McMaster University

Family Medicine

Socio-demographic data collection: Current evidence and practice in primary care research

RKSB Mar 22, 2022

Presented by the Socio-demographic Data (SDD) Working Group:

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Michael G. DeGroote SCHOOL OF MEDICINE

Objectives of RKSB Session

1. Introduce key concepts around sociodemographic data (SDD) collection and use for primary care research
2. Describe the process and findings of the environmental scan to explore this topic
3. Share knowledge and resources with an aim of developing guiding principles for DFM
4. Discuss local experiences and ideas in SDD collection for DFM Research

What is health equity?

Health inequities are health differences between population groups that are systematic, avoidable, and unfair.

> Health equity exists when all people can reach their full health potential and are not disadvantaged from attaining it because of their race, ethnicity, religion, gender, age, social class, socioeconomic status, sexual orientation or other socially determined circumstance.

Source: National Collaborating Centre for Determinants of Health; adapted from Dahlgren and Whitehead, 2006

Current Context: Sociodemographic data collection and use

- Researchers long been advocating for the collection of race-based and socio-demographic data to be able to better understand disparate health outcomes and barriers to equitable care at the population-level
- The COVID 19 pandemic shed light on underlying social inequities and spurred more action by government, standards communities, academics and community organizations to find effective solutions for the collection and best use of these data
- https://www.healthcommons.ca/blog/engaging-communities-in-your-data-collection-initiative

Social Determinants of Health SDoH

Interrelated social, political and economic factors that create the conditions in which people live, learn, work and play

- gender / gender identity
- race / racialization
- ethnicity
- indigeneity
- colonization
- migrant and refugee experiences
- religion
- culture
- education / literacy
- health literacy
- occupation / working conditions
- income / income security
- employment / job security
- early life experiences
- disability
- nutrition / food security
- discrimination / social exclusion / social inclusion
- nutrition / food security
- housing / housing security
- natural and built environments
- social safety net / social protection
- access to health services

National Collaborating Centre for Determinants of Health. Glossary.

Income
Health services
Disability
Early life experiences
Employment and working conditions
Sexual orientation
Housing
Education
Aboriginal status
Food insecurity
Gender
Social exclusion
Gender identity
Race

https://ontario.cmha.ca/provincial-policy/social-determinants/

Race, Ethnicity and Indigenous Identity Data

- Race-based and Indigenous identity data is vital for:
    - the identification and monitoring of health inequalities that stem from racism, bias and discrimination, and
    - to inform interventions to improve equity in health care access, quality, experience and outcomes.
- Currently, data collection on race, ethnicity and Indigenous identity is limited in the health care sector, and where data is available, the way it is collected often varies.

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

Challenges: Sociodemographic data collection and use

- Lack of community benefit when data does not lead to action
- Historical abuse, misuse or misinterpretation information that can deepen inequities
- Privacy, consent and lack of ownership and access
- Missing seat at the data governance tables by racialized and marginalized populations

Current Issues in the Sociodemographic Data

- Call to action for equitable delivery of healthcare
- Healthcare suffers a lack of consensus and interoperable data systems for sociodemographic data collection
- Need to consider collection SDD/SES data
    - Why we ask
    - What we ask
    - How we ask
    - How the data will be used

Key Concepts

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. (AHIMA, 2020)

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.

Data Standardization:

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

SDD Working Group Purpose

- To explore with an environmental scan, the current socio-demographic data collection practices relevant to primary care research
- To recommend guiding principles for the collection of sociodemographic information based on best evidence and practice.

Environmental Scan Methodology

- Current evidence and practice relevant to primary care research
- DFM, McMaster University, local, provincial, national resources
  - Peer-reviewed and grey literature
  - Seminars, presentations
  - Organizational websites
  - Working Groups
  - Interviews, Meetings
  - Email conversations

SDD in Primary Care Research

- Cross sectional, cohort, intervention studies:
  - collecting baseline participant demographic data
- Epidemiological
  - clinical and administrative health record data
- Health data repositories
  - large data trusts amassed from multiple data sources
    - IC/ES
    - Canadian Primary Care Sentinel and Surveillance Network (CPCSSN)
    - Primary Care Ontario Practice-based Learning and Research Network (POPLAR)

Environmental Scan Findings:

McMaster

Equity and Inclusion Office

Office of Community Engagement

McMaster Institute for Health Equity

Health Research Services

HIREB

DFM Research

Current Research

MUSIC

McMaster FHT

Ontario

IC/ES

Ontario Health

Alliance for Healthier Communities

Data and Digital Standards

POPLAR

Community Consultants

Health Commons Solutions Lab

Tamarack Institute

Digital Justice Lab

Canada

Pan Canadian Data Strategy

Canadian Institute for Health Information (CIHI)

Canada Health Infoway

CHIMA

Hamilton

Greater Hamilton Health Network

Community Non-profit

Hamilton Public Health

Global

The Gravity Project (US)

UK

Finland

Academia

Upstream Lab (Pinto)

U Vic (Lau)

U Otawa (Welch)

McMaster (Joseph, Dunn)

Global Leaders

- Gravity Project:
  - US collaborative for consensus-based data standards to improve use and sharing information on social determinants of health
  - UK:

Policy paper

Data saves lives: reshaping health and social care with data (draft)

Updated 10 February 2022

- Finland: Elements of AI free online course for citizens

https://www.elementsofai.com/

The Gravity Project

- US initiative to create social risk data and data standards
- Early work in 2017; Launch in 2019
- Multistakeholder, public collaborative; 1800 participants
- Goal: develop consensus driven data standards to support the exchange of SDOH within health care and with other sectors
- Test, and validate SDOH data for use in patient care, care coordination, between health and social sectors, population health mgt, public health, clinical research and value-based care.

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. May 19, 2021. Retrieved from: https://www.uvic.ca/hsd/hinf/home/news/archive/hts-virtual-miniconference.php

Challenges to SDOH Data Capture and Exchange

- Consent by individuals
- Standardization of data collection and storage (questions and answers)
- Data sharing agreements across the learning health system – interoperability
- Readiness and infrastructure to do the work in health and social sectors
- Keep patient and communities needs as focus of the work

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. May 19, 2021. Retrieved from: https://www.uvic.ca/hsd/hinf/home/news/archive/hts-virtual-miniconference.php

The Gravity Project

Created by Carrie Lousberg, last modified by Sara Behal on Mar 18, 2022

Click on the images below to be redirected to your page of interest!

Project Information

Meetings, Media and Communications

Quick Links

Why the Name "Gravity"

Gravity Project Website

Data Element submission instructions

Gravity Project & Related Events

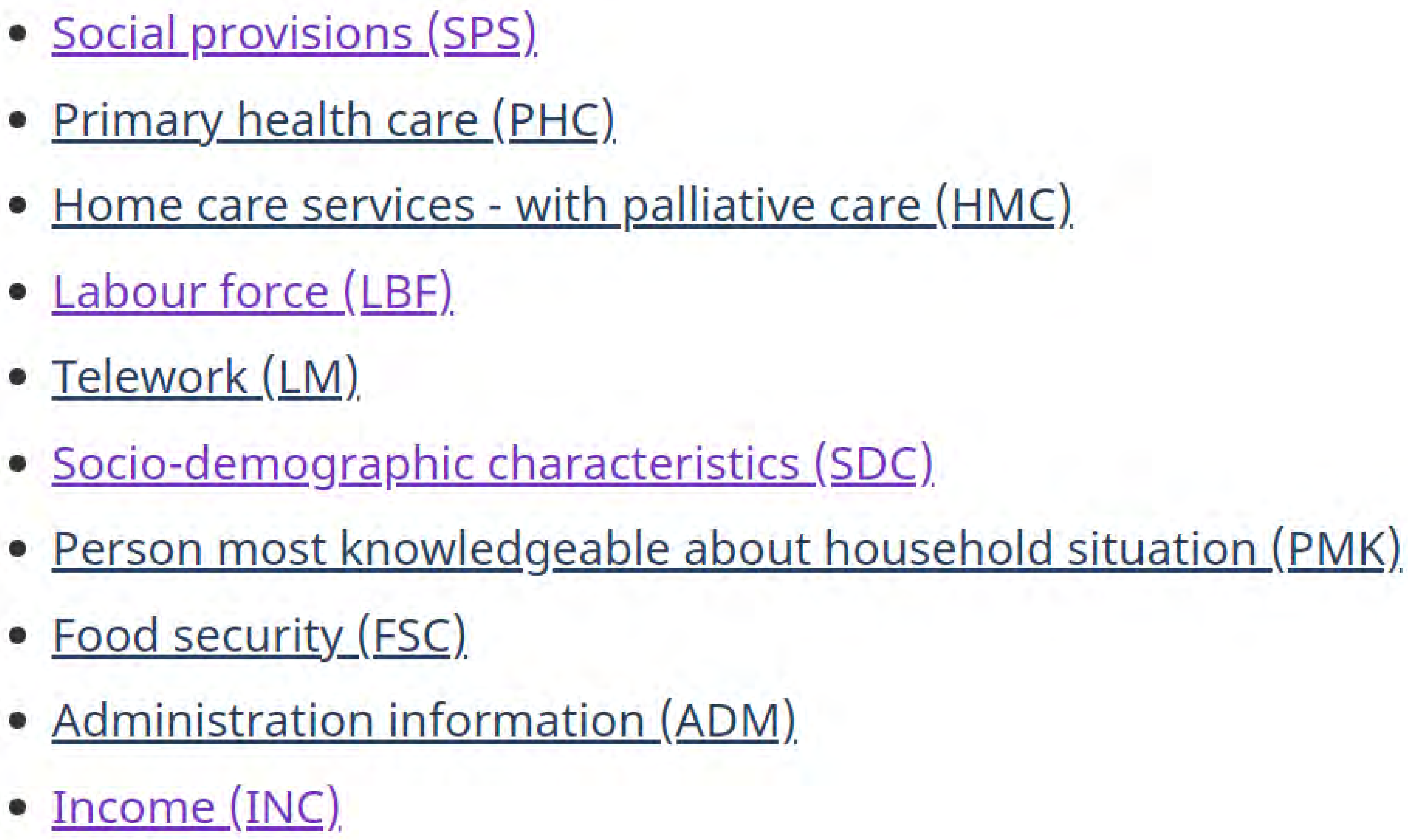
Join the Gravity Project

https://confluence.hl7.org/display/GRAV/The+Gravity+Project

Canada

- Statistics Canada and the Community Health Survey (CCHS)
- Canadian Institute of Health Information (CIHI)
- Canadian Health Information Management Association (CHIMA)
- *Pan-Canadian Health Data Strategy: Building Canada's Health Data Foundation*, championed by Vivek Chair, pan-Canadian Health Data Strategy Expert Advisory Group

Canadian Community Health Survey (CCHS)



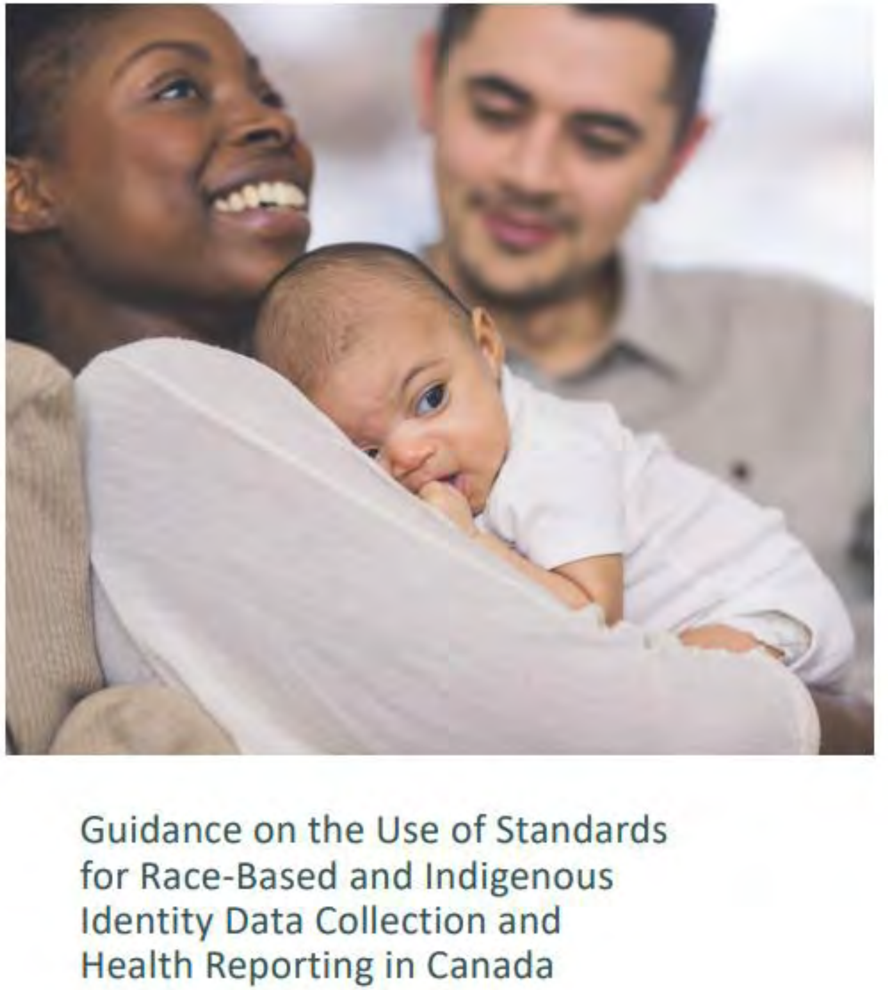
- Social provisions (SPS)
- Primary health care (PHC)
- Home care services - with palliative care (HMC)
- Labour force (LBF)
- Telework (LM)
- Socio-demographic characteristics (SDC)
- Person most knowledgeable about household situation (PMK)
- Food security (FSC)
- Administration information (ADM)
- Income (INC)

Canadian Community Health Survey (CCHS) - Annual Component - September to December – 2021. Retrieved from: https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=assembleInstr&lang=en&Item_Id=1320938#qb1315381

To which **ethnic or cultural groups did your ancestors** belong? (For example: French, Scottish, Chinese, East Indian)		Are you an **Aboriginal person,** that is, First Nations, Métis or Inuk (Inuit)? First Nations includes Status and Non-Status Indians.	Are you **First Nations, Métis or Inuk (Inuit)**?	You may belong to one or more **racial or cultural groups** on the following list. Are you... ?
01: Canadian	11: Jewish	1: Yes	1: First Nations (North American Indian)	01: White
02: French	12: Polish	2: No	2: Métis	02: South Asian (e.g., East Indian, Pakistani, Sri Lankan)
03: English	13: Portuguese	8: RF	3: Inuk (Inuit)	03: Chinese
04: German	14: South Asian (e.g., East Indian, Pakistani, Sri Lankan)	9: DK	8: RF	04: Black
05: Scottish	15: Norwegian		9: DK	05: Filipino
06: Irish	16: Welsh			06: Latin American
07: Italian	17: Swedish			07: Arab
08: Ukrainian	18: First Nations (North American Indian)			08: Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian)
09: Dutch (Netherlands)	19: Métis			
10: Chinese	20: Inuit			09: West Asian (e.g., Iranian, Afghan)
	21: Other - Specify			10: Korean
	98: RF			11: Japanese
	99: DK			12: Other - Specify
				98: RF
				99: DK

Canadian Community Health Survey (CCHS) - Annual Component - September to December – 2021. Retrieved from: https://www23.statcan.gc.ca/imdb/p3Instr.pl?Function=assembleInstr&lang=en&Item_Id=1320938#qb1315381

CIHI Standards



Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada

- Minimum data standards to support harmonized, high-quality race-based and Indigenous identity data in health care
- Implementation encouraged to facilitate monitoring, comparable analysis and reporting related to health care access, quality, experience and outcomes across racialized groups.
- Align with Statistics Canada census and surveys and other national data sources

Canadian Institute for Health Information. Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada. 2022. Retrieved from: https://www.cihi.ca/sites/default/files/document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf.

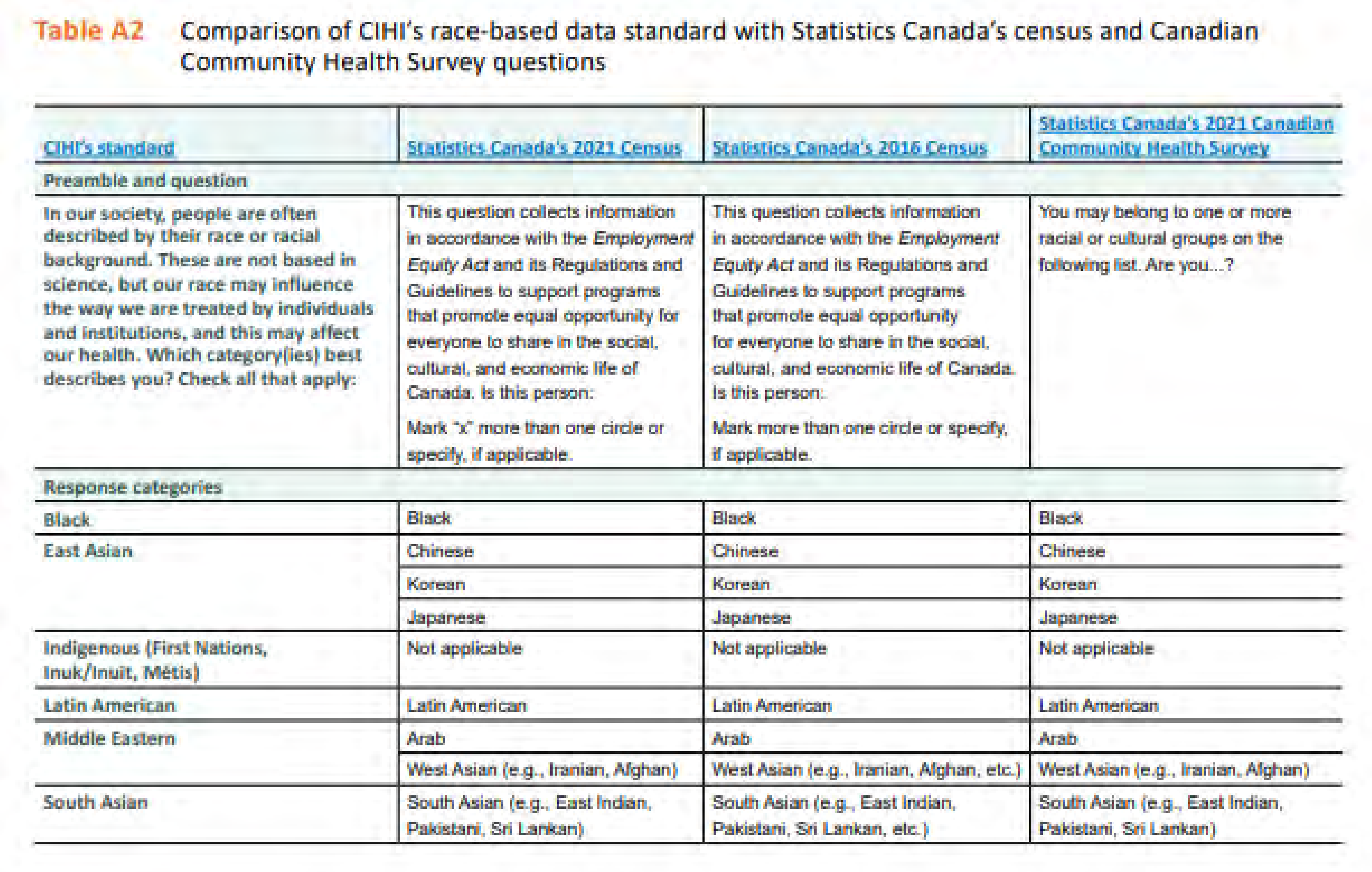


Table A2 Comparison of CIHI's race-based data standard with Statistics Canada's census and Canadian Community Health Survey questions

CIHI's standard	Statistics Canada's 2021 Census	Statistics Canada's 2016 Census	Statistics Canada's 2021 Canadian Community Health Survey
Preamble and question			
In our society, people are often described by their race or racial background. These are not based in science, but 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? Check all that apply:	This question collects information in accordance with the *Employment Equity Act* and its Regulations and Guidelines to support programs that promote equal opportunity for everyone to share in the social, cultural, and economic life of Canada. Is this person: Mark "x" more than one circle or specify, if applicable.	This question collects information in accordance with the *Employment Equity Act* and its Regulations and Guidelines to support programs that promote equal opportunity for everyone to share in the social, cultural, and economic life of Canada. Is this person: Mark more than one circle or specify, if applicable.	You may belong to one or more racial or cultural groups on the following list. Are you...?
Response categories			
Black	Black	Black	Black
East Asian	Chinese	Chinese	Chinese
	Korean	Korean	Korean
	Japanese	Japanese	Japanese
Indigenous (First Nations, Inuk/Inuit, Métis)	Not applicable	Not applicable	Not applicable
Latin American	Latin American	Latin American	Latin American
Middle Eastern	Arab	Arab	Arab
	West Asian (e.g., Iranian, Afghan)	West Asian (e.g., Iranian, Afghan, etc.)	West Asian (e.g., Iranian, Afghan)
South Asian	South Asian (e.g., East Indian, Pakistani, Sri Lankan)	South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)	South Asian (e.g., East Indian, Pakistani, Sri Lankan)

Canadian Institute for Health Information. Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada. 2022. Retrieved from: https://www.cihi.ca/sites/default/files/document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf.

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Canadian Institute for Health Information
Better data. Better decisions. Healthier Canadians.

Measuring Health Inequalities: A Toolkit

Plan your analysis

A. Select relevant equity stratifiers

B. Explore approaches for accessing equity stratifiers

Analyze your data

A. Carry out a stratified analysis

B. Quantify inequalities using summary measures

Report your findings

A. Interpret results for key findings

B. Present findings to your audience

Related resources

- Area-Level Equity Stratifiers Using PCCF and PCCF+ (https://www.cihi.ca/sites/default/files/document/cphi-toolkit-area-level-measurement-pccf-2018-en-web.pdf)
- Supplemental resources: https://www.cihi.ca/sites/default/files/document/cphi-toolkit-supplementary-resources-en-web.pdf

CIHI. Measuring Health Inequalities: A Toolkit. 2018. Retrieved from: https://www.cihi.ca/en/measuring-health-inequalities-a-toolkit

CHIMA

Partner

Francis Lau PhD, FCAHS, Professor
School of Health Information Science, University of Victoria

- April 16, 2020
  Capturing Social Determinants of health-related activities in electronic health records
- April 22. 2021
  Update: Capturing social determinants of Capturing Social Determinants of health-related activities in electronic health records
- March 9, 2022
  Continuing the conversation of social determinants of health data standards for Canada

- Canadian SDOH Working Group to examine SDOH issues in Canadian digital health systems with the support of Canada Health Infoway.
- Virtual mini-conference event on May 19, 2021, with Infoway and CIHI on SDOH data standards in EHRs.
  - Stratton, Equity Standards at CIHI
  - Pinto, SDOH: Lessons from the Upstream Lab
  - DeSilvey, the Gravity Project

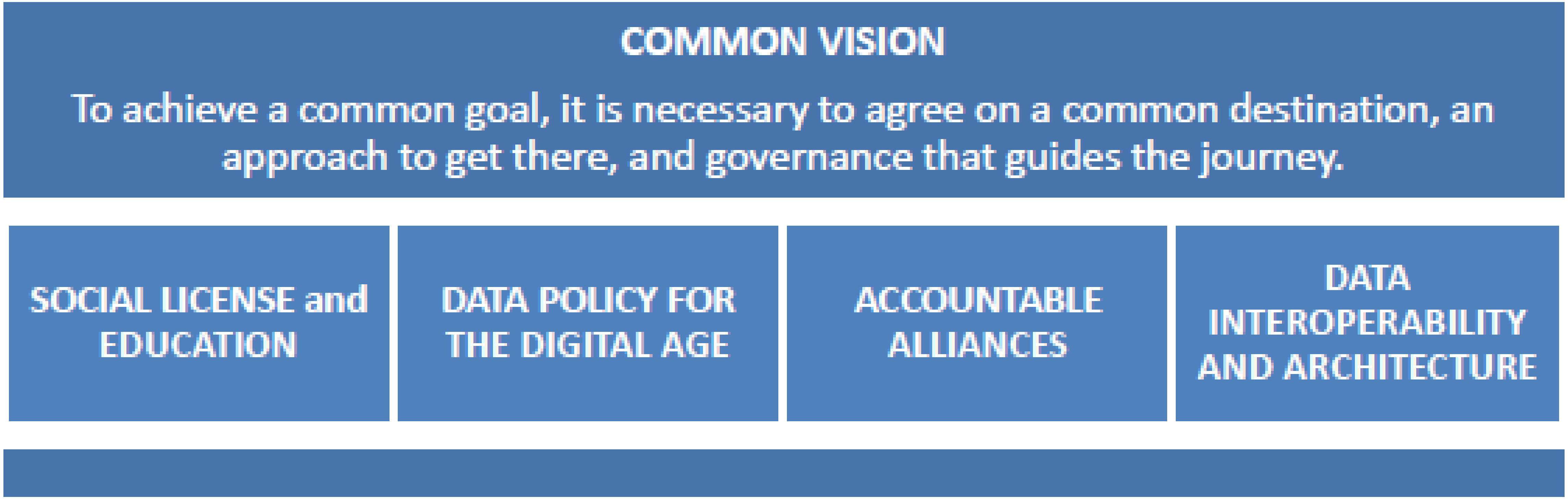
Pan-Canadian Health Data Strategy (PCHDS)

- Focus on strengthening the health data foundations across public health, health system and population health data.
- Aims to support the effective creation, exchange, and use of critical health data for the benefit of Canadians and the health and public health systems they rely on.
- Blueprint to:
  - modernizing health data collection, sharing and interoperability
  - streamlining and updating the approach to privacy and access for the digital age
  - clarifying accountability, sovereignty, and health data governance to bring meaningful change in the way governments share health data.

https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-overview.html

Pan Canadian Health Data Strategy Reports

Expert Advisory Group Report 1: Charting a Path toward Ambition. Summer, 2021



COMMON VISION

To achieve a common goal, it is necessary to agree on a common destination, an approach to get there, and governance that guides the journey.

SOCIAL LICENSE and EDUCATION

DATA POLICY FOR THE DIGITAL AGE

ACCOUNTABLE ALLIANCES

DATA INTEROPERABILITY AND ARCHITECTURE

PCHDS Reports

Expert Advisory Group Report 2: Building Canada's Health Data Foundation November 2021

- Clear health data accountability and governance;
- Built and sustained trust with the public and communities through meaningful engagement;
- Digital-age health data policies;
- Coherent and regulated interoperability standards; and
- Common language and health sector and public data literacy.

Ontario

- Ontario Health (OH) → Ontario Health Teams
- Provincial COVID Response to Social Data collection
- Provincial Equity and Diversity Framework
- Ontario Data and Digital Standards
- IC/ES
- Toronto Healthcare Organizations
- Toronto-based Academia

Ontario Expanding Data Collection to Help Stop Spread of COVID-19

Additional Information will provide a More Complete Picture of the Outbreak

June 15, 2020

Health

Table of Contents

TORONTO — In response to requests by community leaders and public health experts, the Ontario government is proposing a regulatory change to mandate the reporting of data on race, income, language and household size for individuals who have tested positive for COVID-19. This

… proposing a regulatory change to **mandate the reporting of data on race, income, language and household size for individuals who have tested positive for COVID-19**. This will help ensure the province has a **more complete picture of the outbreak**. This change will allow for **the collection of data in a consistent way** across the province, while ensuring the privacy of Ontarians is protected.

https://news.ontario.ca/en/release/57217/ontario-expanding-data-collection-to-help-stop-spread-of-covid-19

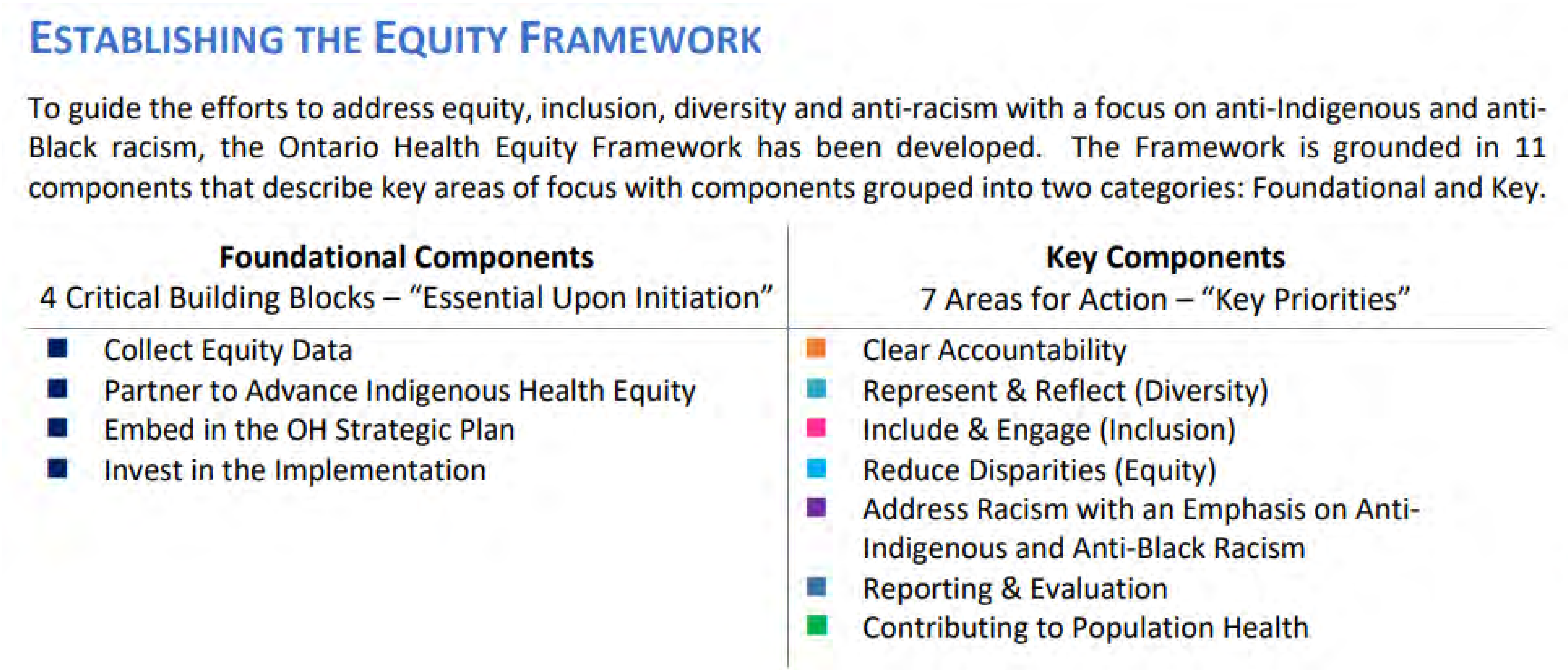
Ontario Health

Digital Health Information Exchange (DHIEX) Standard

DHIEX is the regulation of digital health information exchange in Ontario for consistent sharing of meaningful health information across systems, which benefits both patients and health care providers alike.

https://www.ontariohealth.ca/our-work/digital-standards

Corpus Sanchez International’s Report to Ontario Health



ESTABLISHING THE EQUITY FRAMEWORK

To guide the efforts to address equity, inclusion, diversity and anti-racism with a focus on anti-Indigenous and anti-Black racism, the Ontario Health Equity Framework has been developed. The Framework is grounded in 11 components that describe key areas of focus with components grouped into two categories: Foundational and Key.

Foundational Components
4 Critical Building Blocks – “Essential Upon Initiation”

- Collect Equity Data
- Partner to Advance Indigenous Health Equity
- Embed in the OH Strategic Plan
- Invest in the Implementation

Key Components
7 Areas for Action – “Key Priorities”

- Clear Accountability
- Represent & Reflect (Diversity)
- Include & Engage (Inclusion)
- Reduce Disparities (Equity)
- Address Racism with an Emphasis on Anti-Indigenous and Anti-Black Racism
- Reporting & Evaluation
- Contributing to Population Health

Building a framework and plan to address equity, inclusion, diversity and anti-racism in Ontario. Final Report Submitted to Ontario Health. October 2020. Retrieved from: https://www.ontariohealth.ca/sites/ontariohealth/files/2021-01/CorpusSanchezInternationalReport.pdf

Ontario Health's Equity, Inclusion, Diversity and Anti-Racism Framework

With a focus on addressing anti-Indigenous and anti-Black racism

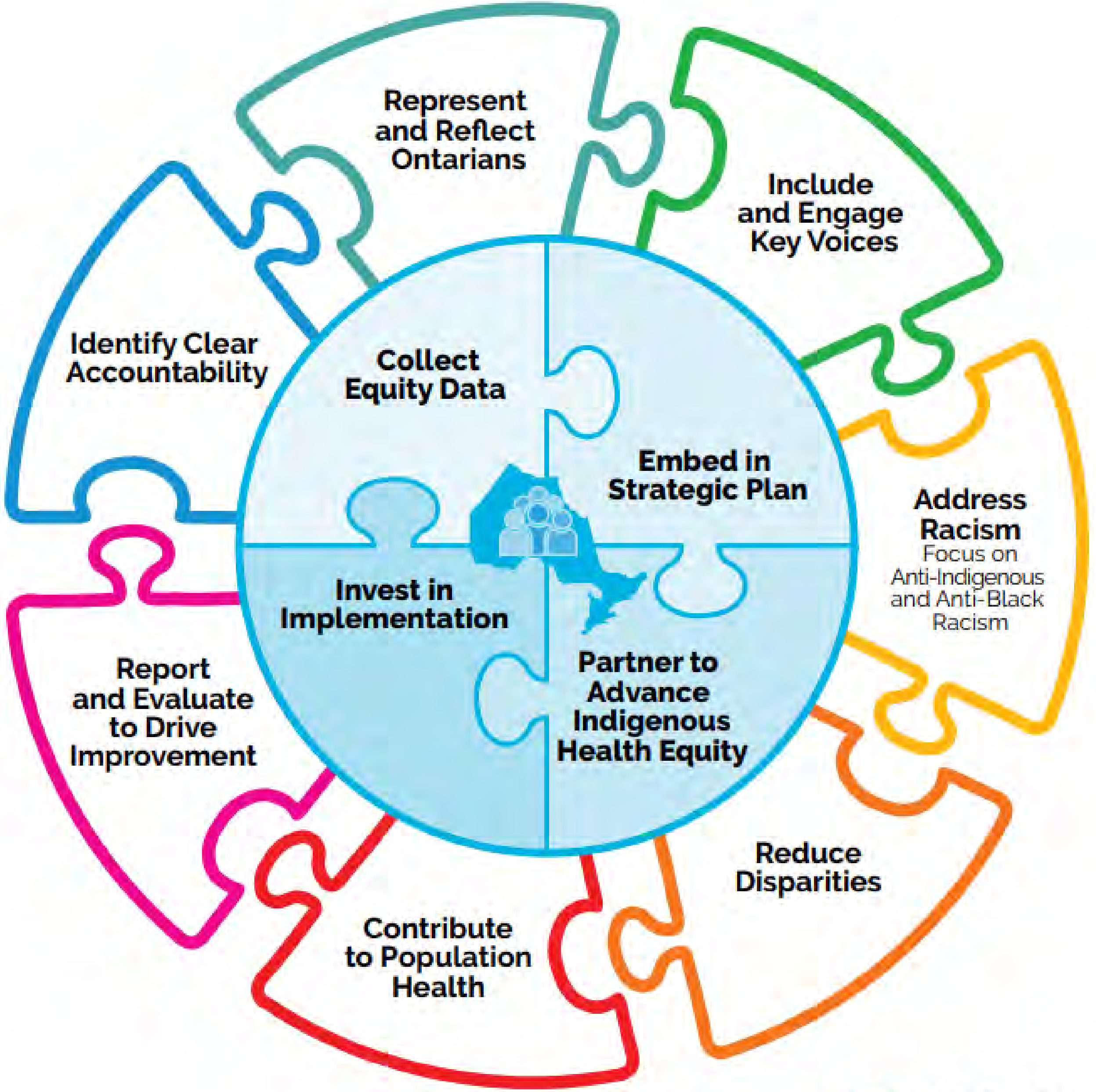
11 Areas of Action

Collect Equity Data
Set up systems and supports to collect, analyze, and use equity data to report findings and inform future decisions

Embed in Strategic Plan
Ensure efforts to address equity, inclusion, diversity, anti-Indigenous and anti-Black racism are at the highest priority for the organization

Partner to Advance Indigenous Health Equity
Recognize that strong relationships with Indigenous leadership and communities - founded on respect, reciprocity, and open communication — are critical in ensuring that the new health care system in Ontario reflects and addresses the needs of Indigenous peoples.

Invest in Implementation
Apply the financial and people resources needed for success and ongoing sustainability



Represent and Reflect Ontarians

Include and Engage Key Voices

Address Racism
Focus on Anti-Indigenous and Anti-Black Racism

Reduce Disparities

Contribute to Population Health

Report and Evaluate to Drive Improvement

Identify Clear Accountability

Collect Equity Data

Embed in Strategic Plan

Invest in Implementation

Partner to Advance Indigenous Health Equity

https://www.ontariohealth.ca/sites/ontariohealth/files/2020-12/Equity%20Framework.pdf
Informed by the Corpus Sanchez International's Report to Ontario Health

For more information, go to: ontariohealth.ca

Ontario Health

IC/ES

Be part of a Peoples' Panel to guide how race and ethnicity data are used in health research in Ontario

March 8, 2021

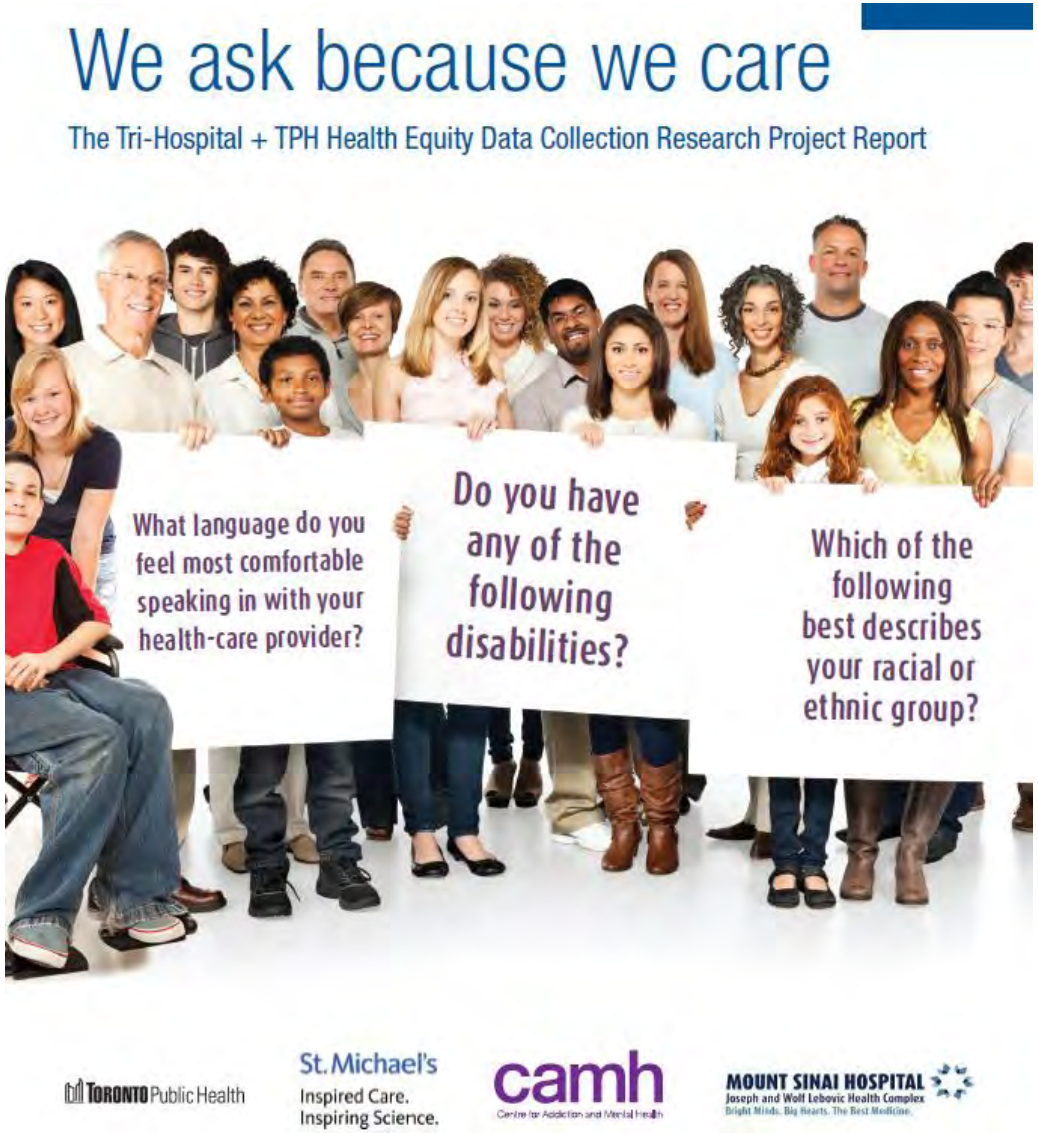
Striving for community-driven, anti-racist use of race, ethnicity and immigration data.

Be part of a Peoples' Panel to guide how race and ethnicity data are used in health research in Ontario.

ICES recognizes the role of data in decolonizing health research and dismantling systemic racism. And as the focus on the need for data on race and ethnicity has increased in Ontario and more widely, the importance of collecting and using these data in a responsible manner is imperative.

ICES, in collaboration with the Tamarack Institute and the Digital Justice Lab, is seeking input from a Peoples' Panel that will consider how race and ethnicity data should be used for health data research in Ontario. An outcome of the panel will be a set of principles and recommendations that will contribute to the creation of a race and ethnicity data framework.

https://www.ices.on.ca/Newsroom/Announcements-and-Events/2021/Striving-for-community-driven-anti-racist-use-of-race-ethnicity-and-immigration-data



We ask because we care

The Tri-Hospital + TPH Health Equity Data Collection Research Project Report

What language do you feel most comfortable speaking in with your health-care provider?

Do you have any of the following disabilities?

Which of the following best describes your racial or ethnic group?

Toronto Public Health

St. Michael's
Inspired Care.
Inspiring Science.

camh
Centre for Addiction and Mental Health

Mount Sinai Hospital
Joseph and Wolf Lebovic Health Complex
Bright Minds. Big Hearts. The Best Medicine.

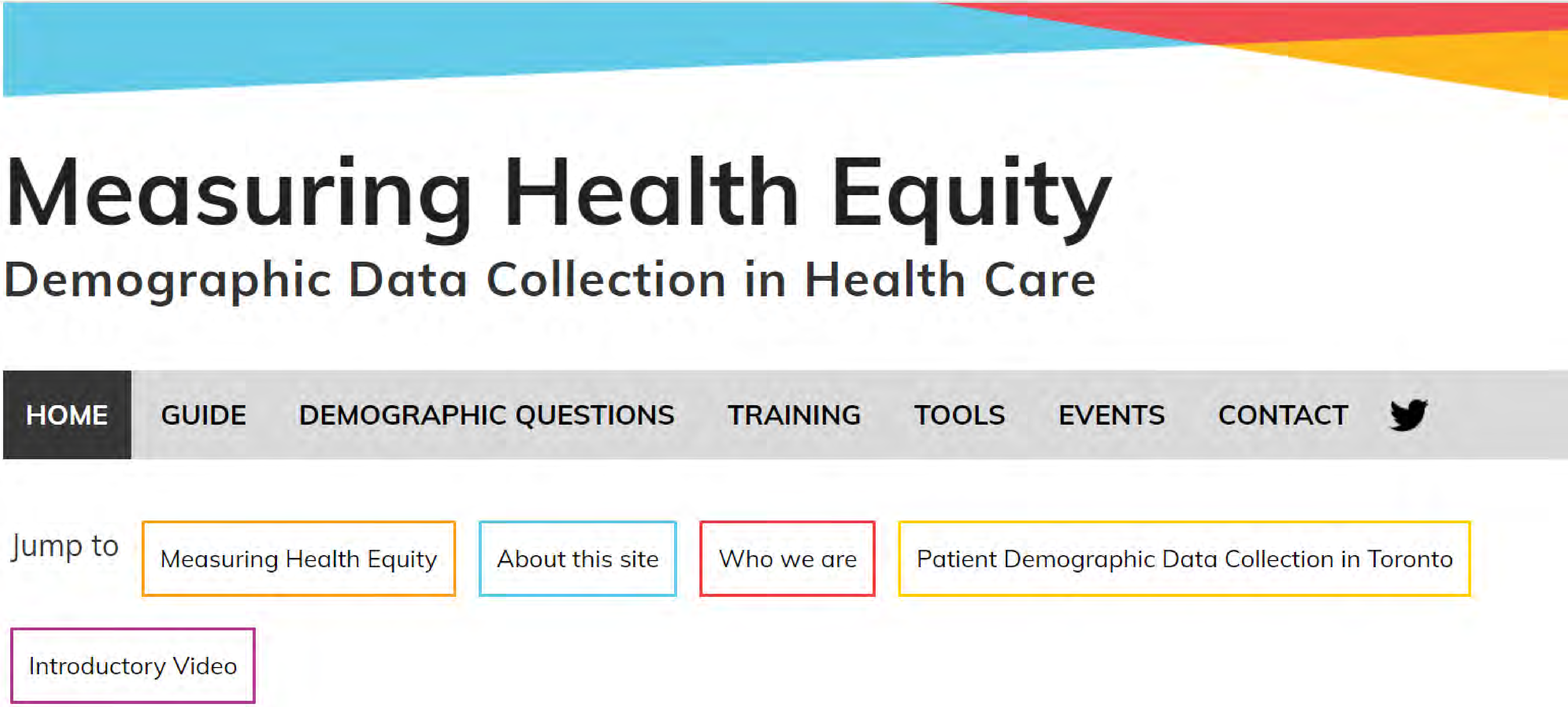
- Early Work in 2010 to establish best practice and standards in asking about SDD
- TC LHIN mandated these standards and orgs like the Community Care Access Centres (Alliance for Healthier Communities) adopted them
- Became foundation for UPSTREAM lab and CIHI SDOH work

Wray (with Ilene Hyman)- DGL Consulting, Agic B, 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. Retrieved from: http://torontohealthequity.ca/wp-content/uploads/2017/05/We-Ask-Because-We-Care-Report.pdf

Questions across Sociodemographic Domains

1. **Born in Canada** - responded “no” they were asked for their year of arrival.
2. **Disability** - adopted the terminology currently used by the Ontario Human Rights Commission
3. **Gender** - trans-male and trans-female to increase clarity and an “other” category was added
4. **Housing** - a product of research on data collected on types of housing across the province.
5. **Income** - salary range options and asking how many supported by that income
6. **Language** - top 30 language requests among Toronto Central LHIN area hospitals
7. **Race/Ethnicity** - adapt blended categorizations utilized by the 2011 Toronto District School Board [TDSB]iv.
8. **Religion** - most commonly identified religious and spiritual groups in Canada (Statistics Canada, 2011) and groups whose religious affiliation can impact medical treatments
9. **Sexual Orientation** – LGB health equity experts and reflect the current standards in collecting information on sexual orientation

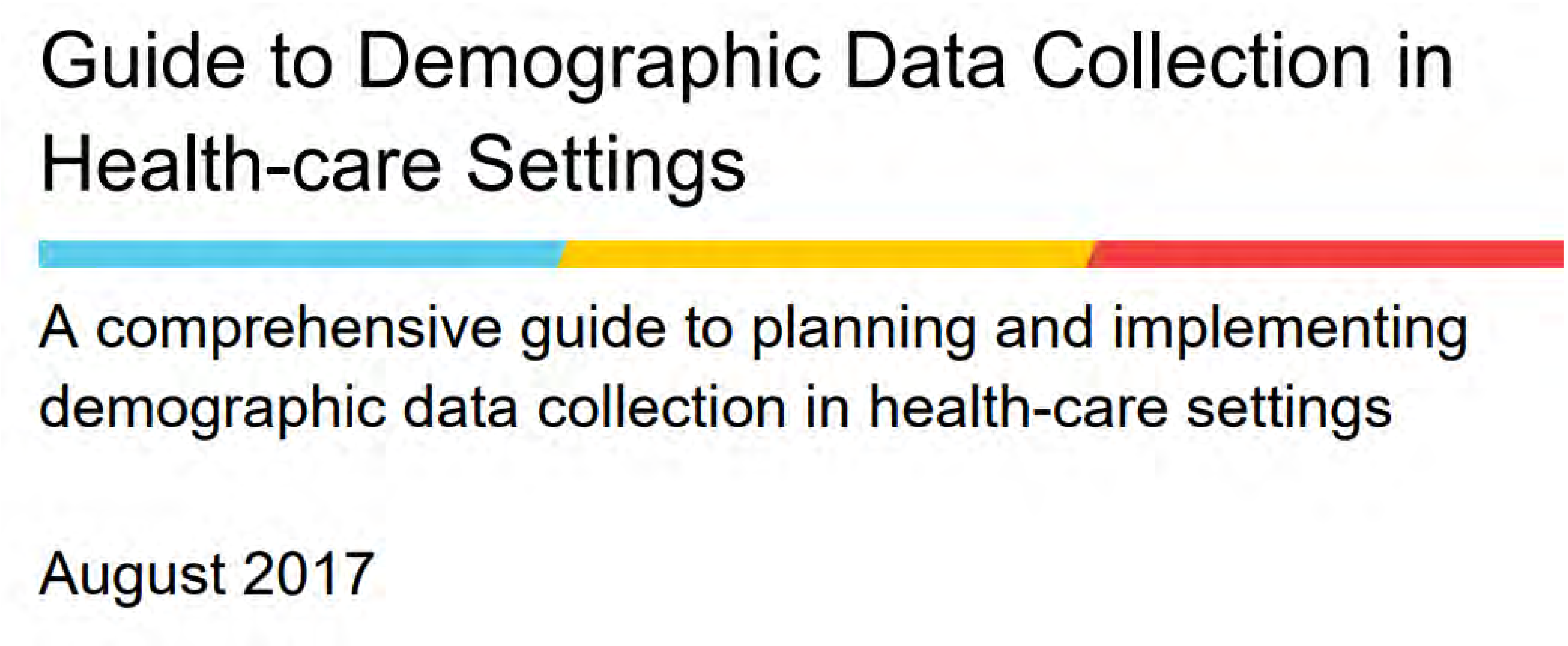
Wray (with Ilene Hyman)- DGL Consulting, Agic B, Bennett-AbuAyyash C, Kanee M, Lam R, Mohamed A, Tuck A. We ask because we care. The Tri-Hospital + TPH Health Equity Data Collection Research Project: Final Report 2013.



Measuring Health Equity

Demographic Data Collection in Health Care

http://torontohealthequity.ca/



Guide to Demographic Data Collection in Health-care Settings

A comprehensive guide to planning and implementing demographic data collection in health-care settings

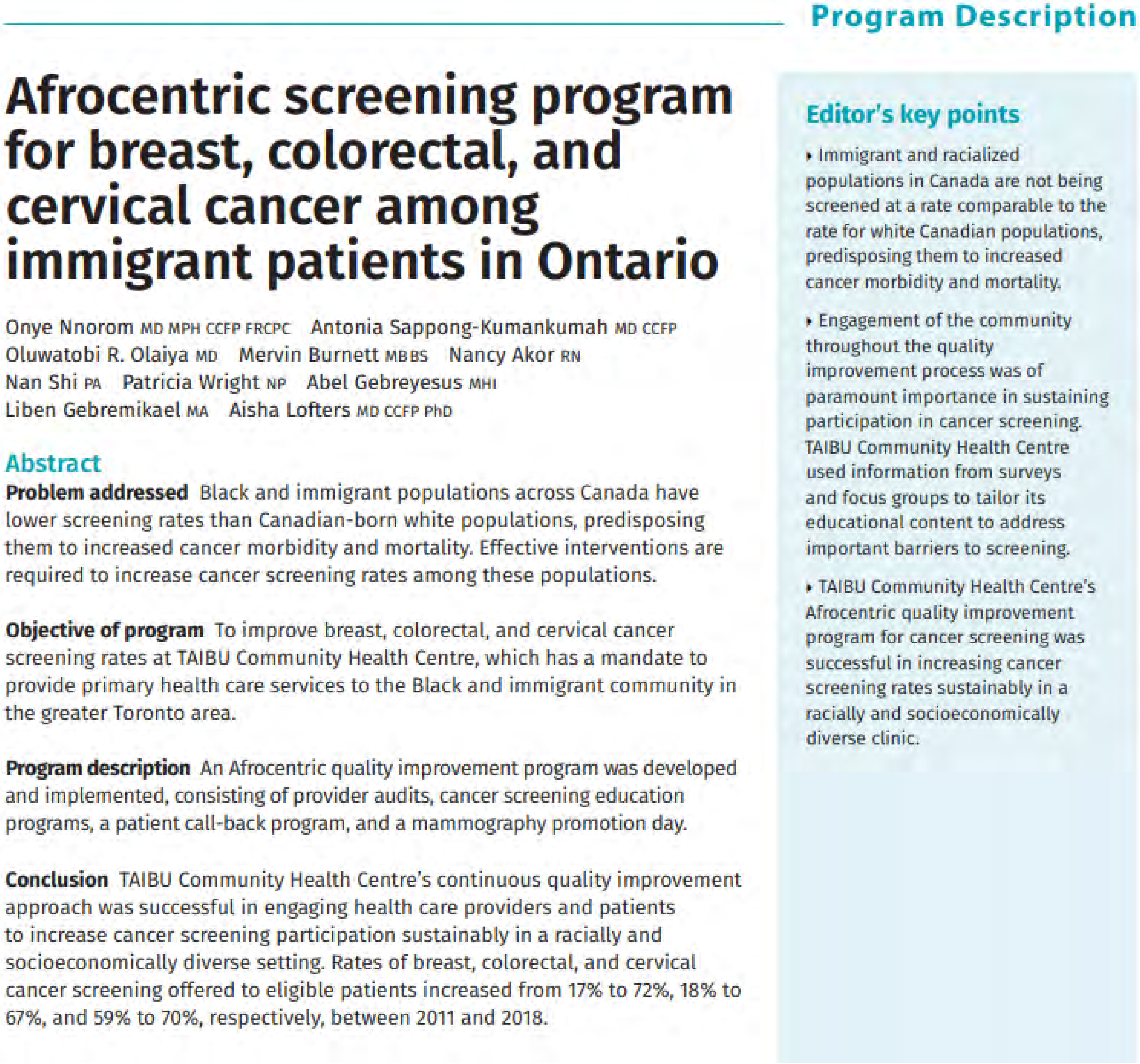
August 2017

Visit torontohealthequity.ca to download “Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres”.

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 August 2017 http://torontohealthequity.ca/wp-content/uploads/2017/10/Measuring-Health-Equity-Guide-to-Demographic-Data-Collection.pdf

Alliance for Healthier Communities
Alliance pour des communautés en santé

- Early starter and now advanced in SDD collection in primary care
- 8 standard sociodemographic questions at intake or via blitz
- Contributes to an evaluation framework of objectives, measures and data elements to understand the work of CHCs as a program
- Use ENCODE-FM (Electronic Nomenclature and Classification of Disorders and Encounters for Family Medicine)
    - contains more than 10,000 terms including those for gender fluidity and sexual health, a section related to health issues of Indigenous Peoples, and terms for social determinants of health and health risk.
    - designed to be an evolving terminology, to be readily updated. ENCODE-FM currently.
    - maps to ICPC and ICD9 and ICD10
- Organizational priority to have 75% completion of SDD by 2024.



Program Description

Afrocentric screening program for breast, colorectal, and cervical cancer among immigrant patients in Ontario

Onye Nnorom MD MPH CCFP FRCPC Antonia Sappong-Kumankumah MD CCFP
Oluwatobi R. Olaiya MD Mervin Burnett MBBS Nancy Akor RN
Nan Shi PA Patricia Wright NP Abel Gebreyesus MHI
Liben Gebremikael MA Aisha Lofters MD CCFP PhD

Abstract

Problem addressed Black and immigrant populations across Canada have lower screening rates than Canadian-born white populations, predisposing them to increased cancer morbidity and mortality. Effective interventions are required to increase cancer screening rates among these populations.

Objective of program To improve breast, colorectal, and cervical cancer screening rates at TAIBU Community Health Centre, which has a mandate to provide primary health care services to the Black and immigrant community in the greater Toronto area.

Program description An Afrocentric quality improvement program was developed and implemented, consisting of provider audits, cancer screening education programs, a patient call-back program, and a mammography promotion day.

Conclusion TAIBU Community Health Centre's continuous quality improvement approach was successful in engaging health care providers and patients to increase cancer screening participation sustainably in a racially and socioeconomically diverse setting. Rates of breast, colorectal, and cervical cancer screening offered to eligible patients increased from 17% to 72%, 18% to 67%, and 59% to 70%, respectively, between 2011 and 2018.

Editor's key points

- Immigrant and racialized populations in Canada are not being screened at a rate comparable to the rate for white Canadian populations, predisposing them to increased cancer morbidity and mortality.
- Engagement of the community throughout the quality improvement process was of paramount importance in sustaining participation in cancer screening. TAIBU Community Health Centre used information from surveys and focus groups to tailor its educational content to address important barriers to screening.
- TAIBU Community Health Centre's Afrocentric quality improvement program for cancer screening was successful in increasing cancer screening rates sustainably in a racially and socioeconomically diverse clinic.

- Mature sociodemographic data at the Alliance supports work in equity interventions
- Nnorom O, Sappong-Kumankumah A, Olaiya OR, Burnett M, Akor N, Shi N, Wright P, Gebreyesus A, Gebremikael L, Lofters A. Afrocentric screening program for breast, colorectal, and cervical cancer among immigrant patients in Ontario. Can Fam Physician. 2021 Nov;67(11):843-849.

Toronto-based Academia

- **The Upstream Lab** was founded in 2016 by Dr. Andrew Pinto to bring together a number of linked projects and initiatives around social determinants of health
- **Gattuso Centre for Social Medicine Innovation** at UHN, led by Dr. Andrew Boozary. The new, first-of-its-kind Centre is a leading voice for social medicine advocacy and policy development in Canada - is focused on the implementation and evaluation of new models of care.

UPSTREAMLAB

Routine collection of sexual orientation and gender identity data: a mixed-methods study

Andrew D. Pinto, Tatiana Aratangy, Alex Abramovich, Kim Devotta, Rosane Nisenbaum, Ri Wang and Tara Kiran

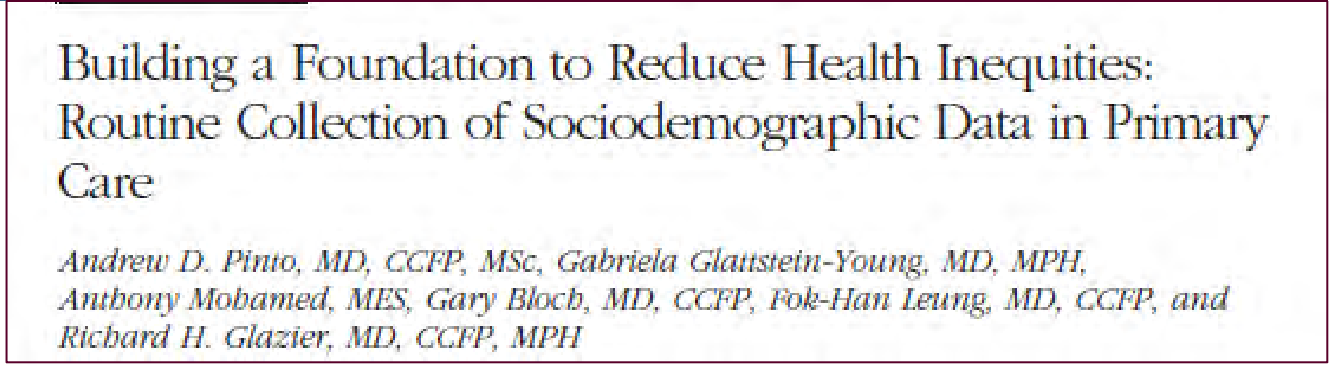
CMAJ January 21, 2019 191 (3) E63-E68; DOI: https://doi.org/10.1503/cmaj.180839

Screening for **P**overty **A**nd **R**elated Social Determinants and Intervening to Improve **K**nowledge of and Links to Resources **(SPARK)** Study

Data to Enable a Learning Health System, Integrating Health & Social Care

In Progress

Social Determinants of Health, Sociodemographic Data Collection



Building a Foundation to Reduce Health Inequities: Routine Collection of Sociodemographic Data in Primary Care

Andrew D. Pinto, MD, CCFP, MSc, Gabriela Glattstein-Young, MD, MPH, Anthony Mohamed, MES, Gary Bloch, MD, CCFP, Fok-Han Leung, MD, CCFP, and Richard H. Glazier, MD, CCFP, MPH

JAMA Network | Open

Research Letter | Statistics and Research Methods

Reporting of Sociodemographic Variables in Randomized Clinical Trials, 2014-2020

Aaron M. Orkin, MD, MSc, MPH; Gina Nicoll; Navindra Persaud, MD, MSc; Andrew D. Pinto, MD, MSc

SPARK Questions

1. What language would you feel most comfortable speaking in with your health care provider?

2. How would you rate your ability to speak and understand English?

3. In what language would you prefer to read health care information?

4a. Were you born in Canada?

*4b. If no, what year did you arrive in Canada?

5. In what year were you born?

6. Which of the following best describes your race?

7. What is your religious or spiritual affiliation?

8. Do you have any of the following disabilities?

9. What is your gender?

10. What is your sexual orientation?

11. What was your total family income before taxes last year?

12. How many people does this income support?

13. What type of housing do you live in?

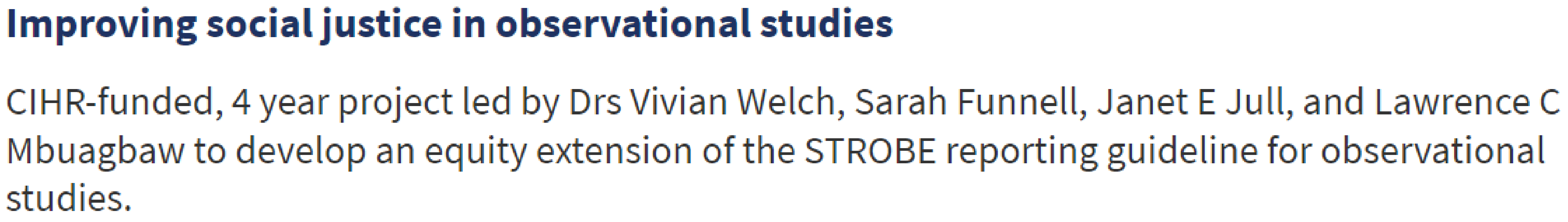
14. In general, would you say your health is…

CIHR Study Outcomes

1. A multi-lingual national standard for socio-demographic data collection in primary care
2. 2. Implementation guidelines for data collection, extraction, analysis and use of data across electronic medical records
3. 3. Guidelines for engaging patients and communities
4. 4. Strong evidence from a national, cluster randomized control trial (RCT) on what is the most effective way to address poverty at the point-of-care, which will guide action on other social needs.

https://upstreamlab.org/project/spark/

STROBE-Equity



Improving social justice in observational studies

CIHR-funded, 4 year project led by Drs Vivian Welch, Sarah Funnell, Janet E Jull, and Lawrence C Mbuagbaw to develop an equity extension of the STROBE reporting guideline for observational studies.

Health inequities can go frequently unreported in observational studies. This international group of scientists, educators, decision-makers, ethicists, funders, and patients, using an integrated knowledge translation approach, proposes to develop an extension to the STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) guideline to deal specifically with these disparities. The project will embed a parallel stream focused on evidence related to Indigenous research. After assessing available guidance for reporting health equity in observational studies and assessing current reporting, they plan to seek international feedback, then conduct an evidence and consensus-driven process to develop a reporting guideline. The project started in January 2021. A series of empirical studies are planned, followed by a consensus meeting, with the final reporting guideline and statement expected in 2024.

Welch V, Funnell S, Jull JE, Mbuagbaw LC. Improving social justice in observational studies. CIHR Project grant. 2021. Retrieved from: https://methods.cochrane.org/equity/projects/strobe-equity

Family Medicine | McMaster University

Consultative Organizations

digital justice lab

Focus on building a more just and equitable future. We engage with diverse communities to build alternative digital futures https://digitaljusticelab.ca/

20 years TAMARACK INSTITUTE

Develops and supports collaborative strategies that engage citizens and institutions to solve major community issues across Canada and beyond. https://www.tamarackcommunity.ca/

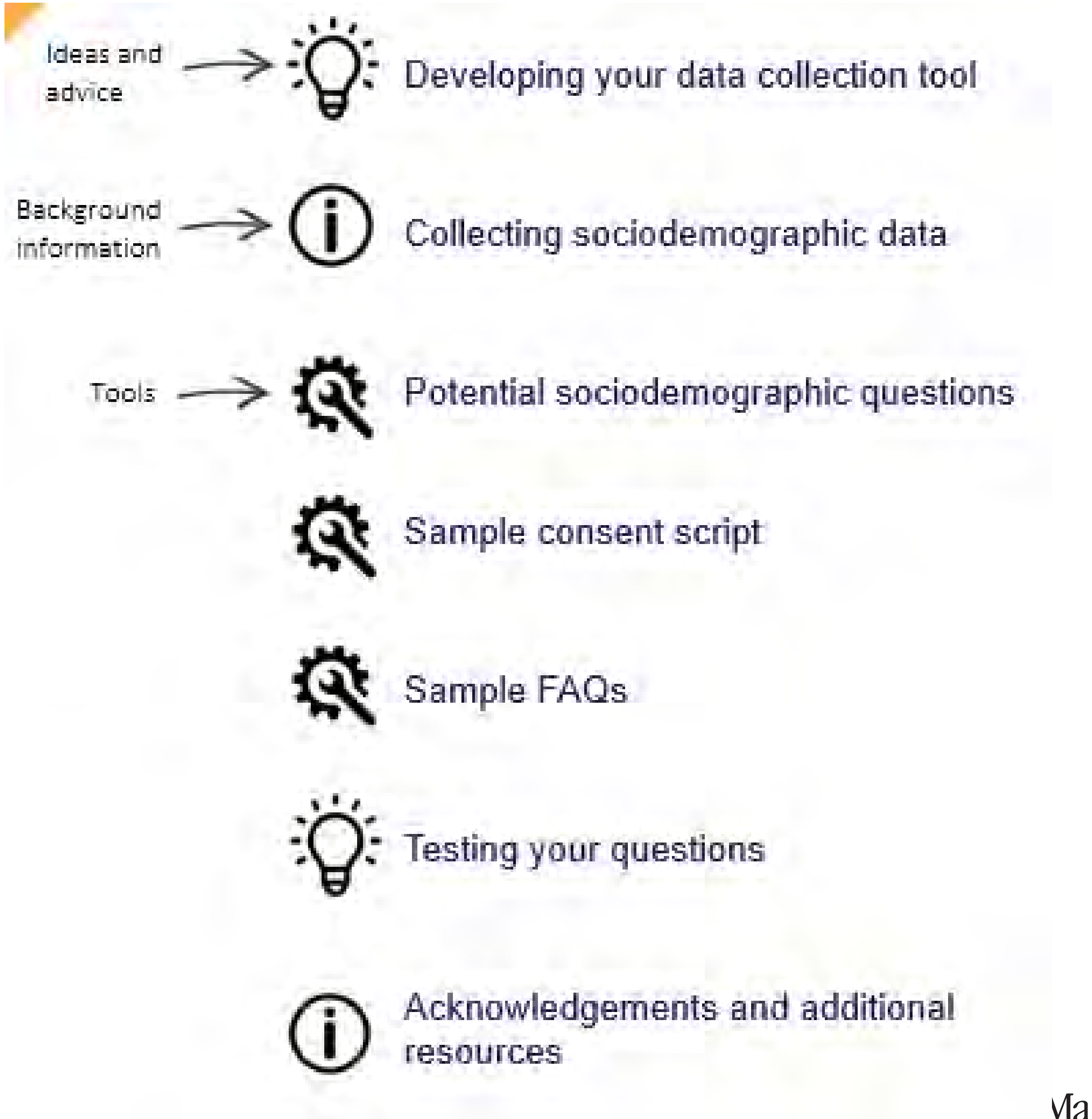
HEALTH COMMONS SOLUTIONS LAB

A publicly funded, not-for-profit innovation lab working with Ontario Health Teams and community organizations to build resilient communities, help all people live with dignity, and improve health and well-being. https://www.healthcommons.ca

TOOLS

Sociodemographic Data Collection

HEALTH COMMONS SOLUTIONS LAB



Ideas and advice → Developing your data collection tool

Background information → Collecting sociodemographic data

Tools → Potential sociodemographic questions

Sample consent script

Sample FAQs

Testing your questions

Acknowledgements and additional resources

https://www.healthcommons.ca/blog/engaging-communities-in-your-data-collection-initiative

Health Commons Solutions Lab

- Measuring inequities in COVID-19: Enhancing socio-demographic data collection
  - Problem solve how Toronto Public Health can fill gap on socio-demographic data collection
  - https://www.healthcommons.ca/project/covid19-sociodemographic-data-collection
- Assessing the Health of a Population – Taking a data driven approach in Muskoka
  - Help a rural community identifying which populations need the most support to achieve better health.
- Black Experiences in healthcare symposium:
  - Partnered with Black Health Alliance and Sinai Health to gather Black leaders to reimagine health in the black community and begin creating specific recommendations for action
  - https://www.healthcommons.ca/blackhealth

BLACK EXPERIENCES IN HEALTH CARE SYMPOSIUM:

Bringing together community and health systems for improved health outcomes

BLACK HEALTH ALLIANCE

HEALTH COMMONS SOLUTIONS LAB

Sinai Health

Key Findings:

1 Require all publicly funded government agencies and health service providers (including Ontario Health and Ontario Health Teams) to be held accountable for:
- Collection and application of race-based data
- Measuring, improving and publicly reporting on care and outcomes of Black Ontarians
- Including Black leadership at all levels including governance, senior and middle management, and advisory committees.

2 Ensure race-based data collection spans across the continuum of care, not just in hospitals and Community Health Centres, to improve data quality, analysis, and the opportunity to positively impact the lives and outcomes of Black communities accessing care.

3 Partner with large health data and information entities like the Canadian Institute for Health Information (CIHI) and Institute for Clinical Evaluative Sciences (IC/ES) to help support race-based data collection and utilization.

4 Standardize and mandate anti-Black racism, anti-oppression, and decolonization training for health care providers, professionals, leaders, and health system planners.

5 Create accessible and culturally competent mental health services throughout the province for all Black people and their communities.

6 Expand funding to create more integrated services that support the families and loved ones of Black people experiencing mental illness.

7 Establish a mechanism to routinely monitor and assess diversity in health system leadership throughout the province.

8 Improve communication with Black communities on the purpose and use of the data that is being collected from them.

9 Create paid positions and roles for community trust builders in health provider organizations who help navigate the relationships between the community and health system. These trust builders need to be recognized and provided fair compensation for their participation from beginning to end of all engagements.

10 Develop a Black-led strategy for identifying Black representatives for provincial/regional community engagement opportunities in health care, and develop engagement practices and methods that reflect the diversity within Black communities.

Report from the 2020 Black Experiences in Health Care Symposium (BEHCS): organized by the BEHCS Planning Committee (Black Health Alliance, Health Commons Solutions Lab with support from the Toronto Central LHIN, Mississauga Halton LHIN, and hosted by Sinai Health.)

Implementation

- Provide staff training - clear direction on how to do this respectfully and in a way that reduces the risks of harm and support for patients with FAQs
- Be clear about the purpose: to identify inequalities that may be the result of racism, bias and discrimination, and to support improvements to the quality of care.
- Explain the benefits/risks of collecting the data.
- Give patients the choice to provide (or not provide) the information and ensure their decision does not impact their care.
- Mitigate risks to privacy • Put protocols, processes and infrastructure in place to ensure the privacy, security and confidentiality of the data.

Report from the 2020 Black Experiences in Health Care Symposium (BEHCS): organized by the BEHCS Planning Committee (Black Health Alliance, Health Commons Solutions Lab with support from the Toronto Central LHIN, Mississauga Halton LHIN, and hosted by Sinai Health.)

Hamilton – Greater Hamilton Health Network - GHHN

Hamilton Health Team's

Health Equity Framework:

An anti-oppression, anti-racism,

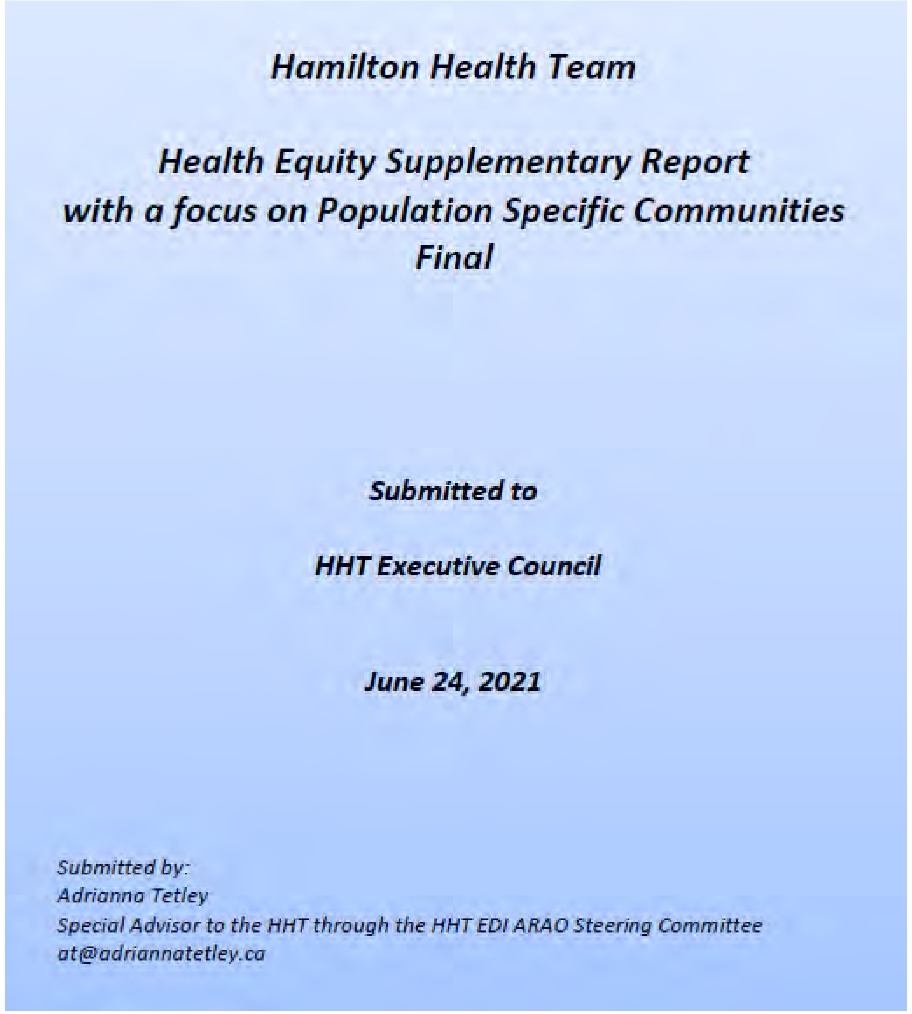
sex/gender based, intersectional approach.

Final Report submitted to

HHT Executive Council

June 24, 2021

Submitted by:
Adrianna Tetley
Special Advisor to the HHT EDI ARAO Steering Committee
at@adriannatetley.ca



Hamilton Health Team

Health Equity Supplementary Report
with a focus on Population Specific Communities
Final

Submitted to

HHT Executive Council

June 24, 2021

Submitted by:
Adrianna Tetley
Special Advisor to the HHT through the HHT EDI ARAO Steering Committee
at@adriannatetley.ca

Retrieved from: https://ihpme.utoronto.ca/wp-content/uploads/2021/12/GHHN-Health-Equity-Framework.pdf

GHHN Plan for Sociodemographic Data

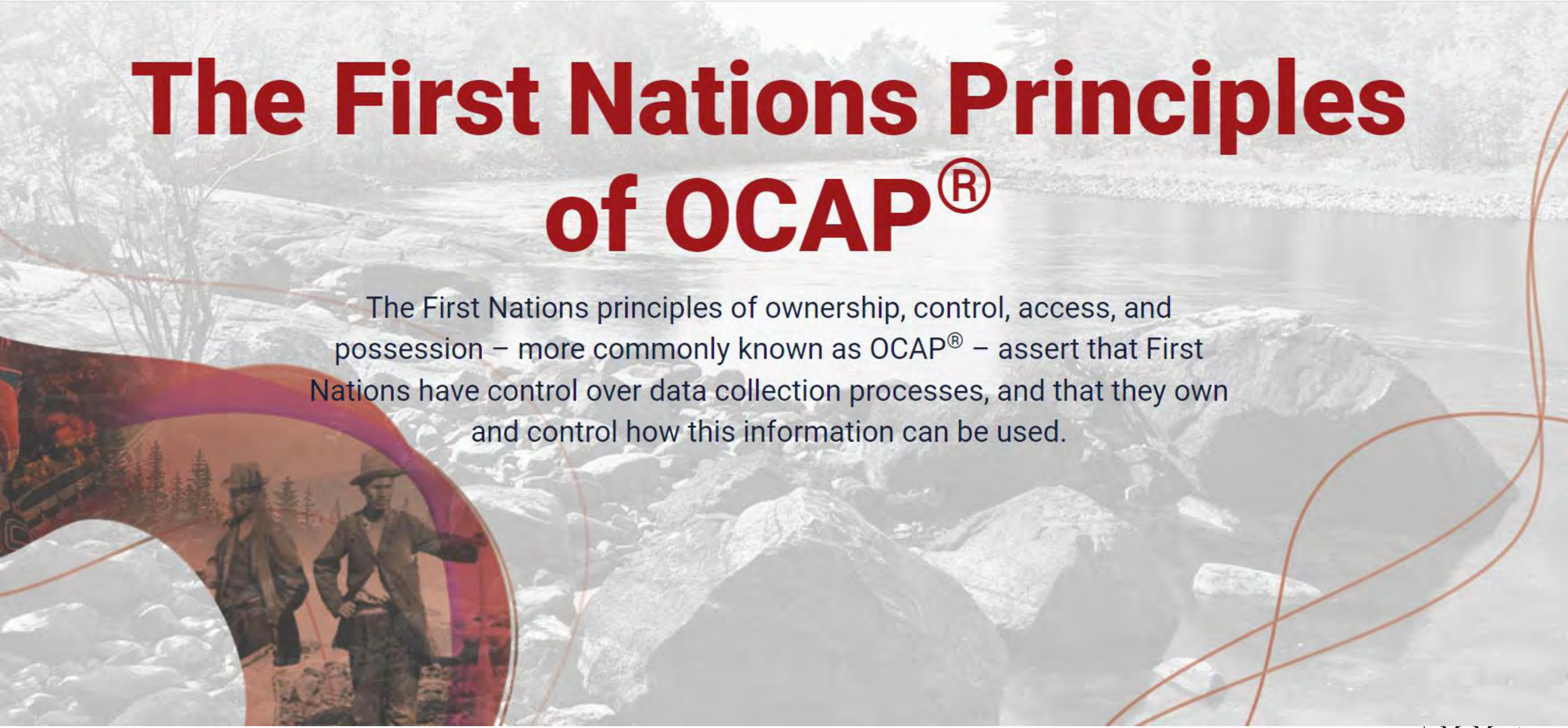
- The GHHN Executive Council has committed to the collection of socio-demographic and race-based data for HHT projects, in response to Ontario Health's recommendation for all health service providers to collect socio-demographic and race-based data, embedded within medical records.
- Next Steps

  1. Establish a community data governance table to oversee the use and analysis of the data.

  2. Develop a strategy to collect disaggregated socio-demographic and race-based data across the partners and in HHT initiatives that include standardized data.

  3. Use the OCAP principles for Indigenous Data and the EGAP principles as outlined in "Engagement, Governance, Access and Protection (EGAP): A Data Governance Framework for Health Data Collection from Black Communities in Ontario."

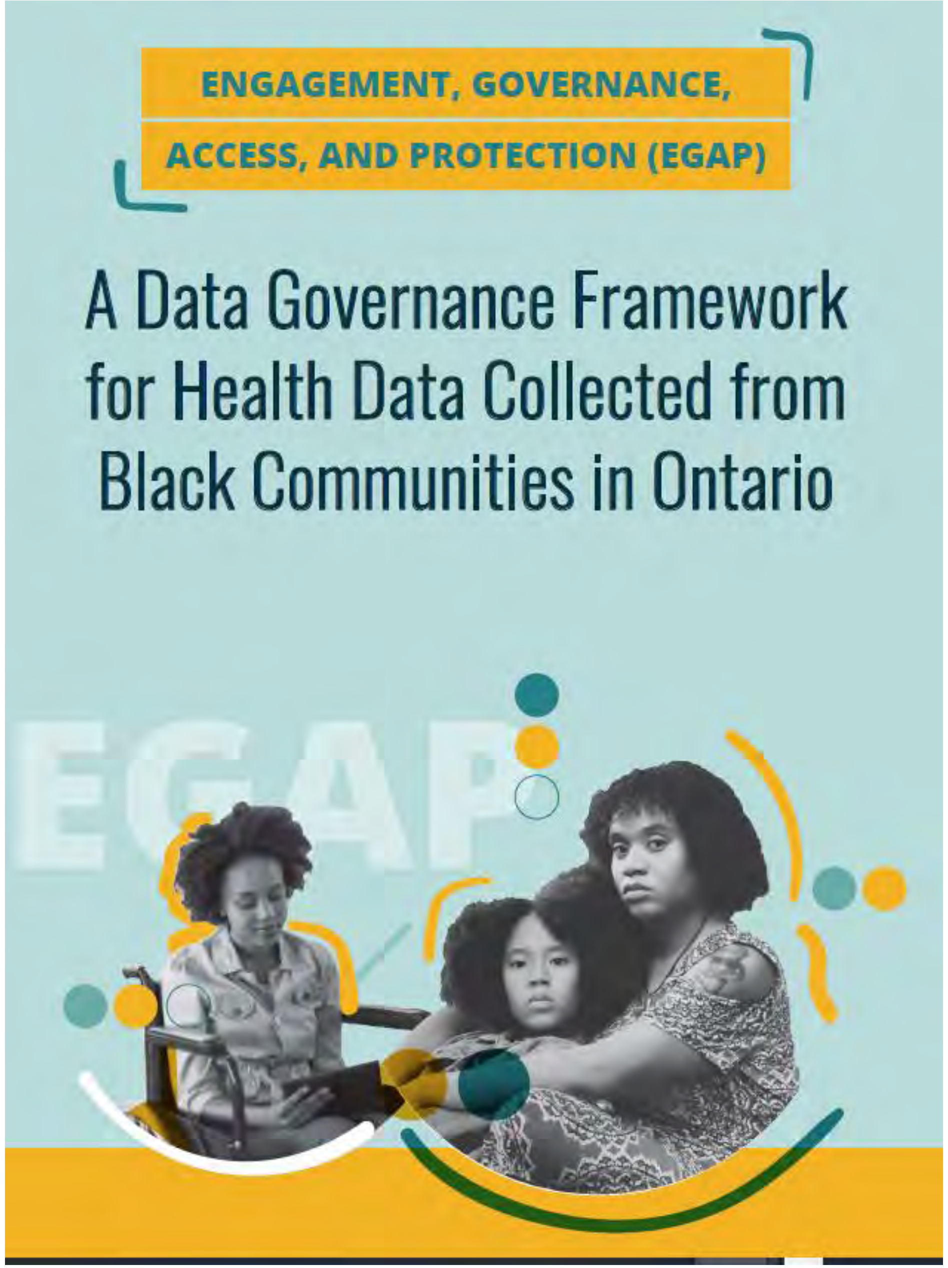
Tetley, A. Hamilton Health Team's Health Equity Framework: An anti-oppression, anti-racism, sex/gender based, intersectional approach. Final Report submitted to HHT Executive Council June 24, 2021. Retrieved from: https://ihpme.utoronto.ca/wp-content/uploads/2021/12/GHHN-Health-Equity-Framework.pdf



The First Nations Principles of OCAP®

The First Nations principles of ownership, control, access, and possession – more commonly known as OCAP® – assert that First Nations have control over data collection processes, and that they own and control how this information can be used.

https://fnigc.ca/ocap-training/



ENGAGEMENT, GOVERNANCE, ACCESS, AND PROTECTION (EGAP)

A Data Governance Framework for Health Data Collected from Black Communities in Ontario

ENGAGEMENT

Genuine, cyclical, accessible consultation with communities regarding data collection, management, analysis, and use.

GOVERNANCE

Community decision-making about engagement processes and data collection, management, analysis, and use, achieved through the establishment of Community Governance Tables.

ACCESS

The right of communities to access their collective data and to determine who else can access it, along with the capacity building required to enable this right.

PROTECTION

The safeguarding of all individual rights and types of data, including identifiable, de-identified, and anonymized data.

(EGAP): A Data Governance Framework for Health Data Collected from Black Communities. 2021. Retrieved from: https://blackhealthequity.ca/wp-content/uploads/2021/03/Report_EGAP_framework.pdf

McMaster University

Equity and Inclusion Office
McMaster University

The EDI Action Plan : 1 **Communication** and coordination of the EDI imperative 2 **Data-informed and evidence-based** EDI planning and decision-making 3 **Inclusivity and interdisciplinarity** in curricula and scholarship 4 Baseline EDI **leadership training** and development 5 Equity-seeking **group consultation**, engagement, and support 6 **Recruitment and retention** of equity-seeking groups

https://equity.mcmaster.ca/

McMaster Institute
for Health Equity

- Encourage new **inter-disciplinary understandings** of the social, economic, cultural, political and bio-physical forces that lead to health inequities
- To **investigate health inequities**, and use research to achieve health equity, across but not limited to, income, class, employment status, gender, language, race, and ethnicity, from the local to the global levels
- Take **leadership** in encouraging evidence-based action on health inequities

https://mihe.mcmaster.ca/

Best practices for questions about race, ethnicity, and indigenous status

1. Separate race, ethnicity, and indigenous status categories
2. Include multiple response options to allow people to identify more than one ethnic affiliation
3. Include an ‘Other’ response option to allow people to self-identify in their own words
4. Design data collection methods that allow people to self-identify and not be assigned to a category based on socially constructed notions of identity
5. Including categories for ‘none’ or ‘refused’ should be allowed

UN Principles and Recommendations for Population and Housing Censuses (United Nations, 2017[3]).

MIHE Seminar Series: Challenging Systemic Racism for Health Equity in Hamilton: Mobilizing Solidarities for Action

January 28, 2022

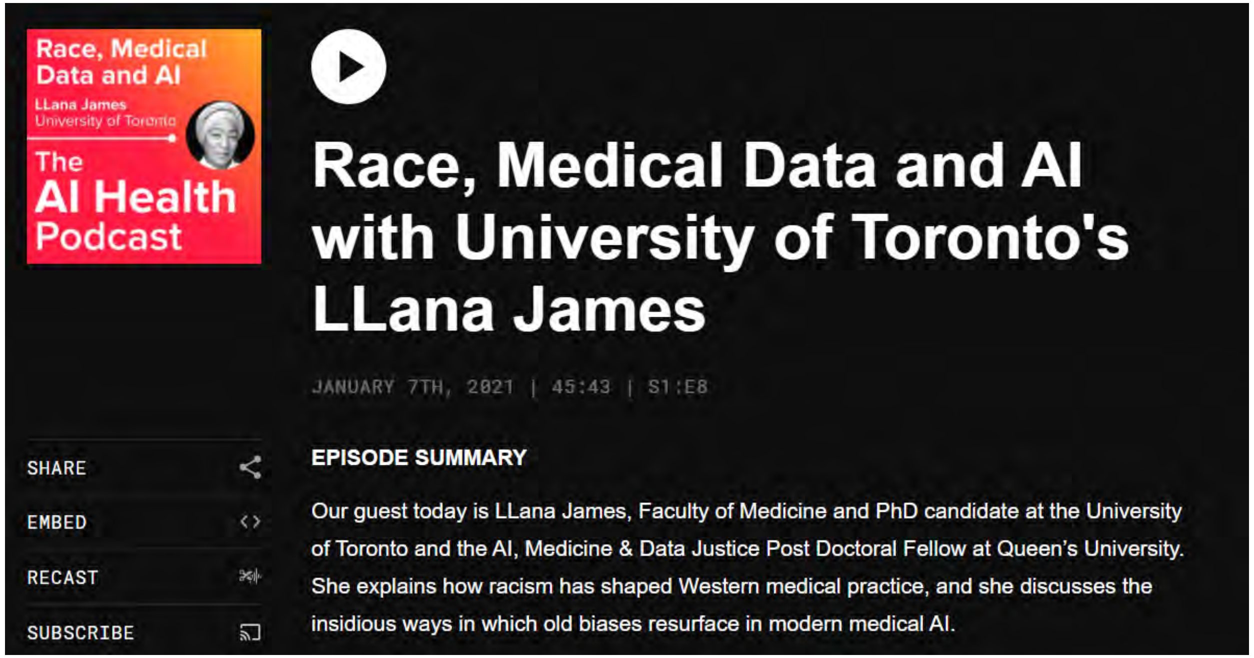
Ameil Joseph

Holder, Faculty of Social Sciences Professorship in Equity, Identity and Transformation | Academic Director, Community Engaged Research and Relationships, Office of Community Engagement | Associate Professor

- Data is not immune to injustice and may fuel perpetuation of injustice
- Analysis of equity data may lead to oversimplification of what are complex equity issues, resulting in ineffective interventions
- Equity data cannot and should only be collected along with the concomitant intention and resources to implement necessary interventions to effect change.

Proceed with Caution

- AI and Machine Learning
  - Risk of perpetuating biases and inequity of healthcare delivery



Race, Medical Data and AI with University of Toronto's LLana James

JANUARY 7TH, 2021 | 45:43 | S1:E8

EPISODE SUMMARY

Our guest today is LLana James, Faculty of Medicine and PhD candidate at the University of Toronto and the AI, Medicine & Data Justice Post Doctoral Fellow at Queen's University. She explains how racism has shaped Western medical practice, and she discusses the insidious ways in which old biases resurface in modern medical AI.

https://theaihealthpodcast.com/episodes/race-medical-data-and-ai-with-the-university-of-torontos-llana-james-taL3wsZR

BIG DATA & SOCIETY

Original Research Article

Big Data & Society
July–December 2017: 1–14

DOI: 10.1177/2053951717736335
journals.sagepub.com/home/bds
SAGE

What is data justice? The case for connecting digital rights and freedoms globally

Linnet Taylor

Abstract

The increasing availability of digital data reflecting economic and human development, and in particular the availability of data emitted as a by-product of people's use of technological devices and services, has both political and practical implications for the way people are seen and treated by the state and by the private sector. Yet the data revolution is so far primarily a technical one: the power of data to sort, categorise and intervene has not yet been explicitly connected to a social justice agenda by the agencies and authorities involved. Meanwhile, although data-driven discrimination is advancing at a similar pace to data processing technologies, awareness and mechanisms for combating it are not. This paper posits that just as an idea of justice is needed in order to establish the rule of law, an idea of *data justice* – fairness in the way people are made visible, represented and treated as a result of their production of digital data – is necessary to determine ethical paths through a datafying world. Bringing together the emerging scholarly perspectives on this topic, I propose three pillars as the basis of a notion of international data justice: (in)visibility, (dis)engagement with technology and antidiscrimination. These pillars integrate positive with negative rights and freedoms, and by doing so challenge both the basis of current data protection regulations and the growing assumption that being visible through the data we emit is part of the contemporary social contract.

Keywords

Privacy, ethics, development, discrimination, representation, surveillance

McMaster DFM

- Sociodemographic collection for research occurs in the absence of major guidelines
- MUSIC Research Database – data schema aligned with CPCSSN database and fed by OSCAR EMR data therefore no SDD beyond sex and postal code are collected
- MUSIC new member of Primary Care Ontario Practice-based Learning and Research Network (POPLAR) which has aims to support Networks in best practice for SDD collection and use

Environmental Scan Findings: Summary

- A profound need for agreed upon standards, guidelines and policies for SDD collection and use in clinical care, population health and research
- Many strong initiatives, pilots, frameworks to consider on how and what to ask and how to standardly collect these data
- Dynamic work - chart progress toward consensus and begin aligning with front-runners; Upstream lab and the Alliance for Healthier Communities model for tools and their implementation; Gravity for data standards
- DFM Research can consider regional directions offered by the GHHN project and forthcoming direction from Ontario Health and minimum standards from CIHI

Group Discussion Questions

Thinking about your experience with SDD, have you ever administered a demographic questionnaire or worked with data that didn’t comply with the principles/guidelines presented today?

What questions or data were they?

What was wrong or limited by the question/response or data?

How would you revise the question/response?

How will you advocate for better collection and use of sociodemographic data in primary care research?

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Upstream Lab

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