

This is a repository copy of Mapping Canadian Data Assets to Generate Real-World Evidence:Lessons Learned from Canadian Real-World Evidence for Value of Cancer Drugs (CanREValue) Collaboration's RWE Data Working Group.

White Rose Research Online URL for this paper: https://eprints.whiterose.ac.uk/id/eprint/184850/

Version: Published Version

Article:

Dai, Wei Fang, de Oliveira, Claire orcid.org/0000-0003-3961-6008, Blommaert, Scott et al. (24 more authors) (2022) Mapping Canadian Data Assets to Generate Real-World Evidence:Lessons Learned from Canadian Real-World Evidence for Value of Cancer Drugs (CanREValue) Collaboration's RWE Data Working Group. Current Oncology. pp. 2046-2063. ISSN: 1718-7729

https://doi.org/10.3390/curroncol29030165

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here: https://creativecommons.org/licenses/

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



Supplementary Table S1: Comparison between pan-Canadian Minimal Oncology Dataset (pCMOD) and CanREValue Interim Data

Category	Data Element from pCMOD	Status	Available in CanREValue Data Report	Notes
Health Service Event	Service Date	М	Yes	The date on which the prescription was dispensed
Organization	Organization ID	M	No	Will explore in future reports
Information (health care facility	Organization Province	М	No	N/A – each province maintains their own datasets;
where the drug was received)	Organization Postal Code	М	No	Will explore in future reports
Prescriber	Prescriber ID	0	No	Will explore in future reports
Information	Prescriber Specialty	0	No	Will explore in future reports
	Prescriber Province	0	Yes	N/A – each province maintains their own datasets;
	Prescriber Postal Code	0	No	Will explore in future reports
Client/patient	Client/Patient ID	M	Yes	
information	Client/Patient Province	М	No	N/A – each province maintains their own datasets;
	Client/Patient Postal Code	М	Yes	
	Client/Patient Gender	М	Yes	
	Client/Patient Date of Birth	М	Yes	
	Client/Patient Height	0	Yes	
	Client/Patient Weight	0	Yes	
	Client/Patient Body Surface Area	0	Yes	
	Body Surface Formula	С	No	N/A – This is a formula and not a variable;
Disease information	Diagnosis Code	М	Yes	
	Topography Code	M	Yes	
	Morphology Code	M	Yes	
	Topography/Morphology Code Version	М	No	Will explore in future reports
	Staging	М	Yes	
	Date of Initial Diagnosis	М	Yes	
Drug Information	Drug product ID / Name	M	Yes	
	Drug Product Strength	С	No	Will explore in future reports
	Drug Product dosage form	С	Yes	
	Regimen/Treatment Plan	0	Yes	
	Quantity Dispensed	М	Yes	
	Measurement Unit	0	No	Will explore in future reports
	Days supply	0	Yes	
	Route of Administration	0	Yes	
	Drug Cost	0	Yes	

Status: M = Mandatory; O = Optional; C = Conditional;

Supplementary Table S2: Additional real-world data elements requiring future exploration

Typo	Variable
Type	Race/Ethnicity
Demographic	
Turnar	Immigration status Site of metastasis
Tumor	
characteristics	Number of metastatic sites
	Node (+/-)
	Tumor mutational burden
	Recurrence vs de novo diagnosis
	Date of progression
	Criteria for evaluating progression
	Date of response
	Response status
	Criteria for assessing response
Biomarker status	Drug and disease biomarkers status
	(e.g. HR+, HER2+, TNBC, EGFR, ALK, ROS1, NTRK, CEA, CA19-9, CA-125)
	Biomarker assay used
	Date of test
	Date of results
Lab test	Lab test
	(E.g. Lymphocyte count, Platelet count)
PROMS, PREMS, and	Quality of life (QoL)
QoL	(e.g. European Organization Research and Treatment of Cancer Quality of Life
	Questionnaire-C30; EuroQol-5D-5L, Patient Reported Functional Status,
	Generalized Anxiety Disorder-7, Patient Health Questionnaire-9, Brief Pain
	Inventory, Chronic Fatigue Syndrome)
	Patient-reported outcome measures (PROMS)
	Patient-reported experience measures (PREMS)
Healthcare	Treatment chair time
Utilization	Nursing time
	Pharmacy time to prepare IV dose
	Advance care planning
Cancer Risk	Smoking
Factors/Confounders	Alcohol
·	Sun Exposure
	Diet
	Physical Activity
	Sleep
	Stress
	Chemical exposure
	Occupational Exposure
	Genetic Changes
	Infectious disease
	Radiation
	Family History

Social Determinants	Income and social status					
of Health	Employment and working conditions					
	Education and literacy					
	Burden of disease on productivity					
	Childhood experiences					
	Physical environments					
	Social supports and coping skills					
	Healthy behaviors					
Outcome Measures	Event-free survival (EFS)					
	Disease-free survival (DFS)					
	Invasive-disease free survival (iDFS)					
	Progression-free Survival (PFS)					
	Progression-free Survival 2 (PFS2)					
	Minimal residual disease (MRD)					
	Pathological complete response (pCR)					
	Time to next treatment (TTNT)					
	Treatment-free interval (TFI)					
	Overall response rate (ORR) and associated strata (stringent Complete					
	Response, Complete Response, Very Good Partial Response, Partial					
	Response, Stable Disease)					

Supplementary Table S3: Potential private/academic databases for RWE analysis

- Disease site specific database:
 - o Canadian Melanoma Research Network: healthie™
 - Pan-Canadian Lung Cancer Observational Study (PALEOS)
 - o Uveal Melanoma Registry
 - o Canadian Prostate Cancer Biomarker Network (BPCBN)
 - o The Alberta Prostate Cancer Research Institute Initiative (APCaRI): Alberta Prostate Registry
 - o The Myeloma Canada Research Network (MCRN) Canadian Multiple Myeloma Database
 - o Canadian Bladder Cancer Information System (CBCIS)
 - o Canadian Kidney Cancer Information System (CKCIS)
 - GlansLook Lung Cancer Database (Alberta)
 - o McPeak-Sirois Breast Metastases Registry (Montreal Region)
 - o Enhanced Pancreatic Cancer Profiling For Individualized Care (EPPIC)
- Pediatric oncology database:
 - o Pediatric Oncology Group of Ontario Networked Information System (POGONIS)
 - o Cancer in Young People in Canada (CYP-C) databases
- IQVIA Databases: Private Drug Claims and RxDynamics
- The Canadian Personalized Healthcare Innovation Network (C-PHIN)'s databases
- Palliative care databases owned by the Alberta Health Service Palliative Care Zonal program leaders
- Patient Support Programs Database (PSPs)
- Private insurance disability registries
- O2 Oncology Outcomes program databases
- Programme de Gestion Thérapeutique des Médicaments databases
- Personalize my Treatment (PMT) Registry
- International registries:
 - o Flatiron Electronic Health Record Database (US)
 - The National Lung Cancer Registry (Sweden)
 - CRISP register (Germany)

Note: The databases were identified through Stakeholder consultation

Supplementary Table S4: Survey on databases and data elements

Category	Variables	Description	Database Name	Notes
Cohort Creation:	Topography			
Identify disease of	Morphology			
interests	Behaviour			
	Date of diagnosis			
Cohort Creation:	Drug Identifier – IV			
Identify treatment of	Drug Identifier – Oral			
interest	Treatment Indication			
	Intent of treatment			
	Line of therapy			
	Date of treatment			
	administration			
	Dispensing date			
Demographic and	Provincial Patient			
Clinical Characteristics	Identifier			

Category	Variables	Description	Database Name	Notes
	Sex			
	Date of Birth			
	Age at first treatment			
	Rural/Urban			
	residence			
	Neighbourhood			
	Income Quintiles			
	Regional Health			
	Authority			
	Charlson's Score			
	Adjusted Clinical			
	Groups(ACG)			
	ECOG-Performance			
	Status			
	Palliative			
	Performance Status			
	Radiation Use			
	Radiation –			
	Dose/minutes per			
	fraction			
	Radiation – Intent			
	Radiation – visit date			
	Surgical resection code			
	Surgical resection date			
Clinical Effectiveness	Date of Death			
	Date of last contact			
Safety & Toxicity	ED Visit - Date of			
	registration ²⁶			
	ED Visit - Main Problem ²⁶			
	ED Visit - Visit			
	disposition code ²⁶			
	Hospital Visit - Date of			
	admission ²⁷			
	Hospital Visit -			
	Diagnosis codes or			
	procedure codes ²⁷			
	Hospital Visit -			
	Discharge disposition ²⁷			
Cost-effectiveness	Drug (IV) – total cost			
COSC CITCUIVEILESS	Drug – reimbursed			
	cost			
L	1 5031	l	1	l

Category	Variables	Description	Database Name	Notes
	Drug (oral) – total			
	cost			
	Drug – Dispensing			
	fees			
	Drug – Compounding			
	fee			
	Physician fee – Billing			
	code			
	Physician fee –			
	Amount paid			
	Outpatient			
	laboratory and			
	imaging services –			
	Billing code			
	Outpatient			
	laboratory and			
	imaging services –			
	Amount paid			
	ED cost/resource			
	intensity weight			
	Hospitalization			
	cost/resource			
	intensity weight			
	Home Care			
	Complex continuing			
	care			
Budget Impact	Doses dispensed –			
	Days supplied			
	Treatment dose			
	given			
	Body Surface area			
	Height			
	Weight			
Patient reported	Edmonton Symptom			
outcomes	Assessment Score			

Supplementary Table S5: Survey on capacity assessment

Intravenous Drug

Analysis	ВС	AB	SK	MN	ON	QB	NS	NB	NFL	PEI
Cohort Creation										
Effectiveness (Survival)										
Safety & Toxicity										
Budget Impact										
Cost Effectiveness Analysis										
Patient reported outcomes										

Oral Drug

Analysis	ВС	AB	SK	MN	ON	QB	NS	NB	NFL	PEI
Cohort Creation										
Effectiveness (Survival)										
Safety & Toxicity										
Budget Impact										
Cost Effectiveness Analysis										
Patient reported outcomes										

Supplementary Table S6: Glossary

AB = Alberta

ACG = Adjusted Clinical Group

BC = British Columbia

CanREValue = Canadian Real-World Evidence for Value of Cancer Drugs

CCI = Canadian Classification of Health Interventions.

CCMB = CancerCare Manitoba

CCO = Cancer Care Ontario

CCP = Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedures;

CIHI = Canadian Institute for Health Information

DAD = Discharge Abstract Database

DIN = Drug Identifier Number

DoH = Departments of Health

ECOG = Eastern Cooperative Oncology Group

ED = Emergency Department.

ENCR = European Network of Cancer Registries

HDNS = Health Data Nova Scotia

HTA = Health Technology Assessment

ICD-O-3 = International Classification of Disease for Oncology Third version.

IV = Intravenous

MB = Manitoba

mCODE = Minimal Common Oncology Data Elements

MoH = Ministries of Health

NACRS = National Ambulatory Care Reporting System

NB = New Brunswick

NL = Newfoundland and Labrador

NS = Nova Scotia

ON = Ontario

pCMOD = pan-Canadian Minimal Oncology Dataset

PEI = Prince Edward Island

QB = Quebec

RCT = Randomized Clinical Trials

RWD = Real World Data

RWD = Real World Evidence

SK = Saskatchewan

WG = Working Group