

Priorities for PRHDN Implementation Plan

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The Pan-Canadian Real-world Health Data Network (PRHDN) will be a distributed data network that allows researchers and policy/decision makers from across Canada to make effective use of linked and linkable administrative (real-world) data holdings and expertise in multi-province studies and initiatives without requiring that data leave provincial boundaries. The PRHDN Leads Team is developing an Implementation Plan and would like your input.

Several questions ask about algorithms. Under the PRHDN, algorithms will be used to prepare harmonized common data at centres across Canada. For example, the PRHDN could set the objective of developing and validating a case definition algorithm that identifies individual records corresponding to people with dementia in a comparable way across multiple provinces.

The PRHDN will focus on algorithms that are most likely to be useful to researchers and policy/decision makers. With the assistance of Lisa Lix, we have compiled a preliminary list of algorithms that define case conditions which have either been validated in multiple provinces, or have been identified as potentially applicable to the data holdings of different provinces. You may find it helpful to download the preliminary list of algorithms before starting the survey. Thank you for taking the time to provide your input.

		# votes
Question 1: Please identify up to five algorithms from the preliminary list of potential algorithms for multi-province studies that would be most useful to you.	Mental Health	26
	Cardiovascular disease	17
	Diabetes	15
	Respiratory disease	8
Question 2: Please identify up to five algorithms from the preliminary list that you feel would be most useful for planning and research generally (not just for you):	Mental Health	20
	Cardiovascular disease	18
	Diabetes	13
	Respiratory disease	12
Question 3: Additional algorithms that you recommend the PRHDN explore: (boxes for up to three entries)	Autism	4
	Mental Health	4
	Pregnancy-related	4
	Dementia	3
	See Q3 tab for more details	
Question 4: Your suggestions on additional priorities for the PRHDN beyond algorithms (e.g., training that the PRHDN might provide, research studies that the PRHDN might perform, etc.):	Data linkage	6
	Training	6
	Partnerships	5
	Comparisons	5
	Documentation	3
	Validation	3
	See Q4 tab for more details	

Question 1: Please identify up to five algorithms from the preliminary list of potential algorithms for multi-province studies that would be most useful to you.

	# votes
11 - Mental Health - Mental disorder	12
9 - Diabetes - Diabetes mellitus	10
12 - Mental Health - Mood and anxiety disorders	9
5 - Cardiovascular Disease - Hypertension	6
1 - Cancer - Cancer, metastatic	5
10 - Diabetes - Diabetes, type unspecified, GDM excluded	5
13 - Mental Health - Schizophrenia	5
20 - Respiratory disease - Chronic obstructive pulmonary disease	5
7 - Cardiovascular Disease - Myocardial infarction	5
21 - Other - Chronic pain	4
4 - Cardiovascular Disease - Heart failure	4
19 - Respiratory disease - Asthma	3
22 - Other - Cirrhosis	2
14 - Musculoskeletal - Hip fracture	1
16 - Musculoskeletal - Osteoporosis	1
17 - Renal disease - Chronic kidney disease	1
23 - Other - Irritable bowel syndrome	1
25 - Other - Severe constipation	1
3 - Cardiovascular Disease - Atrial fibrillation	1
6 - Cardiovascular Disease - Ischemic heart disease	1

	# votes
Mental Health	26
Cardiovascular disease	17
Diabetes	15
Respiratory disease	8

Question 2: Please identify up to five algorithms from the preliminary list that you feel would be most useful for planning and research generally (not just for you):

	# votes
11 - Mental Health - Mental disorder	17
9 - Diabetes - Diabetes mellitus	12
1 - Cancer - Cancer, metastatic	7
21 - Other - Chronic pain	7
2 - Cardiovascular Disease - Acute myocardial infarction	7
19 - Respiratory disease - Asthma	6
20 - Respiratory disease - Chronic obstructive pulmonary disease	6
5 - Cardiovascular Disease - Hypertension	6
17 - Renal disease - Chronic kidney disease	5
12 - Mental Health - Mood and anxiety disorders	3
6 - Cardiovascular Disease - Ischemic heart disease	3
15 - Musculoskeletal - Multiple sclerosis	2
10 - Diabetes - Diabetes, type unspecified, GDM excluded	1
23 - Other - Irritable bowel syndrome	1
3 - Cardiovascular Disease - Atrial fibrillation	1
4 - Cardiovascular Disease - Heart failure	1

	# votes
Mental Health	20
Cardiovascular disease	18
Diabetes	13
Respiratory disease	12

Question 3: Additional algorithms that you recommend the PRHDN explore: (boxes for up to three entries)

Conditions		# votes	System		# votes
Autism		4	High user		1
Dementia		3	Having a GP		1
Mental health	Depression	1			
	Bipolar disorder	1			
	Suicide/self-harm	2			
Pregnancy	Link mom & babies	2			
	Gestational diabetes	1			
	Pregnancy	1			
Pediatric	Cancer	1			
	Other	1			
Cancer	Type and stage	1			
	Deaths	1			
	Incidence	1			
Cerebral palsy		1			
Developmental disabilities		1			
Epilepsy		1			
Inflammatory Bowel Disease		1			
Parkinson's disease		1			
Substance Use Disorder		1			
Vaccinations		1			
Venous thromboembolism		1			
Multimorbidity		1			
Oral health		1			
Funcional GI disorders		1			
ADHD		1			

Question 4: Your suggestions on additional priorities for the PRHDN beyond algorithms (e.g., training that the PRHDN might provide, research studies that the PRHDN might perform, etc.):

Theme	Priority	# votes
Linkage	Health + education data	1
	Health + income data	1
	Health + social outcomes data	1
	Health + Stat Can data (CCHS, SLID)	1
	Accuracy of linkage	1
	Health + drug data	1
Training	For junior investigators	1
	General opportunities	1
	Fellowship	2
	Graduation student program	2
Validation	Algorithms in pediatrics	1
	Algorithms	1
	Shadow billing	1
Documentation	Data dictionary	2
	Tools	1
Comparisons	Across provinces	4
	With clinical trial data	1
Partnerships	With SPOR	1
	Health authorities	1
	Diverse stakeholders	1
	Networking	1
	Conference access	1

		Responder #																		
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
Question 1: 5 Most useful algorithms to you	1st	1 - Cancer - Cancer, metastatic	23 - Other - Irritable bowel syndrome	11 - Mental Health - Mental disorder	1 - Cancer - Cancer, metastatic	13 - Mental Health - Schizophrenia	9 - Diabetes - Diabetes mellitus	3 - Cardiovascular Disease - Atrial fibrillation	11 - Mental Health - Mental disorder	11 - Mental Health - Mental disorder	9 - Diabetes - Diabetes mellitus	9 - Diabetes - Diabetes mellitus	9 - Diabetes - Diabetes mellitus	10 - Diabetes - Diabetes, type unspecified, GDM excluded	9 - Diabetes - Diabetes mellitus	1 - Cancer - Cancer, metastatic	11 - Mental Health - Mental disorder		11 - Mental Health - Mental disorder	11 - Mental Health - Mental disorder
	2nd	21 - Other - Chronic pain	25 - Other - Severe constipation	20 - Respiratory disease - Chronic obstructive pulmonary disease	5 - Cardiovascular Disease - Hypertension	12 - Mental Health - Mood and anxiety disorders	6 - Cardiovascular Disease - Ischemic heart disease	5 - Cardiovascular Disease - Hypertension	12 - Mental Health - Mood and anxiety disorders	12 - Mental Health - Mood and anxiety disorders	4 - Cardiovascular Disease - Heart failure	4 - Cardiovascular Disease - Heart failure	10 - Diabetes - Diabetes, type unspecified, GDM excluded	12 - Mental Health - Mood and anxiety disorders	11 - Mental Health - Mental disorder	11 - Mental Health - Mental disorder	12 - Mental Health - Mood and anxiety disorders			12 - Mental Health - Mood and anxiety disorders
	3rd	1 - Cancer - Cancer, metastatic	22 - Other - Cirrhosis	10 - Diabetes - Diabetes, type unspecified, GDM excluded	21 - Other - Chronic pain	11 - Mental Health - Mental disorder	7 - Cardiovascular Disease - Myocardial infarction	2 - Cardiovascular Disease - Acute myocardial infarction	9 - Diabetes - Diabetes mellitus	13 - Mental Health - Schizophrenia	11 - Mental Health - Mental disorder	20 - Respiratory disease - Chronic obstructive pulmonary disease	12 - Mental Health - Mood and anxiety disorders	5 - Cardiovascular Disease - Hypertension	14 - Musculoskeletal - Hip fracture	13 - Mental Health - Schizophrenia	13 - Mental Health - Schizophrenia			13 - Mental Health - Schizophrenia
	4th	1 - Cancer - Cancer, metastatic	21 - Other - Chronic pain	5 - Cardiovascular Disease - Hypertension	11 - Mental Health - Mental disorder	5 - Cardiovascular Disease - Hypertension	20 - Respiratory disease - Chronic obstructive pulmonary disease	9 - Diabetes - Diabetes mellitus	2 - Cardiovascular Disease - Acute myocardial infarction	9 - Diabetes - Diabetes mellitus	10 - Diabetes - Diabetes, type unspecified, GDM excluded	17 - Renal disease - Chronic kidney disease	11 - Mental Health - Mental disorder	20 - Respiratory disease - Chronic obstructive pulmonary disease	16 - Musculoskeletal - Osteoporosis	12 - Mental Health - Mood and anxiety disorders				22 - Other - Cirrhosis
	5th		18 - Respiratory disease - Active asthma	21 - Other - Chronic pain	10 - Diabetes - Diabetes, type unspecified, GDM excluded	9 - Diabetes - Diabetes mellitus	4 - Cardiovascular Disease - Heart failure	7 - Cardiovascular Disease - Myocardial infarction	4 - Cardiovascular Disease - Heart failure	5 - Cardiovascular Disease - Hypertension	20 - Respiratory disease - Chronic obstructive pulmonary disease	7 - Cardiovascular Disease - Myocardial infarction	19 - Respiratory disease - Asthma	19 - Respiratory disease - Asthma	12 - Mental Health - Mood and anxiety disorders					9 - Diabetes - Diabetes mellitus
Question 2: 5 Most useful algorithms generally	1st	9 - Diabetes - Diabetes mellitus	11 - Mental Health - Mental disorder	6 - Cardiovascular Disease - Ischemic heart disease	1 - Cancer - Cancer, metastatic	11 - Mental Health - Mental disorder	9 - Diabetes - Diabetes mellitus	3 - Cardiovascular Disease - Atrial fibrillation	2 - Cardiovascular Disease - Acute myocardial infarction	11 - Mental Health - Mental disorder	1 - Cancer - Cancer, metastatic	9 - Diabetes - Diabetes mellitus	2 - Cardiovascular Disease - Acute myocardial infarction	21 - Other - Chronic pain	1 - Cancer - Cancer, metastatic	1 - Cancer - Cancer, metastatic	11 - Mental Health - Mental disorder		2 - Cardiovascular Disease - Acute myocardial infarction	2 - Cardiovascular Disease - Acute myocardial infarction
	2nd	12 - Mental Health - Mood and anxiety disorders	12 - Mental Health - Mood and anxiety disorders	9 - Diabetes - Diabetes mellitus	10 - Diabetes - Diabetes, type unspecified, GDM excluded	1 - Cancer - Cancer, metastatic	2 - Cardiovascular Disease - Acute myocardial infarction	9 - Diabetes - Diabetes mellitus	9 - Diabetes - Diabetes mellitus	9 - Diabetes - Diabetes mellitus	11 - Mental Health - Mental disorder	4 - Cardiovascular Disease - Heart failure	9 - Diabetes - Diabetes mellitus	2 - Cardiovascular Disease - Acute myocardial infarction	6 - Cardiovascular Disease - Ischemic heart disease	11 - Mental Health - Mental disorder			9 - Diabetes - Diabetes mellitus	9 - Diabetes - Diabetes mellitus
	3rd	19 - Respiratory disease - Asthma	1 - Cancer - Cancer, metastatic	20 - Respiratory disease - Chronic obstructive pulmonary disease	21 - Other - Chronic pain	9 - Diabetes - Diabetes mellitus	20 - Respiratory disease - Chronic obstructive pulmonary disease	19 - Respiratory disease - Asthma	11 - Mental Health - Mental disorder	5 - Cardiovascular Disease - Hypertension	6 - Cardiovascular Disease - Ischemic heart disease	20 - Respiratory disease - Chronic obstructive pulmonary disease	11 - Mental Health - Mental disorder	5 - Cardiovascular Disease - Hypertension	9 - Diabetes - Diabetes mellitus	20 - Respiratory disease - Chronic obstructive pulmonary disease			11 - Mental Health - Mental disorder	11 - Mental Health - Mental disorder
	4th	5 - Cardiovascular Disease - Hypertension	23 - Other - Irritable bowel syndrome	11 - Mental Health - Mental disorder	11 - Mental Health - Mental disorder	19 - Respiratory disease - Asthma	1 - Cancer - Cancer, metastatic	20 - Respiratory disease - Chronic obstructive pulmonary disease	19 - Respiratory disease - Asthma	12 - Mental Health - Mood and anxiety disorders	17 - Renal disease - Chronic kidney disease	7 - Cardiovascular Disease - Myocardial infarction	17 - Renal disease - Chronic kidney disease	11 - Mental Health - Mental disorder	11 - Mental Health - Mental disorder	17 - Renal disease - Chronic kidney disease			19 - Respiratory disease - Asthma	17 - Renal disease - Chronic kidney disease
	5th		15 - Musculoskeletal Multiple sclerosis	21 - Other - Chronic pain	5 - Cardiovascular Disease - Hypertension	5 - Cardiovascular Disease - Hypertension	11 - Mental Health - Mental disorder	21 - Other - Chronic pain	20 - Respiratory disease - Chronic obstructive pulmonary disease	21 - Other - Chronic pain	21 - Other - Chronic pain	11 - Mental Health - Mental disorder	21 - Other - Chronic pain	17 - Renal disease - Chronic kidney disease	19 - Respiratory disease - Asthma	5 - Cardiovascular Disease - Hypertension				15 - Musculoskeletal - Multiple sclerosis

	Responder #																			
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	
Question 3: Additional algorithms	Entry 1	Cancer deaths	Inflammatory Bowel Disease	Alzheimer's disease or dementia more broadly	Linkage of maternal-infant data	Injury (excluding self-harm attempts)	Venous thromboembolism	Pediatric specific algorithms	How to identify a pregnancy	Dementia	Dementia	diabetes in pregnancy	having a primary care provider	developmental disabilities	Mental health - Bipolar disorder	Substance Use Disorder	oral health indicators - dental caries	Pediatric cancer		
	Entry 2	Incident cancer	Vaccinations	Autism spectrum disorders	N/A	None	N/A	None	Link mothers and babies	Parkinson's disease	Any chronic diseases not noted above that are associated with high resource burden and/or health equity implications	ADHD	multimorbidity	cerebral palsy	Nothing else to add	Mental Health - Self Harming and Suicide-related Behaviour	oral health indicators - cleft palate			
	Entry 3	cancer by type and stage	Functional gastrointestinal disorders (e.g. functional dyspepsia, abdominal pain, IBS, etc)	Depression	N/A	None	N/A	None	autism	Epilepsy	Can't think of anything further	autism	being a high user of the health system	Autism Spectrum Disorder	Nothing else to add					
Question 4: Additional priorities	Entry 1 x		Validation studies (of codes used as outcomes, predictors, and identification algorithms)	Cross-country treatment incidence/prevalence studies for various conditions	Program for graduate students	Coordination with data infrastructure providers (RDC, Provincial health authorities) to make the data available across Canada	User-friendly data dictionary for all algorithms (similar to ICES data dictionary)	Networking	Fellowship training	Increase availability of near contemporaneous data.	Once the data and algorithms are in place, people will be ++ interested in comparing disease prevalence across provinces and health regions.	validation studies of algorithms	accuracy of diagnostic codes and shadow billing	training for junior investigators on research using admin data	Linkage of health data with income data	Continue to bring together diverse stakeholder & researchers to collaborate				
	Entry 2 x		Linkage studies (accuracy of linkage between databases)	Some presence at relevant conferences or other gatherings of potential users	Remote access via VPN	Coordinate with Stat Can for record level linkage to other data sources (e.g., CCHS, SLID)	N/A	Training opportunities		Compare trial evidence with PRHDN real world data	n/a	trends across provinces	pilot cross-province comparisons	other	Linkage of health data with education data					
	Entry 3 x		Enhancing drug data available from outside data sources (e.g. pharmacies)	Explore partnering with complementary groups e.g. SPOR	N/A	None	N/A	None		UG, PG and CPD training in use of PRHDN data	n/a	validation of algorithms in paediatrics	documentation - tools, data dictionaries, etc.	other	Linkage of health data with other outcomes (social assistance, incarceration) data					