eHealth Data Standards and Data Stewardship for Social Determinants of Health in Support of Ontario Learning Health Systems: a State-of-the-Art Review of the Literature

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Scholarly Paper for MSc eHealth

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September 30, 2022

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Executive Summary

Background: Health equity exists when everyone can attain their full potential for health and well-being. It is an important aim across multiple healthcare jurisdictions and a central focus of Ontario Health's innovation plan. Health inequities have a strong relationship to social determinants of health (SDoH), those factors such as income, social status, race, gender, education, and physical environment. The healthcare quality framework the Quadruple Aim supports innovation to improve population health outcomes, patient care and experience, and provider satisfaction with lower costs with better value. To achieve this transformation, upstream social determinants of health must be addressed. The new Quintuple Aim framework embeds health equity in all four quality aims. Currently, there is a dearth of structured and actionable SDoH data in Ontario's healthcare systems. Calls for standardization of the SDoH data collection, exchange, and use are being voiced across policymakers, academics, clinicians, and the public.

Purpose: This report examines the SDoH data standards and data stewardship in the context of addressing health inequity in individuals and populations in Ontario. It will examine Ontario's current state and progress in defining, testing, and using eHealth data standards along with principles of data stewardship, toward collection, use, and sharing of SDoH data within electronic health records.

Method: OVID Medline and grey literature sources were searched to gather evidence to support the objective of this report, applying a state-of-the-art review methodology.

Results: Sixty-nine academic systematic reviews and original papers and 42 grey literature reports (white papers, policy documents, guidelines, websites, personal communication) contributed to the findings of this review. Publication trends in academic literature show increased rates from 2017-2022, with more from the US than Canada, signaling more research activity and further progress spurred by US government mandates for SDoH data collection and use. Current eHealth standards serve as a basis from which to adapt SDoH-specific standards. Canadian national standards and health information agencies serve as stewards to SDoH data standardization for Ontario. Ontario has a foundation of equity frameworks and guidance documents to guide SDoH data standard initiatives as well as two prominent SDoH data collection and use programs: the SPARK study (Toronto) and the Alliance for Healthier Communities. Other literature demonstrates SDoH data standardization facilitators (frameworks, models of practice (Gravity and OCHIN), leadership, stakeholder engagement, and demonstration of value with SDoH data applied to interventions). Challenges include the difficulties in producing complete and consistent SDoH data and the resource requirements to do so.

Discussion: A series of recommendations can be made related to fitting Ontario with eHealth SDoH data standards, drawn from the information collected in this report. First, the foundational work from Ontario-based early adopters of SDoH data collection can be leveraged for a spread-and-scale approach. This work needs to be shepherded with formal SDoH data standards development processes driven by key involvement of national, provincial and standards development experts. Planning, resourcing, and enacting pilot projects to test processes of SDoH data collection and data use in interventions, should inform larger-scale program rollout. To achieve standards in SDoH data collection, exchange, and use, meaningful incentives need to support efforts to enact robust systems newly embedded within healthcare. New roles of data stewardship within organizations will foster coordinated and collaborative work ensuring the promotion and use of SDoH standards to enact robust, secure data collection and use, to the benefit of patients and populations. Taken together, the multiple and complex facets of SDoH data standardization and data use toward health equity initiatives align with the aims of a Learning Health System, where research, informatics, incentives, and culture are combined for continuous improvement and innovation. Finally, fostering and funding Canadian research in SDoH data standardization toward innovation in system design, data processes, and health outcome evaluation will be an important steering component to Ontario’s health equity deliverables.

Conclusion: Standardization of SDoH along with supporting data stewardship is the path forward for the creation of high-quality SDoH data inputs that are critical to Ontario’s health equity and learning health system plan. Ontario has some early development on this front and appears poised to make further progress in the future, aided by a well-laid plan and sufficient resourcing to execute it.

1. Introduction

The call for health equity forms 1 of the 6 aims for quality improvement cited by the 2001 US Institute of Medicine in their *Crossing the Quality Chasm: A New Health System for the 21st Century* report.(1). Similarly, in Canada, there has been a formal call to action for health equity including acknowledgement of the intersectoral work required across government ministries to enact effective policy (2, 3). Health equity is also underscored in the Canadian Institutes for Health Research 2021-2026 strategy document entitled *Accelerate Health Care System Transformation through Research to Achieve the Quadruple Aim and Health Equity for All.*(4)

The Quadruple Aim is a framework to guide the redesign of health care systems and the transition to population health that is centered on four overarching goals: improved population health outcomes, improved care and patient experience, improved provider satisfaction, and lower costs with better value.(4) A call for a fifth aim of health equity within the quality improvement framework, the Quadruple Aim, adds a deliberate focus on addressing health inequities for individuals and communities who have the most to gain through quality improvement programs.(5)

Population health is an approach to health that aims to improve the health of the entire population and reduce health inequities among segments of the populations defined by specific characteristics. It applies analyses of interrelated conditions and factors that influence health over a lifetime, identifying systematic variations and patterns to create knowledge. Knowledge translation enacts policy and action through outreach and engagement to deliver targeted interventions and improve the health and well-being of those.(6, 7) Across population health and quality improvement frameworks, there is consensus for fundamental healthcare transformation toward addressing health equity and this is done by looking upstream to the determinants of health.

Social determinants of health (SDoH), as defined by the World Health Organization, relate to "the conditions in which people are born, grow, live, work and age and the wider set of forces and systems (economic policies, social policies, and political systems) shaping the conditions of daily life".(8) SDoH include factors such as income, education, employment, housing, neighbourhood conditions, transportation systems, food security, social connections. The sociodemographic attributes of race, ethnicity, sex and gender are associated with health inequities by way of linkage to structural racism, social discrimination, and institutional prejudice. As such, these factors are now considered an important focus for achieving health equity and contribute to the SDoH data constellation.(9-13) As non-medical factors, SDoH significantly influence health outcomes, upwards of 50%, when left unaddressed.(8) Quality improvement without directly combating inequities in SDoH has a deleterious affect of widening the health gap where only populations without social risk stand to gain.(5) SDoH as defined by the Public Health Agency of Canada (2018) is provided in Appendix 1.

The global pandemic has spurred greater reflection on the impact of SDoH on the disproportionate burden of COVID19 on those experiencing unmet social needs.(14-16) The public's awareness of the consequences of unaddressed SDoH factors in relation to health and wellbeing has increased due to reports on the particularly deleterious effect of the COVID19 pandemic among socially vulnerable populations.(13) Political awareness of social inequity and its widening gap that leads to substantial health burden is also on the rise. (17)

The recent flood of attention and the multiple streams of work by researchers, clinicians and policy makers on SDoH at the intersection of health systems, calls for clear terminology to avoid confusion and conflation.(18, 19) SDoH are neither negative or positive, but rather contribute to defining social risk factors, such as living and working conditions, which then directly and indirectly impact health status. When social risk factors such as a person's employment status, food security, and housing stability are adverse, individuals and communities experience poorer health. Social risk operates upstream to health outcome and has a gradient effect. Protective social factors such as education and social supports lead to more optimal health, while low-income status leads to more compromised health and homelessness contributes to a devasting toll on health and wellness.(18, 20)

Two other SDoH related concepts, behavioural risk factors and social need are related to but distinct from social risk. Behavioral risk factors, include alcohol use, drug use, smoking, and poor dietary choices, and are distinct from and often modifiable by social risk factors. For example, socioeconomic status as a social risk factor can influence behavioural risk such as a non-nutritious diet. In another layer, unmet social needs are based on patient perception of need to address their social risk factors, which are often framed by the personal contextual factors. For example, escaping intimate partner violence may be prioritized over food and housing needs. Social needs sometime require finer-tuned articulation via patient-provider dialogue. (18, 20). This paper will focus on social risk factor and social needs data as the core data elements relevant to SDoH.

There is a persistent call for disaggregated and standardized SDoH data for studying social risk and their effects on health outcomes, (21, 22) and yet most health information systems lack certain capacity for collection, storage, retrieval and use of SDoH data.(23-25) In a clinical, epidemiological and health planning sense, standardized SDoH data collection allows SDoH trends to be tracked across communities over time, to identify unmet needs, and to inform health services and health promotion planning. Known individual level social risk factors assist in the design of targeted clinical interventions to address patients' social needs. For example, referrals to social and community services like food banks and shelters, legal service, and financial aid, as well as care coordination for complex need patients, can be facilitated through system navigators. (14, 26) Health system information gathering practices around sex and gender and race and ethnicity have demonstrated a need to standardize and disaggregate these often confused and coupled concepts to be able to understand their discrete influence on health outcomes and that of interventions to reduce their associated stigma. (27, 28)

Comprehensive, aggregated SDoH data is critical to population health in order to understand what is contributing to negative community-level health effects.(29) This perspective enables intervention design that best addresses inequities experienced at population levels (e.g., food deserts represented by the lack of affordable, accessible, nutritious food). In another sense, populations that are studied with SDoH related research projects can show unbiased effects of social risk mitigation efforts on heath outcomes. Therefore, at both individual and community levels, the collection of social risk data is critical in addressing health inequities, that is, tipping the balance on social deficits that are linked to poorer health outcomes.(18) The electronic health record (EHR) contains patient' clinical health information, and along with these health data, the EHR holds potential to house individual's SDoH data in standard formats(25) and yet this capacity is not fully realized.(21, 23)

The objective of this paper is to use both academic and grey literature sources to identify and examine the SDoH data standards and data stewardship in context of addressing health disparities in individuals and populations. The findings will be presented in a report and will address Ontario's current state and progress in defining, testing, and using standards for social risk factor and social need data as well as data stewardship as it relates to organizational collection, use and sharing of SDoH data.

2. Method

A *state-of-the-art* literature review was conducted. As SDoH standards are a dynamically advancing area of health informatics, this methodology is appropriate as it aims to capture the current state of knowledge and set priorities for ongoing work, investigation, and research within a targeted realm.(30)

A pragmatic but comprehensive search of peer-reviewed literature using OVID Medline was conducted. The Medline search strategy, composed of controlled vocabulary (Medical Subject Headings or MeSH) and additional keywords terms (Appendix 2). The strategy limited the literature to 2017-2022 to derive a current perspective on SDoH data standards. Further literature was selected by consulting the reference lists of included papers. The retrieved literature was not formally assessed for quality and was selected for inclusion if it was topically aligned with this report's objective, meaning that it discussed some aspect of SDoH data standards or data stewardship in context of EHRs. The geographic focus of these papers was not limited to Ontario to provide the opportunity to glean insights from other jurisdictions.

A Google search was used to retrieve select grey literature including white papers, policy documents, project plans, technical documents, and digital presentations that described SDoH data standards and stewardship. Evidence gathering through personal communication with leaders in health informatics standards provided further information on this topic.

The results of this analysis are organized as follows. Section 2.1 describes the publication trends among the selected literature. Next, Section 2.2 presents an overview of eHealth standards applicable to SDoH data: FHIR (Section 3.21), Terminologies (Section 3.22), and Canadian eHealth standards (Section 3.23). Key frameworks that situate and influence Ontario's data standards and data stewardship are introduced in Section 2.3. Next, the report pivots to describing evidence of Ontario's current state of SDoH standards (Section 3.3) including applicable frameworks (3.31) and standards being currently applied (3.32). The report then transitions to describe SDoH data standards development and implementation research (Section 3.4). Specifically, in Section 3.41 drivers and facilitators to SDoH data standards are discussed and in Section 3.42 the challenges of applying SDoH standards are presented. These findings are then reflected upon throughout the Discussion (Section 4), forming a set of recommendations for Ontario to consider in their journey toward standardized SDoH data applied to advancement health equity.

3. Results

3.1 Literature Trends

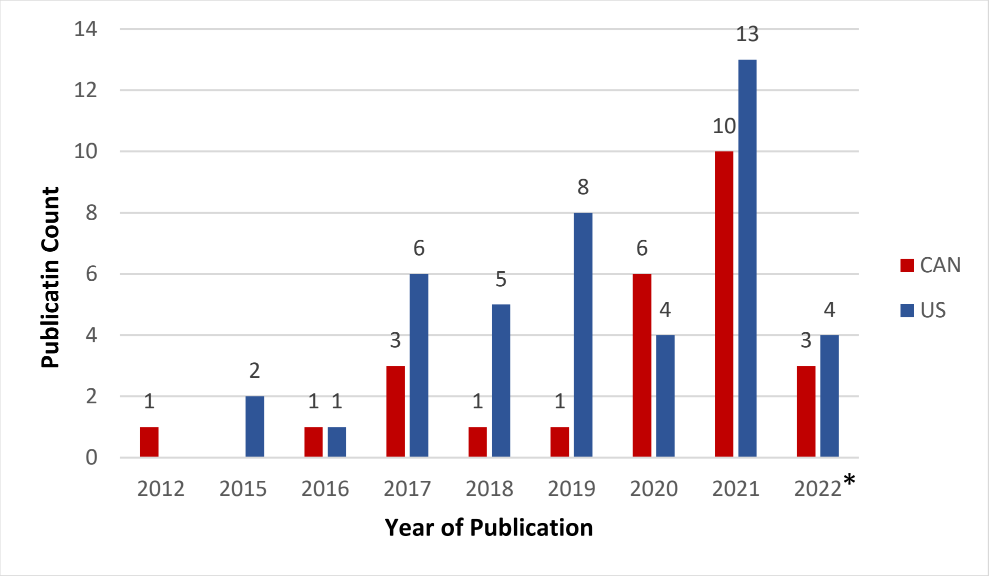
Sixty-nine academic published systematic reviews and original papers contributed to findings of this review. Overall, fewer studies (26) described Canadian research, reflecting our relatively early stage in SDoH data standards work in comparison to the 43 studies by US researchers (Table 1). Figure 1 shows the trend in Canadian and US academic publications by year. A swell of US academic literature is published in 2017-2019 aligning with the timing of the third stage of the Meaningfully Use Act, that required healthcare institutions to demonstrate continuous quality improvement of care and elimination of healthcare inequality across all groups.(19) Fewer studies on SDoH data standards were published in 2020 during the start of the pandemic, but another rise is seen in 2021 and 2022 reflecting renewed attention to the need for standardized SDoH data in support of health equity work. The most recent literature describes experience to date with many calls for data standardization.(5, 14, 25, 31, 32)

Among the grey literature, relevant policy, guideline, and framework type documents from Ontario and Canadian health information agencies, government and standards working groups informed this report (Table 1). Personal communication with team leads in two of Ontario’s prominent SDoH initiatives also provided key information.

Table 1: Categorization of Academic and Grey literature

Type	**Total**
Canadian	
Academic literature	26
Original	22
Review	4
Grey literature	36
US	
Academic literature	43
Original	37
Review	6
Grey literature	5
Global	
Grey literature	1
Total Sum	**111**

Figure 1: Canadian and US Academic Publication Count by Year



*Jan-July 2022 only

3.2 Overview of eHealth Standards for SDoH Data

As SDoH data standards are being considered in context of the EHR, it is relevant to consider existing eHealth data standards that are applicable to the collection, storage, exchange and use of SDoH data. The eHealth Ontario Standards Selection Guide(33) offers a catalogue and selection framework to optimally fit an eHealth standard to its context among categories of fit for purpose, stewardship, and standard quality (Appendix 3). Currently existing eHealth data standards form an important basis for SDoH data standardization but need to be fitted or extended to encompass social risk factor and social needs data, their interventions, and their outcomes. Further, process standardization in terms of method and mode of screening tool administration are required. Standard protocols for data storage in digital systems, data use in clinical research and population health evaluation also need to be specifically fitted to the SDoH data landscape and tested to ensure feasibility, usefulness, and validity.(34)

Data standards encompass rules and recommendations with which to create, store, exchange and use data and are critical backdrop to an interoperable health system. Their application reduces variation thereby increasing the potential of data to be a trusted and reliable asset.(35) eHealth standards currently support Ontario's digital healthcare system, by ensuring clear and comprehensive communication between different systems and providers.(33) They do this by specifying the technical framework and clinical language that enables a myriad of health care providers using different digital documentation tools to communicate and share health information that is contextual and unambiguous in meaning.(35) Data standards contribute to a ‘collect once, use many times’ (COUMT) approach that gives rise to greater efficiency in the collection, sharing and use of digital assets with both primary and secondary value.

The standards development process require rigour and follows these 8 steps:

1. Need Identification - the business need for the standard is identified and prioritized
2. Options Research and Analysis - determines if a standard can be reused or a new one requires development
3. Solution development - engagement with stakeholders and research and development arrive at an optimal standard ready of adoption
4. Testing - new standard is piloted in a pre-production phase to discover required changes
5. Training - those who will interact with the standard need to be educated on its optimal use
6. Implementation - the uptake of the standard is supported with tools, guidelines and advice
7. Conformance - ensure that standards have been properly implemented and collect feedback to inform adjustments
8. Maintenance and Support - regular review and update of published specifications/ standards to ensure relevance and performance

(36)

eHealth standards are grouped as messaging, content and terminology standards.(36) Messaging standards specify formats for the digital exchange of data and include HL7 v2 and v3, DICOM, and SOAP. Content Standards include such HL7 Clinical Document Architecture (CDA), RESTful approaches, and DICOM. Terminology standards includes systems such as SNOMED CT, LOINC, pCLOCD, ICD, and CCI.(33) The application of common tools and methods used at the beginning of the SDoH data lifecycle with screening of social risk factors and unmet social needs, also requires standardization as this sets the stage for meaningful and actionable data.(33, 36)

3.21 FHIR

FHIR® (Fast Healthcare Interoperability Resources) is the latest messaging standard developed by HL7, combing best features of HL7's v2, HL7 v3 and CDA product lines.(35, 36) It defines how clinical, administrative healthcare information created within applications and information sources can be exchanged between different computer systems regardless of their storage format. It offers technical interoperability for the transport of data and semantic interoperability when the data is at rest. FHIR® supports a spectrum of integration among EHRs, mobile phones and institutional data inputs. This connectivity affords collaboration in clinical practice, continuity of health services, and even patient engagement through support of unambiguous, understandable data. FHIR is free and its easy implementation has contributed to its rapid global uptake; Ontario has followed suit in its adoption.(37)

3.22 Terminology Standards

Standardized meaning of specific concepts, or semantics, is offered in the use of standard terms with defined meaning. Health terminology standards provide the ability to represent concepts in an unambiguous manner between a sender and receiver of information that is created and shared within healthcare systems and encompass structured vocabularies, terminologies, code sets (value sets) and classification systems to represent health concepts.(35)

ICD-10-CA is the Canadian modified version of the WHO, International Classification of Diseases (ICD) standard for morbidity data reporting.(38) The Canadian Institute for Health Information (CIHI) maintains, distributes, and supports the application of ICD-10-CA. CIHI also creates the Canadian Classification of Health Interventions (CCI), which is the national standard for classifying health care procedures.(39) ICD-10-CA is mandated for use in Ontario hospitals with codes contributing to the DADS and NACRS databases. Users of ICD-10-CA and/or CCI and materials incorporating either of these products must be properly licensed from the Canadian Institute for Health Information (CIHI).(35) The series of codes at Z55-Z65 map represent "Persons with potential health hazards related to socioeconomic and psychosocial circumstances"(38) and therefore offer a means of collecting SDoH risk factor data (Table 2).

Table 2: ICD 10 Z55-Z65

Codes	**Code Description**
Z55	Occupational exposure to risk factors
Z56	Other problems related to primary support group, including family circumstances
Z57	Problems related to certain psychosocial circumstances
Z58	Problems related to education and literacy
Z59	Problems related to employment and unemployment
Z60	Problems related to housing and economic circumstances
Z62	Problems related to other psychosocial circumstances
Z63	Problems related to physical environment
Z64	Problems related to social environment
Z65	Problems related to upbringing

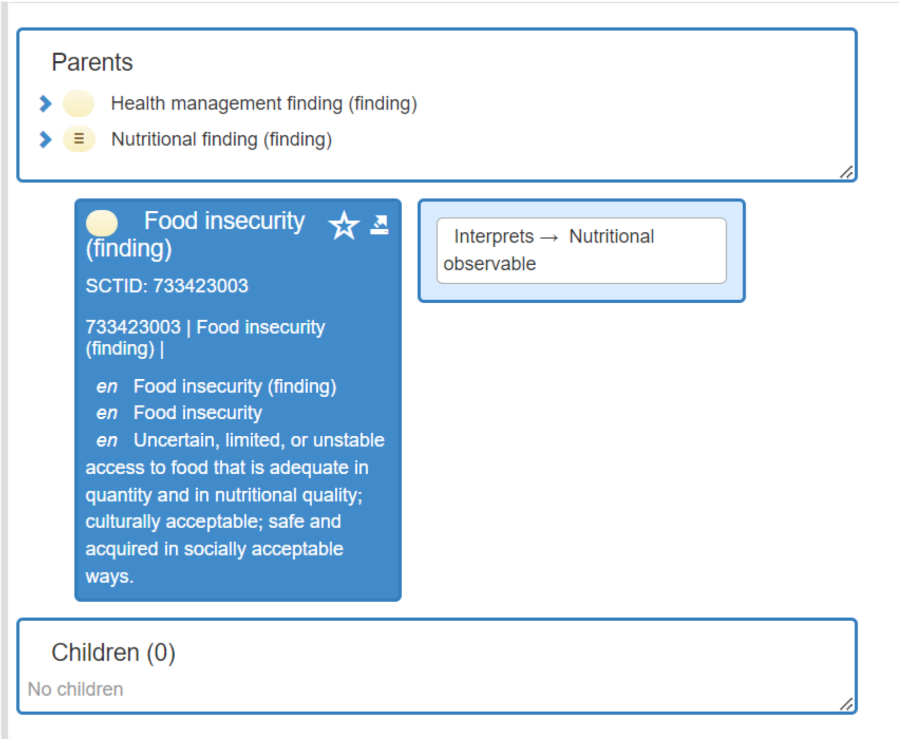
The precursor to ICD10 is ICD9. ICD9 is no longer maintained by the WHO or any other Canadian Standards Entity and yet, despite this obsoletism, it remains the prominent disease classification system used within Ontario-based primary care EMRs.(40) Its terms are somewhat blunt and outdated and has important conceptual gaps. Consistent with these shortcomings, ICD9 is also limited in representing social risk factor and social needs codes (Table 3). To complicate a compromised situation further, the billing modules within Ontario-based primary care EMRs use a different classification system, which is ICD9-like, offering fewer term options to providers who use it to describe the clinical problem billed for in a clinical encounter.(40) Whereas most OHIP and ICD9 codes are largely equivalent by way of a common integer value, the OHIP codes in the SDoH realm have somewhat equivalent term names by unrelated codes. (Table 3).

Table 3: Mapping between OHIP Diagnostic Codes and ICD9 Codes

OHIP Code	OHIP Term	ICD9 Code	ICD9 Term
897	Economic problems	V60.2	INADEQUATE MATERIAL RESOURCES
898	Marital difficulties	V61.10	COUNSELING FOR MARITAL AND PARTNER PROBLEMS, UNSPECIFIED
899	Parent-child problems, e.g., child-abuse, battered child, child neglect	V61.20	COUNSELING FOR PARENT-CHILD PROBLEM, UNSPECIFIED
900	Problems with aged parents or in-laws	V61.3	PROBLEMS WITH AGED PARENTS OR IN-LAWS
901	Family disruption, divorce, grief	V61.0	FAMILY DISRUPTION
902	Educational problems	V62.3	EDUCATIONAL CIRCUMSTANCES
903	Illegitimacy	NA	NA
904	Social maladjustment	V62.4	SOCIAL MALADJUSTMENT
905	Occupational problems, unemployment, difficulty at work	V62.1	ADVERSE EFFECTS OF WORK ENVIRONMENT
906	Legal problems, litigation, imprisonment	V62.5	LEGAL CIRCUMSTANCES
909	Other problems of social adjustment	V62.4	SOCIAL MALADJUSTMENT

SNOMED CT is the largest and most comprehensive clinical reference terminology in the world. It is maintained by SNOMED International, and updates are released twice each year ensuring relevance and currency of its content.(35) A free browser can be found at https://infocentral.infoway-inforoute.ca/en/tools/standards-tools/snomed-ct-browser accessible by way of an Infoway Account. SNOMED CT offer robust semantics and logical hierarchies serving to organize a comprehensive set of clinical concepts and its inclusion of SDoH concepts is robust. Pplease see Figure 1 for the SNOMED CT browser display for the social risk concept of food insecurity.

Figure 1 – SNOMED CT concept Food Insecurity



Parents

Health management finding (finding)

Nutritional finding (finding)

Food insecurity (finding)

SCTID: 733423003

733423003 | Food insecurity (finding) |

en Food insecurity (finding)

en Food insecurity

en Uncertain, limited, or unstable access to food that is adequate in quantity and in nutritional quality; culturally acceptable; safe and acquired in socially acceptable ways.

Interprets → Nutritional observable

Children (0)

No children

Logical Observation Identifiers, Names and Codes (LOINC®) is the international standard for identifying health measurements, observations, and documents, maintained by Regenstrief Institute.(35) The pan-Canadian LOINC Observation Code Database (pCLOCD) is a Canadian subset version of LOINC terminology specifying Canadian criteria. pCLOCD releases contains codes that are specific to use in Canada and is maintained by Canada Health Infoway with two updates per year.(35) LOINC and pCLOCD offer terms for representing screening assessments and measures of SDoH, including questions, answers (value sets), and the collection of these data into forms.

Electronic Nomenclature and Classification of Disorders and Encounters for Family Medicine (ENCODE-FM) is another terminology for coding clinical encounters into primary care EMRs from among 10,000 terms.(41) It was derived from International Classification of Primary Care (ICPC) and ICD-10 and was formed by a team of family medicine clinicians. ENCODE-FM is designed to be an evolving terminology that accommodates updating and it currently maps to other classifications, including ICD9 and ICD10. In terms of SDoH concepts, ENCODE-FM has representative concepts for gender fluidity and sexual health, health issues of Indigenous Peoples, and other social risk and social needs terms.(42)

3.23 Canadian eHealth Standards

Canada has strengths in eHealth standards organizations that provide national level leadership, seats at international tables and multiple Canadian specific standards products.(35) National level eHealth standards are relevant to Ontario and are often a bridge to international versions of the same standard. Where possible, Ontario's use of Canadian standards precludes the intensive resources to create a de novo provincial version as well as the need for its testing, promotion, licensing and maintenance.(36)

The Pan-Canadian Digital Health Strategy (PCDHS) emphasizes the importance of pan-Canadian standards with coordinated uptake across provincial and territorial jurisdictions in a recent series of reports.(43-45) The PCDHS has declared the need for national digital health strategy that fosters digital innovation and interoperability across Canada to support clinical decision making, data analytics and population health management, all of which are key activities associated with SDoH data. The reports call for modernized methods to health data collection, sharing and interoperability, achieved with common data content and exchange standards and that these, as a backbone of health sector data, need to be consistently defined, adopted, evolved, and maintained. Other relevant points within the PCDHS reports, relevant to SDoH data standards, include the need for new approach to privacy and access for the digital age, requiring clarification on accountability, sovereignty, and health data governance.

Canada Health Infoway and the Canadian Institute for Health Information (CIHI) are national leaders in eHealth standards. Canada Health Infoway is an independent, not-for-profit organization, established in 2000 and funded by the federal government Infoway works with governments, health care organizations, clinicians, and patients, towards establishing an interoperability health care system. They establish communities of practices on several digital health initiatives including standards. Their support for pan-Canadian standards provides Ontario with resources and access to communities of practice.(35)

CIHI plays a major role in the management of terminology eHealth standards (ICD10-CA an CCI) and is also a leading advocate for creation and management of health equity data and its analysis. Their recently released guidance document on standards for race-based and indigenous data collection provide key guidance in this standards domain, relevant to

SDoH.(10) This guidance document set out the minimum data standards to support harmonized, high-quality race-based and Indigenous identity data to facilitate monitoring, comparable analysis and reporting on healthcare access, quality, experience and outcomes across racialized group and it aligns with Statistics Canada census and surveys and other national data sources. CIHI has also defined research and data analytic standards for measuring health inequalities with publication of a toolkit that defines how to select equity specific stratifiers, their analysis and interpretation.(46) In this continued work, they have defined 8 equity stratifiers: age, sex at birth, gender, income, geographic location, racialized group, Indigenous identity and education. A larger composite of SDoH data elements were analyzed for coverage across key CIHI data holdings and considerable data were found to be missing.(24) Further, CIHI has recently released the Pan-Canadian Primary Health Care EMR Minimum Data Set toward support of comparable primary health care EMR data. The standard composes 47 data elements, 58 supplementary data elements and associated code systems, including new data elements for race and Indigenous identity. CIHI is engaged in ongoing work to decouple sex and gender.(47)

3.3 Ontario: Current state of SDoH Data Standards

Ontario has made certain progress in the adoption of SDoH data standards. Ontario Health Teams (51 in total: https://www.health.gov.on.ca/) have been formed to address population health, with an early emphasis on connecting appropriate health and social services with vulnerable populations toward achieving greater equity in the healthcare system. SDoH data standards and data stewardship are key facets for appropriate and effective collection and use of social risk factor data for Ontario Health Teams to advance health equity in populations. In summary, the findings from the research evidence suggest that selection and incorporation of standards that specifically relate to SDoH is a work in progress in Ontario. The search of grey and academic literature, as well as personal communication with experts demonstrated that Ontario health systems are currently limited in its collection of standardized social risk factor data. Data standard limitations exist with respect to screening tools, answers to these questions, data collected in social risk and social need reducing interventions, as well as defined formats for SDoH data exchange across the health and social systems. (21, 42, 48, 49) Without a comprehensive, complete and consistent SDoH dataset, health equity interventions and system level planning toward population health initiatives are in turn constrained. The following section discusses the academic and grey literature findings that relate to Ontario SDoH related strategic frameworks, technical requirements, data collection, data coding and interventions in support of equity driven projects.

3.31 Ontario-based Guides and Frameworks

Conceptual and operational frameworks contribute both intention and grounding of data standards and data stewardship practices. Ontario Health's Equity, Inclusion, Diversity and Anti-racism framework was informed by engagement with many health system stakeholders and community organizations from across the province.(17, 50) This framework describes the intention for Ontario Health to invest in practices that contribute to systematic collection of equity data toward its analysis and design of appropriate programs/services and their resource allocation, steered toward achieving greater health equity. The framework sets that data collection *will be mandated* across all health service providers and their organizations, using automated processes and standardized data sets useable within electronic health records to collect, analyze, and report information that is stored in a central data warehouse with controlled release and linking to other data.(17) The OH Equity plan also includes the establishment of an OH Indigenous Equity Unit that will establish relationships with provincial leadership from Indigenous communities, and will jointly lead and direct all planning, implementation and evaluation activities associated with indigenous health.(17)

Further demonstration of the Ontario government commitment to advancing health system interoperability through standards is seen in the creation of the Digital Health Information Exchange (DHIEX).(51) Broadly, the DHIEX regulates digital health information exchange in Ontario toward consistent and meaningful sharing of health information across health systems for the benefit of patients and health care providers. As a regulatory framework, the DHIEX gives Ontario Health the ability to define and implement health information standards and the requirements for their use in interoperability specifications. This capacity was created in an amendment in 2021 to Ontario Regulation 329/04 connected the PHIPA legislation.(52) The DHIEX gives Ontario Health prescribed entity status and establishes its role in leading the interoperability specifications for digital health assets across the province to realize coordinated data access by providers and analysts in research and short- and long-term health strategy planning.(51)

Another contributing framework to Ontario's SDoH data standardization pursuit is that of the Learning Health System. A Learning Health System (LHS) applies patient-centered design, data analytics, and continuous improvement to guide deliberate health system planning and integrated service delivery and dynamic decision making in required contexts. Applying a LHS framework sets the stage for a data collection and data sharing imperative to inform the system and learn how to make improvements.(53-55). The Ontario Ministry of Health is committed to transforming the fractured and reactive health care system into a learning health system(56), evidenced in the creation of Ontario Health Teams. There is good alignment between the framework and aims of the LHS and seeking equity-driven healthcare.(53-55, 57-59) SDoH data standards and data stewardship for guiding the collection of SDoH data within EHRs are important levers for Ontario's LHS and its goal in addressing health equity across the population.

3.32 Ontario-based Data Collection Standards

As with other personal health information collected within a digital health record, the personal and sensitive nature of SDoH data requires data collection methods that are culturally sensitive, framed with appropriate intent and promoted to be of 2-pronged value for the individuals and their communities as well as for healthcare organization's in meeting their health equity service delivery goals.

Ontario healthcare's foray into mandated SDoH data collection was initiated by the Ministry of Health during peak waves of the COVID 19 pandemic in June 2020. The requirement was informed by evidence of COVID-19's disproportionate impact on marginalized communities coupled with the call for disaggregated SDoH data to inform health disparities and systemic racism in healthcare.(60) The call was for regional public health units to quickly take up data collection activities for race, income, language, and household size for individuals who have tested positive for COVID19.(61, 62) Public Health Ontario stepped up to provide the best evidence to guide the collection of these data grounded in health equity principles, evidence, and best practices. They supported practitioners with data entry guidance, hosted webinars for training and learning exchange, and published a resource to support the data collection process.(61)

Outside of pandemic responses, Ontario Primary Care is host to two important SDoH data collection initiatives; the Upstream Lab with its SPARK study, and the Alliance for Healthier Communities with its routine collection of SDoH data across clients. Both initiatives are rooted in work of three Toronto based hospitals and Toronto Public Health who engaged in the health equity data collection research project named "*We ask because we care*". The program focused on establishing best practice and standards in collecting SDoH data. A report was published in 2013(63) alongside a set of data collection tools mandated for use by Toronto region Community Care Access Centres (Alliance for Healthier Communities) and Toronto-area hospitals. A major project finding was that patients understood the rationale for collecting the data for equity-driven service improvement and accepted the process of being asked the SDoH related questions. This project evolved over several years and now takes form as the Toronto Health Equity project that continues to support health equity data collection with guides and tools.(64)

Alliance for Healthier Communities (Alliance) is a network of community-governed primary health care organizations, composing both community care access centres and aboriginal health centres. The Alliance were early adopters of the *We Ask Because We Care* SDoH collection tool and were continuously mentored by the Toronto Equity project. The Alliance now employs a standardized tool that includes 8 standard sociodemographic question used to gather data from patients at time of client intake and now more recently during a well-planned data collection blitz aiming to have 75% completion rate of patient sociodemographic profiles by 2024 (personal communication with Dr. Jennifer Rayner, PhD, Director of Research and Evaluation, EPIC of the Alliance for Healthier Communities). These data directly contribute to the Alliance's evaluation framework. Alliance data is coded with ENCODE-FM, that as described above, and which has SDoH code coverage. Their fuller plan for achieving health equity is described in their white paper "Implementing Health Equity for Change".(22) The Alliance has also defined a means for leveraging this data for strategic planning, action and evaluation of equity embedding services.(22)

Another SDoH research program influenced by the *We Ask Because We Care* model is the Upstream Lab (https://upstreamlab.org/), led by Dr. Andrew Pinto. The Upstream Lab has multiple and synergistic aims of integrating health and social care, population health management and proactive care for learning health systems. Sociodemographic data has been studied in the context of creation of data collection tools for uptake in multicultural primary care communities. Intense community engagement directs their work to achieve effective solutions and several studies and reports have informed their progress. The *Screening for Poverty And Related social determinants and intervening to improve Knowledge of and links to resources* (SPARK) program developed and tested a tool for routinely collecting sociodemographic in primary care and developed guidelines for community engagement and implementing data collection initiatives.(65, 66) The SPARK study began with collaboration of Toronto-based healthcare organizations to identify a set of 14 questions that covered a range of social determinants of health that were translated into 13 languages and administered as a patient self-survey with use of an electronic tablet availed in primary care waiting rooms. Response rate in the sample studied was high and again, patient reported the process to be acceptable.(11)

Both the Alliance and SPARK SDoH tools are formidable examples of the collection of SDoH data in the healthcare sector. Still, the resource intensity of data collection of SDoH within Ontario is not a trifling issue and the scale and spread of these two SDoH initiatives requires further investment in planning, resources, and research.

3.4 SDoH Data Standards Development and Implementation Research

Research helps to inform best practice for SDoH standards development and implementation. The research literature reports on trials and programs of SDoH data collection, exchange and use toward health equity initiatives. This next section discusses reports of these projects and the insights they offer with respect to the standards development, project implementation and facilitators and barriers to the integration of standards into clinical domains. Section 3.41 discusses facilitators including guidance from frameworks and practice models, the engagement of strong leadership and other key stakeholders. Reported challenges are presented in Section 3.42 and include the ongoing gap in SDoH data, despite the call for its collection, as well as data quality and consistency issues as well as resource intensity in data collection. These published accounts of SDoH data standards in action, offer important knowledge that Ontario can heed in their programs of development and adoption of SDoH data standards.

3.41 Drivers and Facilitators to SDoH Data Standardization

Frameworks, models of practice, leadership and stakeholder engagement are four important drivers of SDoH data standards implementation, and each are discussed in more detail below.

3.411 SDoH Frameworks

In the US the National Academies of Sciences, Engineering, and Medicine (NASEM) published a report, *Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health* in 2019 which included a framework (NAM Framework) to guide health care organizations in their social care strategy to address health equity.(14, 67). Details of the NAM framework in context of health equity action by healthcare organizations are described in Table 4.

Table 4: NASEM Framework

NASEM Category	**Definition**
Awareness	Activities related to identifying the social risks and assets of defined patients and populations
Adjustment	Activities related to altering clinical care to accommodate identified social barriers
Assistance	Activities related to reducing social risk by connecting patients with social care resources
Alignment	Activities undertaken by health care systems to understand existing social care assets in the community, organize them to facilitate synergies, and invest in and deploy them to positively affect health outcomes

Advocacy	Activities in which health care organizations work with partner social care organizations to promote policies that facilitate the creation and redeployment of assets or resources to address health and social needs

The OCHIN framework (discussed in detail below), incorporates SDoH data from patients at the point of care (e.g., information on food security, housing status, household income) and geocoded community level data from publicly available sources (median household income within a given geographic area, availability of fresh foods, or accessibility of safe recreation spaces).(68) OCHIN applies this framework in the collection of the SDoH data, presenting and integrating it into primary care workflows, and developing clinical decision support (CDS) systems that suggest adapted clinical care, treatment plans, referrals to community resources to address identified SDoH needs. OCHIN evaluates the impact of these efforts on the triple aim of enhancing patient and health care provider experiences, improving population health, and reducing costs.(68)

The Learning Health System framework is well fitted to the aims of SDoH data collection and use and the need for data standardization toward that aim. Considerable reporting on the positive influence of co-delivering on LHS and SDoH informed equity healthcare delivery has been found in the literature.(53-55, 57-59) For example, the PETAL Framework demonstrates how the LHS framework embeds health equity driven deliverables: **P**rioritize health equity; **E**ngage the community; **T**arget health disparities; **A**ct on the data; and **L**earn and improve (PETAL).(54) Furthermore, the vertical and horizontal infrastructure for the LHS typically supported by the messaging standard FHIR, ensures that the requisite integrated, and coordinated data sharing aspect of SDoH initiatives across the healthcare system are tooled, scalable and otherwise, achievable. (59) LHS models intrinsically leverage data to inform on next steps, before designing fulminant solutions and serve in setting priorities for continuous quality improvement.

These and other frameworks described in the literature (14, 25, 48, 54, 58, 66, 68-70) offer a means of anchoring and guiding the development of plans to pursue SDoH data collection, exchange and use in healthcare systems. Their variety though, also demonstrate the current lack of consensus on defining SDoH related concepts, factors, and priorities, that arise from specific vantage points among policy, clinical care, and research. Furthermore, there is no consensus on what framework best shows the relationship between SDoH and health outcomes, nor to they define the specific SDoH variables, and how their data collection should occur and how the data should be used within healthcare organizations toward health equity initiatives.(25)

3.412 SDoH Standards Model of Practice

A model of SDoH standards development is exemplified in the US led GRAVITY project. The Gravity Project is a multi-stakeholder, public initiative focused on developing consensus-based structured data standards to support the collection, use and exchange of SDOH data, within and across clinical settings, community-based organizations, and service providers. Its scope covers four clinical SDoH related activities of screening, assessment, goal setting, and treatment/ interventions. Gravity conducts its work across 2 major streams of work including the Terminology Component and the Technical Component with the results being the generation of consensus-driven, interoperability-compliant coded SDoH value sets and a means of their interoperable exchange across health and social systems.(71)

A major deliverable by the Gravity project was a compendium of available codes organized by activities of screening, assessment, and interventions across several terminological and classifications(72). This work formed the basis for GRAVITY'S engagement with terminological organizations to address SDoH coverage of concepts used within healthcare systems as well as their gaps and suggestions for new codes. Stakeholder engagement has been a key facet to their work, with 1,800+ participants from across the health and human services ecosystem among clinical provider groups, community-based organizations, standards development organizations, federal and state government, payers, technology vendors and the public fueled by specific and customized community outreach efforts. Finally, the technical stream of Gravity has produced a SDoH-specific FHIR Implementation Guide which is regularly updated. (http://build.fhir.org/ig/HL7/fhir-sdoh-clinicalcare/). Furthermore to promote wide reaching stakeholder engagement across communities, healthcare organizations, policy makers, and the GRAVITY community of practice has organized its information and progress through projects on a shared, accessible web platform using a Confluence Cloud platform.(71)

The Gravity project has tackled myriad challenges associated with SDoH data standardization for capture and exchange. Gravity deliverables include the consent process for individuals, standardization of data collection and its storage, data sharing agreements across the learning health system to necessitate interoperability, as well as investigating the readiness and infrastructure for health and social sector organizations to participate in this work.(71). Applying this comprehensive approach, the Gravity project has seen tremendous impact on building and sustaining momentum in the US with respect to tooling and informing the US strategy on high quality SDoH data to drive their policy mandated health equity imperatives (Appendix 4).

Another major US initiative that contributes to SDoH data standardization is the Oregon Community Health Information Network (OCHIN). OCHIN, Inc, is a national, non-profit community-based health innovation and research network. It is now spread across 45 states and includes over 1000 primary care CHCs, with over 21,000 providers, serving more than 6 million diverse patients nationally, united by a single EHR (EPIC) with one master patient index. OCHIN promotes and supports the use of the SDoH screening tool PRAPARE (Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences) embedded and versioned into the EPIC EHR. The PRAPARE screen tool is used by member CHCs as a standardized approach to SDoH documentation. SDoH data collection occurs by clinic staff documenting them directly into the EHR, or for patients to do so through the patient portal or a tablet at the clinic. As reported in Apr 2021, over 700,000 SDoH screenings for nearly 430,000 patients had been completed.(73-75)

Other groups provide a model in the use of standard classifications and terminologies to cover the breadth of SDoH related activities of screening and risk assessment, intervention, and evaluation. For example, a research group in the US used LOINC codes for indexing both the responses to their SDoH screening tool as well as for the summary scores to facilitate the automatic exchange of key SDoH information between providers and settings. They further used SNOMED-CT codes to standardize the identified problems including complex chronic disease, limited resources, and behavioral health or substance abuse problems. These standardized data facilitated the creation of interoperable problem lists that informed the transition of patients from acute care settings to primary care. (76)

3.413 Leadership

The success of equity driven healthcare solutions first requires the acknowledgement by organizational leadership and their funders as to the importance of high quality, integrated and interoperable SDoH data to inform equity advancing projects. With this goal in mind, success then requires a commitment for resources investment into the design, planning and execution and evaluation of systems for standardized SDoH data collection, use and exchange. Early Canadian work(69) that explored best approaches to equitably delivered primary care and found that there needs to be explicitly articulated commitment to equity in the mission, vision and organizational policy that is upheld and embraced across the organization. This guidance then sets the stage for the development of structures, policies, and processes to support the equity driven work (69) Other research demonstrated the integral role of leadership and other internal and influential advocates(73, 77, 78) within organizations as a driver of SDoH data collection and use practices. In another Canadian study healthcare managers shared that transformational organizational change at multiple levels is required to build and sustain efforts in SDoH projects and this needs to be driven by committed leaders.(48) Similarly, other research found that social risk factors data collection and integration within the EHR in large US health systems was feasible only with buy-in from the health system leadership.(79)

3.414 Stakeholder Engagement

People, process, and technology complexity presents in relation to the integration of SDoH data collection within EHRs systems, which therefore begs representative stakeholder engagement in the design and implementation of projects. The literature demonstrates that those with vested interest in SDoH data collection and use are among policy makers, clinicians, healthcare systems operators, researchers, patients, vendors, standards organizations.(21, 80) Stakeholders need to weigh in on the selection of SDoH variables to collect and standardize, however satisfying all stakeholders priorities for these data is difficult to achieve.(25) This report has demonstrated engagement among policymakers, clinicians, and researchers, health data and standards organizations. Other key stakeholders are patients, vendors and public health practitioners and their inputs as discussed below.

Patient Engagement

Patient engagement is one the key requirements in defining SDoH data standards. Creating systems of equity driven data collection in the absence of patient inputs is bound to omit key data facets that need to be conceptualized, coded, collected, and acted upon, and that only patient perspective can offer. Early work using ethnographic methods exposed the critical importance of the patient perspective in equity driven imperatives, to attain deeper understanding of peoples' experiences of racism, discrimination, and marginalization and how they shape their experiences in primary care.(69) In one study, patients' perspectives and priorities related to social needs were collected from high frequency patients. Findings showed that it was both feasible and effective to collect these critical SDoH facets. This research sets the stage for future work to incorporate patient perspective by way of codesign methods in the implementation of equity driven projects.(81).

Informed stakeholders, especially from diverse community groups and the public, is the lever to social licence. Social license, in the realm of digital health data is the publics' expression of the acceptance of standards, legislation and policy related to the collection and use of their PHI. Plotting meaningful engagement of communities for input on the appropriate approach to the collection and use of SDoH has occurred in the recent years within Ontario (64-66, 82) The design and application of SDoH data standards will require continued diverse community inputs to create trust and support of these data factoring into the Ontario Learning Health System.

Health Technology Vendors

A critical element in SDoH standards consideration is the container in which these data are collected and stored and then released in their exchange. The EHR is currently presenting as the most accessible digital tool to facilitate SDoH data integration into current digital infrastructure supporting healthcare.(19, 25, 74, 80, 83) EHRs are designed for the primary use of clinical data capture and retrieval at point of care, and vendors had not previously considered SDoH components within their software products. EHRs are largely limited to collect SDoH codes in billing and problem lists using ICD10 codes in hospitals systems and primary care EMRs. An exception to that would be the application of ENCODE-FM in primary care data, but its uptake across the province is limited. As with a host of other clinical data, the free-text portion of an EHR, such as encounter notes, remains a common location for SDoH information, preventing easy aggregated and automated data retrieval.

Instead of forcing the extension of current EHR components to cover all aspects of structured SDoH data capture, other SDoH-devoted EHR components need to be developed. These tools need to be fitted within current clinical workflows to avoid burden and disruption and then be presented on front facing portions of EMRs as readily available data during clinical encounters.(84) Also, the backend collection of these data needs to be leveraged for secondary purposes akin to clinical EHR data that has critical importance to research and quality improvement. The fine tuning of SDoH data collection within EHRs requires that health technology vendors be partners in developing solutions for leveraging SDoH data within healthcare operations. Furthermore, data collection efforts should be iterative in nature and co-developed with EHR vendors so that processes are honed to best fit workflows, achieve usability in interfaces and ultimately meaningful and actionable data. Once the data has been collected, research studies that assess the impact of SDoH interventions can feedback upon data collection methods and vendors can fine tune tools and their data variables for future iterations.(25)

US based EHR vendors (both ambulatory and hospital) were asked about their intentions or active work related to producing supportive SDoH components within their product lines.(84) Vendors reported having in place or in development, tools related to SDoH data screening, population health management, referral management, and analytic tools in response to a growing market demand. Most mature components were SDoH screening tools, whereas referral and analytical tools were mostly in early-stage development. They acknowledged the importance of developing solutions to data standardization and interoperability challenges in collaboration with other vendors, health care systems, and government agencies. Vendors articulated the need for more standardization to support the gathering of SDoH performance measures required of federal and state programs, better mapping of SDoH measures to multiple types of codes across LOINC, SNOMED CT and ICD10, and filling any code gaps for SDoH measures of interest. Authors of this study posited that in the absence of clear policy standards around SDoH data, EHR product standards may present as de facto policies that stem from blueprints laid by majority market share vendors like EPIC.(84) This same idea was presented elsewhere, indicating that consensus on the SDoH data standardization needs to occur promptly to avoid the tendency for site-specific solutions requiring translation that can limit shared learning around health equity.(26)

In Ontario, OntarioMD has oversight over Primary Care EMR licensing and product requirements. The current climate would suggest that OntarioMD should require EMR vendors to be actively engaging as key stakeholders toward the planning of SDoH data collection and use for both primary and secondary uses. Ontario Health, with oversight over OntarioMD, is giving signals that explicit EMR regulation will require a suite of SDoH tools for fully supporting the Ontario Health mandate toward equity driven healthcare. Ontario sees considerable variation in EMRs used within primary care, among TELUS Health Practice Solutions Suite (PSS), WELL EMR - OSCAR, and Accuro. Perhaps some amount of government mandate will spur market demand for SDoH data tools to be thoughtfully and standardly built into EHRs, producing market competition to deliver on these requirements.

In hospitals, EPIC is entering the market en force with active Ontario-based implementation projects. With a US-base, Ontario versions of EPIC systems may benefit from the advancement of SDoH solutions built into US products, as incentivized by US programs spurring some momentum on SDoH standardization. Customizing these product lines to Ontario (and Canadian) cultural, payment, service delivery and population health aims will be another requirement to ensure that tools are properly fitted to Ontario health equity aims.

Ontario Public Health

Ontario Public health and its regional health units have an important role in elevating standardized SDoH data as a critical resource in achieving health equity in Ontario. Public health expertise, community reach, organizational structure, and their established standards bring significant assets to the building of a viable solutions for SDoH data standardization needed for collection, exchange, and use. Public and social service engagement are critical in planning data collection and data use processes. Public health has already fostered close, trusting community connections with diverse communities and key local agencies in equity driven work. Public health practitioners have decades of expertise honing theoretical and practical knowledge related to SDoH and have been diligently working at identifying and filling the gaps on social need as it applies to health and wellness of individuals and communities.(55, 85-88) Public health operates as a data driven enterprise guided by provincially set public health standards with an operational focus on population health and reducing health inequities. For these reasons, public health engagement, if not leadership, is a requisite for achieving health equity in Ontario.(55)

3.415 SDoH Interventions

Research has clearly shown the link between social risk factor and poorer health, predicting both morbidity and earlier mortality.(2, 65, 89, 90) Another important research driver of both resource investment and adoption of SDoH data standards is the evidence that demonstrates the value of the data in moving the dial on health equity. Interventions that leverage standardized SDoH data can provide proof of value in reducing health disparities in at risk populations. If research can show that capture and analysis of SDoH brings about improvements to health outcomes, the resource burden of collecting these data become justified.(25)

With a more mature collection of SDoH data in comparison to most Ontario primary care organizations, the Alliance is in the position to leverage their data to apply targeted interventions to individuals in their practices that would benefit from extended or targeted health service reach. The Alliance has reported the use of social prescribing methods to connect patients with non-medical therapies and strategies to meet their social needs (e.g. clubs for social isolation) and address their social risk factors (e.g. supportive housing connections)(91) and facilitate access to preventative services. With a growing data set of socio-demographic data, the Alliance has been able to leverage these data to identify racialized populations and link them to equity interventions.(92)

The Ontario-based Upstream lab has also engaged in multiple interventions to reduce health inequities. One study involved testing interventions of in which attorneys, income support workers, and employment services are embedded within the clinic itself, and available for consultation when patients are identified as having inadequate income.(93a, 93b) A recent assessment with respect to psychometric properties of the tool should be soon released. CIHR funded implementation of the SPARK tool across 5 provinces will further test its feasibility for effectively collecting actionable data across different primary care environments. Sample questions from the final iteration of the SPARK data collection tool is found in Appendix 5 (93b).

Beyond Ontario, considerable research is reported on interventions to address social risk. A systematic review of interventions addressing SDoH found evidence of interventions targeting a wide range of social needs and populations. Study designs were varied as were outcome measures selected that had more to do with process over health outcomes.(94). This finding provides certain indication that interventions need to be further standardized as do their outcome reporting(49). Other research demonstrates a large assortment of data collection systems for sociodemographic data and their application in equity driven interventions(95-97). In their review of intervention literature(97), Yan reports that most studies assessed process measures and social needs while fewer reported on health outcomes and impact on health care cost and utilization. They reported interventions on social needs showed improvement while health and health care cost and utilization findings were mixed.

OCHIN is a front runner in SDoH related research, operating as a community laboratory for health outcomes, policy, and primary care research with vulnerable and underserved populations is OCHIN Inc. Applying its large data repository containing SDoH data collected by way of an EPIC-versioned PRAPARE tool, OCHIN has 45 active research projects, 33 research partners and participation by 44 member Networks. Research has investigated health disparities, evaluated the impact of changes in policy and practice on health outcomes, developed and tested practice- based HIT interventions, and examined the barriers and facilitators to the dissemination and implementation of evidence-based strategies.(68, 73) OCHIN is also conducting a 5-year evaluation (mixed-methods, stepped-wedge trial with realist evaluation) to test detailed guidance on implementing electronic health record-based social determinants of health documentation, including tailored support from an interdisciplinary team, training and technical assistance. Results will track the competencies and resources needed to support the study clinics' implementation efforts toward informing implementation strategies for systems of SDoH documentation by CHCs.(98)

Taken as a whole, there is considerable evidence to show that healthcare organizations are making small to large attempts at health equity endeavours. Collecting and applying SDoH data appears to be occurring most in primary care sectors, which makes sense owing to its furthest reach into the community. In the case of Community Care Access Centres in Ontario and Community Care Centers in the US, these organizations have specific mandates to reach those with greatest health disparities and this organizational commitment, seems to have help focus efforts on early adoption of SDoH data standards.

The literature that describes interventions for SDoH underscore the importance of standardized SDoH data as key data assets in defining individuals and populations with unmet social needs. However, many studies describe shortcomings in the screening tools, and challenges to their meaningful application to enact effective referral or intervention. The following section describes the challenges associated SDoH documentation and application of SDoH standards in data collection and use.

3.42 Challenges to SDoH Standards Application

Collecting and analyzing SDoH data in context of a health care system enables system accountability, and insufficient data can lead to misleading results and generally missing the mark on achieving health equity.(29) The literature reviewed elucidated several challenges to the standard collection and use of SDoH data in EHRs. This next section describes a lack of comprehensively and standardly collected SDoH data in healthcare systems in Ontario and other jurisdictions. The reasons contributing to this lack of SDoH data, or its meaningful application is presented along the continuum of collecting, coding, using, and resourcing related to SDoH data.

3.421 Limited Social Risk Factor Data

Several reports and publications have called for disaggregated SDoH data in order to ensure flexible and specific characterization of SDoH health disparities, the interventions to address them and the evaluation of associated intervention impact.(21, 23, 25, 82) However, the current literature demonstrates that there is a gap in standard SDoH data collection within EHR systems.(61, 72, 97, 99, 100) An Ontario study surveyed and scored publicly available reporting of multiple COVID19 surveillance data including evidence of eight social markers (age, sex, immigration status, race/ethnicity, healthcare worker status, occupational sector, income, and education). The paucity of equity-related indicators resulted in a failing score.(101) Other Ontario-based research(12) examined structured coding for race or ethnicity in a tertiary-level hospital. They found value sets (term options for a given field) were not aligned on with the CIHI standards for race and ethnicity data capture(10) and more aligned with US race and ethnicities (Hispanic or Latino, Mexican), likely owing to the US based source of the EHR product. Overall the authors reported a small proportion of records having structured data indicating race or ethnicity, and some accounts of race and ethnicity stored in free text chart notes, which have major limitations for access in primary use and aggregation required in secondary use.(12)

Several US-based accounts of gaps in SDoH documentation were found in the research literature. A recent systemic review of SDoH collection and coding and found that most studies reported on neighbourhood-level social health data domains and fewer at the level of the individual. (103) Other research explored SDoH data collection methods in mental healthcare environments and found that SDOH data were not systematically included in clinical research or used to inform patient care, which authors linked to deficiency of structured and comprehensive social data.(100) One study of high-risk hospital patients showed that social need data was largely found in consult notes recorded during patient visits with specialists or in social worker notes but otherwise not consistently documented in structured fields.(81) Lasser et al also noted the propensity to collect SDoH data in free-text clinical notes over structured and standardized fields within the EHR, which limits both primary and secondary use. These authors suggest this may be attributed to clinicians' ignorance with respect to its potential use in research and population health management that requires complete, consistent structured data. Other accounts suggests that SDoH data collected for specific research is not otherwise incorporated into patients' EHR record, representing a significant loss of these valuable data for clinical care and population health. Their study participants also reported that an abundance of missing SDoH data limited their confidence of the social risk and system performance analytics that are built on these data.(25)

Other research demonstrating gaps in standardized SDoH data specifically report on the use of SDOH Z 55-65 codes (Z codes). One study found the uptake of Z-codes to be slow, and therefore surmised that the current set of codes amassed in healthcare system is likely an under-representation of the actual burden of social needs experienced by hospitalized patients.(102) This sentiment is echoed in other literature that states that the Z codes hold great potential in inventorying SDoH data, but data collection system lack any consensus on how to use of these codes and therefore they are currently underutilized to document SDOH in patient charts.(26, 103) Other research suggests that the Z codes are inherently limited in their capacity to be sufficiently specific and actionable on addressing social risk at the individual or population level.(26) They found missing Z codes for representing certain social risk, for example, neighbourhood safety. A lack of specificity was found in codes that bundle concepts like "lack of adequate food and safe drinking water (Z59.4). Furthermore, there was certain redundancy in other codes (homelessness (Z59.0) and inadequate housing (Z59.1)(26)

3.422 SDoH Data Variation

The inherent limitations in SDoH codes and the information gaps that result are one issue, however the data variation is another, which contributes to downstream interoperability issues and potentially biased data. Research has demonstrated that SDoH data that is collected has quality issues related to consistency, rendering the data ambiguous and in turn limiting its reliability. A systematic review reported on the state of SDoH data coded in electronic systems and found that there was a lack of SDoH data standardization in EHR sources, compromising its interoperable application. (103) A large survey of SDoH data collected in the OCHIN Network of over 100 Community Health Centres showed variation in documentation of SDoH. Data were both limited to certain domains of SDoH and most most data accumulated in a small proportion of sites in relation the entire Network.(99)

A key influence on the consistency of SDoH data rests with the choice of the collection tool and the method by which it is applied. Many SDoH screening tools have been created, tested and implemented within US healthcare organizations as reported in the literature.(95) These tools vary in their focus (e.g., policy, clinical care, research) stemming from their anchoring frameworks, their composite concepts and the level of data granularity offered. Not all instruments have been validated for adequately targeting intended SDoH measures. Screening tools can range from one question to multi-dimensional, detailed questionnaires and vary with respect to mode of delivery taking both paper and electronic forms as well as clinician/provider collected or self-report by patients.(25)

Several studies found variability with respect to the proportion of questions asked from a given screening instrument. Canadian researchers examined the implementation of social risk screening tools in 3 different organizations and found variation in their use that aligned with the service delivery mandate of the organization.(48) This same latitude is reported in other research where the screening tool's use was adapted to the viewpoint of the organization and questions deemed by physicians and care teams to be most impactful to address were prioritized.(25, 95) The comfort levels of staff asking the questions sometime translates to reluctance to apply the full set questions, trimming them to a subset when surveying patients.(48) This notion was reported elsewhere, with the practice of selective screening where only certain types of patients are assessed by staff based on perceived need from a personal bias or organizational focus.(87) This cherry picking approach has been noted to create data collection bias that affects data quality but can also erode patient trust and exacerbate stigma, discrimination, and health disparities.(87). Similar concerns were raised by other research that came to question the sensitivity, cultural competence, or readiness for actionability in interventions designed to fill social needs.(79) Researchers warn that poor data collection practices can compromise therapeutic relationships and further marginalize patients (Wallace et al., 2020).

Variability in the mode, timing, and context by which the sociodemographic screening questions are asked was also reported in the literature. Modes included paper-based questionnaires, questions asked by a staff person and entered the EHR or use of a waiting room tablet. Furthermore, there is more variability seen with respect to who is asking the question among administrative staff, nurses, doctors other allied care, or no one in the case of patients' direct entry. Ensuring that the patient understands the questions creates another realm of uncertainty across all collection modes. And finally, the research shows that the timing and context of data collection is highly variable; at initial patient intake; during a clinical encounter; or by the patient themselves within the waiting room, or later and external to the clinic experience using secure web tools.(32, 104)

Still, even with these calls for more consistent, and complete SDoH data collection there remains certain expert opinion that concludes that a single approach will not work for all organizations. This opinion holds that SDoH data collection will only be meaningful and therefore feasible if there is allowance to tailor data collection based on the population they serve, the financial resources available, and the capacity of the electronic health record.(105)

3.423 Resourcing Data Collection

The considerable resource burden related to direct and manual collection of SDOH data can be a major disincentive for data collection. Healthcare providers engaged in pilot projects for SDoH data capture noted the task to be time consuming, laborious, and under-resourced. Without training and guidance, the collection of data can be subject to certain personal bias resulting, for example, in certain questions not asked out of discomfort.(48) In a systematic review, the integration of SDoH domains into electronic health records (EHRs) was examined in terms of resource requirements. Authors found evidence for the need for workforce training, capacity planning, community resource identification, and easy allocation of SDoH resources at the point of care.(83) Other ethnographic research(48) discovered that although care providers agreed that the addition of social context through SDoH data collection is useful in the provision of care, the staff capacity and comfort level in its collection of the information were variable. In connection, this research found that having executive level commitment and leadership support for health equity was an important driver for adequate resourcing of SDoH data collection.(48) Other research cited barriers of SDoH data collection linked with no direct reimbursement, time pressures, and competing demands.(25)

The SDoH data collection experience by staff or patients is also influenced by the usability of tools and the strength of the EHR technology for data capture. Poor usability and lack of ability to customize the tools can present barriers in terms of resource consumption and data quality issues which can negatively influence widespread adoption of SDoH data collection and its use.(106). This is echoed in other research that found that the task of SDoH data collection added to busy clinical workflows but that structured formats that included drop-down menus eased the burden somewhat. Clinicians stated that patient-reported data through a patient portal significantly eased the workload and ensured consistent data capture.(25)

Resource implications of SDoH data collection and use is particularly relevant to Ontario’s current climate with healthcare providers stretched to their maximum due to critical shortages in staff and crushing amount of healthcare backlog to provide to Ontarians. The new call for consistently captured SDoH data collection will need to be seamlessly fitted into current workflow and even with that, its resource draw raises considerable red flags.

4. Discussion

4.1 Recommendations

A rich body of research can inform Ontario's SDoH standards journey. Taken together, several recommendations can be gleaned from more mature projects and programs of SDoH data collection and use in US healthcare systems and from smaller studies and explorations piloted within Canadian boundaries. The following section offers suggestions for Ontario in their journey of defining SDoH data standardization.

4.11 Leverage and Support of Early Adopters

Ontario is signaling certain momentum in SDoH data collection and use despite the absence of formal standards, mandates or incentives issued by government or funders. This foundational work is largely occurring in primary care as seen in the processes for collecting and applying SDoH data by way of the SPARK and Alliance initiatives. The SPARK method continues to advance via considerable and current research funding in support of further development and testing its methods and tools in SDoH collection and use. The Alliance collects their social demographic data in line with top organizational goals to serve marginalized Ontario populations and is guided by the key performance indicators serving as benchmarks as well as reporting requirements of equity driven outcomes. These two major initiatives serve as an excellent point from which to scale and spread SDoH collection and use, advancing health equity in Ontario. This advancement requires policy directive to ensure coordination across the province to arrive at standardly applied methods, tools and staff training, coding systems and the interoperable exchange of data across Ontario health and social systems.

4.12 Formalize SDoH Standards Development

Formalized SDoH standards development is the required precursor for adoptable and adaptable SDoH data standards. Current standards experts in the province need to inform standards development using consensus-driven best practice methods and resources need to be directed at SDoH standards communities and working groups. There is current interest in the formation of a Canadian SDoH Standards Group to drive this work at a national level. An upcoming meeting among representatives from CIHI, Canada Health Infoway, health Informatics academics, primary care SDoH-expert practitioners, Public Health Agency of Canada and government representatives is expected to foster key dialogue and a blueprint to SDoH data and system standardization. This group will be charged with defining engagement of key stakeholders, how standards work will be lead, resourced, and managed and how formed standards will be best implemented across provincial jurisdictions.

4.13 Piloting Before Mandates

With respect to Ontario Health's declared plan to mandate the collection of social demographic data, inadequately including and engaged stakeholders will be the recipe for failure. Inputs from across standards experts and standards development organizations, clinicians, researchers, health technology vendors are critical to inform upon the complex interplay of issues related to SDoH considerations with healthcare systems. An adequately resourced and dedicated program trialing the adoption of best practice in SDoH data collection, use and exchange through pilot projects at key sites, leveraging the organizational structure and network of Ontario Health Teams and Primary Care Research and Learning Networks such as POPLAR (https://www.poplarnetwork.ca/), would be next best steps. Results of comprehensive pilot projects that test the implementation of social demographic data collection tools, and primary and secondary use of these data could inform province-wide implementation of new, finalized data standards. Process evaluation can inform whether SDoH data contributes to health equity achievement in Ontario. Ongoing support for continuous quality improvement in the way of development, testing and knowledge translation of SDoH data standardization initiatives will also be key for sustaining work in this dynamic domain.

4.14 Meaningful Incentives

Incentives are important drivers for SDoH data standardization and these need to be directed at EHRs vendors, health care providers and their organizations, researchers and analysts and patients. Several sections of this report have already alluded to what are meaningful incentives across relevant stakeholders. Vendors need regulatory and market pressure to build the EHR tools required to support SDoH standardization. Health care providers need to adequately engage in programs of SDoH data collection and their leadership needs to sponsor and tool staff to do so. Researchers and analysts need to be awarded funding to leverage secondary use of SDoH data to feed the knowledge cycle of progress on SDoH data informing Ontario health equity priorities.

A combined bottom up and top-down incentivization pressure is required. Ministry of Health Funding, mandates for data collection, provisioning of well tested protocols for standards use and their accessible tools is required from the top. On-the-ground work should compose OH Health Team coordination, local championing, promotion across health organizations with full leadership buy-in, staff training and change management. Other critical factors will be the need for consensus driven standards that have some flexibility in their implementation across organizations without compromising their purpose in establishing common ground for collection and use and comparable SDoH data in health systems. This process needs to unfold in a timely manner with focused deliverables and lead time for vendors to see value and act upon market opportunity to build, test, release and monitor product lines for both primary and secondary use of SDoH data.

4.15 Foster the Role of Data Steward

Data stewardship is enacted at organization levels to ensure that data can be used as a consistent, secure, and organized asset that meets policies and standards.(107) The appropriate application of data standards by data stewards offers both transparency and benchmarking opportunities for organizations.(108) Organizations that can demonstrate apt use of data standards benefit from having their policies and processes tangible to stakeholders, funders, and regulators. The practice of data stewardship is intertwined with the application of digital health standards and this role is particularly important for Ontario's burgeoning programs for SDoH data collection, sharing and use. Ontario data stewards would assume the responsibility, guided by professional principles and practices, of ensuring appropriate use of SDoH data, spanning data collection, viewing, storage, exchange, aggregation, and analysis. A named data steward is accountable to the SDoH data and assumes liability associated with inappropriate use. Health data stewardship bridges the benefit to society from using individuals' social information to improve understanding of its effect on health and health care while at the same time respecting individuals' privacy and confidentiality.(108)

Leadership within the Canadian Health Information Management Association (CHIMA), a professional organization for 5,800 health information members across Canada supports the role of data steward in the expansion of professional roles in the health information landscape.(109) Canadian experts state that data stewardship is an imperative for modernizing the health care system with digital health solutions and data science, transforming, and subsuming the antiquated role of health information custodian. Goel (lead of the Pan Canadian Health Data Strategy) and McGrail describe the culture of data stewardship that establishes a clear code of conduct for uses of data, including expectations to:

- reuse data assets (standards, data sets);
- contribute data assets for others to reuse easily;
- simplify data linking to common master data;
- adhere to prescribed privacy law and understand health data policy;
- define scenarios where data must be shared and how new scenarios are reviewed; (31)

In this light, one can not possibly imagine SDoH data standardization without the coordinated practice of data stewardship positioned both vertically and horizontally through Ontario's healthcare system.

4.16 Synergistic Goals: Learning Health System and Equity in Healthcare

This report has demonstrated that timely access to accurate and complete SDoH data is critical for identifying specific and sometimes shifting, social risk factors of individuals and populations. It is a key facet for evolving the health system to effectively meet and deliver on value based, equitable healthcare. SDoH data uses align with those of a learning health system among:

1. Medical Care
2. Population Health Management
3. Community Health Improvement
4. Social risk interventions
5. Risk adjustments
6. Research

(53-55, 57, 58):

A key facet in Learning Health Systems (LHS) for Ontario is the requisite interoperability among the mosaic of digital health systems to support shared information gathering and exchange between systems and the organizations that host them. Nimble, cross-sector exchange of SDoH related information, across the continuum of health and social systems, is critical for addressing social factors that adversely affect health outcomes. Tenets of the LHS are key factors in designing Ontario-based systems for SDoH data collection and a solid foundation of health data standards should form its basis.

4.17 Need for Canadian Research

Many accounts in the literature suggest that the complexity of SDoH data collection, sharing and use toward meaningful interventions and their evaluations require a continuous loop of trials and improvements. Canadian health and social policy experts are calling for the need for more funding to support rigorous evaluation of health services research toward informing health equity reform.(110) The innovation required in Ontario's health equity aims requires new, sizeable investment research for success to be seen health equity projects and programs.(110)

Standardly collected SDoH data and a supporting digital infrastructure are critical to drive research that define health equity gaps, their interventions and the effect of these experimental approaches that inform policy. Programs of health equity research need to first determine the accurate prevalence of health inequity which requires robust SDoH reporting. Next with high fidelity systems that define social risk of individuals and communities, research needs to test interventions with pilots, followed by large scale trials of interventions aimed at closing the equity gap. Finally, knowledge translation activities need to be both nimble and timely on the reporting of all levels of progress back to decision makers to toward operationalizing a learning health system approach.

There is significant commitment to supporting SDoH research in Canada. The Canadian Institutes of Health Research (CIHR) Institute of Health Services and Policy Research (IHSPR) has recently released a strategic plan to guide and support research that informs on robust and meaningful SDoH collection and use within our healthcare systems.(4) The research agenda would include the development and testing of tools for data collection and the use and exchange of these data, epidemiological study of populations afforded with these standardized SDoH data as well as interventions to promote the Quadruple Aim. As discussed previously a Quintuple Aim that embeds equity is all processes is a SDoH upgrade to the Quintuple Aim.(5)

Furthermore, a research standard for equity driven projects should be mandated by top health research funders. Research has shown a dearth in the reporting of SDoH related outcomes (49) However, in response to that gap, there appears to be new support for establishing standards for equity-driven research, for example, Welch et al are funded to develop reporting guidelines for health equity in observational research.(111)

Research leadership of SDoH data standards also has candidacy in the recently launched Strategy for Patient Oriented Research (SPOR)- Primary Care Research Network (PCRN).(112) The SPOR-PCRN is the spawn of the Primary and Integrated Health Care Innovations Network (PIHCIN) which was a key CIHR initiative under the Strategy for Patient-Oriented Research. The aim of the new SPOR PCRN is broad: facilitating reach, adaptation, and accessibility of successful patient-oriented primary and integrated health care innovations to new sites, new settings, and/or new populations. Equity driven outcomes are a key mandate of PCRN which will be fostered through research, training, mentorship, collaborations, and partnerships. These aims align with foundation and strategy needed for SDoH data standardization within primary care.

The SPOR-PCRN capacity to lead and steer resources, expertise, and momentum toward Canada’s SDoH data initiatives could leverage Ontario’s ongoing work in this domain and also see the Ontario population benefit from this nationally coordinated work in SDoH data standards.

4.2 Limitations

This report has provided a limited scope of information related to the collection of indigenous identity data in healthcare systems. Principles of First Nations data collection are guided by OCAP®(https://fnigc.ca/OCAP) and are framed by the tenet of "nothing about us, without us"(113). Dialogue and direct engagement with indigenous communities in Ontario have begun the process of cooperative, community-drive planning of indigenous status data collection. Some health systems, in particular Aboriginal Health Centres operating under the governance of the Alliance for Healthier Communities and other Ontario primary care research and learning networks Northern Ontario School of Medicine Research Toward Health Hub (NORTHH) have prioritized Indigenous data sovereignty. Finally, experts in honouring indigenous data in research and epidemiology are leading the way in bridging academic and health systems communities with indigenous communities (e.g. Jennifer Walker, Indigenous Health Lead, ICES and Associate Professor, Health Research Methods, Evidence, and Impact, McMaster University) and should be engaged as SDoH data standards expert advisors. Still, this topic is only unfurling in the literature(114) and being plotted within guidance documents. Given the overall complexity around indigenous data collection and use, this report has formed fewer recommendations around best practices in SDoH data collection and use as it pertains to indigenous populations.

Another limitation of this research is the constraint of literature searching to that of Medline and the omission of strategy translation and searching within other databases such as EMBASE. Since the focus of this state-of-the-art review was of an Ontario context and the composite of Canadian literature is indexed in Medline, this limitation is considered to not have affected the comprehensiveness of this report.

5. Conclusion

This report serves to demonstrate the importance of SDoH, and its composite social risk factor and social needs data, as important upstream factors affecting the health of individuals and populations and contributing to health inequities. SDoH data are not routinely captured as discrete data elements in a structured and systematic manner within electronic health records (EHRs) in many jurisdictions including Ontario's. Data standards need to be defined, adopted, and managed to support robust SDoH data collection in EHRs, and applied to the appropriate and meaningful use and exchange across health and social systems. Research in Canada and the US can inform on best practices in the SDoH data standards landscape, and this continued research is required to define, develop, and test systems for SDoH data collection and use.

Models of practice for SDoH standardization are available to guide Ontario's work in health equity in step with learning health system development. Collaboration among academia, clinicians and standards and health informatics experts, with resource backing by health system funders will help Ontario realize standardized SDoH data practice.

Glossary

Data governance: The overall administration, through clearly defined procedures and plans, that assures the availability, integrity, security, and usability of the structured and unstructured data available to an organization. (115)

Data standardization: Use of agreed upon terms, codes, processes to collect complete, structured and meaningful data

Data stewardship: The active management of data and processes so data can be used as a consistent, secure and organized asset that meets policies and standards.

Learning health system (LHS) A concept developed in 2007 by the Institute of Medicine (now the National Academies of Medicine) regarding systems in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience.

Health equity: The absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically.

Social determinants of health (SDoH): the conditions in which people are born, grow, live, work and age and the wider set of forces and systems (economic policies, social policies, and political systems) shaping the conditions of daily life". (8)

References

1. Institute of Medicine Committee on Quality of Health Care in A. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US) Copyright 2001 by the National Academy of Sciences. All rights reserved.; 2001.

2. Public Health Agency of Canada. Key Health Inequalities in Canada A National Portrait [Internet]. Ottawa, ON: Public Health Agency of Canada; August 2018 [reviewed 2022 June 16]. Available from: https://www.canada.ca/content/dam/phac-aspc/documents/services/publications/science-research/key-health-inequalities-canada-national-portrait-executive-summary/hir-executive-summary-eng.pdf

3. Lucyk K. Intersectoral action on the social determinants of health and health equity in Canada: December 2019 federal government mandate letter review. Health Promot Chronic Dis Prev Can. 2020;40(10):314-23.

4. Canadian Institutes of Health Research. Strategic Plan 2021–2026: Accelerate Health System Transformation through Research to Achieve the Quadruple Aim and Health Equity for All. [Internet]. Ottawa, ON: CIHI; 2021 [reviewed June 16, 2022]. Available from: https://cihr-irsc.gc.ca/e/documents/ihspr_strat_plan_2021-26-en.pdf

5. Nundy S, Cooper LA, Mate KS. The Quintuple Aim for Health Care Improvement: A New Imperative to Advance Health Equity. JAMA. 2022;327(6):521-2.

6. Public Health Agency of Canada. What is the Population Health Approach? [Internet]. Ottawa, ON: Public Health Agency of Canada; [updated Feb 7, 2012; reviewed June 16, 2022]. Available from: https://www.canada.ca/en/public-health/services/health-promotion/population-health/population-health-approach.html

7. Mohanty N, Salgado C, Rapoport A, Sarma Baxi R, Panzer J, Simon J. The people, process, and technology for population management in community health. Fam Syst Health. 2021;39(1):112-20.

8. World Health Organization - Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. [Internet]. Geneva: World Health Organization; 2008 [reviewed June 16, 2022]. Available from: https://apps.who.int/iris/bitstream/handle/10665/43943/9789241563703_eng.pdf;jsessionid=365271ACE2052888542881700EEDCA8B?sequence=1

9. Cruz TM, Smith SA. Health Equity Beyond Data: Health Care Worker Perceptions of Race, Ethnicity, and Language Data Collection in Electronic Health Records. Med Care. 2021;59(5):379-85.

10. Canadian Institute for Health Information. Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada. [Internet]. Ottawa, ON: CIHI; 2022. [reviewed June 16, 2022]. Available from: https://www.cihi.ca/sites/default/files/document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf.

11. Kiran T, Sandhu P, Aratangy T, Devotta K, Lofters A, Pinto AD. Patient perspectives on routinely being asked about their race and ethnicity: Qualitative study in primary care. Can Fam Physician. 2019;65(8):e363-e9.

12. Lu C, Tago A, Olaiya O, Verhovsek M. Race-based data collection among COVID-19 inpatients: A retrospective chart review. Healthc Manage Forum. 2022;35(3):130-4.

13. McKenzie K. Race and ethnicity data collection during COVID-19 in Canada: if you are not counted you cannot count on the pandemic response. Wellesley Institute; November 12, 2020 [retrieved June 22, 2022]. Available from: https://rsc-src.ca/en/race-and-ethnicity-data-collection-during-covid-19-in-canada-if-you-are-not-counted-you-cannot-count

14. Gottlieb LM, Pantell MS, Solomon LS. The National Academy of Medicine Social Care Framework and COVID-19 Care Innovations. J Gen Intern Med. 2021;36(5):1411-4.

15. Badalov E, Blackler L, Scharf AE, Matsoukas K, Chawla S, Voigt LP, et al. COVID-19 double jeopardy: the overwhelming impact of the social determinants of health. Int J Equity Health. 2022;21(1):76.

16. Ndumbe-Eyoh S, Muzumdar P, Betker C, Oickle D. 'Back to better': amplifying health equity, and determinants of health perspectives during the COVID-19 pandemic. Glob Health Promot. 2021;28(2):7-16.

17. Corpus Sanchez International. Building a framework and plan to address equity, inclusion, diversity and anti-racism in Ontario. Final Report Submitted to Ontario Health. [Internet]. Toronto, ON: CSI Consultancy Inc. Oct, 2020. [reviewed June 16, 2022]. Available from: https://www.ontariohealth.ca/sites/ontariohealth/files/2021-01/CorpusSanchezInternationalReport.pdf

18. Alderwick H, Gottlieb LM. Meanings and Misunderstandings: A Social Determinants of Health Lexicon for Health Care Systems. Milbank Q. 2019;97(2):407-19.

19. Adler NE, Stead WW. Patients in context--EHR capture of social and behavioral determinants of health. N Engl J Med. 2015;372(8):698-701.

20. Davidson KW, Krist AH, Tseng CW, Simon M, Doubeni CA, Kemper AR, et al. Incorporation of Social Risk in US Preventive Services Task Force Recommendations and Identification of Key Challenges for Primary Care. JAMA. 2021;326(14):1410-5.

21. O'Neill B, Ferrer R, O'Brien P, Watt G, Gottlieb L, Pinto A, et al. Improving Equity Through Primary Care: Proceedings of the 2019 Toronto International Conference on Quality in Primary Care. Ann Fam Med. 2020;18(4):364-9.

22. Alliance for Healthier Communities. Implementing Health Equity for Change: A guide for policymakers and health system leaders in Ontario to take action. [Internet]. 2021 [reviewed June 16, 2022]. Available from: https://www.allianceon.org/sites/default/files/documents/implementing_health_equity_for_change_-_full_-_june_7.pdf

23. Cantor MN, Thorpe L. Integrating Data On Social Determinants Of Health Into Electronic Health Records. Health Aff (Millwood). 2018;37(4):585-90.

24. Canadian Institute for Health Information. Resources for measuring health inequalities: Equity Stratifier Inventory. [Internet]. Ottawa, ON: CIHI; 2022 [reviewed June 22, 2022]. Available from: https://www.cihi.ca/en/resources-for-measuring-health-inequalities

25. Lasser EC, Kim JM, Hatef E, Kharrazi H, Marsteller JA, DeCamp LR. Social and Behavioral Variables in the Electronic Health Record: A Path Forward to Increase Data Quality and Utility. Acad Med. 2021;96(7):1050-6.

26. Gottlieb L, Tobey R, Cantor J, Hessler D, Adler NE. Integrating Social And Medical Data To Improve Population Health: Opportunities And Barriers. Health Aff (Millwood). 2016;35(11):2116-23.

27. Davison K, Queen R, Lau F, Antonio M. Culturally Competent Gender, Sex, and Sexual Orientation Information Practices and Electronic Health Records: Rapid Review. JMIR Med Inform. 2021;9(2):e25467.

28. Lau F, Antonio M, Davison K, Queen R, Bryski K. An Environmental Scan of Sex and Gender in Electronic Health Records: Analysis of Public Information Sources. J Med Internet Res. 2020;22(11):e20050.

29. Wellesley Institute. Socio-demographic data and equity in health services in Ontario: building on strong foundations. [Internet]. Toronto, ON, Canada: Wellesley Institute; 2017 [reviewed June 22. 2022]. Available from: https://www.wellesleyinstitute.com/wp-content/uploads/2017/10/Collecting-Socio-demographic-Data.pdf

30. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. Health Info Libr J. 2009;26(2):91-108.

31. Goel V, McGrail K. Modernize the Healthcare System: Stewardship of a Strong Health Data Foundation. Healthc Pap. 2022;20(3):61-8.

32. Wang M, Pantell MS, Gottlieb LM, Adler-Milstein J. Documentation and review of social determinants of health data in the EHR: measures and associated insights. J Am Med Inform Assoc. 2021;28(12):2608-16.

33. eHealth Ontario. Standards Selection Guide. [Internet]. Toronto, ON: ehealth Ontario; 2013 [reviewed June 1, 2022]. Available from: https://ehealthontario.on.ca/files/public/support/Standards/eHealth_Standards_Selection_Framework_en.pdf

34. Hripcsak G, Forrest CB, Brennan PF, Stead WW. Informatics to support the IOM social and behavioral domains and measures. J Am Med Inform Assoc. 2015;22(4):921-4.

35. Canada Health Infoway. Standards: Ensuring clear and comprehensive communication between different systems and providers. [Internet]. Ottawa, ON: Canada Health Infoway; 2022. [reviewed: May 25, 2022]. Available from: https://www.infoway-inforoute.ca/en/digital-health-initiatives/standards

36. eHealth Ontario. Ontario EHR Interoperability Standards. [Internet]. Toronto, ON: eHealth Ontario; 2022. [reviewed June 12, 2022] Available from: https://ehealthontario.on.ca/en/it-professionals/standards

37. Shaw-Verbic T. Why FHIR, Why Now? [Internet] Ottawa, ON: Canada Health Infoway; Dec 14, 2017. [reviewed: June 1, 2022]. Available from: https://infocentral.infoway-inforoute.ca/en/resources/docs/2351-why-fhir-why-now-canada/view-document

38. Canadian Institute for Health Information. International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada (ICD-10-CA): Alphabetical Index and Tabular List. [Internet]. Ottawa, ON: CIHI; 2022. [reviewed July 15, 2022]. Available at: https://icd.who.int/browse10/2016/en#/Z55-Z65

39. Canadian Institute for Health Information. Codes and Classifications. [Internet]. Ottawa, ON: CIHI; 2022. Available from: https://www.cihi.ca/en/submit-data-and-view-standards/codes-and-classifications#:~:text=ICD%2D10%2DCA%20classi%EF%AC%81es%20diseases,and%20lifestyle%20and%20psychosocial%20circumstances.

40. Mangin D, Lawson J, Adamczyk K, Guenter D. Embedding "Smart" Disease Coding Within Routine Electronic Medical Record Workflow: Prospective Single-Arm Trial. JMIR Med Inform. 2020;8(7):e16764.

41. INSITE-Family Medicine Inc. Electronic Nomenclature and Classification of Disorders and Encounters for Family Medicine (ENCODE-FM). [Internet]. 2022. [reviewed June 16, 2022]. Available from: https://www.insite-fm.com/encode-fm

42. Personal communication, Dr. Jennifer Rayner, PhD, Director of Research and Evaluation, EPIC of the Alliance for Healthier Communities.

43. Pan-Canadian Health Data Strategy Expert Advisory Group. Pan-Canadian Health Data Strategy: Expert Advisory Group Report 1: Charting a Path toward Ambition. [Internet]. Ottawa, ON: PCHDS; June 2021. Available from: https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-01-charting-path-toward-ambition/pCHDS-first-EAG-report-en.pdf

44. Pan-Canadian Health Data Strategy Expert Advisory Group. Pan-Canadian Health Data Strategy: Expert Advisory Group Report 2: Building Canada's Health Data Foundation. [Internet]. Ottawa, ON: PCHDS; Nov 2021. Available from: 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-02-building-canada-health-data-foundation.html#a41

45. Pan-Canadian Health Data Strategy Expert Advisory Group. Pan-Canadian Health Data Strategy: Expert Advisory Group Final Report [3]: Toward a world-class health data system. [Internet]. Ottawa, ON: PCHDS; May 2022. Available from: 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-03-toward-world-class-health-data-system.html

46. Canadian Institute for Health Information. Measuring Health Inequalities: A Toolkit. [Internet]. Ottawa, ON: CIHI; 2018 [reviewed June 1, 2022. Available from: https://www.cihi.ca/en/measuring-health-inequalities-a-toolkit

47. Canadian Institute for Health Information. Pan-Canadian Primary Health Care EMR Minimum Data Set for Performance Measurement, Version 1.1. [Internet]. Ottawa, ON: CIHI; 2022. Available from: https://secure.cihi.ca/free_products/phc-emr-mds-v1.1-en.pdf

48. Williams-Roberts H, Neudorf C, Abonyi S, Cushon J, Muhajarine N. Facilitators and barriers of sociodemographic data collection in Canadian health care settings: a multisite case study evaluation. Int J Equity Health. 2018;17(1):186.

49. Orkin AM, Nicoll G, Persaud N, Pinto AD. Reporting of Sociodemographic Variables in Randomized Clinical Trials, 2014-2020. JAMA Netw Open. 2021;4(6):e2110700.

50. Ontario Health. Ontario Health's Equity, Inclusion, Diversity and Anti-Racism Framework. [Internet]. Toronto, ON: Ontario Health; 2020. Available from: https://www.ontariohealth.ca/sites/ontariohealth/files/2020-12/Equity%20Framework.pdf

51. Ontario Health. Digital Health Information Exchange Standard. [Internet]. Toronto, ON: Ontario Health; 2021. Available from: https://www.ontariohealth.ca/our-work/digital-standards/digital-health-information-exchange-standard

52. Ontario Regulation 569/20 made under the Personal Health Information Protection Act, 2004, S.O. 2004, c. 3, Sched. A, (October 9, 2020).

53. Alliance for Healthier Communities. Towards a Learning Health System. [Internet]. Toronto, ON: Ontario Health; 2018 [reviewed May 15, 2022]. Available from: https://www.allianceon.org/Health-Equity-Indicators-Project

54. Brooks D, Douglas M, Aggarwal N, Prabhakaran S, Holden K, Mack D. Developing a framework for integrating health equity into the learning health system. Learn Health Syst. 2017;1(3).

55. Feng P DRE, Reid R, Pinto A, Upshur R. Public Health and Learning Health Systems White Paper. 2021.

56. Embuldeniya G, Gutberg J, Sibbald SS, Wodchis WP. The beginnings of health system transformation: How Ontario Health Teams are implementing change in the context of uncertainty. Health Policy. 2021;125(12):1543-9.

57. Nash DM, Bhimani Z, Rayner J, Zwarenstein M. Learning health systems in primary care: a systematic scoping review. BMC Fam Pract. 2021;22(1):126.

58. Palakshappa D, Miller DP, Jr., Rosenthal GE. Advancing the learning health system by incorporating social determinants. Am J Manag Care. 2020;26(1):e4-e6.

59. Schleyer T, Williams L, Gottlieb J, Weaver C, Saysana M, Azar J, et al. The Indiana Learning Health System Initiative: Early experience developing a collaborative, regional learning health system. Learn Health Syst. 2021;5(3):e10281.

60. Public Health Ontario. COVID-19 – What We Know So Far About…Social Determinants of Health. [Internet]. 2020 [reviewed June 22, 2022]. Available from: https://www.publichealthontario.ca/-/media/documents/ncov/covid-wwksf/2020/05/what-we-know-social-determinants-health.pdf?la=en

61. Abdi S, Bennett-AbuAyyash C, MacDonald L, Hohenadel K, Johnson KO, Leece P. Provincial implementation supports for socio-demographic data collection during COVID-19 in Ontario's public health system. Can J Public Health. 2021;112(5):853-61.

62. Government of Ontario. Ontario Expanding Data Collection to Help Stop Spread of COVID-19. [Internet]. 2020[reviewed June 22, 2022]. Available from: https://news.ontario.ca/en/release/57217/ontario-expanding-data-collection-to-help-stop-spread-of-covid-19

63. Wray (with Ilene Hyman)- DGL Consulting AB, Bennett-AbuAyyash C, Kanee M, Lam R, Mohamed A, Tuck A. We ask because we care. The Tri-Hospital + TPH Health Equity Data Collection Research Project: Final Report. 2013. Available from:

http://torontohealthequity.ca/wp-content/uploads/2017/05/We-Ask-Because-We-Care-Report.pdf

64. Sinai Health System: Human Rights & Health Equity Office. Guide to Demographic Data Collection in Health-care Settings A comprehensive guide to planning and implementing demographic data collection in health-care settings. [Internet]. August 2017. Available from: http://torontohealthequity.ca/wp-content/uploads/2017/10/Measuring-Health-Equity-Guide-to-Demographic-Data-Collection.pdf

65. Pinto AD, Glattstein-Young G, Mohamed A, Bloch G, Leung FH, Glazier RH. Building a Foundation to Reduce Health Inequities: Routine Collection of Sociodemographic Data in Primary Care. J Am Board Fam Med. 2016;29(3):348-55.

66. Pinto AD, Bloch G. Framework for building primary care capacity to address the social determinants of health. Can Fam Physician. 2017;63(11):e476-e82.

67. National Academies of Sciences Engineering, and Medicine. Integrating Social Care into the Delivery of Health Care: Moving Upstream to Improve the Nation's Health. [Internet]. Washington, DC: The National Academies Press; 2019. Available from: https://doi.org/10.17226/25467

68. Cottrell EK, Gold R, Likumahuwa S, Angier H, Huguet N, Cohen DJ, et al. Using Health Information Technology to Bring Social Determinants of Health into Primary Care: A Conceptual Framework to Guide Research. J Health Care Poor Underserved. 2018;29(3):949-63.

69. Browne AJ, Varcoe CM, Wong ST, Smye VL, Lavoie J, Littlejohn D, et al. Closing the health equity gap: evidence-based strategies for primary health care organizations. Int J Equity Health. 2012;11:59.

70. Plamondon K, Neufeld V. Are we there yet? Principles in advancing equity though global public health research. Can J Public Health. 2022;113(2):178-83.

71. DeSilvey S. The Gravity Project. Early reflections on the US initiative to create social risk data and data standards. Health Terminology Standards Virtual Mini-Conference: Incorporating Social Determinants of Health (SDOH) Into Digital Health Systems; VirtualMay 19, 2021.

72. Arons A, DeSilvey S, Fichtenberg C, Gottlieb L. Documenting social determinants of health-related clinical activities using standardized medical vocabularies. JAMIA Open. 2019;2(1):81-8.

73. Gold R, Bunce A, Cowburn S, Dambrun K, Dearing M, Middendorf M, et al. Adoption of Social Determinants of Health EHR Tools by Community Health Centers. Ann Fam Med. 2018;16(5):399-407.

74. Gold R, Cottrell E, Bunce A, Middendorf M, Hollombe C, Cowburn S, et al. Developing Electronic Health Record (EHR) Strategies Related to Health Center Patients' Social Determinants of Health. J Am Board Fam Med. 2017;30(4):428-47.

75. Gold S, Batch A, McClure R, Jiang G, Kharrazi H, Saripalle R, et al. Clinical Concept Value Sets and Interoperability in Health Data Analytics. AMIA Annu Symp Proc. 2018;2018:480-9.

76. Hewner S, Casucci S, Sullivan S, Mistretta F, Xue Y, Johnson B, et al. Integrating Social Determinants of Health into Primary Care Clinical and Informational Workflow during Care Transitions. EGEMS (Wash DC). 2017;5(2):2.

77. Gruss I, Bunce A, Davis J, Dambrun K, Cottrell E, Gold R. Initiating and Implementing Social Determinants of Health Data Collection in Community Health Centers. Popul Health Manag. 2021;24(1):52-8.

78. Alliance for Healthier Communities. Health Equity Indicators Project. [Internet]. 2022. Available from: https://www.allianceon.org/Health-Equity-Indicators-Project

79. Palacio A, Suarez M, Tamariz L, Seo D. A Road Map to Integrate Social Determinants of Health into Electronic Health Records. Popul Health Manag. 2017;20(6):424-6.

80. Wark K, Cheung K, Wolter E, Avey JP. "Engaging stakeholders in integrating social determinants of health into electronic health records: a scoping review". Int J Circumpolar Health. 2021;80(1):1943983.

81. Hahn-Goldberg S, Pariser P, Schwenk C, Boozary A. Opportunity to inform social needs within a hospital setting using data-driven patient engagement. BMJ Open Qual. 2021;10(4).

82. Black Health Equity Working Group. Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities. [Internet]. 2021 [reviewed Feb 2022]. Available from: https://blackhealthequity.ca/wp-content/uploads/2021/03/Report_EGAP_framework.pdf

83. Chen M, Tan X, Padman R. Social determinants of health in electronic health records and their impact on analysis and risk prediction: A systematic review. J Am Med Inform Assoc. 2020;27(11):1764-73.

84. Freij M, Dullabh P, Lewis S, Smith SR, Hovey L, Dhopeshwarkar R. Incorporating Social Determinants of Health in Electronic Health Records: Qualitative Study of Current Practices Among Top Vendors. JMIR Med Inform. 2019;7(2):e13849.

85. Hassen N, Tyler I, Manson H. Influence of revised public health standards on health equity action: a qualitative study in Ontario, Canada. Int J Equity Health. 2017;16(1):187.

86. Hatef E, Weiner JP, Kharrazi H. A public health perspective on using electronic health records to address social determinants of health: The potential for a national system of local community health records in the United States. Int J Med Inform. 2019;124:86-9.

87. Kreuter MW, Thompson T, McQueen A, Garg R. Addressing Social Needs in Health Care Settings: Evidence, Challenges, and Opportunities for Public Health. Annu Rev Public Health. 2021;42:329-44.

88. Plamondon K, Neufeld V. Correction: Are we there yet? Principles in advancing equity though global public health research. Can J Public Health. 2022;113(2):184.

89. Upshaw TL, Brown C, Smith R, Perri M, Ziegler C, Pinto AD. Social determinants of COVID-19 incidence and outcomes: A rapid review. PLoS One. 2021;16(3):e0248336.

90. Zygmunt A, Kendall CE, James P, Lima I, Tuna M, Tanuseputro P. Avoidable Mortality Rates Decrease but Inequity Gaps Widen for Marginalized Neighborhoods: A Population-Based Analysis in Ontario, Canada from 1993 to 2014. J Community Health. 2020;45(3):579-97.

91. Mulligan K, Bhatti S, Rayner J, Hsiung S. Social Prescribing: Creating Pathways Towards Better Health and Wellness. J Am Geriatr Soc. 2020;68(2):426-8.

92. Nnorom O, Sappong-Kumankumah A, Olaiya OR, Burnett M, Akor N, Shi N, et al. Afrocentric screening program for breast, colorectal, and cervical cancer among immigrant patients in Ontario. Can Fam Physician. 2021;67(11):843-9.

93a. Jones MK, Bloch G, Pinto AD. A novel income security intervention to address poverty in a primary care setting: a retrospective chart review. BMJ Open. 2017;7(8):e014270.

93b. Pinto AD, Bondy M, Rucchetto A, Ihnat J, Kaufman A. Screening for poverty and intervening in a primary care setting: an acceptability and feasibility study. Fam Pract. 2019;8;36(5):634-638.

94. Gottlieb LM, Wing H, Adler NE. A Systematic Review of Interventions on Patients' Social and Economic Needs. Am J Prev Med. 2017;53(5):719-29.

95. Parry J, Vanstone M, Grignon M, Dunn JR. Primary care-based interventions to address the financial needs of patients experiencing poverty: a scoping review of the literature. Int J Equity Health. 2021;20(1):219.

96. Eder M, Henninger M, Durbin S, Iacocca MO, Martin A, Gottlieb LM, et al. Screening and Interventions for Social Risk Factors: Technical Brief to Support the US Preventive Services Task Force. JAMA. 2021;326(14):1416-28.

97. Yan AF, Chen Z, Wang Y, Campbell JA, Xue QL, Williams MY, et al. Effectiveness of Social Needs Screening and Interventions in Clinical Settings on Utilization, Cost, and Clinical Outcomes: A Systematic Review. Health Equity. 2022;6(1):454-75.

98. Gold R, Bunce A, Cottrell E, Marino M, Middendorf M, Cowburn S, et al. Study protocol: a pragmatic, stepped-wedge trial of tailored support for implementing social determinants of health documentation/action in community health centers, with realist evaluation. Implement Sci. 2019;14(1):9.

99. Cottrell EK, Dambrun K, Cowburn S, Mossman N, Bunce AE, Marino M, et al. Variation in Electronic Health Record Documentation of Social Determinants of Health Across a National Network of Community Health Centers. Am J Prev Med. 2019;57(6 Suppl 1):S65-S73.

100. Deferio JJ, Breitinger S, Khullar D, Sheth A, Pathak J. Social determinants of health in mental health care and research: a case for greater inclusion. J Am Med Inform Assoc. 2019;26(8-9):895-9.

101. Blair A, Warsame K, Naik H, Byrne W, Parnia A, Siddiqi A. Identifying gaps in COVID-19 health equity data reporting in Canada using a scorecard approach. Can J Public Health. 2021;112(3):352-62.

102. Truong HP, Luke AA, Hammond G, Wadhera RK, Reidhead M, Joynt Maddox KE. Utilization of Social Determinants of Health ICD-10 Z-Codes Among Hospitalized Patients in the United States, 2016-2017. Med Care. 2020;58(12):1037-43.

103. Venzon A, Le TB, Kim K. Capturing Social Health Data in Electronic Systems: A Systematic Review. Comput Inform Nurs. 2019;37(2):90-8.

104. Johnson CB, Luther B, Wallace AS, Kulesa MG. Social Determinants of Health: What Are They and How Do We Screen. Orthop Nurs. 2022;41(2):88-100.

105. Tan-McGrory A, Bennett-AbuAyyash C, Gee S, Dabney K, Cowden JD, Williams L, et al. A patient and family data domain collection framework for identifying disparities in pediatrics: results from the pediatric health equity collaborative. BMC Pediatr. 2018;18(1):18.

106. Troseth MR. American Academy of Nursing Endorses Social Behavioral Determinants of Health in Electronic Health Records. Comput Inform Nurs. 2017;35(7):329-30.

107. Pratt M. What is data stewardship? [Internet]. [updated March 2022; reviewed June 22, 2022]. Available from: https://www.techtarget.com/searchdatamanagement/definition/data-stewardship

108. Baird-Kanaan S, Carr J. Health Data Stewardship: What, Why, Who, How: An NCVHS Primer. [Internet]. Hyattsville, MD: National Committee on Vital and Health Statistics (NCVHS), U.S. Department of Health and Human Services; September 2009. Available from: https://www.ncvhs.hhs.gov/wp-content/uploads/2014/05/090930lt.pdf

109. Canadian Health Information Management Association. What is the real impact of health information? [Internet]. Ottawa, ON: CIHI ; November 26, 2021. Available from: https://www.echima.ca/what-is-the-real-impact-of-health-information/

110. Boozary A, Laupacis A. The mirage of universality: Canada's failure to act on social policy and health care. CMAJ. 2020;192(5):E105-E6.

111. Rizvi A, Lawson DO, Young T, Dewidar O, Nicholls S, Akl EA, et al. Guidance relevant to the reporting of health equity in observational research: a scoping review protocol. BMJ Open. 2022;12(5):e056875.

112. SPOR PCRN. Strategy for Patient Oriented Research (SPOR) [Internet]. Primary Care Research Network (PCRN). June, 2022 [reviewed June 22, 2022]. Available from: https://spor-pihci.com/

113. Carol PH. “Nothing About Us Without Us”: Taking Action on Indigenous Health. [Internet]. Insights. 2017. Available from: https://www.longwoods.com/product/24947

114. Carroll SR, Herczog E, Hudson M, Russell K, Stall S. Operationalizing the CARE and FAIR Principles for Indigenous data futures. Sci Data. 2021;8(1):108.

115. AHIMA. Social Determinants of Health: Improving Capture and Use by Applying Data Governance Strategies. [Internet]. Chicago, IL; 2021. Available from: https://journal.ahima.org/page/social-determinants-of-health-improving-capture-and-use-by-applying-data-governance-strategies

116. Canadian Government. Social determinants of health and health inequalities. [Internet]. [modified: 2022-06-14]. Available from: https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health.html#shr-pg0

Appendix 1: The Public Health Agency of Canada (PHAC) SDOH list

The Public Health Agency of Canada has defined main social determinants of health to include:

1. Income and social status
2. Employment and working conditions
3. Education and literacy
4. Childhood experiences
5. Physical environments
6. Social supports and coping skills
7. Healthy behaviours
8. Access to health services
9. Biology and genetic endowment
10. Gender
11. Culture
12. Race / Racism (116)

Appendix 2 – OVID Medline Search Strategy

Line	Search String	Result
1	social determinants of health.tw,kw. or "Social Determinants of Health"/	12349
2	*"Social Determinants of Health"/	3485
3	health equity.tw,kw. or Health Equity/	7963
4	(Electronic Medical Record or EMR or Electronic Health Records).tw,kw. or Electronic Health Records/	46212
5	Data Collection.tw,kw. or Data Collection/	179377
6	data standards.tw,kw.	782
7	1 or 3	19021
8	4 or 5 or 6	224264
9	7 and 8	761
10	limit 9 to (abstracts and english language and yr="2015 - 2022")	618
11	limit 2 to (abstracts and english language and "review articles" and yr="2017 - 2022")	241
12	10 or 11	853

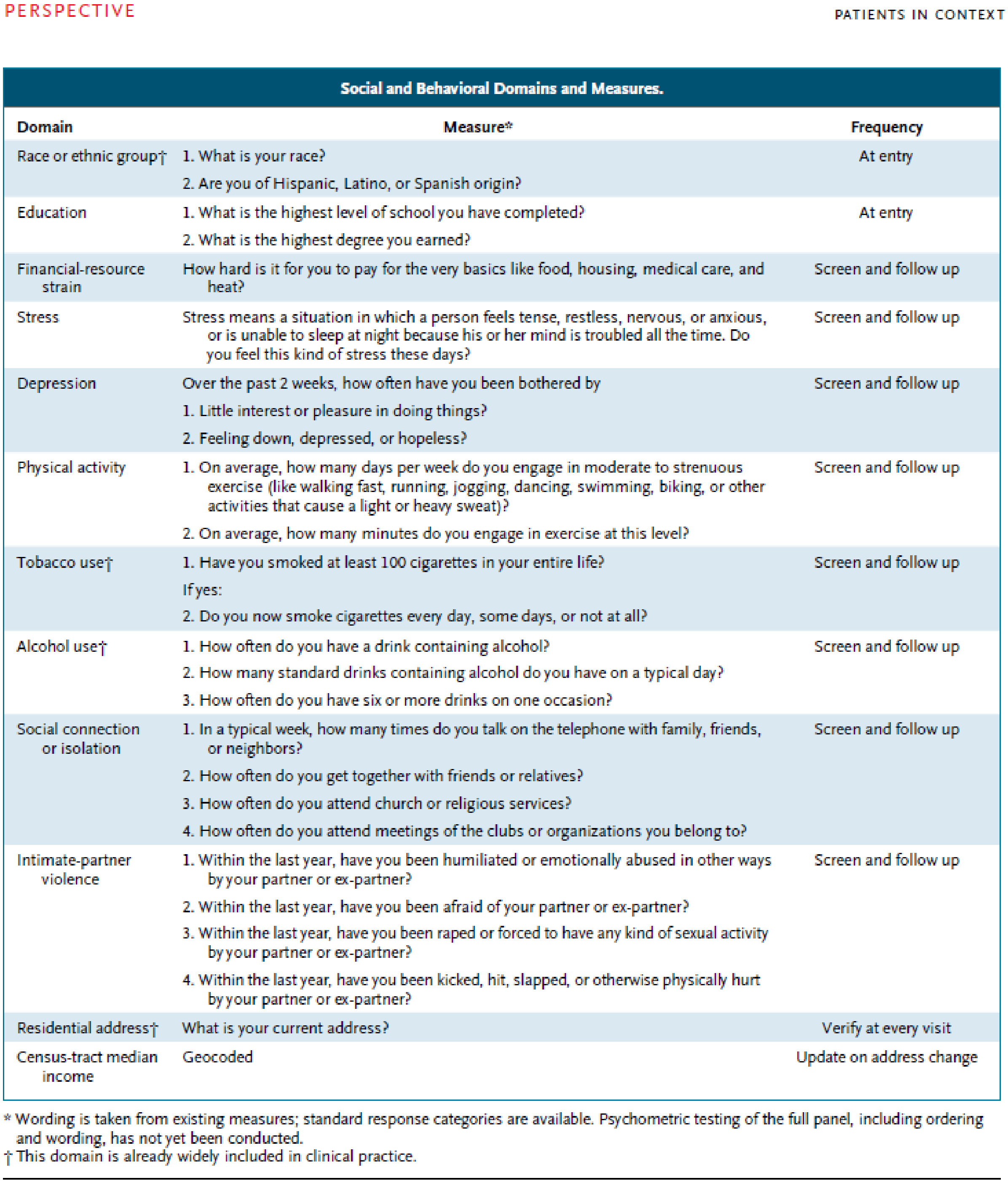
Appendix 3 - Screening Criteria for Ontario eHealth Standards

Fit for Purpose	Aligns to the Ontario EHR Blueprint
	Constrained/extended from existing interoperabiltiy standards
	Supports business requirements
	Supports technical requirements
	Adoption likelihood
	Supports coded data vs. free text
Stewardship	Cost of implementation
	Governance structure
	Intellectual property and licensing costs
	Defined maintenance process
Standard Quality	Provides implementatin support and education
	Enables interoperability
	Implementation and mainteance tools
	Conformance testing methodologies and tools
	Proven stability
	Adaptable and customizable

(33)

Appendix 4 – IOM Social Domains and Measures

The IOM committee developed metrics that reflect social and behavioral determinants of health including standardized questions for four domains that are already widely assessed in clinical practice and for eight additional domains.(19)



PERSPECTIVE

PATIENTS IN CONTEXT

Social and Behavioral Domains and Measures.

Domain	Measure*	Frequency
Race or ethnic group†	1. What is your race? 2. Are you of Hispanic, Latino, or Spanish origin?	At entry
Education	1. What is the highest level of school you have completed? 2. What is the highest degree you earned?	At entry
Financial-resource strain	How hard is it for you to pay for the very basics like food, housing, medical care, and heat?	Screen and follow up
Stress	Stress means a situation in which a person feels tense, restless, nervous, or anxious, or is unable to sleep at night because his or her mind is troubled all the time. Do you feel this kind of stress these days?	Screen and follow up
Depression	Over the past 2 weeks, how often have you been bothered by 1. Little interest or pleasure in doing things? 2. Feeling down, depressed, or hopeless?	Screen and follow up
Physical activity	1. On average, how many days per week do you engage in moderate to strenuous exercise (like walking fast, running, jogging, dancing, swimming, biking, or other activities that cause a light or heavy sweat)? 2. On average, how many minutes do you engage in exercise at this level?	Screen and follow up
Tobacco use†	1. Have you smoked at least 100 cigarettes in your entire life? If yes: 2. Do you now smoke cigarettes every day, some days, or not at all?	Screen and follow up
Alcohol use†	1. How often do you have a drink containing alcohol? 2. How many standard drinks containing alcohol do you have on a typical day? 3. How often do you have six or more drinks on one occasion?	Screen and follow up
Social connection or isolation	1. In a typical week, how many times do you talk on the telephone with family, friends, or neighbors? 2. How often do you get together with friends or relatives? 3. How often do you attend church or religious services? 4. How often do you attend meetings of the clubs or organizations you belong to?	Screen and follow up
Intimate-partner violence	1. Within the last year, have you been humiliated or emotionally abused in other ways by your partner or ex-partner? 2. Within the last year, have you been afraid of your partner or ex-partner? 3. Within the last year, have you been raped or forced to have any kind of sexual activity by your partner or ex-partner? 4. Within the last year, have you been kicked, hit, slapped, or otherwise physically hurt by your partner or ex-partner?	Screen and follow up
Residential address†	What is your current address?	Verify at every visit
Census-tract median income	Geocoded	Update on address change

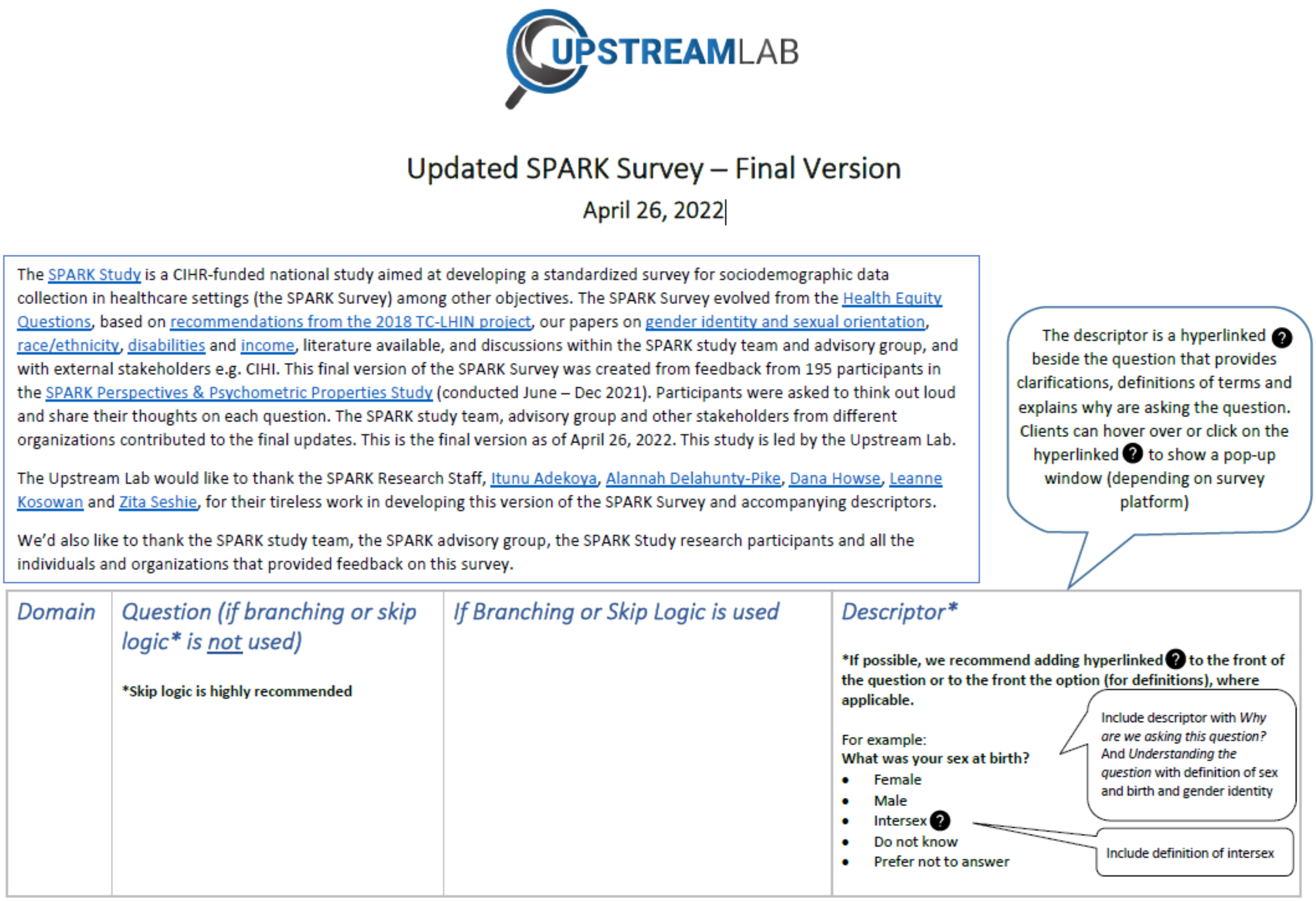
* Wording is taken from existing measures; standard response categories are available. Psychometric testing of the full panel, including ordering and wording, has not yet been conducted.

† This domain is already widely included in clinical practice.

(19)

Appendix 5: Sample of Updated SPARK Survey – Final Version

An excerpt from the SPARK Survey that composes 8 demographic questions, 10 social needs questions and 2 optional questions (93b).



UPSTREAMLAB

Updated SPARK Survey – Final Version

April 26, 2022

The SPARK Study is a CIHR-funded national study aimed at developing a standardized survey for sociodemographic data collection in healthcare settings (the SPARK Survey) among other objectives. The SPARK Survey evolved from the Health Equity Questions, based on recommendations from the 2018 TC-LHIN project, our papers on gender identity and sexual orientation, race/ethnicity, disabilities and income, literature available, and discussions within the SPARK study team and advisory group, and with external stakeholders e.g. CIHI. This final version of the SPARK Survey was created from feedback from 195 participants in the SPARK Perspectives & Psychometric Properties Study (conducted June – Dec 2021). Participants were asked to think out loud and share their thoughts on each question. The SPARK study team, advisory group and other stakeholders from different organizations contributed to the final updates. This is the final version as of April 26, 2022. This study is led by the Upstream Lab.

The Upstream Lab would like to thank the SPARK Research Staff, Itunu Adekoya, Alannah Delahunty-Pike, Dana Howse, Leanne Kosowan and Zita Seshie, for their tireless work in developing this version of the SPARK Survey and accompanying descriptors.

We'd also like to thank the SPARK study team, the SPARK advisory group, the SPARK Study research participants and all the individuals and organizations that provided feedback on this survey.

The descriptor is a hyperlinked ? beside the question that provides clarifications, definitions of terms and explains why are asking the question. Clients can hover over or click on the hyperlinked ? to show a pop-up window (depending on survey platform)

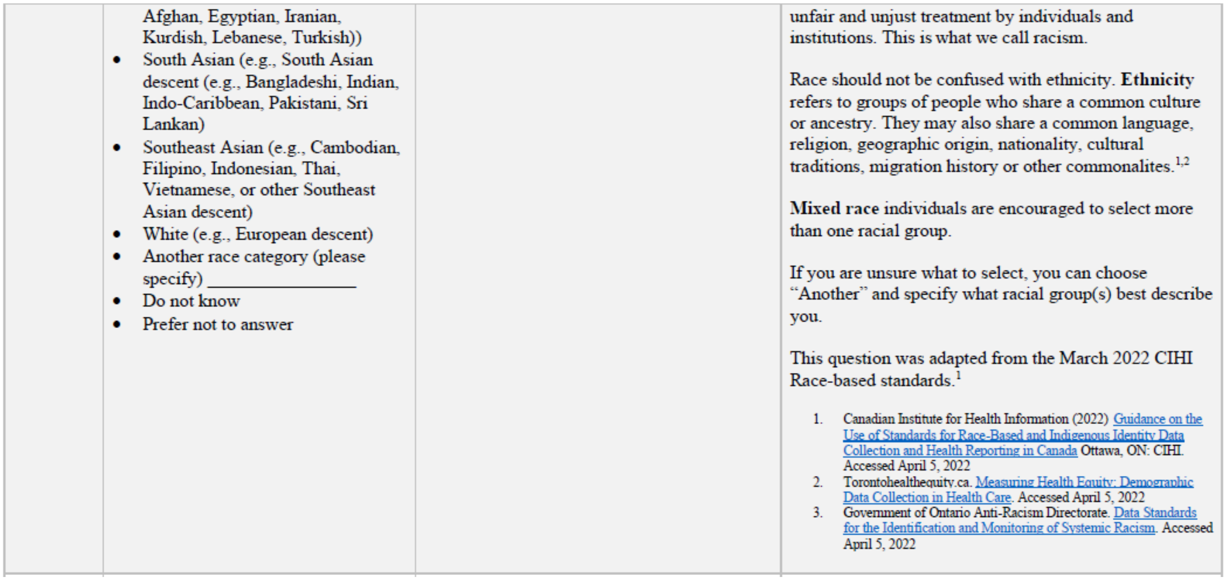
Domain	*Question (if branching or skip logic* is not used)* ***Skip logic is highly recommended**	*If Branching or Skip Logic is used*	*Descriptor** ***If possible, we recommend adding hyperlinked ? to the front of the question or to the front the option (for definitions), where applicable.**
			For example: **What was your sex at birth?** • Female • Male • Intersex ? • Do not know • Prefer not to answer

Include descriptor with *Why are we asking this question?* And *Understanding the question* with definition of sex and birth and gender identity

Include definition of intersex

Demographics			
1: Language	**a) If available, would you prefer your healthcare appointments offered in another language?** • Yes • No • Do not know • Prefer not to answer b) **If yes, which language?** (drop-down menu) • English [if applicable] • French [if applicable] • Arabic • Cantonese • Dene • German • Greek • Gujarati • Hindi • Inuktitut • Italian • Korean • Mandarin • Montagnais (Innu) • Ojib-Cree • Ojibway • Persian (Farsi) • Polish • Portuguese • Punjabi (Panjabi) • Romanian • Russian • Spanish	**a) If available, would you prefer your healthcare appointments offered in another language?** • Yes → Go to question 1b • No → Go to question 2 • Do not know → Go to question 2 • Prefer not to answer → Go to question 2 b) [If yes in 1a] **Which language?** (drop-down menu) • English [if applicable] • French [if applicable] • Arabic • Cantonese • Dene • German • Greek • Gujarati • Hindi • Inuktitut • Italian • Korean • Mandarin • Montagnais (Innu) • Ojib-Cree • Ojibway • Persian (Farsi) • Polish • Portuguese • Punjabi (Panjabi) • Romanian • Russian • Spanish	**Why are we asking this question?** This information lets us know who may want an interpreter or translation services at our clinic. This may also help us provide appropriate care to people who do not speak or read English or French.

4: Race	**In our society, people are often described by their race or racial background. Our race may influence the way we are treated by individuals and institutions, and this may affect our health. Which category(ies) best describes you? Select all that apply**: • Black (e.g., African, African Canadian, Afro-Caribbean descent) • East Asian (e.g., Chinese, Japanese, Korean, Taiwanese descent) • Indigenous (e.g., First Nations, Métis, Inuk/Inuit) • Latin American (Hispanic or Latin American descent) • Middle Eastern (e.g., Arab, Persian, West Asian descent (e.g.,	Not Applicable	**Why are we asking this question?** We are asking this question on race to help us know who we serve at the clinic. We're interested in monitoring the experience our clients have in the clinic to ensure that everyone has a positive experience regardless of their racial background. This information may also help us identify and address differences in health outcomes experienced by different racial groups. **Understanding the question:** **Race** is a term used to classify people into groups usually based on observable physical characteristics (for example, skin colour) but can also include characteristics such as accent or dress.[1,2,3] Although these differences or groupings are created by the society we live in, racial categories can have significant consequences for people's lives, including



	Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish)) - South Asian (e.g., South Asian descent (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan) - Southeast Asian (e.g., Cambodian, Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent) - White (e.g., European descent) - Another race category (please specify) _______________ - Do not know - Prefer not to answer		unfair and unjust treatment by individuals and institutions. This is what we call racism. Race should not be confused with ethnicity. **Ethnicity** refers to groups of people who share a common culture or ancestry. They may also share a common language, religion, geographic origin, nationality, cultural traditions, migration history or other commonalites.[1,2] **Mixed race** individuals are encouraged to select more than one racial group. If you are unsure what to select, you can choose "Another" and specify what racial group(s) best describe you. This question was adapted from the March 2022 CIHI Race-based standards.[1] 1. Canadian Institute for Health Information (2022) Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada Ottawa, ON: CIHI. Accessed April 5, 2022 2. Torontohealthequity.ca. Measuring Health Equity: Demographic Data Collection in Health Care. Accessed April 5, 2022 3. Government of Ontario Anti-Racism Directorate. Data Standards for the Identification and Monitoring of Systemic Racism. Accessed April 5, 2022

(93b)