

COLLECTING SOCIODEMOGRAPHIC DATA FOR EQUITABLE CHANGE

Summary Report 2024



CRHESI Research & Action
for Health Equity

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Collecting Data for Equitable Change: An Overview of the Issue and Synthesis of Promising Practices

Executive Summary

This report was made for the *Centre for Research on Health Equity and Social Inclusion* (CRHESI) whose broad objective is bringing communities together to promote health equity and inclusion through collaborative research for action. At the request of CRHESI's community partners, this project examined how we collect sociodemographic (SD) data from clients at the point of service. These data can help define, describe, track and ultimately reduce inequities, but how data are collected must be carefully examined and requires continual development with ongoing opportunities for process and reporting improvements. Data collection and reporting practices that are rooted in cultural, physical and emotional safety, fairness and ethical approaches are critical for understanding the circumstances and needs of service users, and therefore underpin organizational quality improvement of health care and social service programs work. This report examines some of the key current issues relevant to collecting SD data and summarizes some of the promising practices.

Through a combination of interviews with local experts as key informants and analyses of primary, secondary, and grey literature, this review aims to provide a foundation for knowledge users and organizational leaders to explore, adapt and take up recommendations according to their needs and contexts. Findings indicate that principles guiding SD data collection and use include doing 'good work' that does not harm people or communities, respecting people and enacting justice & and fairness. To ensure safety, especially among those of people and communities who have been harmed and

experience disadvantages, consider data ownership; who has access, to and can share and use data must be specified; ensure that individuals, groups & organizations affected have a say in, and consent to, how their data are used. Collecting SD data alone is not enough to reduce inequities: we must focus on ethically using data to address the social & and structural determinants of health.

Collecting Data for Equitable Change: An Overview of the Issue and Synthesis of Promising Practices

Background

Collecting personal health information (PHI), one form of health-related data, has been a longstanding practice in healthcare systems (Ernstemeyer et al., 2021). PHI is defined as any information relating to the health status, healthcare service attainment, or payment of such services that can be linked back to a specific client and has been categorized as: 1) explicit identifiers used to directly identify the person (e.g. the client's name and phone number); 2) quasi-identifiers, which indirectly narrow down who the patient might be (e.g. age, birth date, and address of the patient), and 3) other sensitive data with privacy attributes such as income, illnesses, and ethnicity (Bajrić, 2020). In Ontario, beginning in 2004, the collection of PHI was legislated by the Office of the Information and Privacy Officer of Ontario under the legislation, *Personal Health Information Protection Act (PHIPA)* (Information and Privacy Commissioner of Ontario, 2015) and includes gathering or obtaining information, including, for example, a physician making notes about a patient, a nurse acting on a person's behalf, or a pharmacist receiving and filling a prescription. Using PHI is defined as viewing or handling such information.

Sociodemographic data (SD) refers to individual- or population-level social and economic determinants of health such as income, immigration status, employment, gender identity, sexual orientation and race or ethnicity (WHO, 2008). Programs, services, and systems that address the social determinants of health (SDOH) are vital for achieving better health outcomes (Stone et al., 2014). Collecting SD, as part of PHI, is encouraged by

the Ontario Human Rights Commission as it enables healthcare providers and system planners to gain a deeper understanding of who they are serving, and not serving, and how to adapt services and programs to meet their needs.

The Wellesley Institute, a Canadian policy and research initiative focused on health equity, states that SD are an important tool for identifying gaps and improving resource allocation for health services and programs (Bates et al., 2017). Collecting SD is one of the steps toward understanding the barriers to and facilitators of equitable access to health and social resources. When service providers and administrators within organizations take steps to improve services for equitable change in transparent ways, trust is improved, which in turn encourages people to access needed services.

Despite its importance, a scan of current practices indicates that SD is not collected consistently by health and social service organizations, with some organizations collecting comprehensive SD and other organizations not collecting any (Public Health Ontario, 2023). The discrepancy may be due to barriers such as hesitation by both providers and clients, resulting from discomfort initiating and during the SD collection process. Staff may lack confidence explaining the reasons to clients (and may not buy into these themselves, especially if data are not usefully fed back to them to improve practice), feel burdened by the amount of data to collect, and struggle integrating data collection processes into current workflows and their care provision role. There is a need for planning, education and training to ensure effective practices are implemented (Alliance for Healthier Communities, 2022; Public Health Ontario, 2023).

When considering practices for collecting SD it is important to understand the ways that structural discrimination causes harm. Discrimination is defined as the negative

treatment or neglect of individuals or groups based on biased and unjust opinions (Togioka et al., 2023). Discrimination may be visible when a group receives services or is blocked from receiving services due to characteristics such as race/ethnicity, gender, ability, socioeconomic status, and sexual orientation (among others).

Viewing issues through an intersectionality lens incorporates an understanding that these multiple identities, combined with other factors, such as substance use, religious or cultural beliefs, etc., and how others perceive these various factors, can be sources of oppression (Kelly et al., 2021). Structural discrimination results in harm for groups, such as those who are racialized, and are a key cause of healthcare and social inequities (Browne et al., 2013). Collecting SD accurately and consistently allows organizations to address social barriers, tailor programs and services, and provide individualized care (Batko and Ślęzak, 2022). Understanding data through the lens of health equity is important to enable systems planners to act to remove barriers and ensure the fair distribution of healthcare to all populations.

This report provides an overview of challenges and best practices synthesized from a scan of peer reviewed and gray literature and interviews with five key informants with experience in the areas of primary health care, community mental health, substance use health, and violence against women, with expertise ranging from senior leadership to direct service provision, data management, and research.

Current Challenges with Existing Data Collection Practices

The following section explores key challenges related to collecting SD data including power imbalances that may lead to fear, anxiety, and distrust and the potential for harm, missing or incomplete data collection, and a lack of resources to conduct ethical and effective data collection and reporting.

Power Imbalances and Potential for Harm

How decisions get made in healthcare systems and organizations, and by whom, are often complex and hidden, influencing how systems are designed and how services are provided to disadvantaged populations (McDonald et al., 2012). These so-called “power dynamics” can play out among professional groups and between professionals and patients or clients receiving care. Collecting and reporting on any kind of data, but especially about people’s identities and circumstances, without understanding how power influences who gets what kind of care, and when, can lead to potential harms to individuals and groups, especially those already facing discrimination and poor care experiences. For example, service providers and organizations may use their power and authority in ways that can re-traumatize people due to historical and current trauma. Service providers might assume, based on a stereotype that they hold, that an Indigenous person is showing signs of substance related intoxication, rather than symptoms of infection or stroke. They would, based on this assumption, deny the person immediate care, leading to much worse outcomes, including, in documented cases in Canada, death (<https://www.cbc.ca/news/canada/manitoba/winnipeg-brian-sinclair-report-1.4295996>).

Clients may be concerned about their dignity and even safety in health or social

services and avoid them in the first place, or not return for needed follow-up. They may also feel as though they have little control or influence over their personal information or access to healthcare and may provide their data out of fear of being excluded from health care or services if they refuse. Some clients may simply be unaware of their rights to refuse to provide data, or control how what they do provide is used, due to language, cultural or other barriers.

Missing or Incomplete Data

While there are current initiatives aimed at improving the collection of SD in hospitals, public health, and primary care, SD that are collected tend to be incomplete and/or inconsistent (Clarke et al., 2019). One reason may be linked to the way SD concepts are understood and defined within organizations. For example, there may be a difference between race and ethnicity, where race is a social construction, based primarily on physical appearance, while ethnicity refers to membership in a cultural group and other domains (CIHI, 2022). Asking people in a combined question to identify their “race/ethnicity” may therefore get different responses according to how this is defined both by those asking, and those responding.

To create a comprehensive understanding of service users, data must be sufficient in volume and collected in a standardized way across all service times, not just those convenient to data collectors (e.g., not collecting data during night shifts because of less staffing would miss important differences in who uses services at night). Some organizations have not collected SD due to a lack of knowledge, training, protocols, and/or policies. Organizational leaders may not be clear about which data to collect due to the lack of a common set of SD indicators or domains. Importantly, according to the Ontario

Human Rights Commission, organizational policies could be deemed discriminatory if they lead to not collecting SD as the lack of this data may contribute to inequities, systemic barriers and inadvertently endorsing policy that disproportionately negatively affects specific populations.

There are also barriers for service providers when attempting to collect SD. Without an understanding of the rationale (including how it can improve their own practice), some service providers may perceive the questions they ask as intrusive and may avoid asking. At an organizational level, hiring policies that exclude diverse representation may mean that the SD data collection process is mostly driven by individuals who do not share the same backgrounds as clients, which can contribute to discomfort for clients (Ontario Centre of Excellence for Child & Youth Mental Health, 2021).

An important misconception among many is that the SD data collection process is a ‘one-off’ and time limited, occurring at intake or at beginning of a healthcare or social service encounter. Key informants described the process of gathering SD data as continuous, while building trust with clients and ensuring cultural safety and trauma- and violence-informed approaches, prioritizing the client’s needs rather than obtaining data.

Lack of Resources

Effective data collection requires various kinds of resources, mainly in the form of trained staff to collect, analyze, interpret and report finding, including how data will inform new or existing quality improvement initiatives, and time to conduct these activities. For example, Williams-Roberts et al. (2018) found that implementing data collection practices would require longer appointment times to accommodate clients, especially those with unique needs. Pinto et al. (2023) noted that where PHI and SD data is recorded in the

patient record is often inconsistent, contributing to inefficiencies. And finally, where clients intermittently access services such as food banks or substance use harm reduction programs service providers may repeat the process of collecting SD data each time visit, which can not only reduce trust but be inefficient.

Review of Best Practices

Data collection practices are successful in working to promote health equity when they: 1) support organizations to identify who is being served and not served, 2) inform health system planning, resource allocation, and 3) identify inequities in healthcare processes and outcomes (Williams-Roberts et al., 2018). Disaggregated data, which is detailed information separated into specific categories such as age, race or ethnicity, gender, income level or geographic location (Kauh et al., 2021), allows health and social service programs to identify unique needs among different groups and raise awareness about issues, for example related to diversity of clients served, and inclusion/exclusion of various groups (Kauh et al., 2021). It is important to develop standardized SD data that can be disaggregated so that high quality data can be compared across regions, organizations, and systems (CIHI, 2022).

Learning Collaborative Approach

To address inequities through the collection of SD and for quality improvement around the *quadruple aim of health system improvement* (i.e. improved health outcomes, patient and provider experience and value), Community Health Centres (CHCs) delivering primary care in Ontario have participated in a learning collaborative (LC) approach, seeking to tailor healthcare and organizational practices around SD data collection and use (see

[Foundations of Equity: Improving Sociodemographic Data Collection and Use](#)). An LC

approach includes:

- measurable goals
- a defined group of participants
- is time limited (up to 15 months)
- builds knowledge through teaching, practice and sharing (see <https://www.allianceon.org/Learning-Collaboratives>).

Across diverse teams of CHCs, Nurse Practitioner-Led Clinics, and Aboriginal Health Centers, varying in mandate, size, funding framework, and serving diverse communities, learning tools were developed to support SD data collection and reporting practices. Through learning and sharing sessions, aimed broadly at increasing knowledge of quality improvement (QI) methods, and supporting development and organizational change (Alliance for Healthier Communities, 2023), there were three key findings:

- 1) Common collection methods are necessary for improving rates of SD data collection completion rates.
- 2) Increasing skills in Quality Improvement leads to capacity building.
- 3) Integrating external expertise (i.e., a coach) was highly valued.

One key strategy of the LC for SD data collection included training staff to increase their understanding of the importance of SD in identifying the ways populations may be excluded when designing programs and workflows. Training was found to be more effective when it was specifically tailored to staff needs, rather than a 'one size fits all' approach. In one example, staff comfort level increased during training when facilitating discussions with clients focused on gender identity and sexual orientation by use of scripts, (which

were co-developed with clients). Using an SD data resource package supported the development of relevant organizational protocols and processes (see [Resources Package to Support Sociodemographic Collection and Use](#)). Throughout the LC process, consistently scheduled, frequent meetings supported implementation and adaptation of new processes. Key findings and strategies from the LC were shared with members of the primary care alliance to further build capacity across the network.

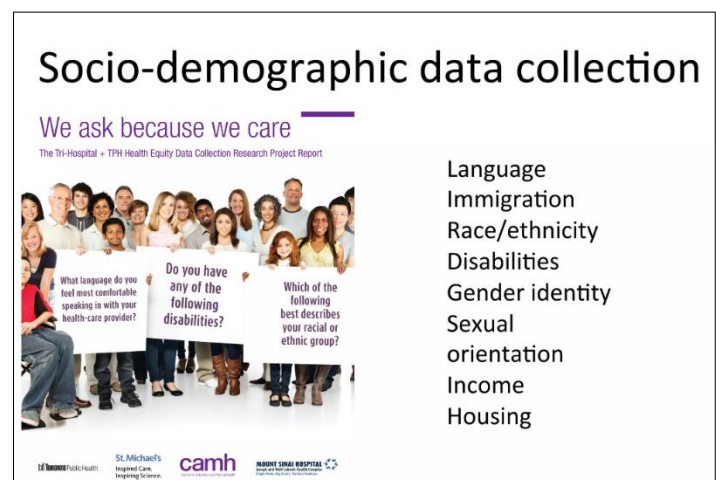
Staff Training

An equity-oriented training program that focused on the needs of hospital and community health settings developed by the Sinai Health System in Toronto, Ontario informed the Alliance’s primary care initiative (Pinto et al., 2016). Following the slogan, “We ask because we care”, first developed in 2009, the SD collection training program supported staff in developing an understanding of health equity principles, the purpose of collecting SD data and terminology related to the questions.

Training materials included:

- in-person sessions
- eLearning virtual modules
- role-playing using real-life scenarios to address questions and challenging situations.

These methods addressed the most common issue for services providers, which was discomfort and anxiety when collecting SD data. Plain language scripts with clear wording facilitated smoother communication between staff and clients. Scripts included the



rationale for collecting SD data and where and when it would be used. Data were collected in physical spaces where clients and staff members felt respected and safe (Sinai Health System, 2017) and standardized forms, posters, and brochures, available in multiple languages, were provided.

The diversity of scope and size of healthcare and social service organizations can influence data collection practices. SD data collection was generally more prevalent in large organizations during the COVID-19 pandemic, in part due to the human and financial resources available. In publicly funded public health agencies, guidelines and training increased SD data collection when a provincial mandate to collect these data was introduced (PHO, 2023).

Prioritizing Safety for Indigenous Communities

While ensuring the safety of all equity-deserving communities who access health or social services is crucial, this is a particular priority for Indigenous communities.

Indigenous Peoples and communities in Canada have historically been and continue to be subjected to and harmed by discriminatory and racist health and social policies and practices. Though the implementation of the principles of Indigenous data governance, the

City of Toronto has developed *Data for Equity Guidelines* based on the First Nations



Information Governance Centre's framework, *Ownership, Control, Access and Possession (OCAP)*

(see <https://fnigc.ca/ocap-training/>).

The municipality included the following key guidance:

- 1) Collaborate and honour long-standing, committed relationships with Indigenous communities,

2) Ensure benefits are reciprocal and empower Indigenous communities with knowledge and tools,

3) Recognize Pan-Indigenous identity and provide choices for self-identification, distinct from race or ethnicity questions (see <https://www.toronto.ca/city-government/accessibility-human-rights/equity-diversity-inclusion/data-for-equity/>).

Support for Smaller-Sized Organizations

Smaller social service agencies such as food banks, shelters, neighbourhood resource and family centres may not have access to the same level of resources as larger organizations to implement a comprehensive process of collecting SD data. *Policy Wise*, a non-partisan, Alberta-based organization mandated to build capacity of social policy for nonprofit organizations, provided guidance for “meaningful, useful and well-managed data” to improve the well-being of families, children and communities (see <https://policywise.com/buildbetterdata>).

The Policy Wise **Data Lifecycle framework** includes:

- Considerations and Lenses
- Plan
- Build
- Collect
- Prepare
- Analyze
- Inform



Themes Related to Practices for Collecting Data for Equitable Change

From this synthesis, four main themes are noted for collecting SD data for equitable change in healthcare and social services, including small and Indigenous-led organizations:

- 1) Attend to organizational culture
- 2) Standardize data collection
- 3) Collaborate for collective action
- 4) Engage communities in meaningful ways

1) Attend to Organizational Culture

Following are three ethical principles on which to build an organizational culture that supports health equity (Gaddy & Scott, 2020):

- **Beneficence:** the commitment to maximize benefits and avoid causing harm.
- **Respect for persons:** the responsibility to uphold people's power to make decisions in their best interest and protect those who do not have that power.
- **Justice:** the fair distribution of burdens and benefits.

It is important to support all staff, from first contact administrative roles to clinical providers to Board members - to better understand the perspectives and experiences of populations who experience health inequities and who have typically been excluded from service design. Additionally, integrating key dimensions of equity-oriented care such as cultural safety training and harm reduction/substance use health practices can reduce the impacts and experiences of re-traumatization and contribute to the health and well-being of clients and staff (see <https://equiphealthcare.ca/learn-more/>). Trauma and Violence

Informed Care (TVIC), an equity-oriented approach focuses on fostering a safe and equitable environment with an understanding of the impacts of trauma and violence. A TVI approach considers the impacts of historical and ongoing structural violence, as well as trauma, which can be defined as an individual's experience of and response to an (or multiple) overwhelmingly negative event(s) to which the exposure could lead to severe and long-term negative impact, including post-traumatic stress disorder (Wathen et al., 2023). Providing staff training during the onboarding of new staff and through continuing learning can influence organizational culture at high levels, and reduce harms to staff and clients, while improving the quality of programs and services through SD collection and use (Gaddy & Scott, 2020).

2) Standardizing Collection

Standardization of SD collection practices should include defining data collection methods and processes, including storage, where client needs are prioritized, and human rights are protected. Primary Care and Public Health organizations have begun to standardize elements of SD data collection, for example determining through consultation, standardized domains and practices (see [Alliance Member Case Studies on Sociodemographic Data Collection and Use](#) and Public Health Ontario, 2023). An example of SD domains collected by health services, clinics and programs (e.g. Family Health Teams, CHCs) includes:

- Language client is most comfortable speaking with healthcare provider
- Born in Canada
- Racial or ethnic group

- Disabilities, accessibility
- Gender
- Sexual orientation
- Family income, and number of people income supports.

The following are considerations for standardizing SD collection that arose during this exploration:

- Extend SD collection from a single event to a longer-term process where possible.
- Prioritize establishing trust and focusing on the client's priorities before SD collection; implement principles of TVIC and cultural safety.
- Part of the consent process is explaining the voluntary nature of client offering SD information, with an option to withdraw consent at any time without affecting their access to or quality of care.
- Communicate clearly about who has access to the data, its safe storage, how and to whom it will be reported, and potential impacts (both positive and negative) on the client and community in ways that the client can understand.
- Find ways for clients and communities to control and use their collective health data.
- Find ways to balance consistent SD collection with policies and practices tailored to follow the lead and pace of the client regarding how much and what kind of information the client wants to share.
- IT protocols for data protection standards for healthcare and social service organizations to secure networks and databases must be established and

maintained and be communicated to clients.

3) Collective Actions

Consistent reporting, sharing resources and collective action can reduce structural barriers and increase equity among organizations. Health and social service organizations have necessarily tended to compete for resources due to scarcity/austerity ideology stemming from governing policies and parties. Communities of practice can promote development, learning and build on new and established practices, as well as models such as the Learning Collaborative, previously discussed. Collective actions are important for smaller, often grass-roots, organizations that can reach underrepresented populations or communities with unique needs, not met elsewhere (Mamatis et al., 2019). Collective actions also help smaller organizations with human, financial, and technological resource constraints in SD data collection, reporting and use. Finding ways to streamline data sharing across agencies and organizations is one way to share resources.

4) Engaging in Meaningful Ways

Meaningful engagement recognizes the lived and living experiences of people as a valued and valuable resource (World Health Organization, 2023). Guiding principles for meaningful community engagement include:

- Listen deeply, reflect on, acknowledge assumptions or biases and work to take action on the ways that biases influence relationships with communities, clients, their families and community partners.
- Create processes for continuous listening to communities and clients to build and maintain trust and long-term relationships with depth.

- E.g. the First Nations Principles of Ownership, Control, Access, and Possession (First Nations Information Governance Centre, 2024) establish the way First Nations data and information is to be collected, utilized, and shared.
- Adopt a collaborative, learning-based approach that seeks to co-develop solutions rather than a prescriptive or top-down approach (Turin et al., 2021).
- Build capacity by committing to supporting clients, staff, communities and community partners to build the skills and attributes necessary to face challenges and act on opportunities.
- Focus on continuous engagement, which emphasizes that interactions between service providers and clients should not be time-limited, one-way, or transactional.

Conclusion

This review has explored some of the successful efforts made by organizations and service providers to implement SD data collection and reporting processes, but there are ongoing challenges. Both the literature and key informants identified gaps in collecting comprehensive SD data from underserved populations. Continuing efforts should focus on improving organizational culture to be well aligned with an equity orientation, including cultural safety, and trauma- and violence-informed approaches. Training staff to increase comfort and build communication skills around SD, and meaningful engagement of communities to build lasting relationships and trust are paramount. Collaborative and collective action is key in mitigating scarcity of resources and reducing structural barriers. This iterative process is ultimately aimed at reducing inequities (see [Collecting Data for Equitable Change](#) infographic).

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