"If you can't measure it, you can't manage it" **Addressing Disease Risk Factors in Primary Care Settings**

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Director, Research and Quality Improvement and the Manitoba Primary Care Research Network
Department of Family Medicine, Rady Faculty of Health Sciences, University of Manitoba

Health Information Exchange Standards – Approaches
May 6, 2024

The University of Manitoba campuses are located on original lands of Anishinaabeg, Cree, Oji-Cree, Dakota, and Dene peoples, and on the homeland of the Métis Nation.

We respect the Treaties that were made on these territories, we acknowledge the harms and mistakes of the past, and we dedicate ourselves to move forward in partnership with Indigenous communities in a spirit of reconciliation and collaboration.

Conflict of Interest – A. Singer

- Paid by University of Manitoba for academic work
- Grant funding from CIHR, Research Manitoba, PHAC
- Principal Investigator on grant funded by IBM and Calian administered by the Canadian Institute for Military and Veterans Health Research related to the identification of PTSD in electronic medical records
  - There are no products related to these funders that will be discussed in this program

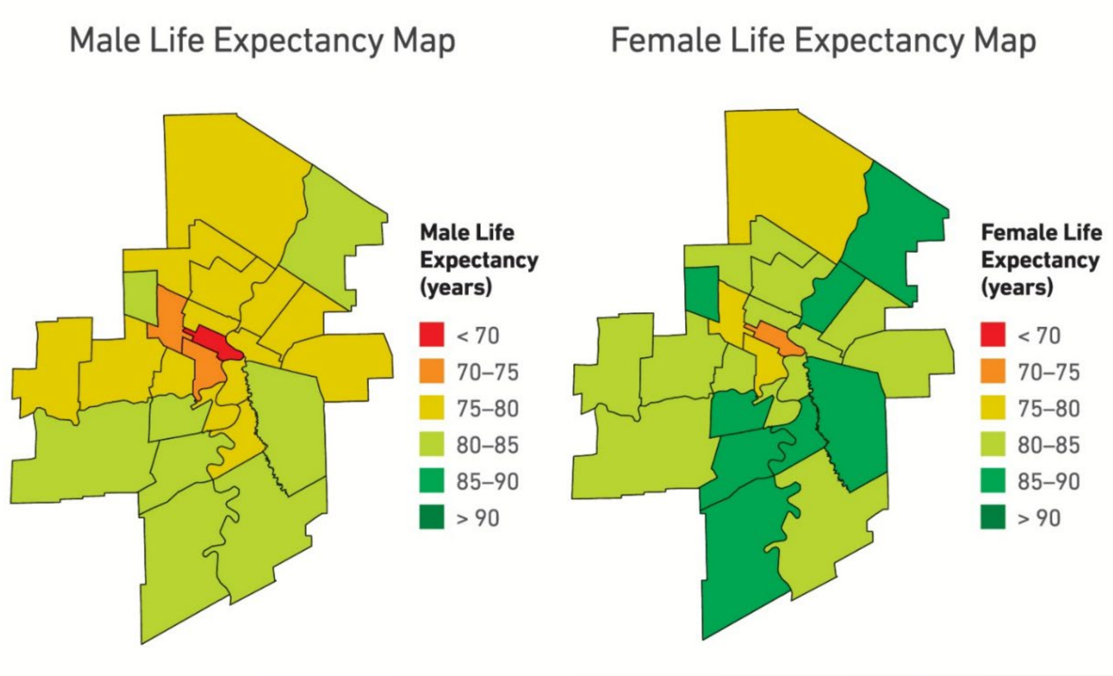
Learning objectives

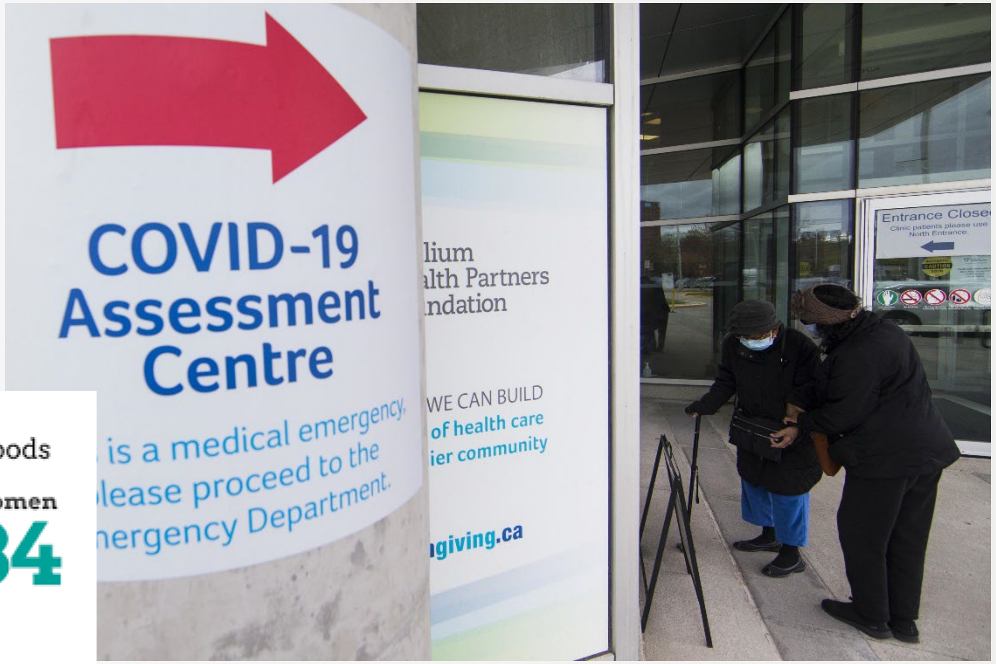
- Describe the importance of clinical importance and relevance of social determinant of health and behavioural risk factors to health
- Explore the role of Practice Based Research and Learning Networks in extracting and processing these data
- Consider the current and potential future state of collection of this information to assist in direct patient care and population health

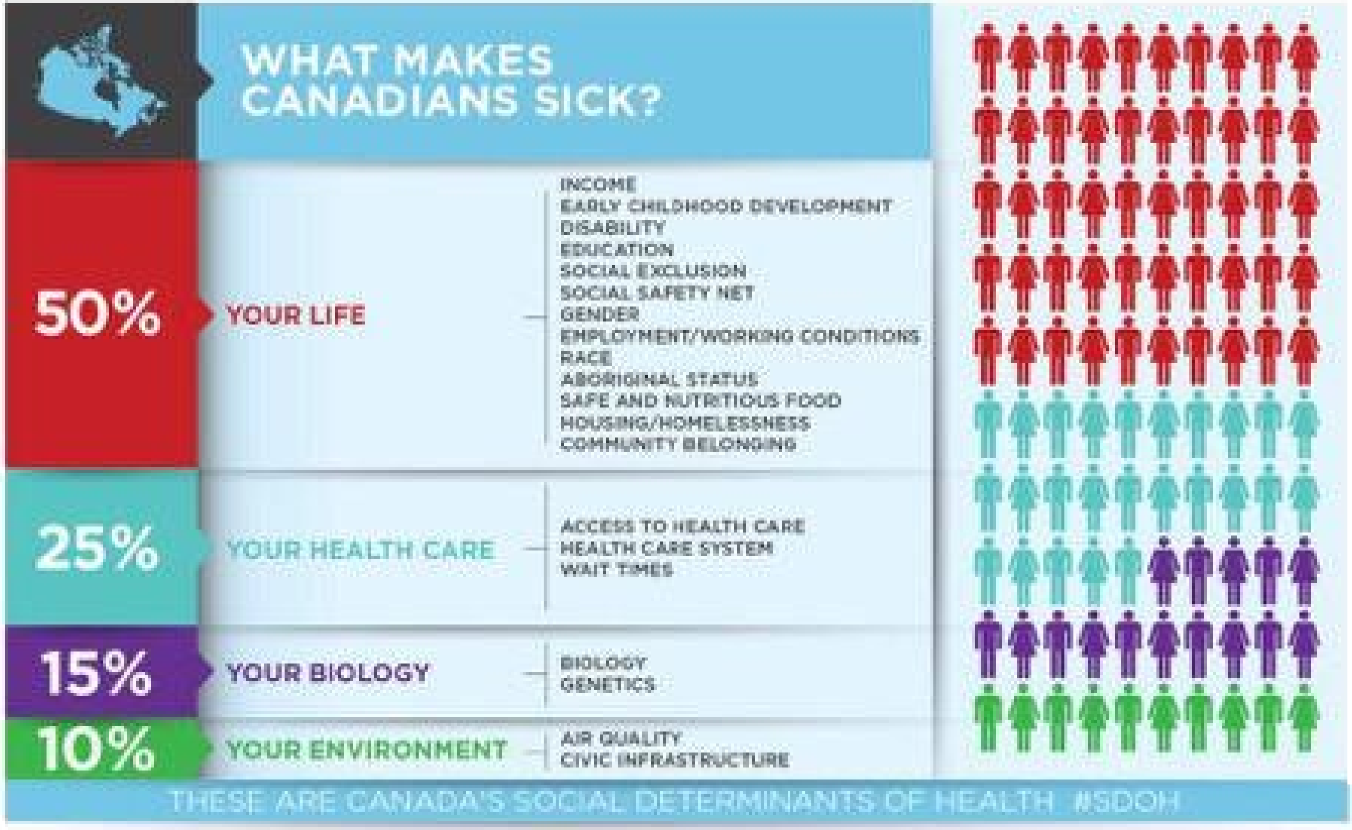
Introduction

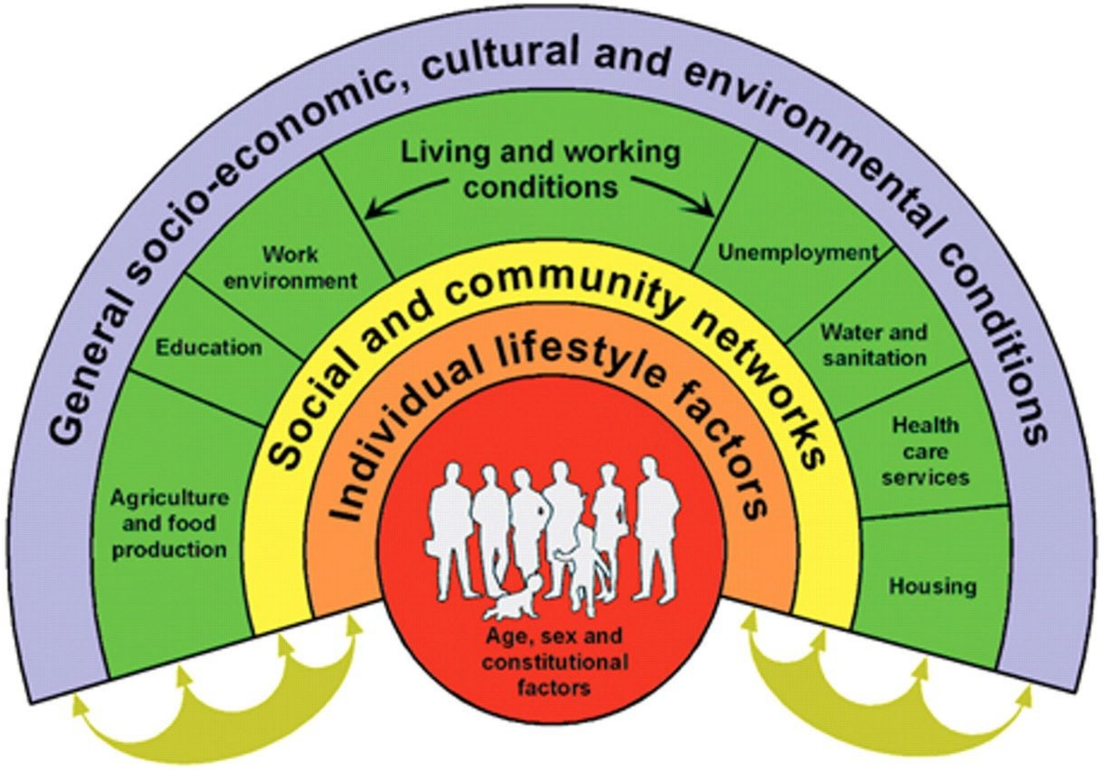
- Risk factors for acute and chronic diseases include social, environmental and health related behaviours
- Many these inequities were further exacerbated during the COVID-19 pandemic
- Robust Practice Based Research and Learning Networks can help understand and address the underlying risk factors contributing to poor health

Medicine is not the most important driver of health outcomes…









CMA; https://www.cma.ca/health-care-canada-what-makes-us-sick

Dahlgreen, G. and Whitehead, M. (1991). Policies and Strategies to Promote Social Equity in Health. Stockholm: Institute for Future Studies.

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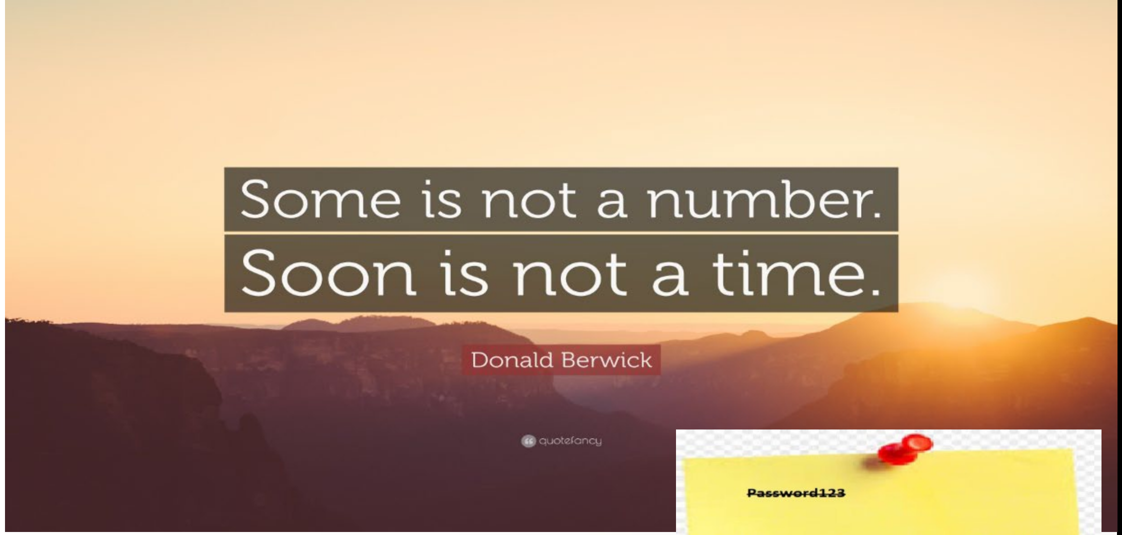
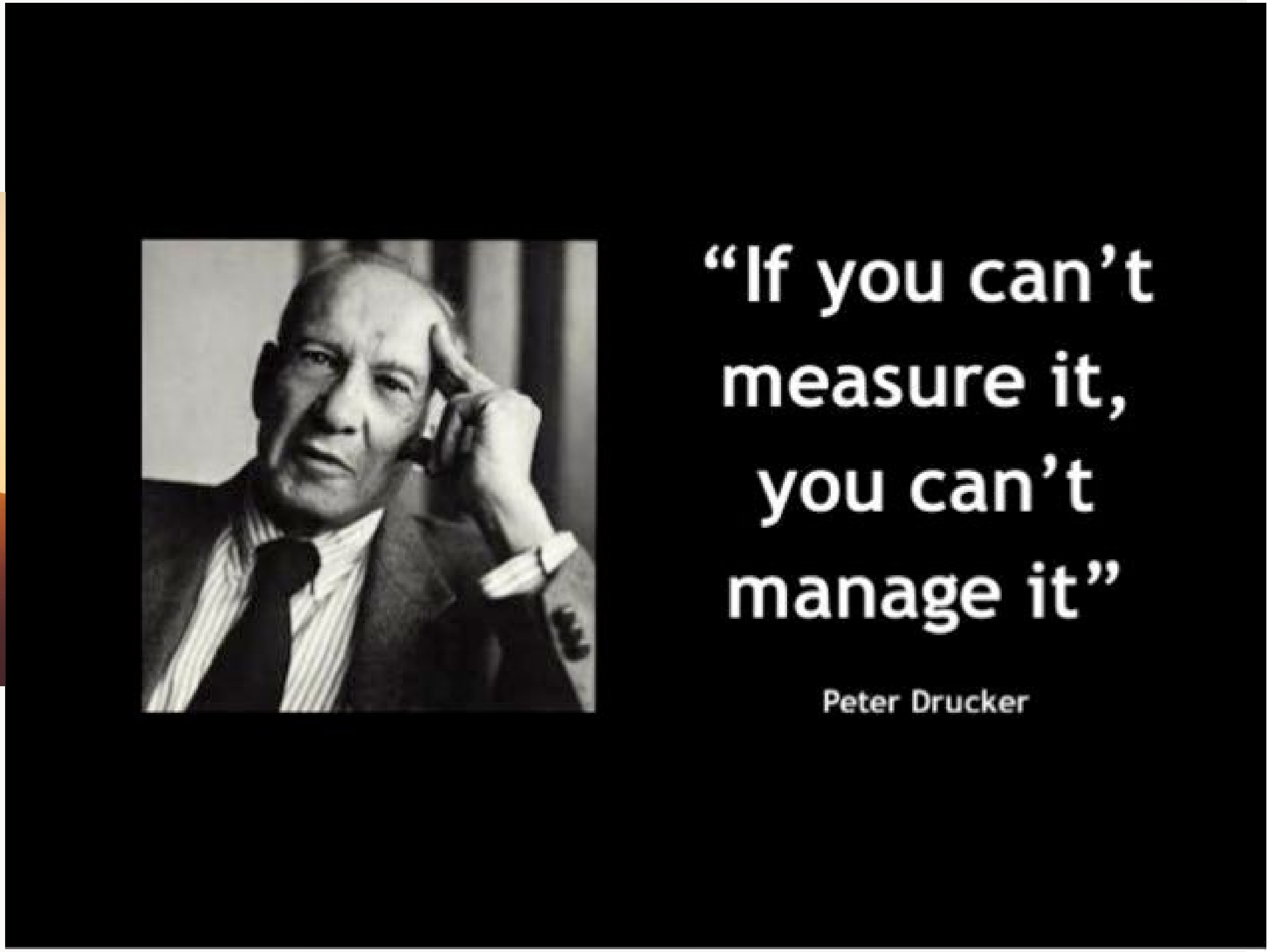

Some is not a number.
Soon is not a time.
Donald Berwick
quotefancy


~~Password123~~
"Hope is not a plan"
- Alex Singer


"If you can't measure it, you can't manage it"
Peter Drucker

GIGO = Garbage in Garbage Out and Bias

COMPUTING

Racial Bias Found in a Major Health Care Risk Algorithm

Black patients lose out on critical care when systems equate health needs with costs

By Starre Vartan on October 24, 2019

READ THIS NEXT

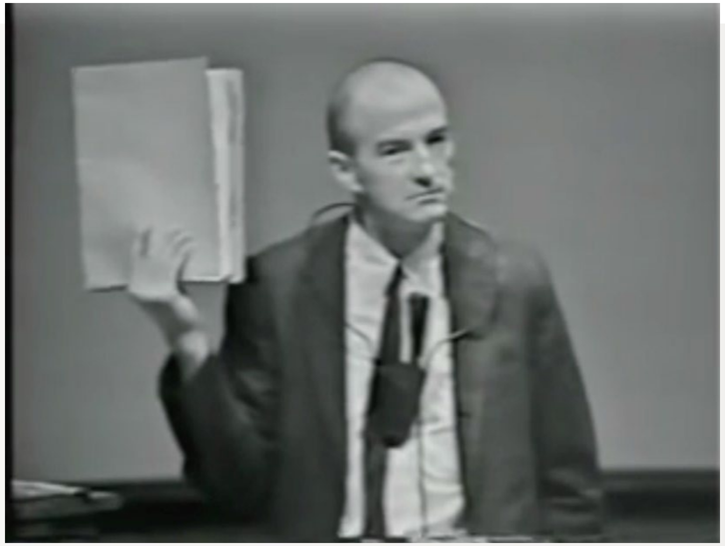
THE SCIENCES

Even Kids Can Understand That Algorithms Can Be Biased

Evelyn Lamb

- “If we accept the limits of discipline and form as we keep data in the medical record, the physician’s task will be better defined…”

- *“Coding is caring”*



MaPCReN
Manitoba Primary Care Research Network

Laurence Weed, 1968

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Practice Based Research and Learning Networks

POPLAR is a network of networks for primary care across Ontario.

It includes all six of the regional PBLNs in Ontario as well as the Alliance's EPIC PBLN.

POPLAR stands for *Primary Care Ontario Practice-Based Learning and Research.*

CPCSSN RCSSSP

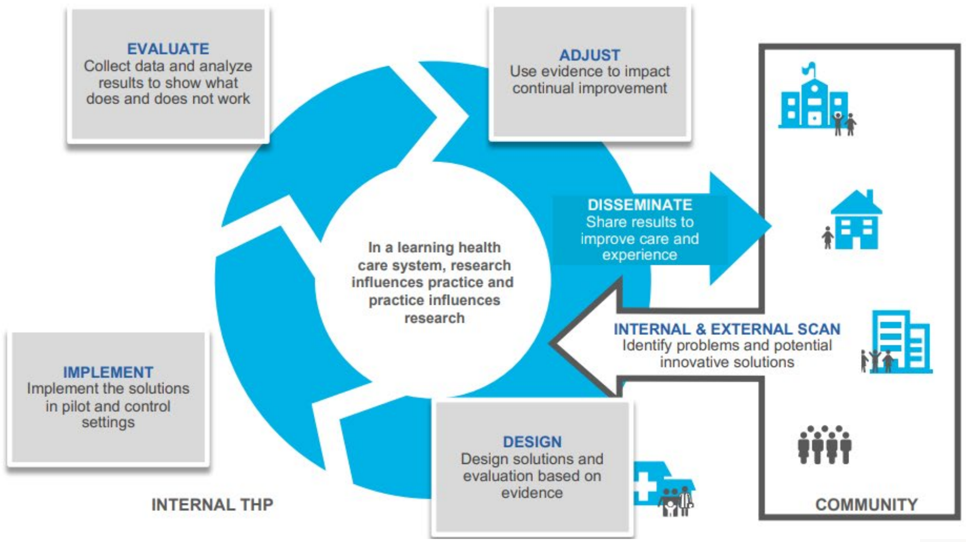
Canadian Primary Care Sentinel Surveillance Network

Réseau canadien de surveillance sentinelle en soins primaires

MaPCReN

Manitoba Primary Care Research Network

LEARNING HEALTH SYSTEM



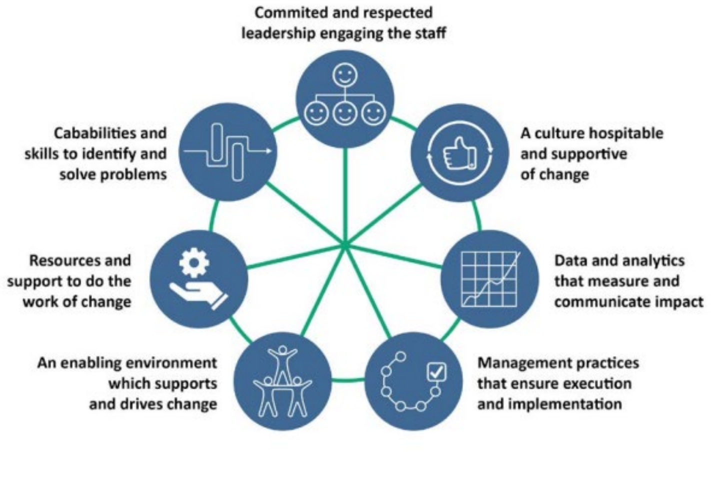
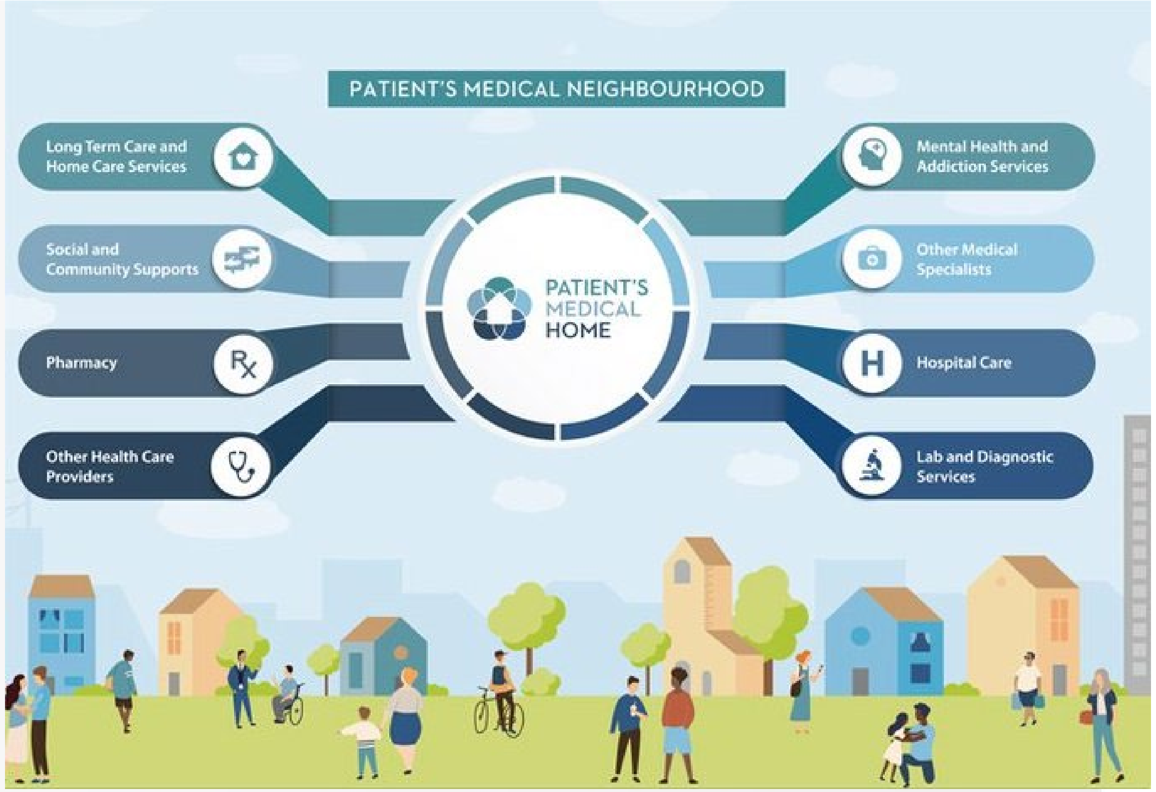


Figure 1. Seven success factors for change in the NHS. Reproduced from [39]

RESEARCH Open Access

Strategies for working across Canadian practice-based research and learning networks (PBRLNs) in primary care: focus on frailty

Manpreet Thandi[1*], Sabrina T. Wong[2], Sylvia Aponte-Hao[3], Mathew Grandy[4], Dee Mangin[5], Alexander Singer[6] and Tyler Williamson[7]



Allcock, C., et al., Constructive comfort: accelerating change in the NHS. 2015, The Health Foundation: London

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PBRLN's role in Patient Risk Factors and Social Determinants of Health

1. Measuring behavioural risk factors
2. Using surrogate measures to understand social determinants of health and inequities health outcomes
3. Contribute to Learning Health Systems in order to address underlying inequalities to build cultures of quality improvement

Behavioural Risk Factors:
Tobacco, Alcohol, Substance Use

ARTICLE IN PRESS

Are We Asking Patients if They Smoke?

Missing Information on Tobacco Use in Canadian Electronic Medical Records

Michelle Greiver, MD, Babak Aliarzadeh, MD, Christopher Meaney, MSc, Rahim Moineddin, PhD, Chris A. Southgate, BA, David T.S. Barber, MD, David G. White, MD, Ken B. Martin, MSc, Tabassum Ikhtiar, MD, Tyler Williamson, PhD

Contents lists available at ScienceDirect

Preventive Medicine Reports

journal homepage: www.elsevier.com/locate/pmedr

ELSEVIER

PMR Preventive Medicine Reports

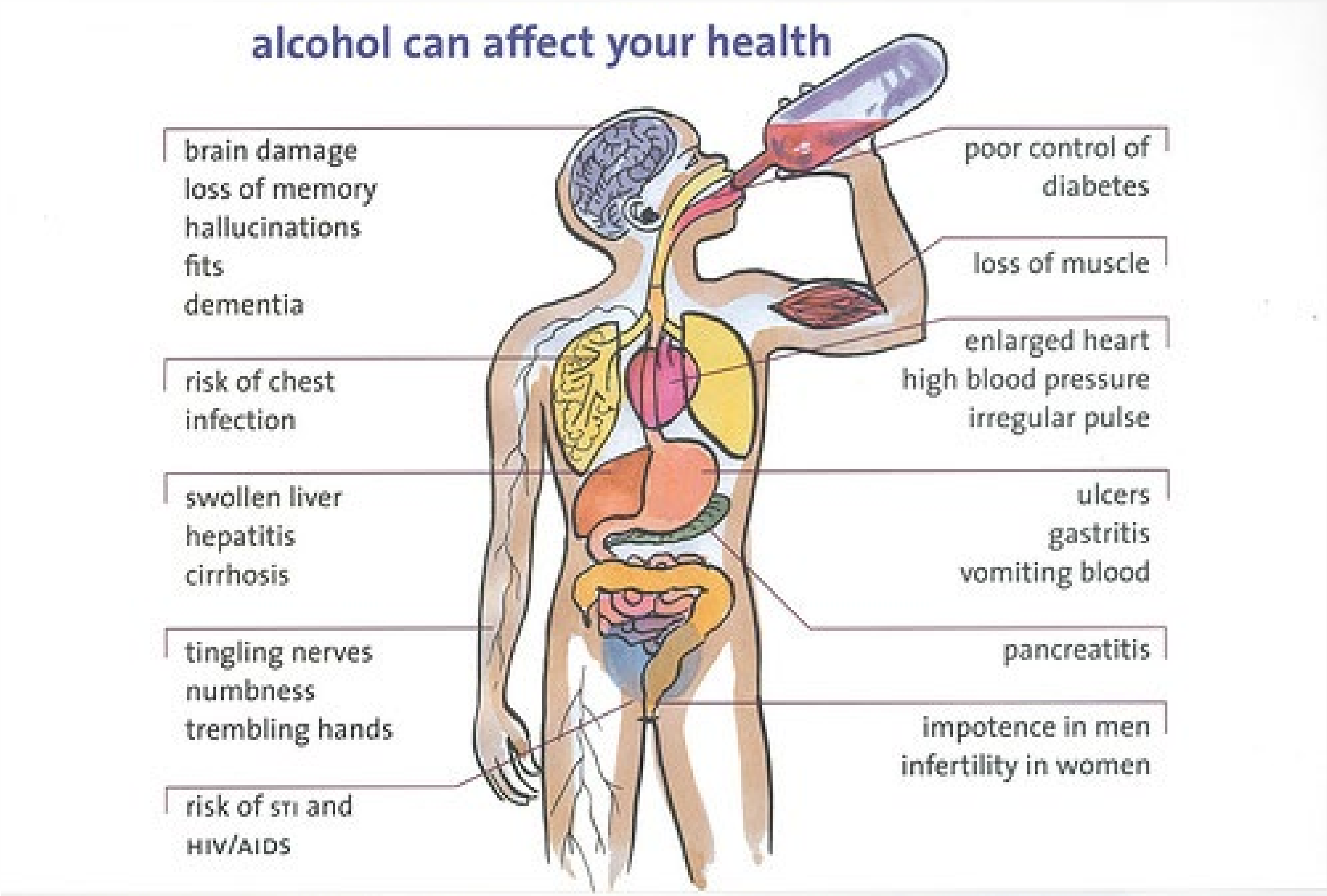
Who is asked about alcohol consumption? A retrospective cohort study using a national repository of Electronic Medical Records

Alexander Singer [a,*], Leanne Kosowan [a], Shilpa Loewen [a], Sheryl Spithoff [b], Michelle Greiver [b], Joanna Lynch [a]

[a] Max Rady College of Medicine, Rady Faculty of Health Sciences, University of Manitoba, Winnipeg, Manitoba, Canada
[b] Department of Family and Community Medicine, University of Toronto, Toronto, Ontario, Canada

Why Record Alcohol Consumption in EMR?

- Contributed to 7.7% of Canadian deaths in 2005
- Associated with major medical comorbidities
- What’s the use of recording alcohol consumption?
  - Track patient’s alcohol use screening history
  - Offer appropriate programs and additional care
  - Target patients who could benefit from a more organized approach to prevent alcohol dependence or reduce alcohol use


alcohol can affect your health
brain damage
loss of memory
hallucinations
fits
dementia
risk of chest
infection
swollen liver
hepatitis
cirrhosis
tingling nerves
numbness
trembling hands
risk of STI and
HIV/AIDS
poor control of
diabetes
loss of muscle
enlarged heart
high blood pressure
irregular pulse
ulcers
gastritis
vomiting blood
pancreatitis
impotence in men
infertility in women

Who gets asked about alcohol?

- Only 40.6% of patients had their alcohol use documented
- More commonly documented in males, older age, patients who saw their PCP more often (>3 visits per year), some comorbid conditions (hypertension, depression), heavy consumption
  - All moderate increases in odds ratios (1-3X)

Singer A, Kosowan L, Loewen S, Spitoff S, Greiver M, Lynch J. Who is asked about alcohol consumption? A retrospective cohort study using a national repository of Electronic Medical Records. Prev Med Rep. 2021 Mar 9;22:101346. doi: 10.1016/j.pmedr.2021.101346. PMID: 33767948

But EMR data is not clean…

No EtOH, Occasional ETOH, alchol use disorder, binge drinking, binge drinker, bnge drunker, drinks 5 units per day, drinks 5/u p/d, binge drnks on weekend, 2 beers per day – more on the wknd, 10-12 units of alcohol per week, hepatits related to etoh use, hepatititis 2ndary to alcohol use disorder, hipititis related to etoh, tx for alc use disorder now abstint

Data cleaning example : medication table

EMR Text	Cleaned Text	ATC Code
(Polytrim) drops 1 drop qhourly today then reduce to QID tomorrow	Combinations of Different Antibiotics	S01AA30
PERCOCET (Tabs) Sig 1 tab(s) Oral PRN if migraine Quantity 25 tab(s)	Oxycodone and Paracetamol	N02AJ17
TOUJEO SOLOSTAR 300 UNIT/ML (300/ML)	Insulin Glargine	A10AE04

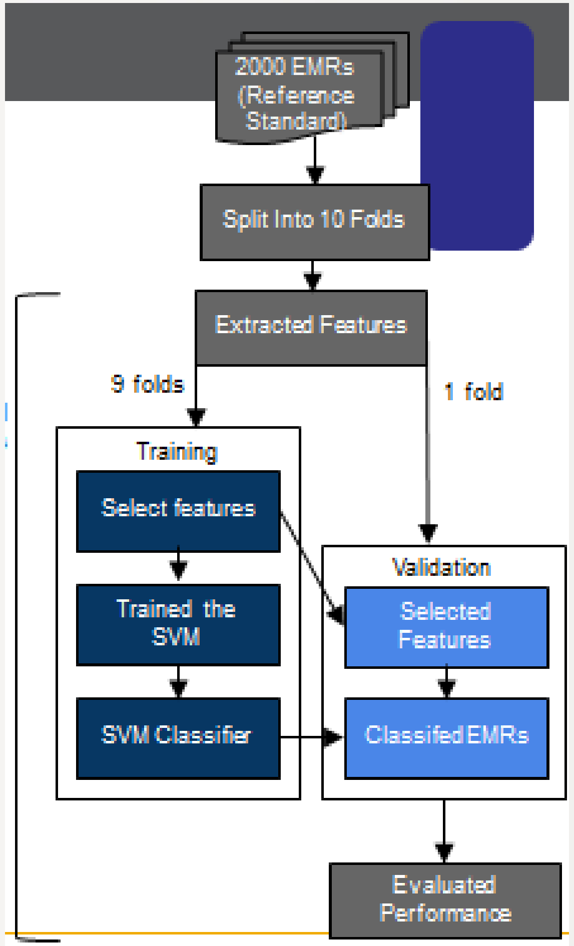
CPCSSN RCSSSP

Canadian Primary Care Sentinel Surveillance Network

Réseau canadien de surveillance sentinelle en soins primaires

Natural Language Processing: Methods

1. Extracted data
2. Develop reference standard
   - Agreement and consensus of clinical experts
3. Apply reference standard
4. Train and validate classification algorithm
   - Bag-of-Words model
     - Unigrams (i.e single word) and Bigrams (i.e. pairs of words)
     - Text processed into suitable form



Singer A, Kosowan L, Loewen S, Spitoff S, Greiver M, Lynch J. Who is asked about alcohol consumption? A retrospective cohort study using a national repository of Electronic Medical Records. Prev Med Rep. 2021 Mar 9;22:101346. doi: 10.1016/j.pmedr.2021.101346. PMID: 33767948

Natural Language Processing: Results

Table 1

Documentations of Alcohol Use in the Electronic Medical Record of CPCSSN participating primary care providers.

Alcohol category	Percent (n)
Non-drinker	21.4% (57,712)
Light	43.6% (117,779)
Moderate	30.4% (82,178)
Heavy	3.0% (8088)
Past	1.7% (4519)
Total*	270,276

*There were 13,992 patients with documentation of alcohol in the EMR that were not classified (i.e. record focused on family history, health conditions or did not specific an amount).

Singer A, Kosowan L, Loewen S, Spitoff S, Greiver M, Lynch J. Who is asked about alcohol consumption? A retrospective cohort study using a national repository of Electronic Medical Records. Prev Med Rep. 2021 Mar 9;22:101346. doi: 10.1016/j.pmedr.2021.101346. PMID: 33767948

Who gets asked about Substance Use Disorders?

Substance Use…

- Dataset from 2020Q4, considered patients with substance use ICD9 codes, substance use documented in the risk factor table, and substance use in encounter notes
- Two medical students reviewed drug use documentation in the risk factor table
  - Categorized using drug type (using DSM categories).
  - Agreement compared – some disparity particularly for status (i.e. high risk, moderate, occasional, past).
- Work underway to improve our processing algorithms and analyze treatment/management plan documentation (if offered/declined, etc.)

MaPCReN Patients
N=289,000

Active MaPCReN Patients (i.e. appointment in the last 2 years January 1, 2018-January 1, 2020)

N=191,331

Patients with substance use documented in Risk Factor Table

N=48,957

Type of substance (current use) in risk factor table

Alcohol = 29,799

Tobacco = 33,873

Drug = 10,934

Patients with substance use

ICD-9 code

N=9,465

Type of substance in ICD-9 code

Alcohol = 3,002

Tobacco = 4,376

Drug = 3,152

Current and Future State

- Example of automated detection of substance use using NLP
- Use of postal codes to derive SDOH from census data
- Aspirational integration into digital record systems

Research and Applications

Automated detection of substance use information from electronic health records for a pediatric population

Yizhao Ni,[1,2] Alycia Bachtel,[1] Katie Nause,[3] and Sarah Beal[2,3]

[1]Division of Biomedical Informatics, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA, [2]Department of Pediatrics, College of Medicine, University of Cincinnati, Cincinnati, Ohio, USA, and [3]Division of Psychology, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, USA

Yizhao Ni, Alycia Bachtel, Katie Nause, Sarah Beal, Automated detection of substance use information from electronic health records for a pediatric population, *Journal of the American Medical Informatics Association*, Volume 28, Issue 10, October 2021, Pages 2116–212

Automated Detection of substance use info in a pediatric population

- Developed an automated substance use detection system (ASUDS) to identify substance use information using structured EHR data and unstructured clinical narratives from a pediatric population and setting.
- The analysis suggested that structured EHR data only documented 22.0% of screening results, consistent with the literature.
- Use of logic rule matcher (LRM) achieved close to perfect performance, NLP was also very good and added large volume of data not captured in structured form
  - Rules might need customization when applied to additional institutions
- 121,656 encounters in EHRs, 19,478 (16.0%) encounters had screening information and 11,063 (9.1%) encounters had documented substance use information.
  - Higher proportion of females were screened (16.2% female vs 15.4% male)
  - Higher proportion of BIPOC participants were screened (16.1% BIPOC vs 15.5% White).

Yizhao Ni, Alycia Bachtel, Katie Nause, Sarah Beal, Automated detection of substance use information from electronic health records for a pediatric population, *Journal of the American Medical Informatics Association*, Volume 28, Issue 10, October 2021, Pages 2116–212

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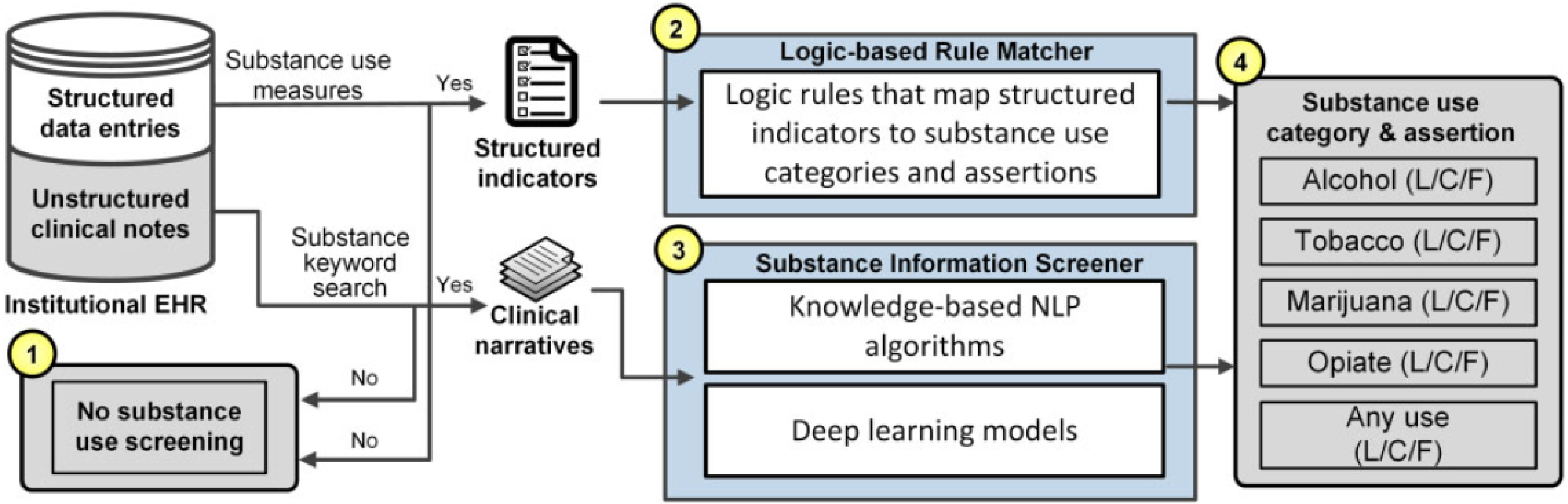

Figure 1. An overview of the automated substance use screening system. C: current; EHR: electronic health record; F: family use; L: lifetime; NLP: natural language processing.

Yizhao Ni, Alycia Bachtel, Katie Nause, Sarah Beal, Automated detection of substance use information from electronic health records for a pediatric population, *Journal of the American Medical Informatics Association*, Volume 28, Issue 10, October 2021, Pages 2116–212

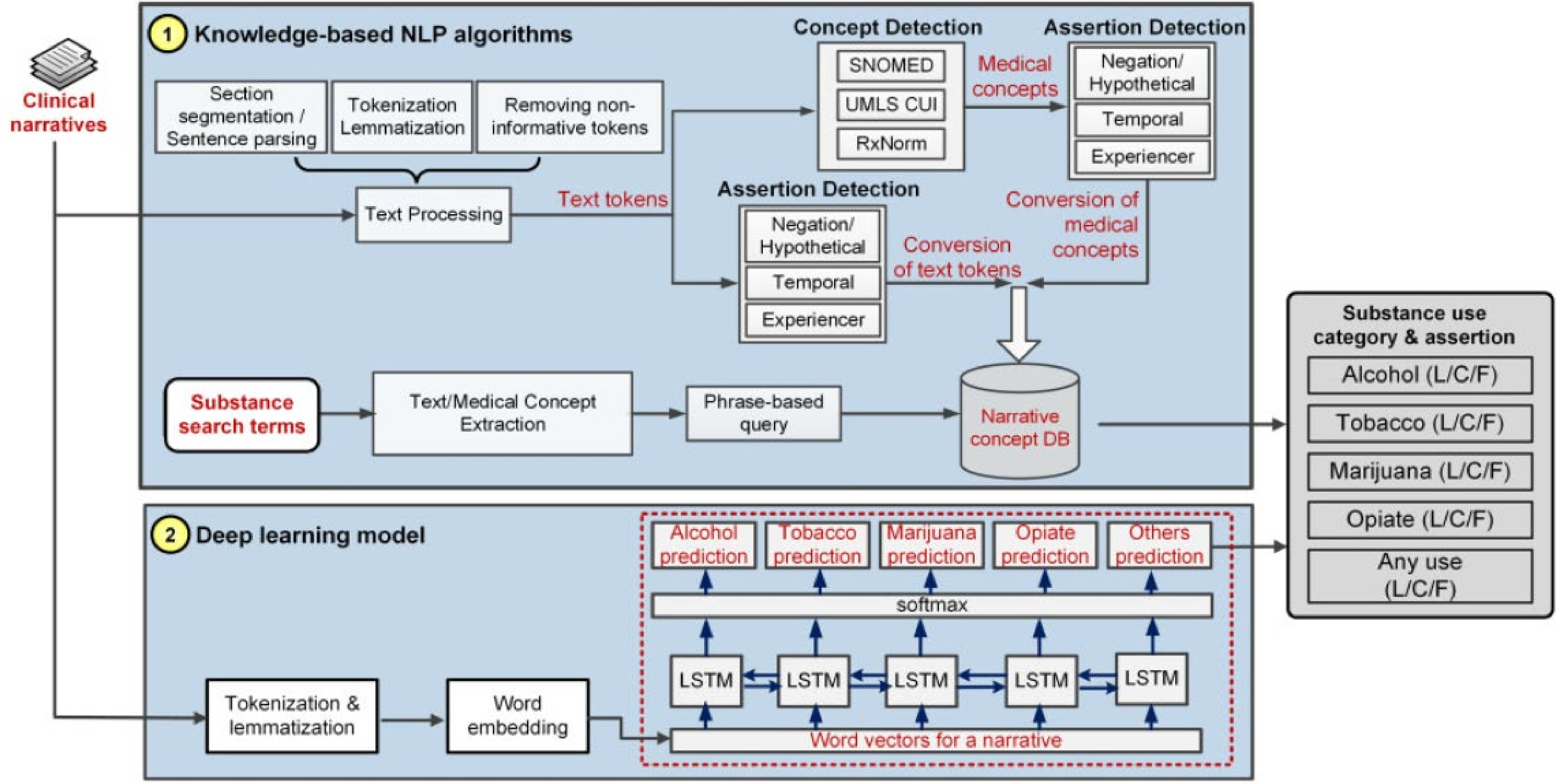

Figure 2. An overview of the substance information screener. C: current; CUI: concept unique identifier; F: family use; L: lifetime; LSTM: long-short term memory; RxNorm: normalized names for clinical drugs; SNOMED: Systematized Nomenclature of Medicine Clinical Terms; UMLS: Unified Medical Language System.

Table 2. Numbers of encounters with substance use information documented in structured indicators and clinical notes

Category	Structured indicators			Clinical notes			Total		
	Lifetime	Current	Family	Lifetime	Current	Family	Lifetime	Current	Family
Alcohol	434	311	0[a]	1740	1315	3702	1817	1387	3702
Marijuana	1108	916	0[a]	3406	2765	264	3596	2953	264
Opiates	67	61	0	123	99	164	171	145	164
Tobacco	1015	858	0	2729	2234	796	3094	2605	796
Any use	2143	1840	0	5881	5095	7135	6402	5618	7135
Total	4767	3986	0	13 879	11 508	12 061	15 080	12 708	12 061

[a]16 (0.4%) subjects had indicators of fetal drug exposure (fetal alcohol syndrome, neonatal abstinence syndrome) in structured problem lists, indicating potential maternal drug use. These indications were patient/family reported and were not companied by any encounter diagnoses made by clinicians. For that reason, they were excluded from the analysis.

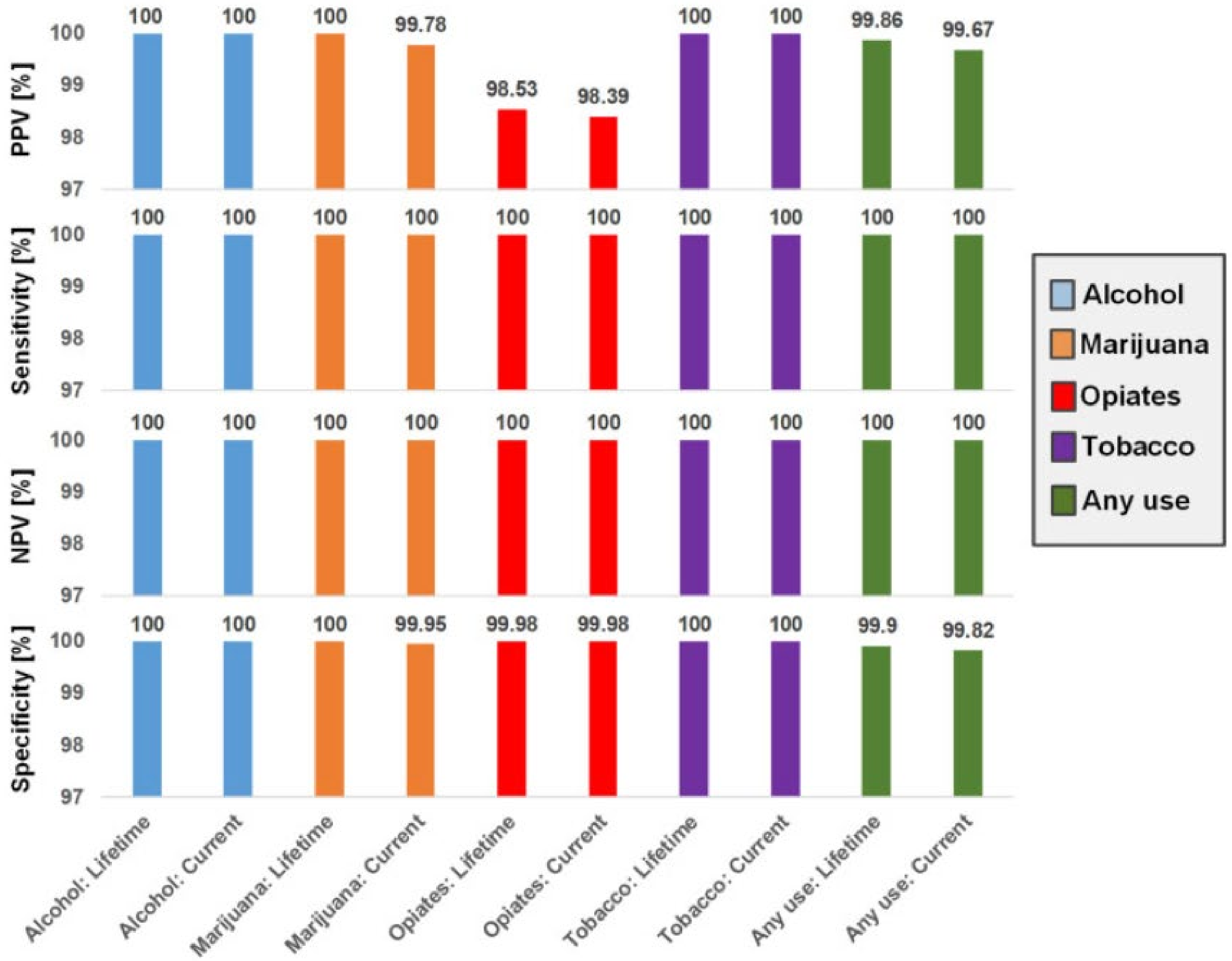

Figure 3. Performance of the logic-based rule matcher in classifying structured indicators. Note that the structured indicators did not contain assertion of family use. The logic-based rule matcher generated determinate classification rather than probabilistic predictions; therefore, we did not report area under the receiver-operating characteristic curve in the evaluation. NPV: negative predictive value; PPV: positive predictive value.

Yizhao Ni, Alycia Bachtel, Katie Nause, Sarah Beal, Automated detection of substance use information from electronic health records for a pediatric population, *Journal of the American Medical Informatics Association*, Volume 28, Issue 10, October 2021, Pages 2116–212

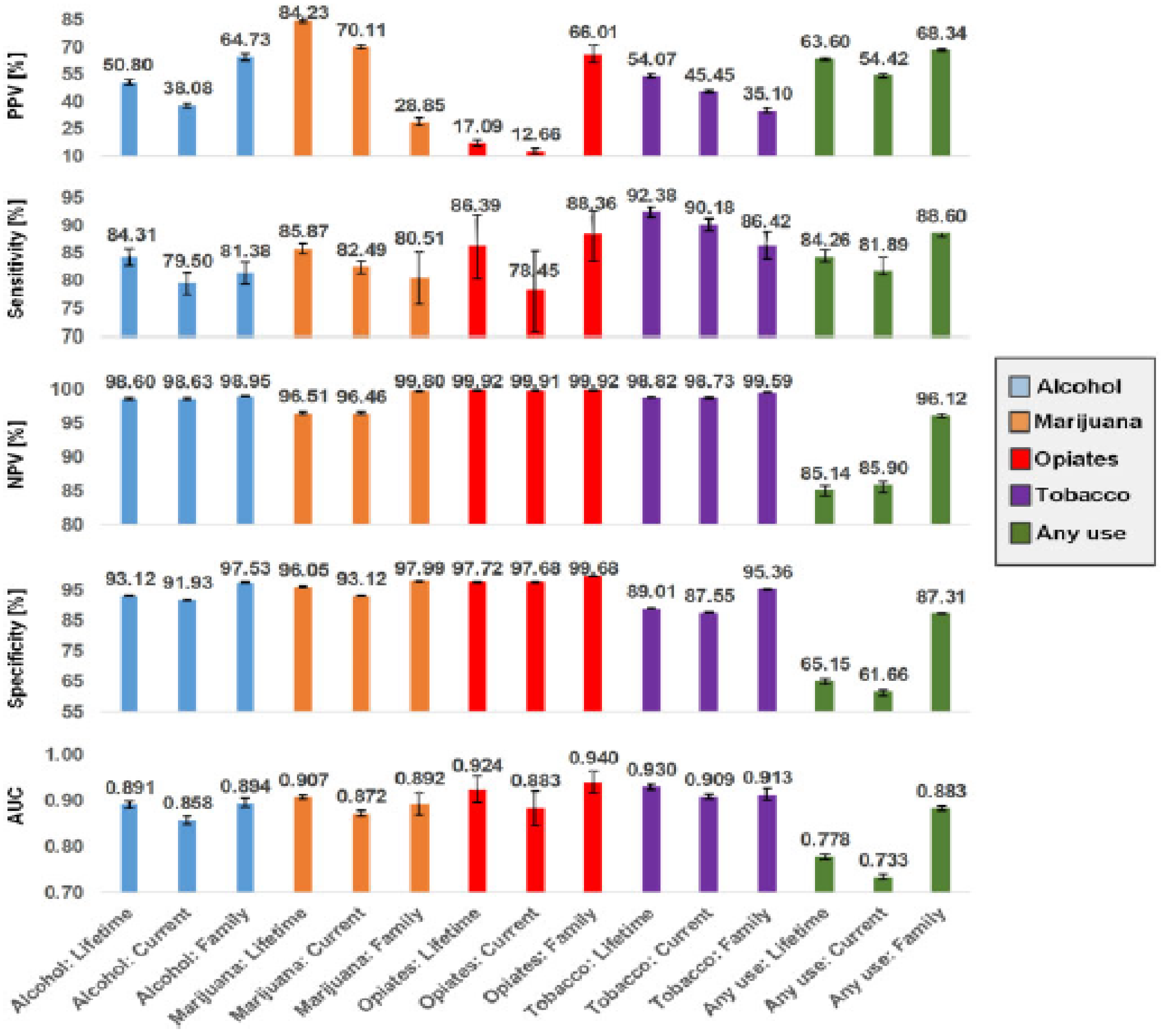

Figure 4. Performance of the knowledge-based natural language processing system in detecting substance use categories and assertions on individual clinical narratives. Error bars indicate 95% confidence intervals. AUC: area under the receiver-operating characteristic curve; NPV: negative predictive value; PPV: positive predictive value.

Yizhao Ni, Alycia Bachtel, Katie Nause, Sarah Beal, Automated detection of substance use information from electronic health records for a pediatric population, *Journal of the American Medical Informatics Association*, Volume 28, Issue 10, October 2021, Pages 2116–212

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Review

Extracting social determinants of health from electronic health records using natural language processing: a systematic review

Braja G. Patra,[1] Mohit M. Sharma,[1] Veer Vekaria,[1] Prakash Adekkanattu,[2] Olga V. Patterson,[3,4] Benjamin Glicksberg,[5] Lauren A. Lepow,[5] Euijung Ryu,[6] Joanna M. Biernacka,[6] Al'ona Furmanchuk,[7] Thomas J. George,[8] William Hogan,[9] Yonghui Wu,[8] Xi Yang,[8] Jiang Bian,[8] Myrna Weissman,[10] Priya Wickramaratne,[10] J. John Mann,[10] Mark Olfson,[10] Thomas R. Campion Jr,[1,2] Mark Weiner,[1] and Jyotishman Pathak[1]

Measuring SDOH by indices

- Growth, Pediatric hypertension, CKD and PTSD

ARTICLE IN PRESS
KI REPORTS
KIReports.org
CLINICAL RESEARCH

Prevalence and Demographics of CKD in Canadian Primary Care Practices: A Cross-sectional Study

Aminu K. Bello[1], Paul E. Ronksley[2], Navdeep Tangri[3], Julia Kurzawa[1], Mohamed A. Osman[1], Alexander Singer[4], Allan Grill[5], Dorothea Nitsch[6], John A. Queenan[7], James Wick[8], Cliff Lindeman[9], Boglarka Soos[2,10], Delphine S. Tuot[11,12], Soroush Shojai[1], Scott Brimble[13], Dee Mangin[14] and Neil Drummond[2,9,10]

Paediatrics & Child Health, 2021, 1–9
https://doi.org/10.1093/pch/pxab081
Original Article
OXFORD

Original Article

Pediatric hypertension screening and recognition in primary care clinics in Canada

Linda Ding MD[1,2], Alexander Singer MD[1,3], Leanne Kosowan MSc[1,3], Allison Dart MD MSc[1]

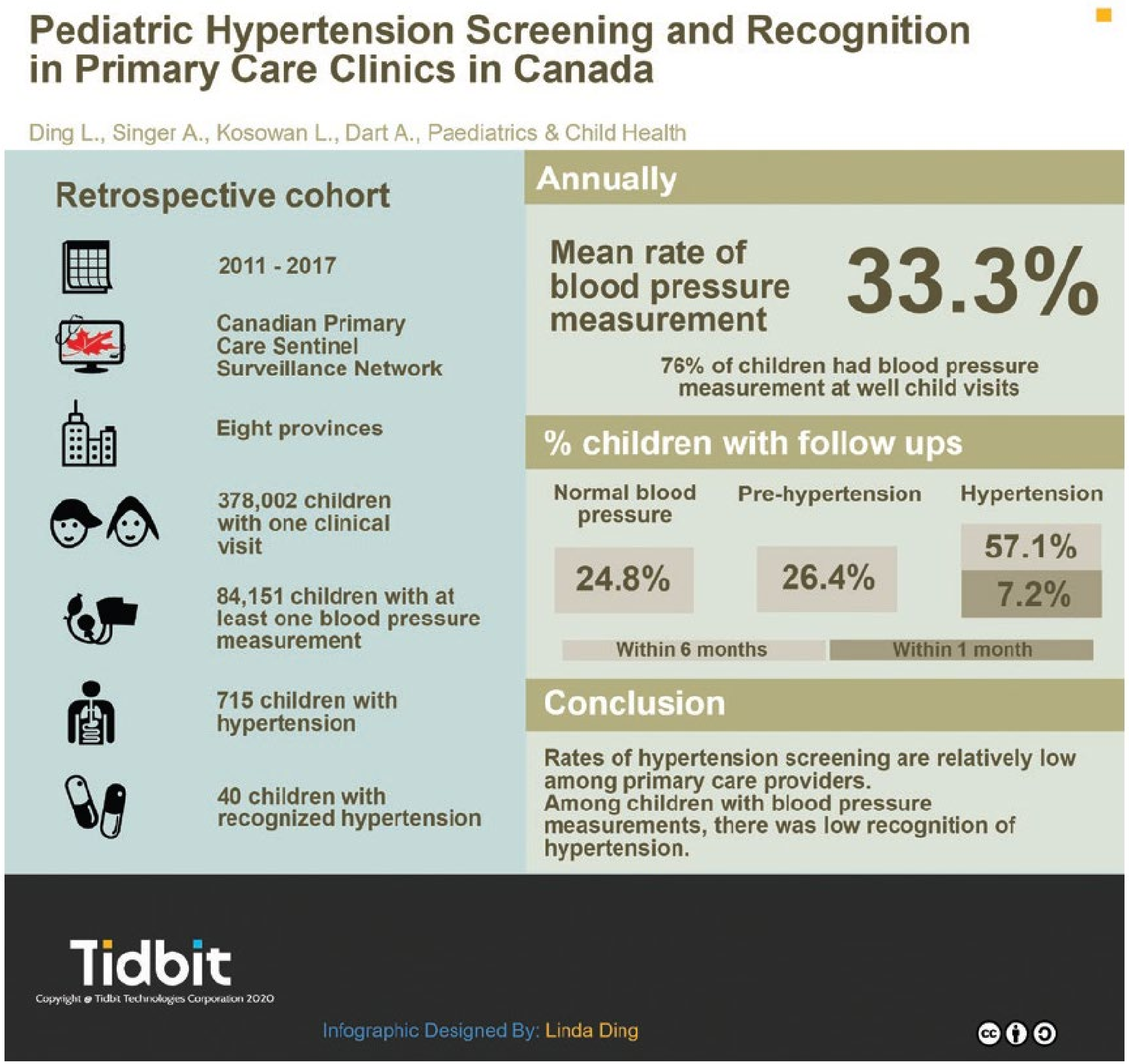
[1]Department of Pediatrics and Child Health, Max Rady College of Medicine, University of Manitoba, Winnipeg, Manitoba, Canada; [2]Department of Pediatrics, Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada; [3]Department of Family Medicine, Max Rady College of Medicine, University of Manitoba, Winnipeg, Manitoba, Canada

Correspondence: Linda Ding, 4480 Oak Street, Room K4-153 BC Children's Hospital, Nephrology Vancouver, British Columbia V6H 3V4, Canada. Telephone 403-680-9569, e-mail linda.ding@cw.bc.ca

RESEARCH ARTICLE Open Access

Characteristics associated with pediatric growth measurement collection in electronic medical records: a retrospective observational study

Leanne Kosowan[1], John Page[2], Jennifer Protudjer[3], Tyler Williamson[4], John Queenan[5] and Alexander Singer[1*]



Ding L, Singer A, Kosowan L, Dart A. *Pediatric hypertension screening and recognition in primary care clinics in Canada*. Paediatrics & Child Health. Oct 2021.

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Children with hypertension

Table 1. Characteristics of Canadian children with high blood pressure (HBP) and normal blood pressure (BP).

	Normal Blood Pressure	High Blood Pressure	
Variable	N=79316	N=6571	P-value
Sex (% male)	48.2	55.1	<0.001
Age at first BP measurement in years (mean, SD)	10.8 $\pm$ 4.7	10.6 $\pm$ 4.5	<0.0001
Age categories for HBP (%)			
0-5 years		13.6	
6-12 years		35.8	
13-18 years		50.6	
Combined Material/Social Deprivation Quintile (%)			
Quintile 1 (least deprived)	23.4	25. 8	<0.001
Quintile 2	26.0	25.0	
Quintile 3	19.5	17.2	
Quintile 4	15.2	14.1	
Quintile 5 (most deprived)	15.9	17.9	
BMI z-score (mean, SD)	0.2 $\pm$ 1.1	0.7 $\pm$ 1.1	<0.0001
BMI >30 (%)	20.5	36.9	<0.0001
Urban (vs rural) clinic (%)	94.6	93.9	<0.0001
Diabetes (%)	0.5	1.4	<0.0001
Depression (%)	5.1	7.5	<0.0001

Ding L, Singer A, Kosowan L, Dart A. *Pediatric hypertension screening and recognition in primary care clinics in Canada*. Paediatrics & Child Health. Oct 2021.

Social and Material Deprivation Indices

- **Social Deprivation Index** - reflects the deprivation of relationships among individuals in the family, the workplace, and the community. This index includes the following indicators: proportion of the population separated, divorced, or widowed; proportion of the population that lives alone; and proportion of the population that has moved in the past five years.

- **Material Deprivation Index** - reflects the deprivation of goods and conveniences. This index includes the following indicators: average household income; unemployment rate; and high school education rate (Pampalon and Raymond, 2000).

http://mchp-appserv.cpe.umanitoba.ca/viewConcept.php?conceptID=1415

Not all "deprivation" has the same effect

Table 2. Sex stratified regression analyses evaluating association between high BP and clinical characteristics (univariate, and corrected for age, BMI z-score and combined deprivation score). All deprivation scores compare the most deprived quintile to the least deprived quintile.

	Females N=43,979		Males N=41,836	
	OR (95%CI)	Adjusted OR (95%CI)	OR (95% CI)	Adjusted OR (95%CI)
Age at 1st bp	0.984 (0.977-0.992)	0.957 (0.941-0.974)	0.997 (0.989-1.004)	0.971 (0.955-0.987)
BMI z-score	1.461 (1.406-1.515)	1.475 (1.362-1.598)	1.429 (1.383-1.476)	1.505 (1.407-1.61)
Combined Deprivation	1.019 (0.878-1.182)		0.954 (0.832-1.094)	
Material Deprivation	1.056 (0.905-1.232)	0.936 (0.794-1.103)	**1.184 (1.031-1.360)**	1.063 (0.918-1.231)
Social Deprivation	0.983 (0.838-1.153)		1.031 (0.891-1.192)	

Ding L, Singer A, Kosowan L, Dart A. *Pediatric hypertension screening and recognition in primary care clinics in Canada*. Paediatrics & Child Health. Oct 2021.

Adult Chronic Kidney Disease and Deprivation Scores

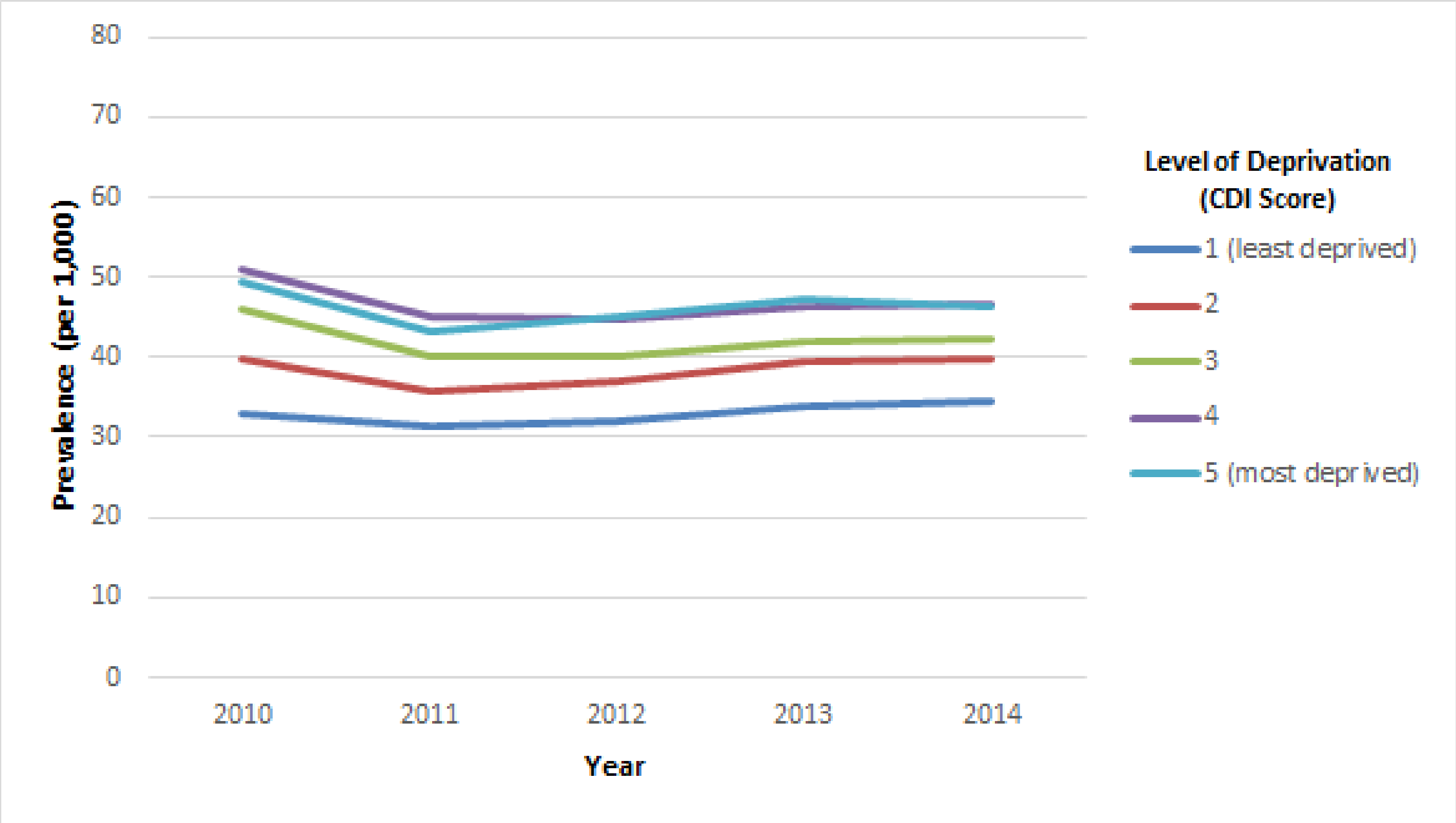


Figure 4. (a) Period prevalence of chronic kidney disease (CKD) by year and deprivation index. Level of deprivation of Canadian Deprivation Index score: 1 (least deprived), dark blue; 2, red; 3, green; 4, purple; 5 (most deprived), light blue. (b) Period prevalence of CKD by year and urban/rural residence. Participant residence: urban (blue); rural (red).

Bello AK, Ronksley PE, Tangri N, Kurzawa J, Osman MA, Singer A, Grill A, Nitsch D, Queenan JA, Wick J, Lindeman C, Soos B, Tuot DS, Shojai S, Brimble S, Mangin D, Drummond N. Prevalence and Demographics of CKD in Canadian Primary Care Practices: A Cross-sectional Study. Kidney Int Rep. 2019 Jan 21;4(4):561-570. doi: 10.1016/j.ekir.2019.01.005. PMID: 30993231; PMCID: PMC6451150.

Post Traumatic Stress Disorder (PTSD)

- Same pattern as CKD in term of the impact of social and material deprivation on prevalence

- Demonstrated in cohort within the Canadian Primary Care Sentinel Surveillance Network

- Cohort evaluated of 689,000 patients from across Canada

Singer A, Kosowan L, Muthumuni D, Katz A, Zafari H, Zulkernine F, Richardson JD, Price M, Williamson T, Queenan J, Sareen J. Characterizing primary care patients with posttraumatic stress disorder using electronic medical records: a retrospective cross-sectional study. *Under Review* Family Practice.

Material and Social Deprivation and PTSD

Table1: Characteristics of patients with and without PTSD N=689,301			
Variable	Patients without PTSD	Patients with PTSD	P-value
Urban (No., %) vs rural residency	510,755 (80.4%)	6,804 (85.2%)	<.001
Material Social Deprivation Index[a], No. (%)			
Q1 (least deprived)	9458 (18.0%)	68 (6.2%)	<.001
Q2	10,067 (19.1%)	104 (9.4%)	
Q3	13,266 (25.2%)	278 (25.2%)	
Q4	9,537 (18.1%)	245 (22.2%)	
Q5 (most deprived)	10,293 (19.6%)	409 (37.1%)	
Annual visit frequency, mean (SD)	2.8 (3.4)	4.8 (5.0)	<.001

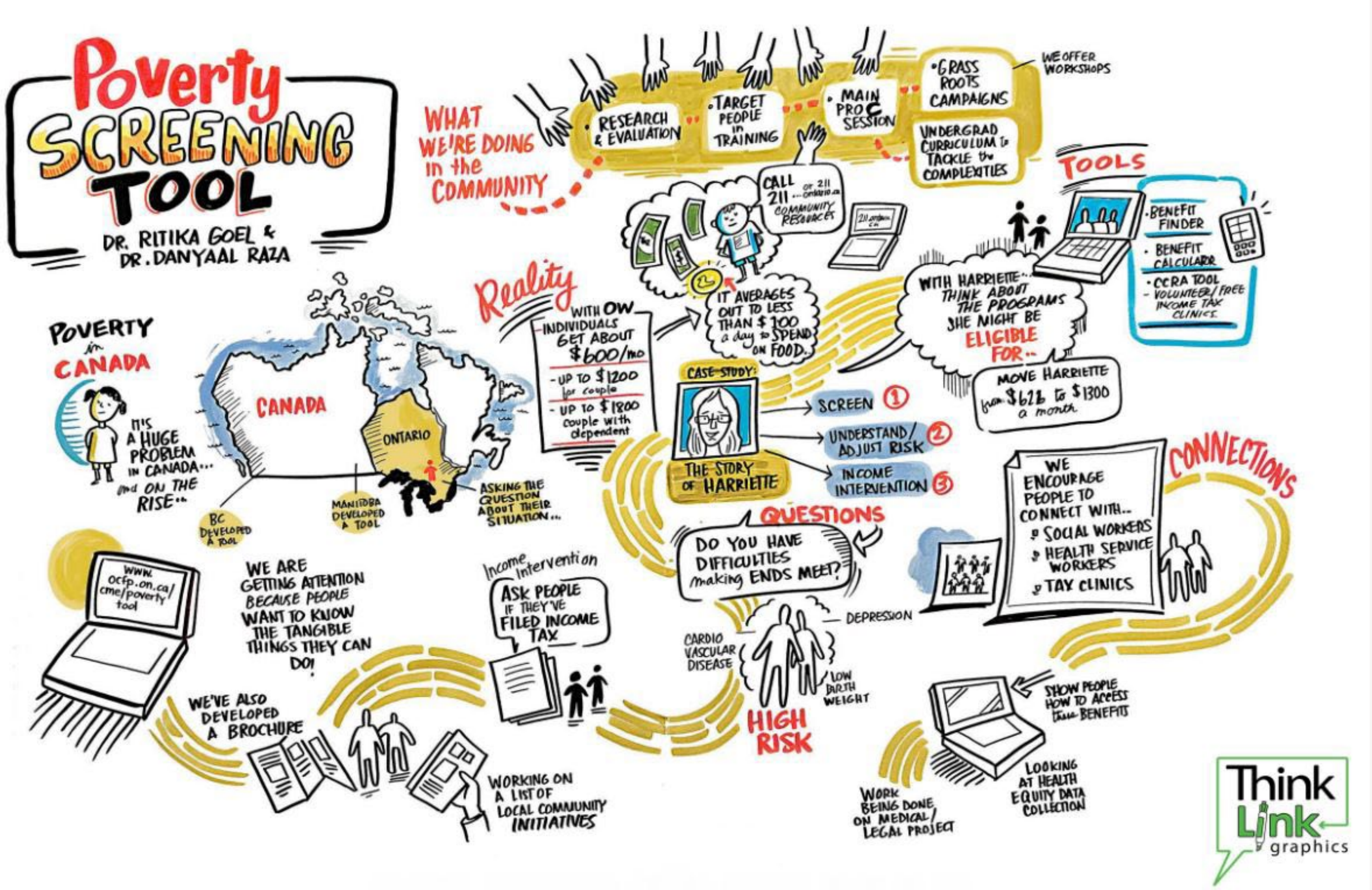
Singer A, Kosowan L, Muthumuni D, Katz A, Zafari H, Zulkernine F, Richardson JD, Price M, Williamson T, Queenan J, Sareen J. Characterizing primary care patients with posttraumatic stress disorder using electronic medical records: a retrospective cross-sectional study. *Under Review* Family Practice.

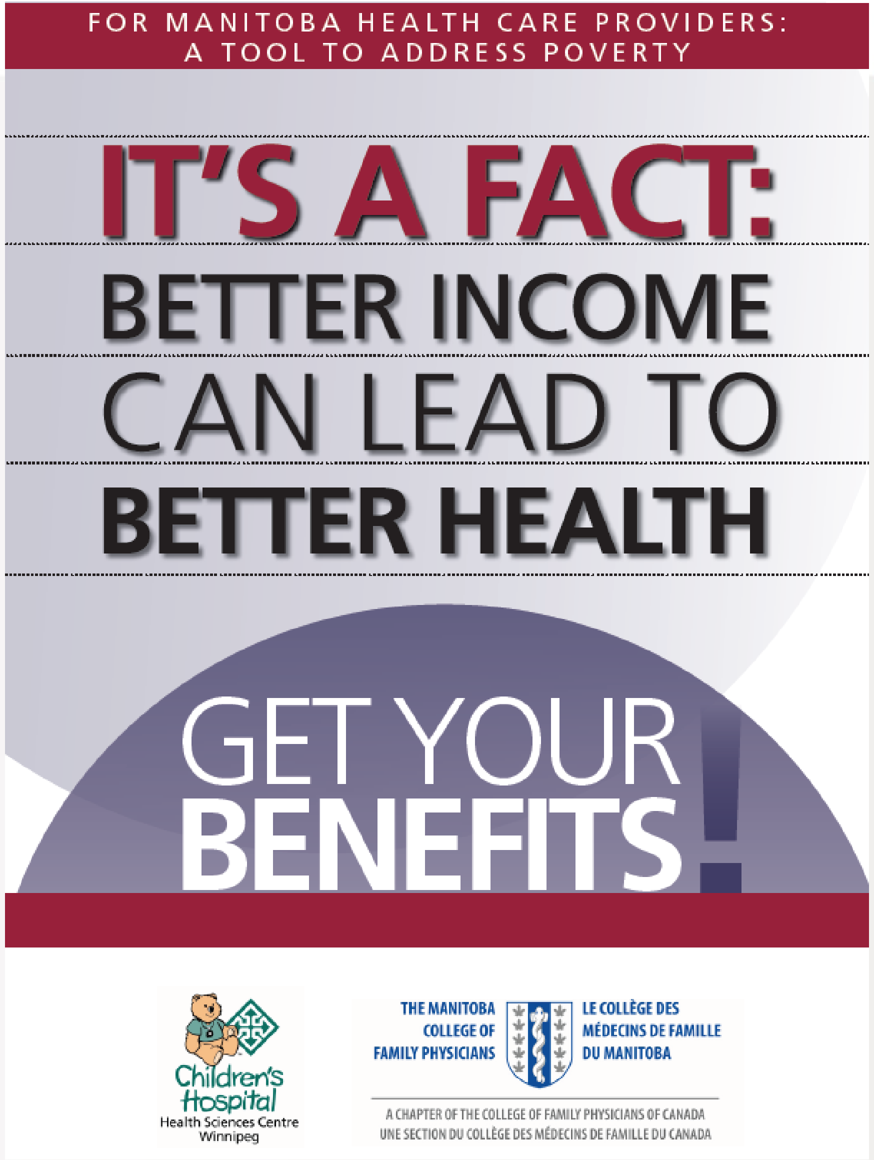
Odds Ratios for Impact of Deprivation on PTSD

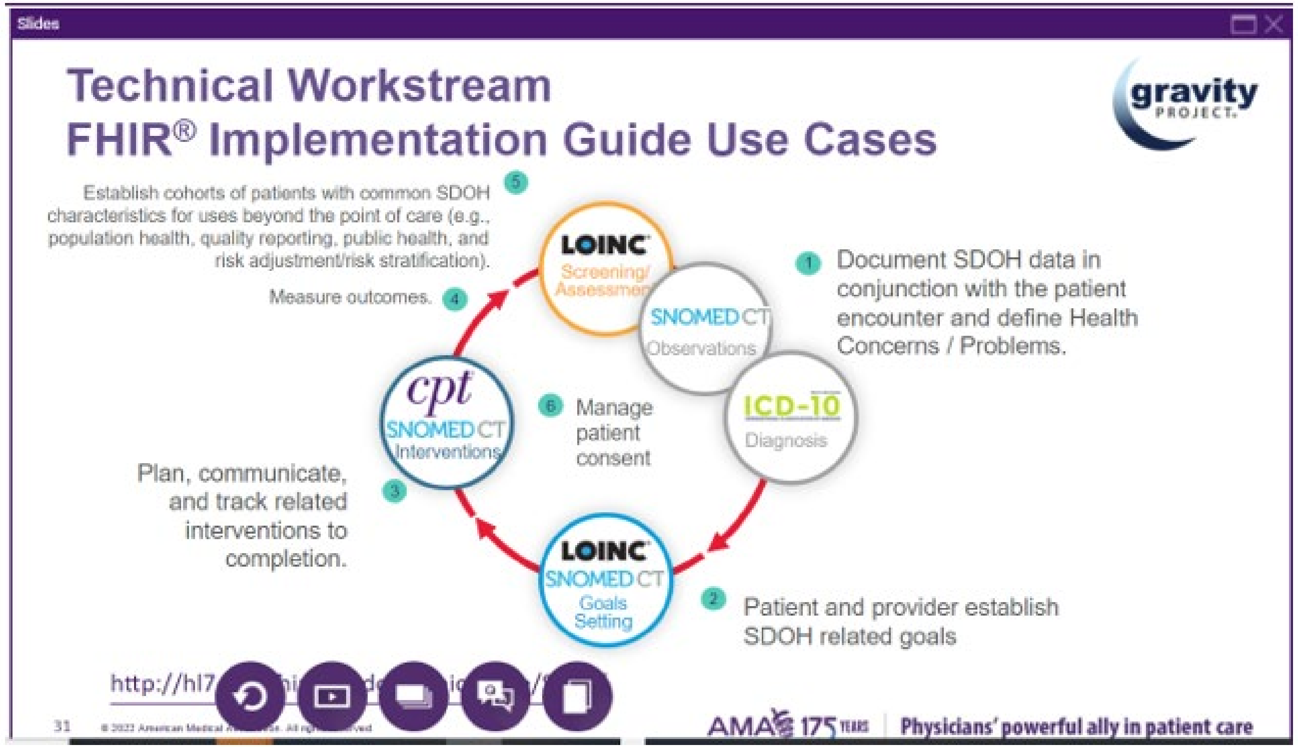
	Adjusted Odds Ratio
Material deprivation	
5 (most deprived) vs. 1 (least deprived)	2.1, 1.45-2.06
4 vs. 1 (least deprived)	1.31, 1.07-1.61
3 vs. 1 (least deprived)	1.1, 0.9-1.34
2 vs. 1 (least deprived)	0.91, 0.74-1.12
Social deprivation	
5 (most deprived) vs. 1 (least deprived)	3.78, 2.72-5.25
4 vs. 1 (least deprived)	2.37, 1.69-3.33
3 vs. 1 (least deprived)	1.69, 1.18-2.42
2 vs. 1 (least deprived)	1.55, 1.05-2.3

Singer A, Kosowan L, Muthumuni D, Katz A, Zafari H, Zulkernine F, Richardson JD, Price M, Williamson T, Queenan J, Sareen J. Characterizing primary care patients with posttraumatic stress disorder using electronic medical records: a retrospective cross-sectional study. *Under Review* Family Practice.

So how can this be addressed?







Pan-Canadian Health Data Content Framework

Data Content Standard: Open Review

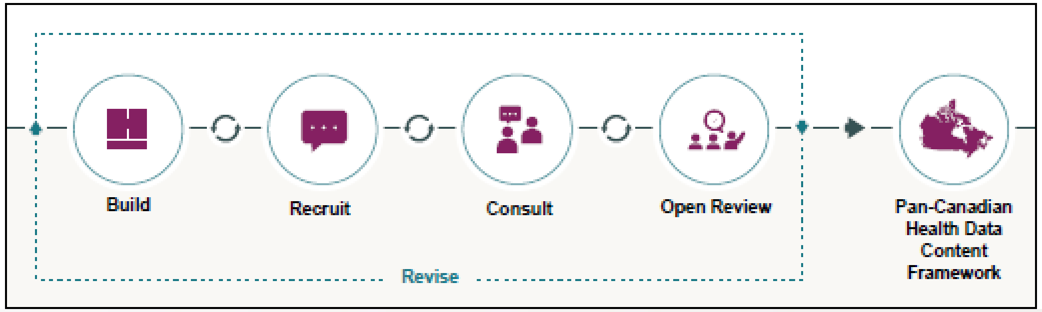
March 2024

Canadian Institute for Health Information
Institut canadien d'information sur la santé

Development process

The data content standard was created through collaborative efforts, standards, conducting gap analyses and engaging stakeholders such as clinicians, researchers, Indigenous partners, policy-makers, government agencies and data architects (see Figure 1).

Figure 1 Pan-Canadian Health Data Content Framework development cycle



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Social determinants of health

The following data elements pertain to a detailed assessment of a person's needs related to the social determinants of health, including social and demographic information.

Data element name	Data element definition	Data element maturity	Value set (Code System)	Value set examples	Value set maturity
Sociodemographic Information and Equity Stratifiers					
Language	The person's preferred language of service	0: In development	To be confirmed	n/a	n/a
Education Level	The person's highest level of education obtained	0: In development	To be confirmed	n/a	n/a
Relationship Status	The person's legal marital, common-law or union status	0: In development	To be confirmed	n/a	n/a
Born in Canada Status	An indication of whether or not the person was born in Canada	0: In development	To be confirmed	n/a	n/a
Time since Arrival in Canada	The timeframe since arrival in Canada	0: In development	To be confirmed	n/a	n/a
Race	The person's self-identified racial background	0: In development	RacializedGroupCode (SNOMED CT CA, HL7)	• East Asian • Indigenous • Latin • American • Middle Eastern • Southeast Asian • South Asian • Black • White • Do not know • Another race category	1: Draft

Data element name	Data element definition	Data element maturity	Value set (Code System)	Value set examples	Value set maturity
Sociodemographic Information and Equity Stratifiers (continued)					
Indigenous Self-Identification	The person's self-identification as either First Nations, Métis and/or Inuk/Inuit	0: In development	IndigenousIdentityCode (SNOMED CT CA, HL7)	• First Nations • Inuk/Inuit • Métis • Do not know • Not applicable • Asked but declined	1: Draft
Ethnicity	The person's ethnic or cultural background	0: In development	To be confirmed	n/a	n/a
Religious or Spiritual Affiliations	The person's religious or spiritual affiliations	0: In development	To be confirmed	n/a	n/a
Gender, Sex and Sexual Orientation (GSSO)					
Gender Identity	An individual's personal experience of being a woman, a man, non-binary or something else. People may identify with more than one gender identity or use different gender identities in different settings.	0: In development	Gender identity (LOINC)	• Woman / Girl • Man / Boy • Non-binary	0: In development
	An individual's personal experience of being a woman, a man, non-binary or something else. People may identify with more than one gender identity or use different gender identities in different settings.	0: In development	NullFlavor (HL7)	• Prefer not to answer • Unknown • Unable to ask • Unsure	0: In development

Data element name	Data element definition	Data element maturity	Value set (Code System)	Value set examples	Value set maturity
Employment and Finance Information					
Employment Status	The person's current job status	0: In development	To be confirmed	n/a	n/a
Household Income	The sum of the total incomes of all members of a household	0: In development	To be confirmed	n/a	n/a
Financial Stability	Information about a person's ability to pay for their household's basic needs, including food, water, housing and clothing	0: In development	To be confirmed	n/a	n/a
Housing Information					
Housing Stability	The person's current housing situation, including whether they are housed or unhoused	0: In development	T		
Housing Condition	The physical infrastructure of the residence, including overcrowding, a leaking roof, no bath/shower and no flushing toilet, or a dwelling considered too dark	0: In development	T		
Household Composition	Information about who the person lives with, such as parents, children, spouse or roommates	0: In development	T		
Accessibility Information					
Access to Food	The person's ability or inability to access food over the past 12 months	0: In development	T		
Access to Medication	The person's ability to access or afford medicine	0: In development	T		
Access to Internet	The person's ability to access or afford internet over the past 12 months	0: In development	T		
Access to a Phone	The person's ability to access or afford a telephone over the past 12 months	0: In development	T		

Data element name	Data element definition	Data element maturity	Value set (Code System)	Value set examples	Value set maturity
Accessibility Information (continued)					
Access to Transportation	The person's access to public or private transportation over the past 12 months	0: In development	To be confirmed	n/a	n/a
Access to Utilities	The person's ability to access and afford utilities, such as heat, electricity, water, sewage and waste services over the past 12 months	0: In development	To be confirmed	n/a	n/a
Access to Child Care	The person's ability to access or afford child care in the past year over the past 12 months	0: In development	To be confirmed	n/a	n/a
Social Needs					
Social Supports	The actual or perceived availability of family, friends, neighbours and/or community that a person can confide in or rely on to feel more socially connected and secure	0: In development	To be confirmed	n/a	n/a
Incarceration History	The person's experiences with the judicial system such as spending time in a jail, prison, detention centre or juvenile correctional facility	0: In development	To be confirmed	n/a	n/a

UPSTREAMLAB

Collecting data on race during the COVID-19 pandemic to identify inequities

April 14, 2020

Andrew D. Pinto MD MSc
Ayu Hapsari MSc

CIHI Update | **May 2020**

Race-Based Data Collection and Health Reporting

Summary

There is heightened awareness of and interest in collecting information to better understand the spread of COVID-19 and the impact of the pandemic, particularly within racialized communities.
The lack of data on race in Canada makes it difficult to monitor racial health inequalities. To help harmonize and facilitate collection of high-quality data, the Canadian Institute for Health Information (CIHI) is proposing an interim race data collection standard based on work that has been ongoing for a number of years, including engagement with researchers, clinicians, organizations representing racialized communities, and federal, provincial and territorial governments. It is intended for use by any jurisdiction or organization that decides to collect this type of data.

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THE UPSTREAM LAB

RECOMMENDATIONS ON COLLECTING RACE DATA DURING COVID-19

1 **COLLECT DATA ON RACE & OTHER SOCIAL FACTORS**

All Canadian jurisdictions should routinely collect data on race and other key factors such as income or housing, that can impact outcomes or shape the public health response.

2 **USE SAME QUESTIONS ACROSS PROVINCES**

Jurisdictions should use the same questions to allow for country-wide comparisons and rapid use by relevant public health centres.

3 **PREFACE FOR UNDERSTANDING**

Asking about race is uncommon in Canadian health care settings. Explaining why questions are asked about race can help patients understand the context and avoid reinforcing false ideas about race.

4 **BE TRANSPARENT**

Commit to transparency and engagement with local leaders on questions used, proper question administration, and to help create community-based interventions to reduce inequities.

INFOGRAPHIC BY: BREAGH & BRIANNA CHENG
SOURCE: ANDREW PINTO, AYU HAPSARI, UPSTREAM LAB
https://upstreamlab.org @upstreamlab Created April 17, 2020

Rady Faculty of Health Sciences | University of Manitoba

The <u>S</u>creening for <u>P</u>overty <u>A</u>nd <u>R</u>elated social determinants to improve <u>K</u>nowledge of and access to resources (SPARK) project

Patients will receive the SPARK tool by:

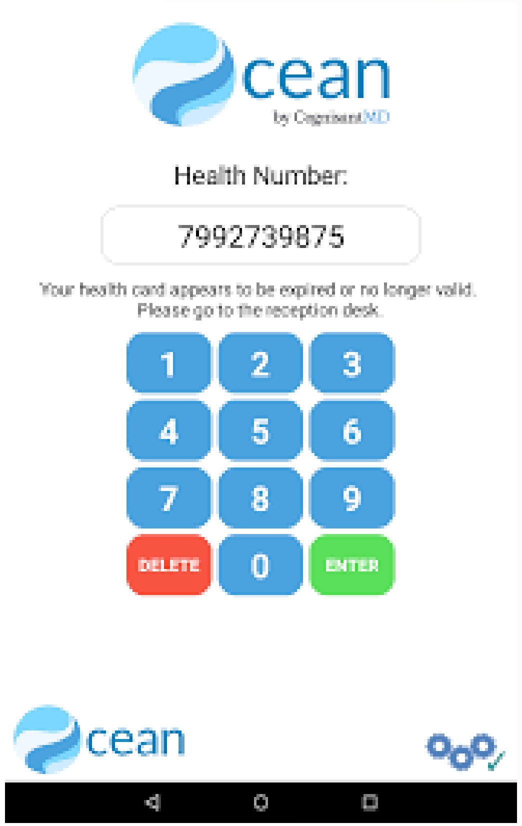
- Automated emails with a patient appointment reminder and a link to complete SPARK online
- Tablets in the waiting room

SPARK responses automatically appear in an encounter note in the EMR

SPARK responses will be used by:

a) Healthcare provider

b) Research



Two tablets available at your clinic for SPARK

On the homepage there is an Ocean app

Open the Ocean app and enter the patient health care number

The SPARK tool will appear

Yes, hand patient the tablet	No, select no on the tablet

https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-01-charting-path-toward-ambition.html

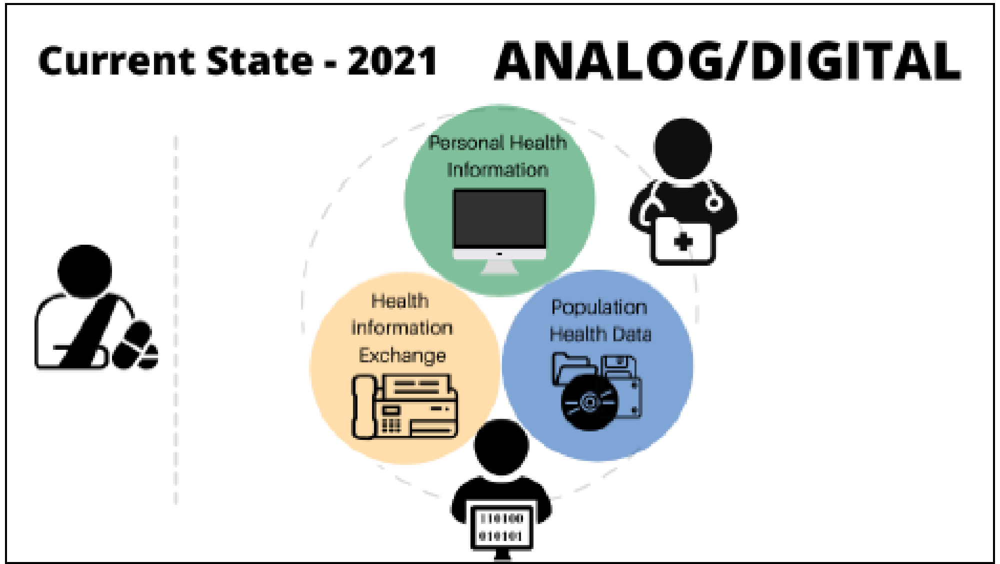


Figure 3b. 2021- Providers act as custodians of digitized health records. Some patient access and sharing. Barriers make it difficult to share data between silos.

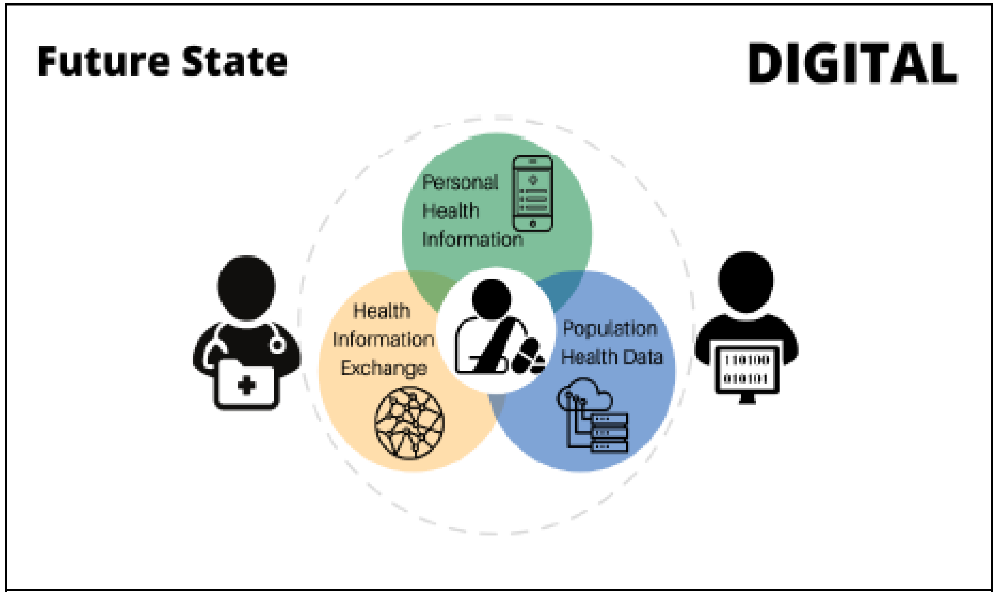


Figure 3c. Future - Person-centred data provides the right data to the right people at the right time by design.

Concluding Remarks

- Risk taking behaviours and social/material circumstances impact disease prevalence and outcomes and need to be measured in order to be addressed
- Practice Based Research and Learning Networks can serve as a key driver of testing improvements that contribute to Learning Health systems

MaPCReN
Manitoba Primary Care Research Network

CPCSSN RCSSSP
Canadian Primary Care Sentinel Surveillance Network
Réseau canadien de surveillance sentinelle en soins primaires

Thanks for listening!
Any questions?

University of Victoria