

Sociodemographic Data Collection and Use in Ontario CHCs - Report

April 2022



**Alliance for
Healthier Communities**

Alliance pour des
communautés en santé

Introduction

During the Alliance for Healthier Communities’ 2020 annual general meeting, member centres set an ambitious goal of achieving a 75% completion rate for sociodemographic data collection by 2024. To help reach this goal, the Alliance embarked on a study during the summer of 2021, to examine the collection and use of sociodemographic data (SDD) in Ontario Community Health Centres (CHCs). The aims of this study were to determine how this data was currently being collected and used, understand the roles of staff, leaders and board members within these processes, as well as identify barriers to collection and use. In addition, the Alliance sought out what resources, tools, and knowledge would support centres in data collection and use.

In total, eight CHCs volunteered to participate in the study, including a mix of rural, urban, Northern, and Francophone centres. Within each centre, 3-6 staff members were individually interviewed, and each CHC executive leader along with 2-5 board members participated in a focus group. Overall, 33 individual interviews with staff* and 8 focus groups were conducted. As one of our goals of the study was to understand the various roles involved in data collection and use, study participants included:

- Administrative personnel
- Primary care providers
- Interprofessional team members
- Management
- Executive leaders and CEOs
- CHC board members

Of these, the majority were female, full-time employees, and had been employed at the CHC for 7 years.

This report will relay the study’s key findings, illustrate the current processes of sociodemographic data collection, how different roles use the data, and what concerns participants had regarding collection and use. The report also highlights participants’ recommendations for centers on how to improve data collection and use as well as the steps the Alliance will be taking to support this endeavor.

*Please note that the term “Staff” is used to describe all CHC staff excluding the executive director/leader, while the term “provider” is used specifically for primary care providers and interprofessional team members.

Summary of Key Findings

Our study revealed that most participants value sociodemographic data (SDD), and view its collection and use as important to providing equitable access to care and meeting the needs of their clients. Most participants also knew of the requirement for their CHC to collect SDD, however, certain barriers hindered progress in reaching target completion rates. For example, many participants highlighted that data collection can

be both burdensome and uncomfortable for clients and staff, due to the type (e.g. income and sexual orientation) and amount of data being collected, and staff difficulty in explaining why this data is being collected.

Key Finding #1: Information about sociodemographic data collection and use needs to be more clearly communicated

Staff understood why it was important to collect this data but were largely unaware of what the completion rate for their centre was or examples of how this data was actually used to improve care for clients at their centre. Increasing awareness of this knowledge may motivate collection as a personal priority and soften perceived burden. **Board members**, similarly desired greater awareness on whether their center was meeting targets in order to better understand obstacles and challenges to collecting this data, and for accountability purposes. Lastly, all participants agreed that it was challenging to communicate to **clients** how SDD is relevant to healthcare and how it can be directly beneficial to their current or future care. Creating a script or handout in multiple languages could increase comfort in sharing sociodemographic information.

Key Finding #2: There is a disconnect between the current process of data collection and the need for trusting client-provider relationships

The majority of study participants emphasized the importance of establishing a **trusted client-provider relationship** in order for clients to comfortably share SDD. However, the current process of SDD collection is typically done prior to/during the client's first visit and by administrative staff as providers feel this task is outside of their scope of work. As a result, client intake forms collecting SDD are often incomplete and when SDD is shared after the initial visit, this information is frequently inputted into clinical notes where data cannot be extracted.

Key Finding #3: Using sociodemographic data beyond reporting purposes

For most centres, data collection was largely seen as work for others (e.g., Ministry, funding agencies, and the Alliance) for reporting purposes and in order to secure funding for programs and services. Participants highlighted that intense and frequent reporting requirements left very little time to use collected data beyond this purpose. For example, to use collected data to look at screening rates, track health markers, to provide targeted, helpful solutions to clients, and identify gaps in who was being served. Given the disparity between how participants value collecting SDD and its current use, moving towards a learning health system that will enable these initiatives seems timelier than ever.

Sociodemographic Data Collection and Use at CHCs

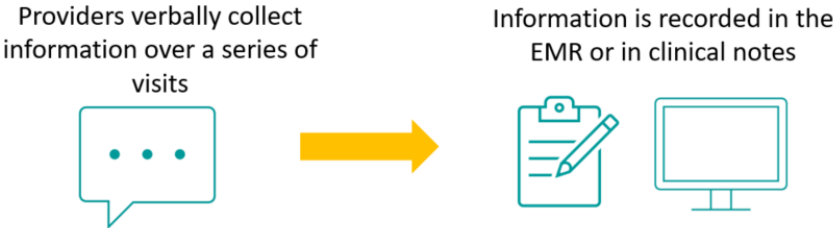
Data Collection Methods

There were two main pathways identified for how SDD is collected in CHCs, both of which are outlined in the diagram below. **The primary method of data collection** involves a client completing an intake form received by administrative staff prior to their visit. Providers may continue SDD collection with clients during their visit and then record the data in the EMR or administrative may directly input data from the intake forms into the EMR. **The secondary method** involves providers collecting SDD over multiple visits as they build a therapeutic relationship with the client. In this scenario, collected information is likely to be recorded in clinical notes which cannot be used for data collection efforts.

Primary Collection Method



Secondary Collection Method



Use of Sociodemographic Data

Outlined below is generally how providers, leaders including managerial staff, and board members are currently using collected SDD at their centres:



Providers use sociodemographic information to guide and tailor client care.



Leaders and managerial staff use sociodemographic data to plan and tailor services, demonstrate need to funders and partners, and hire and train staff to meet clients' needs.



Board members are presented with this data for decision making purposes, i.e. approve funding for new programs/services at the centre.

Concerns

Concerns raised by staff, leaders and board members during interviews and focus groups were grouped into four overarching categories of accessibility, burden, discomfort, and limited resources and capacity.

Accessibility

- Language used in collection instruments is at times unsuitable for clients with low literacy, and for clients whom English or French is not their first language.
- Increasing use of technology for data collection is a barrier for some due to low digital literacy.

Burden

- Lengthy client intake forms result in fatigue and incomplete data (e.g. last page/section of form is often left blank).
- Client may become overwhelmed with the amount of data being asked, which can have a negative impact on forming client-provider relationships.
- Staff may already collect similar data for other funders but each funder requires data entry into a different database.
- Technology used to input or view data is not user-friendly.
- Leaders and board members found collecting sociodemographic data isolating, as it is a unique initiative by CHCs and is only now being done within other healthcare settings.

Discomfort

- Clients are less likely to answer questions regarding income, sexual orientation, gender identity, and ethnicity. Such topics are seen as invasive, personal, and offensive by clients and even some staff. Some clients fear their care will be negatively impacted depending on their answer.
- For long-standing clients, providers may find it awkward to collect SDD “out of the blue” as they are unsure of how to explain to clients why this information is being collected at this point in their care.
- Few staff discussed feeling discomfort when privacy could not be offered to clients when providing data due to the limited physical space available in the center.

Limited Resources and Capacity

- Providers are “stretched thin” and cannot take time away from the clients’ appointment to aid in data collection.
- Limited budgets restrict the purchase of digital technology (e.g., of tablets).
- The pandemic has resulted in prioritizing care provision over SDD collection during client visits.

Recommendations

During interviews and focus groups, study participants shared recommendations and solutions for improving data collection and use. Participants also shared where their own centers found success, which were included as recommendations for other centers to implement. A summary of the most common recommendations is presented in the table below.

Recommendation Area	Description
<i>Collection of Data</i>	<ul style="list-style-type: none"> • Create a script for staff that will aid in answering client’s questions. • Review collection instrument for accessibility. Consider literacy, technology access, education level, age, inclusivity, and cultural sensitivity. • Utilize technology to improve the process of collection and input, e.g., email links, tablets, and kiosks. • Make data entry easily accessible for ongoing data entry (i.e. embed the toolbar) and ensure SDD form in the EMR mirrors the intake form for accurate data entry.

	<ul style="list-style-type: none"> Identify a time of year to run a j-report on collected SDD for all active clients to identify clients with missing SDD.
<i>Communication</i>	<p>For clients:</p> <ul style="list-style-type: none"> Consider notifying clients in advance that this information will be collected. Convey the link between sociodemographic and health. Communicate the “why” of collection (i.e., improving services, meeting client’s needs, tailoring care according to client’s SDD). <p>For staff and board members:</p> <ul style="list-style-type: none"> Communicate goals, targets, and current progress. Communicate how data is being used for decision making and the success or benefits that have come from collection efforts (e.g. funding for new programs, changes to services, etc.) Include “We ask because we care” materials in new staff orientation package https://aohc.site-ym.com/page/Socio-Demographic-Data-Collection
<i>Meaningful Use of Data</i>	<ul style="list-style-type: none"> Look at the full breadth of data collected and create a guide that highlights examples on how to use data beyond reporting requirements. For example, to look at screening rates, tracking health markers, to provide targeted, helpful solutions to clients, identifying gaps in who is being served.

Next Steps for the Alliance in Supporting Centres

Initiative	Description
<i>Share a guide on how to use the toolbar in PSS to access the extended demographics form*</i>	<ul style="list-style-type: none"> The Alliance will re-share a brief guide on how to access the extended demographics form in the toolbar within PSS. This will enable staff to easily access the extended demographics form for ongoing entry. This would help ensure any additional SDD collected after the initial visit can be extracted and counted towards completion rates.
<i>Create a data placemat for Centres to monitor progress</i>	<ul style="list-style-type: none"> Presented as visual graphic this data report will enable centres to quickly assess their progress in reaching targeted completion rates as well as compare their progress with other centres.

<i>Share resources including training materials for staff*</i>	<ul style="list-style-type: none"> Resources will include a staff script, plain language glossary and client brochure adapted from the “We ask because we care” initiative as well as centre created resources.
<i>Share a summary of case studies on collection and use of SDD*</i>	<ul style="list-style-type: none"> A collection of case studies will be created for centres that will explore how they were successful in data collection and use.
<i>Sociodemographic Data Collection Learning Collaborative</i>	<ul style="list-style-type: none"> Early 2022, the Alliance will be starting their Learning Collaborative focused on improving sociodemographic data collection. By joining, you will have the opportunity to apply quality improvement methods to improve data collection. Lessons learning from this collaborative will be shared with the entire Alliance membership.

*This resource can be found in the accompanying resource package.

Alliance for Healthier Communities



500-970 Lawrence Ave. W.

Toronto, Ontario M6A 3B6

Canada

416-236-2539

www.AllianceON.org



**Alliance for
Healthier Communities**

Alliance pour des
communautés en santé