date and time. Also records the fraction number of RT course e.g. fraction X out of the planned Y.
Radiation – start date, end date	Start date and end date for course of therapy.	CMS (ARIA RO)	From CMS (ARIA RO), start and end dates can be derived from radiotherapy treatment dates and course data. SCR also records radiotherapy start and end dates.
Surgical resection code – Intervention code	Intervention code	MSB DAD, NACRS	ICD-9 procedure/surgery codes available in SCR. Limited to surgeries/procedures occurring near time of diagnosis or at coding reviews. Incomplete information.
Surgical resection date	Procedure date	MSB, SCR DAD, NACRS	Surgery dates available in SCR. Dates can also reflect biopsy dates occurring before cancer diagnosis. Dates have to be used with caution.

Abbreviation: SCR = Saskatchewan Cancer Registry; CMS = Clinical Management System; MSB = Medical Services Billing; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ICD = International Classification of Disease; RT = Radiotherapy;

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of Death	SCR	
ED Visit - Date of registration	Date of registration to emergency department	NACRS	Limited ED data is available between
ED Visit - Main Problem	Most clinically significant diagnosis, condition, problem or circumstance	NACRS	2012 - 2016. Post December 2016 data is available for certain regions.
ED Visit - Visit disposition code	Type of separation from the ambulatory care service	NACRS	available for certain regions.
Hospital Visit - Date of admission	Date of admission to inpatient	DAD	
Hospital Visit - Diagnosis codes or procedure codes	ICD diagnosis code and type (most-responsible diagnosis)	DAD	
Hospital Visit - Discharge disposition	Status of the patient upon leaving the hospital	DAD	

Abbreviation: SCR = Saskatchewan Cancer Registry; ED = Emergency Department; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ICD = International Classification of Disease;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost	Total cost of IV drug dispensation.	SCA Pharmacy	Total cost of dispensed IV drug.



			value-based decisions from Real World Evidence
Drug – reimbursed cost	Total cost of drug to a drug program, if different from total cost (i.e., if patient pays co-pay)	SCA Pharmacy	
Drug (IV) – administration cost	Cost to administer IV drug at the cancer clinic	SCA Pharmacy	Costing exercise is required to calculate average cost of IV administration.
Drug (oral) - total cost	Total cost of oral drug dispensation.	SCA Pharmacy	Total cost of dispensed oral drugs. Costs of dispensing/compounding are not included
Drug – dispensing fees	Total cost of drug dispensing fee to a drug program	N/A	
Drug – compounding fees	Total cost of drug confounding fee to a drug program	N/A	
Physician fee - Billing code	Fee for service billing code	MSB	Only for physicians paid through Fee for service. No
Physician fee - Amount paid Fee for service; amount approved for reimbursement		MSB	shadow billing records available for Oncology services (non- fee for service).
Outpatient laboratory and imaging services - Billing Code	Fee for service billing code	MSB	
Outpatient laboratory and imaging services - Amount paid	Fee for service; amount approved for reimbursement	MSB	
ER - cost/resource intensity weight	Resource intensity weights	NACRS	
Hospitalization - cost/resource intensity weight	Resource intensity weights	DAD	
Complex continuing care	Cost for complex continuing care services	CCRS	Minimal data available from CCRS.

Abbreviation: SCA = Saskatchewan Cancer Agency; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; CCRS = Complex continuing reporting system; IV = Intravenous; MSB = Medical Services Billing; N/A = Not Available;

Variables to identify budget impact

Variables	Description	Database	Notes
Days supplied	Estimated days' supply of oral anti-cancer drug.	SCA Pharmacy	
Treatment dose given	Treatment dosage drug.	SCA Pharmacy Oncology	Available for oral drugs. For IV drugs, it is a derived variable based on total cost reported and unit price.
Body Surface Area	Body Surface Area (derived from height and weight). Used to determine dosage for certain anti-cancer drugs.	SCA Pharmacy CMS (ARIA MO)	Recorded in pharmacy database, but it is not available for all patients.





		SCA Pharmacy	Fall 2018, height and weight will be directly recorded in
Height	Height of patient	Oncology,	electronic charts (ARIA). Feasibility of extracting data will
		CMS (ARIA MO)	need to be explored further.
	Weight of patient. Sometimes used to	SCA Pharmacy	
Weight	determine dosage for certain anti-cancer	Oncology	
	drugs.	CMS (ARIA MO)	

Abbreviation: SCA = Saskatchewan Cancer Agency; CMS = Clinical management system; IV = Intravenous;

Variables to identify patient reported outcomes:

,, p			
Variables	Description	Database	Notes
Edmonton Symptom	Patient reported symptoms	CMS (ARIA MO)	Available starting from August 2016, and onwards. Further
Assessment Score			exploration is required to determine usability in analysis.

Abbreviation: CMS = Clinical Management System;



Manitoba (MB):

Variables to identify disease of interest:

Variables	Description	Database	Notes
Topography	Code from International Classification of Diseases (ICD)	MCR	Prior to January 1, 1982: ICD-9-CM and SNOP
code	representing the part of the body affected by disease or		Jan 1, 1982 to Dec 31, 2000: ICD-9-CM and ICD-O2
	the site of origin of the neoplasm.		Jan 1 2001 to Dec 31, 2001: ICD-9-CM and ICD-O3
			Jan 1, 2002 to present: ICD-10 and ICD-03
Morphology	The ICD-O2 code representing the morphology of the	MCR	To be entered for cases diagnosed between January 1, 1982
code: Morph2	malignancy		to December 31, 2000
Morphology	The ICD-O3 code representing the morphology of the	MCR	January 1, 2001 to present
code: Morph3	malignancy		
Behaviour	Reportable histologic behavior- the 5 th digit of reported	MCR	
code	histology, based on the Reported Site		
Date of	Date the diagnosis was made, based on the most definitive	MCR	The earliest diagnosis date of cytological diagnosis,
Diagnosis	method of diagnosis		histologically diagnosis, including cases diagnosed only on
			autopsy, date of non-microscopically confirmed diagnosis

Abbreviation: MCR = Manitoba Cancer Registry; CM = Clinical Modification; SNOP = Systematized Nomenclature of Pathology;

Variables to identify treatment of interest:

Variables	Description	Database	Notes
Drug Identifier – Drug	IV Chemo drug Name	ARIA	Dispensing records from CCMB pharmacy and
name/code/regimen	TV Chemo drug Name	ANIA	community oncology sites
Drug Identifier – Drug	This is a 8-didgit number assigned by the		Variable entered by all pharmacies in Manitoba on
Identification Number	Therapeutic Products Directorates (Health Canada)	DPIN	disposition of a prescription drug to signify the identity of
(DIN)	to each drug product approved for use in Canada		the drug dispensed
Intent of treatment	Adjuvant, curative, or palliative	CCMB Drug	
		approval	
		database	
Line of therapy	Line of therapy such as first-line setting	TBD	Need chart review
Dates of treatment	Date of treatment	MCR	MCR has start date; ARIA has specifics;
Dates of treatment	Date of treatment	ARIA	ivien has start date, Ania has specifics,
Dispensing date	Date service provided (dispense date)	DPIN	For oral cancer drugs

Abbreviation: CCMB = Cancer Control Manitoba; MCR = Manitoba Cancer Registry; DPIN = Drug Program Information Network; TBD = To be determined;

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Unique patient identifier	MHIR, MCR, ARIA,	
		DAD, Claims, DPIN	
Gender	Patient Gender	MCR, MHIR	MHIR also, but there are sometimes discrepancies
Date of birth	Date of birth	MCR, MHIR	MHIR also, but there are sometimes discrepancies
Rural/urban residence	Postal code	MCR	This is postal code at diagnosis, which is not the same as
			'current postal code'
Neighbourhood- Level Income	Defined from both postal code	Postal code +	Note that for Manitoba, Rural and Urban quintiles should be
	and the PCCF macro	Census data	determined separately
Regional Health Authority	Regional health authority	MCR	
Charlson's Score	Comorbidity Scores	DAD	Calculated by macro
Adjusted clinical groups (ACG)	Comorhidity Scores	DAD,	Calculated by Johns Hopkins ACG software.
Aujusteu ciiriicai groups (ACG)	Comorbidity Scores	Medical claims	
Eastern Cooperative Oncology	Porformance status: ECOC DS	ARIA	May be in progress notes, so not very minable
Group – Performance Status	Performance status: ECOG-PS		
Palliative Performance status	Performance Status: PPS	N/A	

Abbreviation: MCR = Manitoba Cancer Registry; DPIN = Drug Program Information Network; MHIR = Manitoba Health Insurance Registry; DAD = Discharge Abstract Database; N/A = Not Available;

Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Identifies patients who received radiation	MCR, ARIA-RO	MCR contains RT y/n, and one record per course of therapy. Includes brachytherapy.
Radiation – Dose, fraction	The amount of radiation absorbed by the tumor per dose (fraction)	ARIA-RO	Total dose, total number of fractions
Radiation - Intent	The intention of radiation treatment as determined by the radiation oncologist at the time of booking the planning/treatment visit	ARIA-RO	Not reliable
Radiation – start date, end date	Start date and end date	MCR, ARIA-RO, medical claims	May have some data in Physician Claims
Surgical resection code – Intervention code CCP/CCI Code	The CCI procedure code describing the procedure administered to the patient	MCR, DAD	MCR contains surgery CCI code and date of procedure for definitive surgery. CCP/CCI codes available in DAD database
Surgical resection date	Date of surgical intervention	MCR, DAD	

Abbreviation: MCR = Manitoba Cancer Registry; DAD = Discharge Abstract Database; RT = Radiotherapy; CIHI = Canadian Institute for Health Information; CCI = Canadian Classification of Health Interventions; CCP = Canadian Classification of diagnostic, therapeutic, and surgical procedure (CCP);

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of death	MCR, MHIR, Vital Statistics	MHIR data provides the health registration cancellation code='2' if the person is deceased and the date of cancellation
ED Visit - Date of registration	Date of registration to emergency department	NACRS	ED data is available through Winnipeg Regional Health Authority (WRHA) EDIS (Emergency Department Information
ED Visit - Main Problem	Most clinically significant diagnosis, condition, problem or circumstance	NACRS	System) database however, only utilization data is available, no costing information.
Hospital Visit - Date of admission	Date of admission to inpatient	DAD	
Hospital Visit - Diagnosis codes or procedure codes	ICD diagnosis code and type (most-responsible diagnosis)	DAD	
Hospital Visit - Discharge disposition	Status of the patient upon leaving the hospital	DAD	

Abbreviation: MCR = Manitoba Cancer Registry; MHIR = Manitoba Health Insurance Registry; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ED = Emergency Department;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost	Cost of dose administered	ARIA / CCMB Pharmacy	Would be available via CCMB pharmacy in principle. Would have list price not actual cost.
Drug – reimbursed cost	Total cost of drug to a drug program, if different from total cost (i.e., if patient pays co-pay)	N/A	
Drug (IV) – administration cost	Cost to administer IV drug at the cancer clinic	TBD	
Drug (Oral) - total cost	Total amount claimed	DPIN	Available only for adjudicated claims (excluding rejected, reversed and claims sent for drug utilization review (DUR))
Drug (Oral)- Dispensing fee	Total cost of drug dispensing fee to a drug program	DPIN	
Drug(Oral) - Drug cost allowed	Total cost of drug compounding fee to a drug program	DPIN	
Physician fee - Billing code	Professional fee claimed	Medical Claims	



Value-based decisions from Real World Evidence						
Physician fee - Amount paid	Total amount paid and professional fee paid	Medical Claims	Only for physicians paid through fee-for-service (FFS). No shadow billing records available for Oncology services (non-FFS).			
Outpatient laboratory and imaging services - Billing Code	Tariff code	Medical Claims				
Outpatient laboratory and imaging services - Amount paid	MHSC Approved Fee	Medical Claims				
ED - cost/resource intensity weight	Resource Intensity weights (RIW)	NACRS	Only Misericordia Urgent Care Centre submits level 3 data to NACRS (i.e., all data elements which include CACS-RIW) no other hospitals in Manitoba submits level 3 data to NACRS.			
Hospitalization - cost/resource intensity weight (inpatients and day procedures)	Resource intensity weights (RIW)	DAD	Cost Per Weighted Case (CPWC), prior 2010 Cost of a Standard Hospital Stay (CSHS), 2010-onward			
Home Care	Cost associated with home care	TBD				
Complex continuing care	Cost of complex continuing care	TBD				

Abbreviation: DPIN = Drug Program Information Network; CCMB = Cancer Control Manitoba; IV = Intravenous; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ED = Emergency Department; CACS = Comprehensive Ambulatory Classification System; IV = Intravenous; N/A = Not Available; TBD = To be determined;

Variables to identify budget impact

Variables	Description	Database	Notes
Number of doses dispensed – Days supplied	Metric quantity claimed-Days supply on the prescription	DPIN	For oral cancer drugs
Treatment dose given	Dose administered and dose requested	ARIA	For IV cancer drugs
Body Surface Area	Patient body surface area at actual treatment claim is submitted	ARIA	For IV cancer drugs
Height	Patient height in cm	ARIA	For IV cancer drugs
Weight	Patient weight in kg	ARIA	For IV cancer drugs

Abbreviation: DPIN = Drug Program Information Network; IV = Intravenous;

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
Edmonton Symptom	Patient reported outcome	ARIA	May be in progress notes, so not very minable
Assessment Score (ESAS)			



Ontario (ON):

Variables to identify disease of interest:

Variables to lacing	ranables to lacinify discuse of interest.					
Variables	Description	Database	Notes			
Topography code	Code from International Classification of Diseases to identify the part of the body affected by	OCR				
	disease or the site of origin of the neoplasm.					
Morphology code	Code from the morphology section of the International Classification of Diseases to identify the	OCR				
	microscopic structure of cells, tissues, and organs.					
Behaviour code	Reportable histologic behavior- the 5 th digit of reported histology, based on the Reported Site	OCR				
Date of diagnosis	Diagnosis date – the date of first diagnosis of the primary site of cancer	OCR				

Abbreviation: OCR = Ontario Cancer Registry

Variables to identify treatment of interest:

Variables	Description	Database	Notes
Drug Identifier – Policy name/Description	Description of eligible disease and indication for which reimbursement is being requested.	NDFP	For indication specific use; available only for IV drugs (ICES pre 2013) Line of therapy can be identified at CCO and at ICES (only pre 2013 at ICES).
Drug Identifier – Drug name/code/regimen	Drug name. A set of anti-cancer and supportive medications given during an active course of systemic chemotherapy that is named and defined in CCO's provincial Formulary.	NDFP ALR	For IV cancer drugs
Drug Identifier – Drug Identification Number (DIN)	Health Canada Drug Identification Number. Uniquely identifies that drug product by its manufacturer, name and strength of active ingredients, route of administration and pharmaceutical dosage form.	ODB	For oral cancer drugs
Intent of treatment	Adjuvant, curative, or palliative	ALR	
Line of therapy	Line of therapy such as first-line setting	NDFP, ALR	
Dates of treatment	Date of treatment	NDFP, ALR	
Dispensing date	Dispensing date	ODB	For oral cancer drugs

Abbreviation: NDFP = New Drug Funding Program; ALR = Activity Level Reporting; ODB = Ontario Drug Benefit; IV = Intravenous;

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Unique patient identifier		
		RPDB, DAD, NACRS	
Gender	Patient gender	OCR, RPDB	



Date of birth	Date or birth	OCR	
Rural/urban residence	Urban or Rural residence	OCR,RPDB	
Neighbourhood- Level Income	Defined from Postal Code and PCCF macro	TBD	
Regional Health Authority	Regional Health Authority	OCR, RPDB	
Charlson's Score	Comorbidity Scores	CIHI-DAD	
Adjusted clinical groups (ACG)	Comorbidity Scores	OHIP, DAD, NACRS	
Eastern Cooperative Oncology Group –	Dorformanco status; ECOC DS	NDFP	
Performance Status	Performance status: ECOG-PS	Symptoms Management database	
Palliative Performance status	Performance Status: PPS	Symptoms Management database	

Abbreviation: OCR = Ontario Caner Registry; RPDB = Registered Person Database, NDFP = New Drug Funding Program; ALR = Activity Level Reporting; ODB = Ontario Drug Benefit; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System;

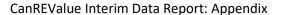
Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Identifies patients who received radiation	ALR	
Radiation - Dose/ minutes per fraction	The amount of radiation absorbed by the tumor per dose (fraction)	ALR	
Radiation - Intent	The intention of radiation treatment as determined by the radiation oncologist at the time of booking the planning/treatment visit	ALR	
Radiation - visit date	The patient's visit date	ALR	
Surgical resection – Intervention code	The CIHI CCI/CCP procedure code describing the procedure administered to the patient	OHIP, DAD, NACRS	
Surgical resection date	Date of surgical intervention	OHIP, DAD, NACRS	

Abbreviation: ALR = Activity Level Reporting; ODB = Ontario Drug Benefit; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; OHIP = Ontario Health Insurance Plan; CCI = Canadian Classification of Health Interventions; CCP = Canadian Classification of diagnostic, therapeutic, and surgical procedure (CCP);

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of death	OCR, RPDB, ALR	ICES commonly use RPDB
ED Visit - Date of registration	Date of registration to emergency department	NACRS	
ED Visit - Main Problem	Most clinically significant diagnosis, condition, problem or circumstance	NACRS	
ED Visit - Visit disposition code	Type of separation from the ambulatory care service	NACRS	
Hospital Visit - Date of admission	Date of admission to inpatient	DAD	





Hospital Visit -	ICD diagnosis code and type (most-responsible diagnosis)		
Diagnosis codes or		DAD	
procedure codes			
Hospital Visit -	Status of the patient upon leaving the hospital	DAD	
Discharge disposition		DAD	

Abbreviation: OCR = Ontario Caner Registry; RPDB = Registered Person Database, ALR = Activity Level Reporting; ODB = Ontario Drug Benefit; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ED = Emergency Department; ICD = International Classification of Disease;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost	Cost of dose administered to patient	NDFP	
Drug – reimbursed cost	Total cost of drug to a drug program, if different from total cost (i.e., if patient pays co-pay)	NDFP	
Drug (IV) – administration cost	Cost to administer IV drug at the cancer clinic	NDFP	
Drug (oral) - total cost	Drug cost	ODB	
Drug - Dispensing fee	Dispensing fee	ODB	
Drug - Compounding fee	Compounding fee	ODB	
Physician fee - Billing code	OHIP fee code	OHIP	
Physician fee - Amount paid	Total fee paid to physician	OHIP	
Outpatient laboratory and imaging services - Billing Code	OHIP fee code	OHIP	
Outpatient laboratory and imaging services - Amount paid	Total fee paid to physician	OHIP	
ER - cost/resource intensity weight	Direct/Indirect Cost Provincial CACS Resource intensity weights (RIW);	NACRS	Total cost = cost per standard hospital stay x RIW
Hospitalization - cost/resource intensity weight	Resource Intensity weights	DAD	
Home care – care unit cost	Cost of Home Care	OHCAS HCD	OHCAS for earlier years
Complex continuing care	Cost of complex continuing care	CCRS	

Abbreviation: NDFP = New Drug Funding Program, ODB = Ontario Drug Benefit; OHIP = Ontario Health Insurance Plan; DAD = Discharge Abstract Database; CACS= Comprehensive Ambulatory Classification System; NACRS = National Ambulatory Care Reporting System; HCD = Home Care Database; CCRS = Complex Care Reporting System; OHCAS = Ontario Home Care Administrative System;



Variables to identify budget impact

Variables	Description	Database	Notes
Number of doses			
dispensed – Days	Estimated number of days supplied	ODB	For oral cancer drugs
supplied			
Treatment dose given	Dose given to patient	NDFP	For IV cancer drugs
Body Surface Area	Patient body surface area at actual treatment claim is submitted	NDFP	
Height	Patient height in cm	NDFP	
Weight	Patient weight in kg	NDFP	

Abbreviation: NDFP = New Drug Funding Program, ODB = Ontario Drug Benefit; IV = Intravenous drugs;

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
ESAS	Edmonton Symptom Assessment Score	Symptoms Management database	

29 | Page



Québec (QB):

Variables to identify disease of interest:

Variables	Description	Database	Notes
Topography code	ICD code indicating the tumor site	MED-ECHO	Completeness, quality, and level of
Morphology code	ICD-O2 code representing the morphology of the tumor – digits 1-4	MED-ECHO	detail need to be assessed.
Behaviour code	Histologic behavior- the 5 th digit of ICD-O2 code	MED-ECHO	detail fleed to be assessed.
Date of diagnosis	Could create an algorithm using hospital and MD billing data. For example, the earliest date of one cancer diagnosis code in the hospitalization data OR two cancer diagnosis codes in the physician billing data, separated by at least 30 days in a 2-year period.	MED-ECHO and SMOD	See Diop et al. 2018, BMC Medical Research Methodology

Abbreviations: MED-ECHO = Maintenance et exploitation des données pour l'étude de la clientèle hospitalière; SMOD = Services rémunérés à l'acte; ICD-O = International Classification of Disease for Oncology

Variables to identify treatment of interest:

Variables	Description	Database	Notes
Drug Identifier – Policy name/Description	Grouping of therapeutic indications by anatomic system	SMED	14 general categories, including oncology
Drug Identifier – Drug name/code/regimen	Drug name by common denomination	SMED	
Drug Identifier – Drug Identification Number (DIN)	DIN code	SMED	
Line of therapy	Line of therapy such as first-line setting	N/A	Cannot be identified (except via assumption in cases where coverage policies restrict the use of certain medications to certain lines).
Dates of treatment	Chemotherapy treatment codes from MD billing and hospitalization data	SMOD, MED-ECHO	See Diop et al 2018
Dispensing date	Service date of prescriber OR Start date of the application period	SMED	

Abbreviations: SMED = Services pharmaceutiques; MED-ECHO = Maintenance et exploitation des données pour l'étude de la clientèle hospitalière; SMOD = Services rémunérés à l'acte; N/A = Not Available;

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Unique identifier	FIPA	
Gender	Sex	FIPA	

Quebec: Real-world Data Elements



Date of birth	Month and year of birth	FIPA	
Rural/urban residence	Various options	FIPA	Linkable via StatCan Dissemination Areas
Neighborhood- Level Income	5 categories of 2016 median after-tax	FIPA	
	income, by 4 geographic regions		
Regional Health Authority	Région sociosanitaire	FIPA	
Charlson's Score	Comorbidity Scores	MED-ECHO	Coming soon
Adjusted clinical groups (ACG)	Comorbidity Scores	MED-ECHO	
Eastern Cooperative Oncology Group – Performance Status	Performance status: ECOG-PS	N/A	
Palliative Performance status	Performance Status: PPS	N/A	

Abbreviations: MED-ECHO = Maintenance et exploitation des données pour l'étude de la clientèle hospitalière; FIPA = Fichier d'inscription des personnes assurées; N/A = Not Available;

Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Radiation treatment codes from MD billing and hospitalization data	SMOD, MED-ECHO	
Radiation - visit date	Date of treatment codes from MD billing and hospitalization data	SMOD, MED-ECHO	Soo Dion at al
Surgical resection code – Intervention code	Surgical treatment codes from MD billing and hospitalization data	SMOD, MED-ECHO	See Diop et al 2018
Surgical resection date	Date of surgery treatment codes from MD billing and hospitalization data	SMOD, MED-ECHO	

Abbreviations: MED-ECHO = Maintenance et exploitation des données pour l'étude de la clientèle hospitalière; SMOD = Services rémunérés à l'acte; ICD-O = International Classification of Disease for Oncology

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Month and year of death	Registre décès (ISQ),FIPA	
Discharge date	Discharge date	MED-ECHO	
Date of registration	Admission date	MED-ECHO	
Visit disposition code	Destination after leaving hospital	MED-ECHO	
Main problem	Diagnostic code: admission, death, primary, secondary	MED-ECHO	
Main problem	Reason for visit; Diagnostic code	BDCU	

Abbreviations: ISQ = Institut de la statistique du Québec; FIPA = Fichier d'inscription des personnes assurées; MED-ECHO = Maintenance et exploitation des données pour l'étude de la clientèle hospitalière; SMOD = Services rémunérés à l'acte; ICD-O = International Classification of Disease for Oncology; BDCU = Banque de données communes des urgences ;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (oral) - total cost	Total cost of dispensed drug	TBD	Add up component parts
Drug (oral) - Dispensing fee	Service charge authorized by the RAMQ	SMED	
Drug (oral) - Drug cost before fees	Amount authorized by the RAMQ for the medication or product	SMED	
Drug (IV) – administration cost	Cost to administer IV drug at the cancer clinic	N/A	
Physician fee - Billing code	Act code	SMOD	
Physician fee - Amount paid	Fee amount paid for service provided	SMOD	
Outpatient laboratory and imaging services - Billing Code	Billing codes for service	SMOD	Can use act codes for MD to read the results, not for the test itself
Outpatient laboratory and imaging services - Amount paid	Amount paid for service	SMOD	Can use billing codes for MD to read the results, not for the test itself
ED - cost/resource intensity weight	Resource Intensity	TBD	Can observe LOS in ED; would have to use some sort of per-unit average cost. We can use the MD billings during a ED visit.
Hospitalization - cost/resource intensity weight	Niveau d'intensité relative des ressources utilisées (NIRRU)	APR-DRG	
Home care – care unit cost	Cost of home care visit	I-CLSC	Home care visits can be observed; have to use a per-unit average cost

Abbreviations: SMED = Services pharmaceutiques; SMOD = Services rémunérés à l'acte; APR-DRG = Performance hospitalière; I-CLSC = Système d'information sur la clientèle et les services des CSSS - mission CLSC; TBD = To be determined;

Variables to identify budget impact

Variables	Description	Database	Notes
Number of doses dispensed – Days supplied	Treatment duration specified on the Rx demand for payment OR quantity of medication dispensed	SMED	
Body Surface Area	Patient body surface area at actual treatment claim is submitted	N/A	
Height	Patient height in cm	N/A	
Weight	Patient weight in kg	N/A	

Abbreviation: SMED = Services pharmaceutiques; N/A = Not available

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
ESAS	Edmonton Symptom Assessment Score	N/A	

Abbreviation: N/A = Not available



New Brunswick (NB):

Variables to identify disease of interest:

Variables	Description	Database	Notes
Topography code	The site of origin of the neoplasm	NBCR	
Histology code	Histological description of the neoplasm	NBCR	Formerly known as Morphology
Behaviour code	Behaviour associated with the histological description of the neoplasm	NBCR	
Date of diagnosis	Date of diagnosis	NBCR	

Abbreviation: NBCR = New Brunswick Cancer Registry

Variables to identify treatment of interest – orally administered chemotherapy:

Variables	Description	Database	Notes
Plan ID	The unique identifier of the drug benefit plan contributing toward this claim.	NBDPC Database	This information is only available for publicly funded plans.
Drug Identifier – Drug name/code/regimen	Drug name and code	NBCT	Database migration has not been scheduled yet
Drug Identifier – Drug Identification Number (DIN)	The Drug Identification Number (DIN), assigned by Health Canada, or the Pseudo-DIN (PIN), assigned by the plan, that identifies the benefit.	NBDPC Database	Injectable drugs are administered in hospitals and ambulatory care clinics throughout the province. The data are centrally collected at hospitals/ambulatory cancer clinics and may be compiled on to electronic databases. There is no centralized provincial data collection for services provided by ambulatory care clinics or injectable cancer therapies. cancer drugs dispensed at retail pharmacies has been collected by a centralized drug information system since 2017.
Intent of treatment	Adjuvant, curative, or palliative	N/A	Not available but may occasionally be inferred based
Line of therapy	Line of therapy such as first-line setting	N/A	on type of drug and information in the cancer registry
Dates prescriptions filled	The dates the prescriptions are filled	NBCT	

Abbreviation: NBDPC = New Brunswick Plans Claims Database; NBCT = New Brunswick Cancer Treatment Access Repository; DIS = Drug Information System; N/A = Not Available;

Variables to identify treatment of interest – orally administered chemotherapy:

Variables	Description	Database	Notes
Drug Identifier – Drug name/code/regimen	TBD	Oncology clinics	Collection and compilation are underway
Drug Identifier – Drug Identification Number (DIN)	The Drug Identification Number (DIN), assigned by Health Canada,	Oncology clinics	





Intent of treatment	Adjuvant, curative, or palliative	Oncology clinics	Not universally collected but may be collected by
Line of therapy	Line of therapy such as first-line setting	Oncology clinics	some clinics
Dates of treatment	Date of administered IV treatment	Oncology clinics	

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Unique patient identifier	NBCT, NBCR, DAD, CitizenDB	
Gender	Patient Gender	NBCR	
Date of birth	Date of birth	NBCR	
Rural/urban residence	Urban or rural residence	NBCR, CitizenDB	
Neighbourhood- Level Income	Defined from both postal code and the PCCF macro	TBD	
Regional Health Authority	Regional health authority	NBCR	
Charlson's Score	Comorbidity Scores	DAD	
Adjusted clinical groups (ACG)	Comorbidity Scores	DAD	Comorbidity score only available for hospital inpatients
Eastern Cooperative Oncology Group – Performance Status	Performance status: ECOG-PS	N/A	
Palliative Performance status	Performance Status: PPS	N/A	

Abbreviation: NBCR = New Brunswick Cancer Registry; NBCT = New Brunswick Cancer Treatment Access Repository; DAD = Discharge Abstract Database; N/A = Not Available; TBD = To be determined;

Variables to identify surgical and radiotherapy treatments:

Variables	Description		Notes
Radiation Use	Identifies patients who received radiation	NBCT	
Radiation - Dose/minutes per fraction	The amount of radiation absorbed by the tumor per dose (fraction)	N/A	
Radiation - Intent	The intention of radiation treatment as determined by the radiation oncologist at the time of booking the planning/treatment visit	NBCT	Only two categories are available: radical and palliative
Actual First Treatment Date	Date on which first treatment is delivered to patient	NBCT	
Surgical resection code – Intervention code The CIHI CCI/CCP procedure code describing the procedure administered to the patient		DAD	
Surgical resection date	Date of surgical intervention	DAD	

Abbreviation: NBCT = New Brunswick Cancer Treatment Access Repository; DAD = Discharge Abstract Database; N/A = Not Available; CCI = Canadian Classification of Health Interventions; CCP = Canadian Classification of diagnostic, therapeutic, and surgical procedure (CCP);

Can REValue

Value-based decisions from Real World Evidence

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of Death	NBCR, CitizenDB	
Hospital Visit - Date of admission	Date of admission to inpatient	DAD	
Hospital Visit - Diagnosis codes or procedure codes	ICD diagnosis code and type (most-responsible diagnosis)	DAD	
Hospital Visit - Discharge disposition	Status of the patient upon leaving the hospital	DAD	
Main problem	ICD diagnosis code and type (most-responsible diagnosis)	DAD	
ED visit	Visits to an emergency room	eHealthNB	NB does not participate in NACRS so this is not readily available. Hospitals would have this information on their own systems but there is no centralized data structure to obtain it. ED encounters will potentially be available to us soon but those data do not have diagnostic code.

Abbreviation: NBCR = New Brunswick Cancer Registry; DAD = Discharge Abstract Database; NACRS = National Ambulatory Care Reporting System; ED = Emergency Department;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug Quantity	The quantity of drug that was approved for payment by the plan.	NBDPC	
Accepted Ingredient Amount	Total prescription cost accepted that relates to the drug ingredient cost accepted by the plan.	NBDPC	Pricing is likely only available for drugs prescribed through pharmacies. Clinics may have IV drug prices but may be limited from disclosing them
Dispensing fee Amount	The amount from the total prescription cost accepted that relates to the professional fee, including dispensing fee and/or compounding fee.	NBDPC	Pricing is likely only available for drugs prescribed through pharmacies.
Accepted Markup Amount The amount from the total prescription cost accepted that relates to the pharmacy drug up-charge or pharmacy drug mark-up.		NBDPC	Pricing is likely only available for drugs prescribed through pharmacies.
Physician fee - Billing code	Fee for service billing code	NBPB	
Physician fee - Amount paid	Fee for service – amount approved for reimbursement	NBPB	

CanREValue Interim Data Report: Appendix



Value-based decisions from Real World Evidence

		Tutue Duseu decis	ions from Real World Evidence
Outpatient laboratory and imaging services - Billing Code	Fee for service billing code	NBPB	No diagnosis code/CCI code
Outpatient laboratory and imaging services - Amount paid	Fee for service – amount approved for reimbursement	NBPB	
Hospitalization - cost/resource intensity weight	Resource intensity weights	DAD	
Home care – care unit cost	Care Unit Cost	NB Long Term Care Database	

Abbreviation: NBDPC = New Brunswick Plans Claims Database; NBPB = New Brunswick Physician Billing Database; DAD = Discharge Abstract Database; CCI = Canadian Classification of Health Interventions;

Variables to identify budget impact:

Variables	Description	Database	Notes
Days supply	The number of days supply dispensed.	NBDPC	
Days supply	The number of days supply dispensed.	Database	
Dose administered	TBD Oncology clinics		
Body surface area	Patient body surface area at actual treatment	N/A	
	claim	N/A	
Height	Patient height in cm	TBD	Patient height/weight is not in the initial data
Weigh	Dationt weight in kg	TDD	coming from the RHAs but would be available
	Patient weight in kg	TBD	from hospital charts

Abbreviation: NBDPC = New Brunswick Plans Claims Database; RHA = Regional Health Authority; N/A = Not Available; TBD = To be determined;

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
ESAS score	Edmonton Symptom	TBD	Potentially available
	Assessment Score		

Abbreviation: TBD = To be determined;

Note: The variables to identify drug, drug cost, and budget impact in Nova Scotia will be iteratively updated after completing a real-world analysis in Nova Scotia.



Nova Scotia (NS):

Variables to identify disease of interest:

Variables	Description		Notes
Topography code	The site of origin of the neoplasm	NSCR	
Morphology code	Morphology description of the neoplasm		
Behaviour code	Behaviour associated with the histological description of the neoplasm	NSCR	
Date of diagnosis	Date of diagnosis	NSCR	

Abbreviation: NSCR = Nova Scotia Caner Registry

Variables to identify treatment of interest:

Variables	Description	Database	Notes
Drug Identifier – Drug name/code/regimen			
Drug Identifier – Drug Identification Number (DIN)			
Intent of treatment			
Line of therapy			
Dates of treatment			
Dispensing date - IV			
Dispensing date – Oral			

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Unique patient identifier	MSI	This is in all datasets as it is required for linkage purposes
Gender	Patient Gender	NSCR	
Date of birth	Date of birth	NSCR, MSI	
Rural/urban residence	Urban or rural residence	NSCR	
Neighbourhood- Level Income	Defined from both postal code and the PCCF macro	TBD	
Regional Health Authority	Regional health authority	TBD	Can compute using postal codes
Charlson's Score	Comorbidity Scores	DAD	
Adjusted clinical groups (ACG)	Comorbidity Scores		ACG will likely not be available. HDNS does not have ACG;
Eastern Cooperative Oncology Group – Performance Status	Performance status: ECOG-PS	TBD	Potentially available
Palliative Performance status	Performance Status: PPS	TBD	Potentially available from 1 palliative care service (central)

Abbreviation: MSI = Medical Services Insurance; NSCR = Nova Scotia Caner Registry; DAD = Discharge Abstract Database; HDNS = Health Data Nova Scotia; TBD = To be determined;



Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Identifies patients who received radiation	OPIS	
Radiation - Dose/minutes per fraction	The amount of radiation absorbed by the tumor per dose (fraction)	OPIS	
Radiation - Intent	The intention of radiation treatment	OPIS	
Radiation - visit date	Date of start of radiation	OPIS	
Surgical resection code – Intervention code CCP/CCI Code	The CCI procedure code describing the procedure administered to the patient	DAD, MSI billings	
Surgical resection date	Date of surgical intervention	DAD, MSI billings	

Abbreviation: DAD = Discharge Abstract Database; OPIS = Oncology Patient Information System; ; CCI = Canadian Classification of Health Interventions; CCP = Canadian Classification of diagnostic, therapeutic, and surgical procedure (CCP); MSI = Medical Services Insurance;

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of Death	NCSR, Vital Statistics	
ED Visit - Date of registration	Date of registration to emergency department	TBD	
ED Visit - Main Problem	Most clinically significant diagnosis, condition, problem or circumstance	TBD	
ED Visit - Visit disposition code	Type of separation from the ambulatory care service	TBD	
Hospital Visit - Date of admission	Date of admission to inpatient	DAD	
Hospital Visit - Diagnosis codes or procedure codes	ICD diagnosis code and type (most-responsible diagnosis)	DAD	
Hospital Visit - Discharge disposition	Status of the patient upon leaving the hospital	DAD	

Abbreviation: NSCR = Nova Scotia Caner Registry; DAD = Discharge Abstract Database; ED = Emergency Department; ICD = International Classification of Disease; TBD = To be determined;



Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost			
Drug (IV) – administration cost			
Drug – reimbursed cost			
Drug (oral) - total cost			
Drug - Dispensing fee			
Drug - Compounding fee			
Drug - Drug cost allowed			
Physician fee - Billing code			
Physician fee - Amount paid			
Outpatient laboratory and imaging services - Billing Code			
Outpatient laboratory and imaging services - Amount paid			
Hospitalization - cost/resource intensity weight			
Emergency Department – cost/resource intensity weight			
Home Care Cost		_	
Complex continuing care		_	

Variables to identify budget impact:

Variables	Description	Database	Notes
Number of doses dispensed –			
Days supplied			
Treatment dose given			
Body surface area			
Height			
Weigh			

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
ESAS score	Edmonton Symptom Assessment Score	TBD	Potentially available

Abbreviation: TBD = To be determined;

Note: The variables to identify drug, drug cost, and budget impact in Nova Scotia will be iteratively updated after completing a real-world analysis in Nova Scotia.



Newfoundland and Labrador (NL):

Variables to identify disease of interest:

Variables	Description	Database	Notes
Topography code	The site of origin of the neoplasm	Oncolog	
Morphology code	Morphology description of the neoplasm	Oncolog	
Behaviour code	Behaviour associated with the histological description of the neoplasm	Oncolog	
Date of diagnosis	Date of diagnosis	Oncolog	

Variables to identify treatment of interest:

Variables Variables	Description	Database	Notes
Drug Identifier – Drug name/code/regimen	Regimen of IV chemotherapy	ARIA MO Meditech PSTD	IV drugs are recorded in ARIA MO, the clinical patient information system, by regimen not individual drug. Dispensing data on individual drugs would be available in Pharmacy Module of Meditech or Provincial Systemic Therapy database. ARIA is not available in all sites where chemotherapy is delivered but it would cover most cancer patients receiving IV chemo.
Drug Identifier – Drug Identification Number (DIN)	DIN for oral chemotherapy	NLPDP	Oral drugs are collected by NL pharmacy network. Only full provincial coverage of all community pharmacies since 2017
Intent of treatment	Adjuvant, curative, or palliative	ARIA, OPIS	Not consistently coded at all centers;
Line of therapy	Line of therapy such as first-line setting	ARIA, PSTD	Can be routinely pulled in at Cancer Centre in St. John's. In other centres we may have to resort to physician notes
Dates of treatment	Date of treatment	ARIA MO OPIS	Patient receiving IV chemo at centres that have ARIA would have treatment date captured. ARIA has been used in the teritary site since 2014 and other places since late 2017. Prior to this dispensing date in Meditech would be the best proxy.
Dispensing date - IV	Date for treatment for IV administration	Meditech	Proxy for treatment date for IV administrations not captured in ARIA
Dispensing date – Oral	Date of dispensing	NLPDP Pharmacy Network	Oral chemo - Date order was written

Abbreviation: PSTD = Provincial Systemic Therapy Database; NLPDP = NL Prescription Drug Program; OPIS = Oncology Patient Information System

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Unique patient identifier	Oncolog, ARIA,DAD	
Gender	Patient Gender	Oncolog	
Date of birth	Date of birth	Oncolog	
Rural/urban residence	Urban or rural residence	Oncolog	
Neighbourhood- Level	Defined from both postal code	Oncolog	
Income	and the PCCF macro		
Regional Health Authority	Regional health authority	Oncolog	
Charlson's Score	Comorbidity Scores	DAD	Do not capture directly but can be derived based on ICD codes
Adjusted clinical groups (ACG)	Comorbidity Scores	N/A	
Eastern Cooperative		ARIA MO	Not sure whether this is captured in a discrete standardized
Oncology Group –	Performance status: ECOG-PS	(Medical Oncology)	way. Pending
Performance Status			
Palliative Performance	Performance Status: PPS	Palliative Care	Patients can be referred to the palliative care program within
status	remormance status. PPS	Program	the city. May not be captured electronically.

Abbreviation: DAD = Discharge Abstract Database; ICD = International Classification of Disease; N/A = Not available;

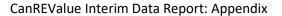
Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Identifies patients who received radiation	ARIA RO	
Radiation - Dose/minutes per fraction	The amount of radiation absorbed by the tumor per dose (fraction)	ARIA RO	
Radiation - visit date	Date of start of radiation	ARIA RO	
Surgical resection code – Intervention code	The CCI procedure code describing the procedure administered to the patient	DAD	
Surgical resection date	Date of surgical intervention	DAD	

Abbreviation: DAD = Discharge Abstract Database; CCI = Canadian Classification of Health Interventions;

Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of Death	Oncolog	
ED Visit - Date of registration	Date of registration to emergency department	Meditech	ED visits are captured in emergency department module in Meditech. However, no diagnosis or disposition information is recorded.
ED Visit - Main Problem	Most clinically significant diagnosis, condition, problem or circumstance	N/A	





ED Visit - Visit disposition code	Type of separation from the ambulatory care service	N/A	
Hospital Visit - Date of admission	Date of admission to inpatient	DAD	
Hospital Visit - Diagnosis codes or procedure codes	ICD diagnosis code and type (most-responsible diagnosis)	DAD	
Hospital Visit - Discharge disposition	Status of the patient upon leaving the hospital	DAD	

Abbreviation: DAD = Discharge Abstract Database; ED = Emergency Department; ICD = International Classification of Disease; N/A = Not Available;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost	Total cost of IV drug dispensation	Meditech	
Drug (IV) – administration cost	Cost to administer IV drug at the cancer clinic	TBD	
Drug – reimbursed cost	Total cost of drug to a drug program, if different from total cost (i.e., if patient pays co-pay)	Meditech	
Drug (Oral) - total cost	Total cost of oral drug dispensation	Meditech	The data will provide the absolute drug cost, not what patient paid, i.e. pharmacy markup. Cost data may also be available from NL Provincial Drug
Drug - Dispensing fee	Dispensing fee	TBD	Pharmacy Network linked with Atlantic Pharmaceutical Services Inc. price lists
Drug - Compounding fee	Compounding fee	N/A	Varies by individual pharmacy. We don't
Drug - Drug cost allowed	Drug cost allowed	N/A	capture.
Physician fee - Billing code	Fee for service billing code	MCP Billing	Will have physician foos for non-calaried
Physician fee - Amount paid	Fee for service – amount approved for reimbursement	MCP Billing	Will have physician fees for non-salaried physicians.
Outpatient laboratory and imaging services - Billing Code	Fee for service billing code	TBD	
Outpatient laboratory and imaging services - Amount paid	Fee for service – amount approved for reimbursement	TBD	
Hospitalization - cost/resource intensity weight	Resource intensity weights	DAD	
ED – cost/resource intensity weight	Resource intensity weights	TBD	





Home Care Cost	Cost associated with home care	TBD	
Complex continuing care	Cost of complex continuing care	TBD	

Abbreviation: DAD = Discharge Abstract Database; MCP = Medical Care Plan; ED = Emergency Department; IV = Intravenous; N/A = Not Available; TBD = To be determined;

Variables to identify budget impact:

Variables	Description	Database	Notes
Number of doses dispensed –	Dave cumplied	NLPDP	
Days supplied	Days supplied	Pharmacy Network	
Treatment dose given	Dose administered and dose requested	ARIA MO	
Treatment dose given	Dose administered and dose requested	OPIS	
Body surface area	Patient body surface area at actual treatment	ARIA MO	Will have data for patients treated in centres
	claim		where ARIA is used as the clinical system
Height	Patient height in cm	OPIS	
Weigh	Patient weight in kg	ARIA MO	

Abbreviation: NLPDP = NL Prescription Drug Program; OPIS = Oncology Patient Information System;

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
ESAS score	Patient reported outcome	Screening for Distress database	Not all patients are screened but many are.

Prince Edward Island (PEI):

Variables to identify disease of interest:

Variables	Description		Notes
Topography code	The site of origin of the neoplasm		
Morphology code	Morphology description of the neoplasm		
Behaviour code	Behaviour associated with the histological description of the neoplasm	PEICR	
Date of diagnosis	Date of diagnosis	PEICR	

Abbreviation: PEICR = Prince Edward Island Caner Registry

Variables to identify treatment of interest:

Variables	Description	Database	Notes
Drug Identifier – Drug regimen	Regimen of intravenous chemotherapy	CIS drug usage reports	For intravenous cancer drugs
Drug Identifier – Drug Identification Number (DIN)	DIN for oral chemotherapy	DIS	For oral cancer drugs
Treatment Indication	Specific indication for use	TBD	Don't currently track drug use by indication
Intent of treatment	Adjuvant, curative, or palliative	DIS	
Line of therapy	Line of therapy such as first-line setting	DIS	
Date of treatment administration	Date when IV drugs were received	CIS	Have the first date of treatment administration
Dispensing date	Dispensing Date	DIS and PEICR	

Abbreviation: CIS = Clinical Information System; DIS = Drug Information System; PEICR = Prince Edward Island Caner Registry; TBD = To be determined;

Variables to identify baseline characteristics:

Variables	Description	Database	Notes
Provincial Patient Identifier	Unique patient identifier	Cerner, Client Registry, PEICR, ARIA	
Gender	Patient Gender	Cerner, Client Registry, PEICR, ARIA	
Date of birth	Date of birth	Cerner, Client Registry, PEICR, ARIA	
Rural/urban residence	Urban or rural residence	Cerner, Client Registry, PEICR, ARIA	
Neighbourhood- Level Income	Defined from both postal code and the PCCF+ macro	PEICR and PCCF+	
Charlson's Score	Comorbidity Scores	DAD, CIS	Can find some with chart review
Adjusted clinical groups (ACG)	Comorbidity Scores	N/A	
Eastern Cooperative Oncology Group – Performance Status	Performance status: ECOG-PS	N/A	
Palliative Performance status	Performance Status: PPS	N/A	

Abbreviation: CIS = Clinical Information System; DAD = Discharge Abstract Database; PEICR = Prince Edward Island Caner Registry; N/A = Not available;

Variables to identify surgical and radiotherapy treatments:

Variables	Description	Database	Notes
Radiation Use	Identifies patients who received radiation	ARIA, PEICR	
Radiation - Dose	The dose of radiation	ARIA, PEICR	
Radiation - Fraction	The amount of radiation absorbed by the tumor per dose (fraction)	ARIA, PEICR	
Radiation - Intent	The intention of radiation treatment	ARIA	
Radiation - visit date	Date of start of radiation	ARIA, PEICR	
Surgical resection code – Intervention code	The CCI procedure code describing the procedure administered to the patient	DAD, PEICR	CCI codes used in DAD , FORDS codes used in PEICR
Surgical resection date	Date of surgical intervention	DAD, PEICR	

Abbreviation: PEICR = Prince Edward Island Caner Registry; CIS = Clinical Information System; DAD = Discharge Abstract Database; CCI = Canadian Classification of Health Interventions;

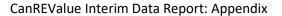
Variables to identify effectiveness & safety:

Variables	Description	Databases	Notes
Date of death	Date of Death	PEICR	
Discharge date	Date of discharge from acute care	DAD	
Hospital Visit - Date of admission	Date of admission to inpatient	DAD, CIS	CIS has this if transferred from ED
Hospital Visit - Discharge disposition	Status of the patient upon leaving the hospital	DAD	
Hospital Visit - Diagnosis codes or procedure codes	ICD diagnosis code and type (most-responsible diagnosis)	CIS FirstNet	

Abbreviation: PEICR = Prince Edward Island Caner Registry; CIS = Clinical Information System; DAD = Discharge Abstract Database; ED = Emergency Department;

Variables to identify cost:

Variables	Description	Databases	Notes
Drug (IV) - total cost	Total cost of IV drug dispensation.	CIS	
Drug (IV) – administration cost	Cost to administer IV drug at the cancer clinic	N/A	
Drug (Oral) - total cost	Total cost of oral drug dispensation.	Pharmacare	
Drug – reimbursed cost	Total cost of drug to a drug program, if different from total cost (i.e., if patient pays co-pay)	TBD	
Drug - Dispensing fee	Dispensing fee	Dispensing fee Pharmacare	
Drug - Compounding fee	Compounding fee	Pharmacare	
Drug - Drug cost allowed	Drug cost allowed	Pharmacare	
Physician fee - Billing code	Fee for service billing code	Master Agreement	





Physician fee - Amount paid	Fee for service – amount approved for reimbursement	Claims Processing System-Medicare
Outpatient laboratory and imaging services - Billing Code	Fee for service billing code	Master Agreement
Outpatient laboratory and imaging services - Amount paid	Fee for service – amount approved for reimbursement	Claims Processing System-Medicare
Hospitalization - cost/resource intensity weight	Resource intensity weights	DAD
ED – cost/resource intensity weight	Resource intensity weights	TBD
Home Care Cost	Cost associated with home care	N/A
Complex continuing care	Cost of complex continuing care	TBD

Abbreviation: CIS = Clinical Information System; DAD = Discharge Abstract Database; ED = Emergency Department; IV = Intravenous; N/A = Not available; TBD = To be determined;

Variables to identify budget impact:

Variables	Description	Database	Notes
Number of doses dispensed – Days supplied	Days supplied	DIS	
Treatment dose given	Dose administered and dose requested	CIS	
rreatment dose given	Dose administered and dose requested	DIS	
Body surface area	Patient body surface area at actual	CIS	
	treatment claim is submitted		
Height	Patient height in cm	Paper chart (CIS not	Height/weight currently not recorded in CIS at CTC
	Patient neight in chi	always up-to-date)	Height/weight currently not recorded in CIS at CTC - may have historical information available in CIS but
Weigh	Patient weight in kg	Paper chart (CIS not	may not be most up-to-date)
	Patient weight in kg	always up-to-date)	I may not be most up-to-date)

Abbreviation: CIS = Clinical Information System; DIS = Drug Information System;

Variables to identify patient reported outcomes:

Variables	Description	Database	Notes
ESAS	Edmonton Symptom Assessment Score	ARIA	