

Socio-demographic data and equity in health services in Ontario: building on strong foundations

Wellesley Institute works in research and policy to improve health and health equity in the GTA through action on the social determinants of health.

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Statement on Acknowledgement of Traditional Land

We would like to acknowledge this sacred land on which the Wellesley Institute operates. It has been a site of human activity for 15,000 years. This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. The territory was the subject of the Dish With One Spoon Wampum Belt Covenant, an agreement between the Iroquois Confederacy and Confederacy of the Ojibwe and allied nations to peaceably share and care for the resources around the Great Lakes.

Today, the meeting place of Toronto is still the home to many Indigenous people from across Turtle Island and we are grateful to have the opportunity to work in the community, on this territory.

Revised by the Elders Circle (Council of Aboriginal Initiatives) on November 6, 2014

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We have long been proud of our public health care system and its promise of equal and affordable access to health services. In recent years, Ontario has emphasized looking beyond affordability to broader questions of quality, equity and accessibility in health. The *Excellent Care for All Act* (ECFAA)¹ and the creation of Health Quality Ontario (HQO) marked a significant symbolic and practical step forward. The Preamble to the ECFAA defines a high-quality health care system as “accessible, appropriate, effective, efficient, equitable, integrated, patient centered, population health focused, and safe.”² More recently, the *Patients First Act, 2016*³ aimed to bring a renewed emphasis on the navigability, coordination, transparency and accountability of Ontario’s health care system.⁴

Realizing the goals of ECFAA and *Patients First* calls for practical tools. Socio-demographic data has been recognized as an important tool for identifying and addressing gaps and shortfalls in health services.

There is currently significant interest in the potential of socio-demographic data to advance equity. Ontario’s new *Anti-Racism Act* requires the creation of standards that provide for the collection, use and management of information, including personal information, by public sector organizations (although not health information custodians) to identify and

monitor systemic racism and racial disparities. The post-*Patients First* move towards population-based health planning at the local level, together with the new mandates of the Local Health Integration Networks (LHINs) regarding health equity and the social determinants of health, have focused the attention of LHINs on the need for such tools. The new Population Health Solutions Lab is championing the idea of collecting socio-demographic data through the OHIP card renewal process. The Measuring Health Equity Project in Toronto Central LHIN has demonstrated the possibilities and feasibility of standardized data collection in Toronto-area hospitals and Community Health Centres.⁵ There have been calls from community to use data collection to improve the health system experiences of marginalized communities.⁶

Wellesley Institute has prepared this paper as a contribution to the current discussions in Ontario about socio-demographic data and health services. In addition to our scan of Ontario’s policy environment and a review of the relevant literature, it reflects the valuable discussions that we have had with a range of persons knowledgeable about and interested in data collection in health in Ontario. An earlier version of this Paper was shared with the Population Health Solutions Lab to assist the development of its project on data collection through the OHIP card. This paper reflects on the value of socio-demographic data in the context of health services, considers how we can build on existing strong foundations, and identifies some principles and considerations that can shape new initiatives on socio-demographic data collection and usage in health to ensure improved health and health equity.

Understanding the Value of Socio-demographic Data in Health Services

There are inequities and barriers to access in health services

Across Ontario's population, there are differences in the risk of illnesses, in access to health services, and in outcomes from health services interventions. These differences are associated with a variety of social and demographic factors, including language, race and ethnicity, sexual orientation and immigration status,⁷ as well as access to appropriate housing, adequate income, social inclusion and other factors. Because of this, needs for health promotion, illness prevention and treatment will differ for different groups.

Wellesley Institute's research has identified a number of these disparities.⁸ They include:

Language

- Individuals who speak only French are more likely to report poor or fair health than those who speak only English, or who speak English and another language.⁹

Disabilities

- Canadians with disabilities report less access to health care and greater unmet health care needs than those without disabilities.¹⁰

Immigration

- Immigrants tend to arrive in Canada in good health, but see their health deteriorate over time.¹¹
- In the Peel Region of the GTA, the infants of immigrants have, on average, significantly lower birthweights than the infants of non-immigrants.¹²

Racism, Racialization and Colonialism

- Recent research on racism, discrimination and health in Canada, points to health disparities and inequities in health care access and delivery for racialized Canadians.¹³⁻¹⁴
- There are enormous disparities in the health outcomes of Indigenous peoples in Ontario, as compared to other Ontarians.¹⁵
- Men who self-identify as Black are twice as likely to report poor health as those who self-identify as Arab or Asian.¹⁶

Income and Employment

- In Toronto, children from high poverty neighbourhoods are likely to stay longer in hospital than those from other neighbourhoods.¹⁷

- Life expectancy at birth in Toronto is 2.7 years lower for men in the lowest income quintile, as compared to men in the highest income quintile;¹⁸ similarly, when considering remaining life expectancy at age 25, Statistics Canada found a 7.4-year difference for men in lowest income decile vs. highest income decile.¹⁹

It should be noted that these studies can provide only a partial picture of existing disparities. As is detailed below, without comprehensive socio-demographic data on health services users, our ability to identify, understand and address such disparities is limited.

Socio-demographic data can help us to understand, address and prevent inequities

An important step in addressing inequities in access to health services and in health outcomes is to develop a thorough understanding of the disparities. We must ask: How do different groups access and navigate the full range of health services? How do health outcomes differ based on sex, income, sexual orientation, race and ethnicity, language, age, disability and other factors? There are many possible effective interventions, but only with an understanding of the disparities can they best be selected, implemented and evaluated.²⁰ Collecting data on characteristics of health service users, including race, ethnicity, religion, immigration, language, sexual orientation, age, gender and disability is a vital tool in designing equitable and effective health services.

The collection of socio-demographic data has raised concerns about privacy and the potential for misuse.²¹ However, in recent years there has been broader acceptance of the value of collecting and analyzing socio-demographic data as a means of addressing inequities. The Ontario Human Rights Commission (OHRC) has pointed out that collecting and analyzing data that identifies individuals by their race, ethnicity, citizenship, sexual orientation, or similar factors can assist institutions or systems to protect and promote human rights. This type of data can be used to prevent or address systemic barriers to access to services, or to improve equitable service delivery and programs.²² When data is collected, tracked and analyzed for appropriate purposes, and using credible methods, it tells us a great deal about the experiences of those using health care services. Very recently, the OHRC called on the Minister responsible for the Anti-Racism Directorate to strengthen requirements for race-based data collection, including in health care, in order to advance human rights.²³

In the context of addressing systemic racism, the Strategic Plan of Ontario's new Anti-Racism Directorate emphasizes that, "To address racial inequities, we need better race-based disaggregated data — data that can be broken down so that we further understand whether specific segments of the population are experiencing adverse impacts of systemic racism."²⁴ The new *Anti-Racism Act, 2017* creates a comprehensive regime for the collection, use and management of information by public sector organizations (excluding health information custodians). The information to be collected includes that related to race, ethnic origin,

religion, age, sex, sexual orientation or other factors. The goal of this data collection is to identify and monitor systemic racism and racial disparities, for the purpose of working towards their elimination. It is accompanied by comprehensive protections for the privacy of citizens.

Applying these approaches to health systems, a recent international review of health equity strategies found that all such strategies place robust monitoring and evaluation systems at their core.²⁵ As a specific example, in the wake of the death of an African Caribbean man while in the care of a psychiatric facility, the UK Department of Health's developed its 2005 Action Plan, *Delivering Race Equality in Mental Health Care*. The Plan embraced, as one of its three pillars for reform, a commitment to improved monitoring of ethnicity, better dissemination of information and good practice, and improved knowledge about effective services, in order to improve services and equity in outcomes. This included annual surveys of the experience of Black and Minority Ethnic users of mental health services, a national census of mental health inpatients, and a requirement for mental health service providers to record ethnicity and other relevant data, such as language and religion, for care planning purposes. The Plan emphasized that such data is vital to improve services, develop new strategies and services, and ultimately to increase equity in outcomes.²⁶

In Ontario, the feasibility and value of collecting and analyzing personal data in the context of health services has been illustrated by the Measuring Health Equity in Toronto Central LHIN project, lead by Mount Sinai Hospital's Human Rights and Health Equity Office. Beginning in 2009 with the "We Ask Because We Care" initiative, this pioneering project has resulted in socio-demographic data collection in 16 Toronto-area hospitals and Community Health Centres. As of November 2015, more than 261,000 patients had been approached for data collection. The project has demonstrated the willingness of patients and clients to participate in data collection and a growing understanding of the value of this data in advancing health equity. It is also a source of helpful materials and transferable best practices.²⁷

We can see already the potential power of this data for improving health. A recent study by Lofters *et al.* describes how patient data was used to identify the connections between low income, housing status and rates of colorectal, cervical and breast cancer screening, and illustrated the importance of targeted interventions to reduce income disparities in cancer screening.²⁸

Socio-demographic data can help us to improve outcomes and effectively allocate resources

Ensuring that *all* Ontarians receive excellent care that addresses their specific needs and reduces the disparities in health outcomes must be central to our understanding of health quality. In committing to building equity into concepts of quality, Health Quality Ontario has stated that, "We know that opportunities for optimal health vary among populations, that not

everyone has ready access to high-quality care, and that many individuals living in Ontario do not have the resources required to build and maintain optimal health.”²⁹

Collecting and analyzing data is essential to the efficiency and effectiveness of the health care system. It enables system accountability, tracking of geographical and demographic data patterns, tracking of pathways of health outcomes, disease patterns and program interventions. Insufficient data can lead to misleading results; meaning that our understanding of the strengths and challenges facing communities is incomplete or misinformed.³⁰

Population-level data collection can serve as an effective tool to describe demographic trends and transitions across communities over time, to identify unmet needs across communities, and to inform health services and health promotion planning.^{31,32} Such data illuminates what service needs are being met and where disparities exist, across and within communities. With it, we can identify those who are in highest need and prioritize their treatment. Data collection can also assist us to design successful interventions to address the underlying causes of health inequities.

In this way, comprehensive data collection is critical to population health.

The value of such data for system improvement has been recognized in the context of education. For example, the Toronto District School Board regularly collects demographic information about students, including information on Aboriginal status, race, gender, special education needs, sexual orientation, and socio-economic status. The aims of collecting this data include helping schools to close the achievement gap for students in need. The survey data has been used for improvement planning, programming, policy-making and resource allocation. System level initiatives drawing on this data have included the Model Schools for Inner Cities program, the Young Women on the Move program, and an expansion of the Boys2Men program, among others. At the school level, it has been used to, for example, select texts and materials that reflect students’ cultural and racial background, and to offer more targeted workshops and after school programs.³³

If we understand the sources of health disparities, we can address “upstream” issues that increase the risk of illness. Connecting socio-demographic data to health services information allows us to more effectively target resources. Good quality demographic data enhances our ability to understand and assess health care needs, the services that are being offered, and health outcomes over time.^{34,35}

Learning from others: data collection systems in the United Kingdom

The benefits of data collection and analysis for effective health systems have been well recognized elsewhere.

As one example, the United Kingdom has a comprehensive system for data collection related to health. The *National Health Service Act 2006*³⁶ enables the Secretary of State to make provision for prescribed patient information for medical purposes, in the interests of improving patient care or in the public interest. Health data linked to the social determinants are collected via Hospital Episode Statistics (HES) and primary care institutions. Socio-demographic data, such as ethnicity, is patient-reported by either a check list or by face-to-face interaction with a health care professional. The *Data Protection Act*³⁷ makes thorough provision for the protection of personal information, and a National Data Guardian for Health and Social Care provides advice to government and challenges the health and social care system to help ensure that citizens' confidential information is safeguarded securely and used properly.³⁸ The London Public Health Observatory provides a consistent and coordinated centre-point by monitoring and reporting on data about health inequities, drawing on a range of datasets that link health data with socio-demographic and other information related to the social determinants of health.³⁹

The National Data Guardian for Health and Social Care has described the benefits of their data collection system as follows:

Information is essential for high quality health and care, to support the provision of excellent care and for the running of the health and social care system. It is also essential to improve the safety of care, including through research, to protect public health, and support innovation. It can be beneficial to join health data with other types of information, to provide better services to people.⁴⁰

With the increasing recognition of the existence of health disparities among various communities and an analysis of health services accessibility that moves beyond the cost of services there has come an understanding that we need better tools for health services planning. This includes the collection and analysis of socio-demographic information about users of health services. Such data can help us to understand the nature and sources of health disparities, the variances in patterns of use of health services, and the effectiveness of health programs and interventions in promoting health among all Ontarians. Socio-demographic data can help us to advance more equitable health outcomes and ensure effective, appropriate and high-quality health services for all.

Ontario Socio-Demographic Data Collection in Health

Current Sources of Data

There is a considerable history of data collection in public health, ranging from vital statistics and disease surveillance, to population health surveys to administrative data to the Census.⁴¹

Currently, health-related data in Ontario is collected through the Census, sample surveys, administrative data, and administrative registries.⁴²

As well, some demographic information has long been collected through the OHIP card issuance and renewal process. This includes age, sex and area of residence, but not race, ethnicity, place of birth, language, disability or gender.

Census Data: Every five years, Statistics Canada conducts the Census, which aims to be a complete count of the population.⁴³ The Census provides a picture of the country and how the population is changing in a number of ways, such as education, work, income, household size, and ethno-cultural diversity. This information is used by governments at all levels to support program planning and administration, evaluation, and policy development. Census information is also used by researchers, business, non-profit and public-sector organizations, and citizens.

The cancellation of the mandatory long form Census and its replacement with the voluntary, household survey in 2010 brought to the surface questions and discussions on the value and need for universal data collection.^{44,45} Notably, the replacement National Household Survey (NHS) in 2011, with its much lower national response rate,⁴⁶ was widely perceived as undermining the representation of many communities in data collection, especially those from marginalized or disadvantaged communities. This lack of representation was seen as ultimately weakening and damaging health care and population health planning. Without accurate and valid information, efforts to address public health issues, to identify and reduce health disparities, and to conduct emergency preparedness were compromised.⁴⁷

The reinstatement of the mandatory long form Census in 2016 has marked a significant turning point in data collection in Canada, signaling a recognition of the importance of universal population-level data as a tool in health and social policy research, and in health services planning. The overwhelming support for the 2016 Census demonstrated a commitment to, and acknowledgement that, universal data collection can reinforce the inclusion of community experiences in population level data.

Survey Data: Surveys are used to collect information from a group of respondents that is then used to estimate characteristics for a larger population of interest. Surveys can be more cost and time efficient than a census.⁴⁸

For health services, the most important of these is the Canadian Community Health Survey (CCHS). According to Statistics Canada, the main purpose of the CCHS is to provide the information needed for health surveillance and population health research: for health departments, service providers, and government agencies to inform health-promoting programs; for researchers to conduct health research; and for non-profits and media to raise awareness about health issues. The CCHS collects information once a year from a representative sample of Canadians about their health status, health care use, and health

determinants.⁴⁹ Questions are answered directly by respondents and participation is voluntary.

The CCHS collects information on several socio-demographic characteristics, including country of origin, immigrant status, years since immigration, ethnic or cultural ancestry, Aboriginal status, racial or cultural group, language, sexual orientation, sex, income, dwelling type, and age.

Administrative Data: Administrative data are information collected by governments agencies, service providers, etc. for their own purposes while delivering programs and services.⁵⁰ Drawing on administrative data collection when conducting health research and evaluation can be more cost effective and less burdensome than directly collecting data through surveys.

Administrative data is collected when people use health services. For example, hospitals collect information about patient admission, discharge, diagnosis and intervention. Most physicians must submit provider claims to the Ontario Health Insurance Plan (OHIP) about the billed services they have provided and information about diagnoses. Assessment information is collected for all patients accessing continuing or long-term care. The administrative data from sources like these provide a picture of the health care experiences of Ontarians. This information can help us to better understand quality of care, patient diagnoses, treatments and outcomes.

The only socio-demographic data available across this administrative health data is patient sex, age, and postal code/residency. This data is collected by Service Ontario for the Ministry of Health and Long-Term Care (MOHLTC) and entered into the Registered Persons Database (RPDB), which includes information about all individuals who are or have been registered with OHIP.

Institute for Clinical Evaluative Sciences (ICES)

The Institute for Clinical Evaluative Sciences (ICES) plays a central role in Ontario research aimed at identifying health inequities, and developing and evaluating health policy and services. ICES brings together research, data and clinical experts to lead advanced studies that evaluate health care delivery and outcomes. An independent not-for-profit research institute, ICES receives its core funding from the Ministry of Health and Long-Term Care (MOHLTC).

ICES is the data repository for much of the publicly funded administrative health services records for the Ontario population eligible for universal health coverage. These health data sets are record-level, coded and linkable.

ICES is able to receive and hold this data through a special designation granted by the Information and Privacy Commissioner of Ontario under the *Personal Health Information Protection Act*. This designation is subject to ongoing IPC oversight, and is renewed every three years. It is based on ICES' thorough measures for protecting privacy and confidentiality,

including physical security measures, technological safeguards like encryption and a comprehensive framework of policies and procedures.

ICES projects have linked its data to many different government data sets to allow for better understanding of health services usage.

Limitations in current collection of socio-demographic data

The promotion of health equity across systems and across communities relies on the introduction of metrics that capture the complexity and diversity of our populations over time. However, researchers, advocates and decision-makers in Canada have struggled with issues of access to strong and comprehensive data at population levels. There are considerable strengths in the current system: for example, ICES play a unique and vital role in providing a trusted repository for data and supporting advanced research, and the Measuring Health Equity project has pointed to the potential for point of care collection. However, the data sources currently available have significant limitations in terms of their ability to support the kind of broad-scale equity-focused health services planning that is required. There are serious gaps in our ability to document and track over time the health inequities and health outcomes for some populations, for example, racialized communities.

Underrepresentation: Identifiers for some sub-populations are inconsistent, for example, in Indigenous communities. This can undermine their representation in population level data collection and population health planning.⁵¹

Broad categories: In Statistics Canada surveys, important distinctions in individual and community demographics have historically been masked by broad, ill-fitting categories. As a result, social, ethnic or linguistic diversities, as well as categories of sexual orientation and gender identity, are obscured by catch-all categories that fail to shed light on the complex demography of Canadian society. For example, as described in a recent Statistics Canada report, on Visible Minority Women, they note the category of visible minority effectively operates as a catch-all including: “South Asian, Chinese, Black, Filipino, Latin American, Arab, Southeast Asian, West Asian, Korean and Japanese” as well as individuals of mixed racial origin.⁵² Without more complex categories to reflect the socio-demographic characteristics of Canadian communities, our understanding of health issues, service use and unmet needs remains fragmented at best.⁵³

Lack of standardization: Linking survey and census data with current administrative datasets can improve our ability to understand the experiences of specific population groups or communities.⁵⁴ For example, administrative health data can be linked with Census data to tell us the neighbourhood-level income quintile of patients. Evidence on data linkages in the US have demonstrated the value of connecting information across existing data systems; enabling more complex analyses and interpretation of health patterns.⁵⁵ Currently in Canada, linking and comparing information across data sets is limited by the fact that the data that

we currently collect is not standardized. Socio-demographic indicators are not defined in the same way and shared identifiers are not used across the various data sets. This reduces our ability to connect data, and to identify meaningful patterns.

Building on Existing Foundations

Recent Point of Care Initiatives

Health service providers have identified this limited collection of patient-level socio-demographic data, and the difficulty in accessing and using linked data sources, as a barrier to their efforts towards understanding and improving health equity. These limitations gave rise to the Measuring Health Equity in Toronto Central LHIN project, briefly highlighted above.

This project has mandated Toronto-area hospitals and community health centres to collect standardized patient-level, self-reported socio-demographic data for the following factors which were deemed to be priorities for health equity planning: length of stay in Canada, disability, gender identity, income, language preference with health care provider, race/ethnicity, and sexual orientation.

As noted above, this project has successfully demonstrated the viability and usefulness of this type of data collection, and is a source of expertise and best practices which form a strong foundation for further expansion. For example, the Mississauga Halton LHIN and the Central West LHIN have initiated data collection projects.

Point of care collection is particularly important for addressing the experiences of residents who are not covered by OHIP, collecting data that is subject to frequent change (such as income, and tailoring questions to reflect the local context.

Current Proposals

There is interest in building on these successes to expand data collection beyond hospitals and community health centres, and to explore the possibilities of universal, consistent and standardized data collection across the province. Such proposals look to complement the strengths of the kinds of point of care data collection now being developed through projects such as the Measuring Health Equity initiative, by addressing the following needs:

Data that more closely reflects the complete population: The discussions following the cancellation of the 2010 Census highlighted the importance of ensuring that the data collected reflects the diversity of the population. The purposes and processes surrounding the Census differ in some ways from the specific context of health services planning. There are specific privacy concerns and service context surrounding socio-demographic information related to health. While it is important to ask for information on socio-demographics, making

it mandatory for Ontarians to provide this data when requested is likely not appropriate; an opt-out option would be best. However, it is important that all communities and health services users see themselves reflected in the data collected. Planning on the basis of incomplete data will result in inefficiencies and inequities. This points to the need for universal, system-wide collection.

Data that is standardized: Standardized data is comparable and linkable, adding immensely to its analytical power. Our current system for collecting socio-demographic data related to health is fragmented. Different information is gathered through the various instruments, and terms are not defined in standard ways. While this promotes flexibility and tailoring, it limits the ability to link information and to draw meaningful conclusions.

Data that is high quality: A core benefit of census and survey data is its regular collection and comparability across time. Socio-demographic data collected through administrative health data is limited, largely not validated, and not always regularly gathered.

The OHIP card renewal proposal, highlighted earlier, presents an opportunity achieve these goals. Because the OHIP card renewal process is regular, centralized and system-wide, it offers an opportunity to obtain relatively comprehensive, current and standardized data for system planning, and to build capacity for the LHINs and their sub-regions to fulfil their mandates related to health inequities and the social determinants of health. The proposal focuses on data that do not change frequently and that cannot currently be accessed through linkage of data sets.

Considerations and Principles for Socio-Demographic Data Collection

As we move forward to strengthen socio-demographic data collection in Ontario, we can build on the experiences and foundations in place, to ensure that the implementation of new initiatives is effective and moves us towards our shared goals.

In designing new initiatives, key considerations include:

Clarity about the purposes for which we collect this data: Socio-demographic data may be collected for a range of purposes, including research, improving patient experiences at the point of care, health system planning, and system improvement. The purpose for which we collect the data will shape the method of collection. For example, if our purpose is health system planning, standardization and universality become particularly important. If we are collecting socio-demographic data to directly affect the patient experience at the point of care, this is a high trust endeavour that may be easiest to implement in the context of a trusting relationship between the patient and the care provider.

Understanding the goals and concerns of affected communities: Communities affected by health inequities are generally communities that have experienced marginalization, discrimination or oppression. These histories will affect relationships with the health system and health providers, and the appropriate goals and protections surrounding data collection. For example, lesbian, gay and bi-sexual patients will have particular concerns about being “outed” to health services providers, particularly in small communities. Histories of medical experimentation, forced sterilization, or use of data to justify discriminatory treatment will shape the concerns of some communities. These experiences must be understood and addressed in designing data collection initiatives.

Building trust: As the Measuring Health Equity project has demonstrated, many Ontarians are willing, in the context of carefully thought-through and effectively implemented programs, to share very personal, and potentially very sensitive, information about themselves. The project reports emphasize the importance of creating respectful and inclusive environments, and building strong relationships. This was mirrored in our discussions with individuals and organizations engaged in or affected by data collection. We heard about the importance of public education, inclusive messaging, and high-quality training for staff engaged in data collection.

Community engagement: It is historically marginalized communities, who tend to experience health inequities, who both have the most to risk and the most to gain from the collection and use of socio-demographic data. We heard how important it is to engage community in the design of socio-demographic data collection initiatives, to ensure that such projects address the goals of these communities, are designed to take community needs and experiences into account, and are implemented in ways that are inclusive and respectful.

Comprehensive data governance: The learnings for the Measuring Health Equity project, the experiences with comprehensive health data collection in the United Kingdom, and the perspectives of Ontario stakeholders all point towards the importance of thinking beyond data collection to data *governance*. This includes the kinds of privacy protections that are in place, how and where the data is held, who accesses data and how, how the effectiveness of the data collection system is monitored and strengthened – all these and many other issues must be considered in designing and implementing any socio-demographic data initiative.

Support for effective use: It is important to think beyond the collection of data to support for its usage to effect meaningful change in health systems and advance health equity. Without demonstrated positive outcomes, it will be difficult to sustain or justify the collection of sensitive personal information. In discussions, stakeholders emphasized that health care organizations may need support to understand how to make the best use of such data to improve their services.

Based on all of the above, we propose nine guiding principles and best practices for implementing initiatives to strengthen socio-demographic data collection in Ontario.

1. Collecting data for appropriate purposes

Socio-demographic data collection must be collected and used for appropriate purposes, consistent with Canada's human rights framework.

The Ontario *Human Rights Code* aims to advance the understanding and respect for all people without discrimination. Most importantly in this context, it prohibits discrimination in services, including health care services, based on Code grounds. These grounds include race, ancestry, colour, ethnic origin, place of origin, age, gender, gender identity, sexual orientation, and disability. That is, the socio-demographic identifiers that are important for health equity purposes are also protected grounds under the Code. This means that such data cannot be gathered for any purpose, or used in any way, that would lead to discrimination in service provision based on Code grounds.

Collection of socio-demographic data should not only respect the Code, but promote the realization of human rights. Such data can be used to monitor and evaluate potential discrimination or to identify and remove systemic barriers.⁵⁶ For example, such data could help to identify differences in the ways in which Code-protected groups access health care services. A recent Wellesley Institute project identified that Ontario seniors who are ethnically or culturally diverse use less government-provided home care, and face longer wait times for long-term care.⁵⁷ Therefore, collection could also identify differences in health outcomes for Code-protected groups. Understanding these differences is a first step to understanding systemic barriers to health for such groups and to designing and improving programs that improve health and health services access for these Ontarians. In this way, socio-demographic data can be used to reduce discrimination in the provision of health services.

2. Privacy and protection of data

A key consideration in data collection is the protection of privacy and confidentiality in collection, storage, sharing and usage. Data protection and privacy measures are critical for public support and to ensure confidentiality and dignity. For example, the United Kingdom has found that failure to provide adequate data security has undermined public support for the collection of data.⁵⁸ To protect patient privacy, the National Data Guardian for Health in the UK⁵⁹ recommends data security standards, compliance mechanisms, and a model for secure information-sharing of data.

Ontario has an effective set of privacy laws, including laws specifically focused on health data.⁶⁰ The *Personal Health Information Protection Act, 2004 (PHIPA)* governs the collection, use and disclosure of personal health information within the health-care system. These laws guide all data collection efforts, including those related to socio-demographic data collection. Recent legislative initiatives in Ontario to collect race-based data have paid considerable attention to data privacy. The *Anti-Racism Act, 2017* includes extensive

provisions regulating the collection, storage, use and access to race-based data. It states that the Minister “shall establish data standards for the collection, use and management of information, including personal information, to identify and monitor systemic racism and racial disparities” (Section 6(1)) and requires that all public-sector organizations that collect data will be required to de-identify any personal information (Section 7(9)).⁶¹

Institutional safeguards include Ontario’s Information and Privacy Commissioner (IPC), who plays a crucial role in safeguarding personal information that is held by government and establishes rules about how government organizations may collect, use, and disclose personal data.⁶² As was noted above, a special designation by the IPC under *PHIPA* enables ICES to provide a secure storage and access site for Ontario’s health-related data (including population-based health surveys, anonymous patient records, and clinical and administrative databases).⁶³

3. Informed consent

As was noted earlier in this paper, the sensitivity of both socio-demographic and health information means that health systems users will have significant interests in understanding the purposes for which their information is collected and the uses to which it will be put, as well as the opportunity to make a choice about the collection of their data.

The concept of informed consent for the collection and use of identifying personal health information is foundational to *PHIPA*. Where data is not anonymized and significant privacy interests are at stake, *PHIPA* provides a thorough scheme for consent to the collection, use and disclosure of such information.⁶⁴

4. Transparent data collection

The OHRC recommends that data collection systems ensure that the public is informed of how and why data are collected, its benefits, and what measures are in place to protect privacy and confidentiality.⁶⁵ Transparency in data collection ensures patients are informed about the use of their personal data, for instance, who is collecting their data, why data are being collected and how data are being used. Ensuring that patients understand the purpose of their data collection is essential to quality and accuracy in data collection.⁶⁶ In the United Kingdom, the *Data Protection Act*⁶⁷ supports transparency and accountability by giving individuals the right to find out what information the government and other organizations are storing about them. Ontario’s new anti-racism legislation, the *Anti-Racism Act, 2017* provides an example of how transparency can be ensured when collecting socio-demographic data. Section 7 (4)⁶⁸ of the *Anti-Racism Act, 2017* states that if

information is collected directly from the individual to whom the information relates, the public-sector organization shall inform the individual of:

- a) the purpose for which the personal information is intended to be used;
- b) the fact that, under subsection 6 (8), no program, service or benefit may be withheld because the individual does not provide, or refuses to provide, the personal information; and
- c) the title and contact information, including an email address, of an employee who can answer the individual's questions about the collection.

5. Opt-in/opt-out framework

In addition to transparency, patient consent is an effective way to build trust in the systems that collect personal and confidential data.⁶⁹ The OHRC recommends that participation should be voluntary for socio-demographic data collection, to limit intrusiveness.⁷⁰ A practice adopted in the United Kingdom that helps enable patient consent is the mandatory opt-in/opt-out framework. According to the National Guardian for Health and Care,⁷¹ the opportunity to opt-out of data collection enables patients to make informed decisions about whether to provide their information for collection that goes beyond their direct care and remains an important measure for patient privacy. In Ontario, section 6 (8) of the *Anti-Racism Act, 2017* protects all persons' rights to opt-out of data collection by indicating that no program, service or benefit may be withheld because an individual does not provide, or refuses to provide, information for the purpose of standardized data collection.⁷²

6. High-quality data

Methods that support high-quality data are important for socio-demographic collection. Quality data promote accuracy and consistency and can support institutional trust. Standardized and self-reported data are two evidence-based ways to enhance the quality of socio-demographic data.

7. Standardized data

Standardized data collection is essential to provide dependable, accurate and quality data. For instance, when data collection was not standardized in Scotland and England, race and ethnicity data varied greatly from organization to organization. Fragmented and non-standardized data limited organizational capacity to assess improvements in relation to the observed risk and prevalence of differences in health.⁷³ When there are standards for implementation across the board it vastly improves consistency and accuracy and reduces variations that may impact data quality.⁷⁴

The Tri-Hospital + TPH pilot demonstrates how this may be done. This data collection initiative involved standardized, evidence-informed definitions of socio-demographic factors and meaningful close-ended response categories; an environmental scan, key

informant consultations, and pilot evaluation were used to develop and implement the data collection.⁷⁵ The OHRC recommends consulting affected communities when developing data collection processes.⁷⁶

8. Self-reported data

Self-reporting of socio-demographic data by individuals is a generally considered the “gold standard.”⁷⁷ Self-reporting means it is the patient who is answering socio-demographic questions themselves, rather than the provider. Self-reporting improves data accuracy and precision and reduces bias and errors in classification. Researchers have found, for example, that when staff classify a patient’s ethnicity based on their last name rather than allowing for self-reporting, more than half of patients are misclassified or not classified at all.⁷⁸ Ontario’s new *Anti-Racism Act, 2017* recognizes the importance of self-reporting by requiring that “any personal information collected shall be collected directly from the individual to whom the information relates unless another manner of collection is authorized by the applicable data standards” (Section 7 (3)).⁷⁹

9. Trained staff

To maintain quality in data collection and security, properly trained and educated staff are essential.⁸⁰ According to research, rates of patient compliance have been largely dependent on staff training and low compliance can often be attributed to a lack of staff acceptance and comfort in data collection.⁸¹ Therefore, training and educating staff in the importance of data collection is necessary for successful implementation of standardized data collection.⁸² In their review, the National Data Guardian recommends embedding mandatory role standards for staff in all health care organizations to ensure quality and consistency in data.⁸³ Collecting socio-demographic data to address disparities in our health systems involves staff who are well-trained, dedicated and equipped to collect consistent and high quality information.

By drawing on existing good practices in Ontario and elsewhere, we can ensure socio-demographic data collection efforts optimize both privacy and quality, and are consistent with human rights legislation.

Conclusion

Considerable efforts are being made in Ontario to improve the quality and equity of our health services and to promote good health outcomes for all Ontarians. The collection of socio-demographic data is an important tool for advancing these goals. As with all public services, health services must be founded on strong evidence about the characteristics and needs of the population that is being served. Without socio-demographic data, we cannot effectively identify differing needs and evaluate our programs and services.

At this time, our access to such data is limited. Our current combination of census, survey and administrative data does not give us the information that we need. We need new approaches to provide us with information that is system-wide, standardized, linkable and high quality.

The socio-demographic information collection systems in the United States and the United Kingdom, as well as the innovative work done in the Measuring Health Equity Project, shows us that such data can be collected. Their success also demonstrates that building on the foundation laid out in Ontario's existing laws and institutions, we can do so in a way that respects the rights to privacy and informed consent, and that earns the public trust.

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