

Lessons learned from the collection of sociodemographic data during the COVID-19 pandemic

FINAL REPORT AND RECOMMENDATIONS



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Locally Driven Collaborative Project Core Team

Lead followed by members listed in alphabetical order



Peel Public Health (Lead Public Health Unit):

- Monali Varia, Director, Public Health Intelligence
- Greg Kujbida, Manager, Population Health Assessment
- Shilpa Raju, Epidemiologist, Infection Prevention & Surveillance
- Helen Stylianou, Master of Public Health Practicum Student, Dalla Lana School of Public Health



Ottawa Public Health (Co-Lead Public Health Unit):

- Aideen Reynolds, Knowledge Exchange Specialist
- Laurie Dojeiji, Knowledge Exchange Specialist
- Ikenna Mbagwu, Program Planning and Evaluation Officer
- Sydnee Burgess, Master of Public Health Practicum Student, University of Waterloo



Upstream Lab based at MAP Centre for Urban Health Solutions, St. Michael's Hospital (Academic Partner):

- Dr. Andrew Pinto, Founder & Director
- Menna Komeiha, Research Assistant
- Dr. Oluwasegun Ogundele, Research Coordinator
- Joseph O'Rourke, Research Coordinator

Additional Support:

- Peel Public Health:
 - Margaret Lebold, Social Determinants of Health Public Health Nurse
 - Dannielle Nicholson-Baker, Social Determinants of Health Public Health Nurse
- Upstream Lab:
 - Geil Astorga, Communications Specialist
- Public Health Ontario:
 - Emma Firsten-Kaufman, Knowledge Exchange Specialist

Knowledge Users

Organizations and representatives listed in alphabetical order

- **Canadian Institute for Health Information:** Geoff Hynes
- **CMHA Peel Dufferin:** Michelle Lewis, Annalisa Rasmussen
- **Dixie Bloor Neighbourhood Centre:** Hameed Shaheer, Priyanka Sheth
- **Indus Community Services:** Gurpreet Malhotra
- **Middlesex London Health Unit:** Dr. Alexander Summers
- **Ontario Health:** Corey Bernard, Trish Chatterpaul, Cynthia Damba, Carie Gall
- **Ontario Ministry of Health:** Carley Hay, Rachelle Larocque, Hanna Ziada
- **Ottawa Local Immigration Partnership:** Hindia Mohamoud
- **Punjabi Community Health Services:** Ansjyot Kapoor, Baldev Mutta
- **Rideau-Rockcliffe Community Resource Centre:** Sophia Jacob
- **Roots Community Services:** Angela Carter, Shane Joseph
- **Statistics Canada:** Lawson Greenberg
- **Toronto Public Health:** Effie Gournis, Dr. Na-Koshie Lamptey
- **Wellfort Community Health Services:** Marsha Brown, Kimberly Floyd

Disclaimer: The views expressed in this publication are the views of the Project Team and do not necessarily reflect those of Public Health Ontario.

List of Acronyms

APHEO: Association of Public Health Epidemiologists in Ontario

CCM: Case & Contact Management Solution

COMOH: Council of Medical Officers of Health

COVID-19: Coronavirus disease 2019

LDCP: Locally Driven Collaborative Project

OPH: Ottawa Public Health

PHO: Public Health Ontario

PHU: Public Health Unit

PPH: Peel Public Health

SDD: Sociodemographic data

SDOH: Social determinants of health

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Introduction

The COVID-19 pandemic was initially portrayed as a "great equalizer," implying, in the context of a novel virus, that everyone would be equally susceptible to both the virus and the economic consequences of the lockdown imposed to contain its spread. However, existing knowledge indicates that pandemics have the potential to exacerbate pre-existing inequalities. With the increase in our understanding and data about the COVID-19 pandemic, it became apparent that not all would be equally affected by it ([ref.](#)). Certain determinants of health were found to be associated with an increased risk of contracting COVID-19. Long-standing structural and systemic inequities, as well as barriers to accessing healthcare and social services which are directly influenced by the social determinants of health (SDOH), significantly contributed to people's risk for COVID-19 exposure and infection. For example, in several regions of Ontario, Canada, including Ottawa and Peel, people from racialized communities were overrepresented among those diagnosed with COVID-19 ([ref.](#)).

The SDOH refer to a specific group of social and economic factors within the broader determinants of health that influence health and health outcomes. Among these are income, social status, employment, working conditions, education, literacy, physical environments, access to health services, gender, and race ([ref.](#)). The Government of Canada recognizes the importance of addressing these determinants to tackle health inequities.

Before the COVID-19 pandemic, several Canadian health organizations collected standardized sociodemographic data (SDD). In Ontario, a report by the Wellesley Institute in 2017 discussed existing strong foundations for SDD collection and identified considerations that could shape future initiatives ([ref.](#)). The report described several factors that facilitate SDD collection, which included the openness of patients/clients to sharing SDD, the importance of integrating data collection into existing workflows and infrastructures,

and the critical role of training in ensuring successful data collection. Accordingly, several strategies, principles, and considerations are in place to collect data and build up indicators of health inequalities. These were however based on lessons learned pre-pandemic. Moreover, the known lessons learned, strategies, and training developed for SDD collection are typically geared towards surveys and administrative data targeting larger geographical areas, rather than smaller populations like a public health unit (PHU) or catchment area.

SDD collection is vital for identifying and addressing health inequities, as well as tailoring public health policies and interventions to diverse populations' needs. Early in the pandemic, communities and community leaders were vocal advocates for the collection of SDD during pandemic interventions ([ref.](#)). In June 2020, the Ontario government introduced regulatory changes under the *Health Protection and Promotion Act*, which mandated the collection and reporting of SDD for individuals who tested positive for COVID-19. This included race, income, language, and household size. In the first 10 months of data collection, it was observed that data completeness was low across PHUs in the province, which hindered PHU and the sector's ability to use this data for decision-making. A lack of complete data could negatively impact public health decisions, such as identifying disparities in COVID-19 cases and deaths across different populations, and priority populations for vaccination.

Since the introduction of COVID-19 vaccinations in December 2020, the collection of SDD at the time of vaccination and entry into the provincial COVID-19 vaccination portal (COVaxON) has been encouraged, but not mandated. As of April

6, 2022, approximately 5% of people vaccinated in Ontario had provided SDD, with PHU completion rates ranging from 0% to 14%, according to the Ontario Ministry of Health. This low completion rate made it difficult to identify and address disparities in vaccination uptake across different populations.

The pandemic acted as a catalyst to implement rigorous SDD collection in the public health context. However, the COVID-19 pandemic presented challenges and opportunities for PHU staff when collecting SDD. To develop evidence-based policies that support SDD collection as part of public health practice, it is essential to better understand the barriers to SDD collection and document the lessons learned.

The health inequities that the COVID-19 pandemic illuminated have re-set public and community stakeholders' expectations for health data reporting, including the collection and reporting of SDD elements, further increasing the importance of scaling this work in the years ahead. While much work has been done to understand and develop best practices for the collection of SDD in healthcare settings, a better understanding of successful SDD collection strategies in public health settings is needed.

The lessons learned from the collection of sociodemographic data during the COVID-19 pandemic study was a nine-month study funded by Public Health Ontario's (PHO) Locally Driven Collaborative Project (LDCP) program. Collaborators on this project are Peel Public Health (PPH), Ottawa Public Health (OPH), and Upstream Lab based at MAP Centre for Urban Health Solutions, St. Michael's Hospital, and Unity Health Toronto.



Research Question and Objective

For this research, the focus was on data completeness, operationalized as the extent to which a dataset has all the relevant and necessary information from the target population, that is, the clients who interact with PHUs during COVID-19 case management or vaccination. The reason for this focus was that a level of completeness is required for subsequent critical steps of analysis, reporting and use. An incomplete set of data may be deemed unusable, unreliable for analysis, or produce biased results if it does not accurately represent the target population. While the focus was on data completeness, during the focus groups and interviews, researchers sought to also capture the experiences of PHU staff with SDD analysis, reporting, and use. Accordingly, the project team sought to address the following research question and objective:

Research question: What PHU-led practices enabled higher levels of data completeness during the collection of SDD for COVID-19 case management and vaccine administration?



Research objective: To identify SDD collection enablers and barriers that PHUs can reference as they scale up their SDD collection beyond COVID-19-specific activities. For the purpose of this study, PHUs were asked about their experiences collecting the SDD that were included in Ontario’s Case & Contact Management Solution (CCM) database and the COVaxON vaccination database. Data fields included: official language, childhood language, racial identity, ethnic origin (COVaxON only), household income and household size.





GOAL: understand the experiences of Public Health Units and the barriers and facilitators to data collection during COVID-19

Project Design & Methodology

This project aimed to identify PHU-led practices that contributed to achieving higher levels of data completeness during SDD collection during the COVID-19 pandemic, both as part of case management and vaccination. Additionally, the project sought to understand the experiences of PHUs, and specifically, the perceived enablers and barriers to SDD collection and data completeness in these two contexts. It was hoped that the findings from this project would provide tangible, accessible considerations and/or recommendations for initiating, scaling up, or expanding SDD collection beyond COVID-19 to other public health programs and services.

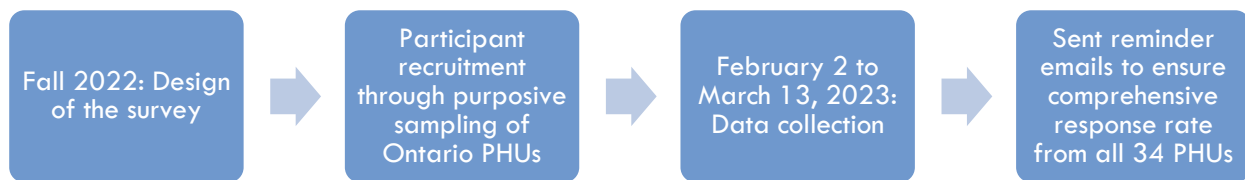
The project design was guided by the significant experience and expertise of the Core Team members in the field of public health.

Ethical approval was granted by the Unity Health Toronto Research Ethics Boards (#

22-261C). The project was conducted in two distinct phases. During the first phase, a survey consisting of both multiple-choice and open-ended questions was administered. In the second phase, a combination of focus group discussions (16) and one-on-one interviews (8) were conducted, allowing for sharing of deeper insights and perspectives, and providing rich qualitative data that complemented the survey findings.

All interviews were recorded using Zoom and only after informed consent was obtained from the participants. The digital recordings were stored on Unity Health Toronto's secure servers with only Upstream Lab's staff having access to them. The rest of the Core Team members had access to the de-identified scripts only.

Below is a detailed explanation of the methodology used in the two phases of this project.



Phase 1: Public Health Unit Survey

The survey was designed during the Fall of 2022, and data collection occurred between February 2nd and March 13th, 2023, from participants recruited through purposive sampling of Ontario PHUs. A call for survey completion was sent out by the Core Team through two electronic mailing lists: The Association of Public Health Epidemiologists in Ontario (APHEO) and the Council of Medical Officers of Health (COMOH). Participation in the survey was voluntary and anonymous. The consent form was included in the recruitment emails, and to ensure a comprehensive response rate and to hear from all PHUs, reminder emails were sent by the Core Team to specific PHUs that had not yet responded, ultimately resulting in the participation of all 34 PHUs. Each PHU submitted answers that were representative of their organization's overall experience. Only one response was permitted per PHU.

The survey consisted of two sections: Section 1 focused on the collection of SDD as part of COVID-19 case management and was comprised of 11 questions: nine categorical questions, one ranking question, and one open-ended question. Section 2 addressed SDD collection in the context of COVID-19 vaccination clinics and comprised 12 questions: 10 categorical questions, one ranking question, and one open-ended question (Appendix A).

Surveys were submitted electronically via Qualtrics, and de-identified data were shared with the Core Team for further analysis. Survey data were extracted and imported into Stata 17.0 for cleaning and subsequent analysis. Descriptive statistics were computed for the responses of categorical and ranking variables. PHUs were grouped based on Region, Statistics Canada Peer Groupings (Appendix B), and Urban/Rural classifications (based on the peer groupings criteria) (Appendix B). Data from the multiple-choice questions were de-identified and formatted into a .csv file, which was then imported into Stata 17.0 for coding and subsequent descriptive analysis.

Two open-ended survey questions provided an opportunity for respondents to offer additional insights about their PHU's experience with collecting SDD during the COVID-19 pandemic (Appendix A). Data were manually extracted into a Microsoft Word document. Analysts developed a codebook in a Microsoft Excel document and applied inductive content analysis to enable subjective identification of emerging patterns from the data. Inductive content analysis is a method used to make sense of a large amount of data by grouping and organizing the data into smaller, more manageable categories or themes toward a research question by focusing on important concepts that emerge from the data ([ref.](#)). Each analyst independently

coded the text data, and through an iterative process and constant comparison, these patterns were further revised, refined, and grouped into categories or themes. This allowed for a comprehensive exploration of the data, ensuring that multiple perspectives were considered and a rich understanding of the themes emerged. The collaborative nature of the

analysis process further enhanced the validity and reliability of the findings.

Early thematic analysis of the qualitative survey data provided the Core Team with insights into the potential enablers and barriers that could emerge through the qualitative component of the study. This iterative process helped develop the in-depth interview guide.

Phase 2: Public Health Unit Focus Groups and Key Informant Interviews

Recruitment for focus groups and interviews started during Phase I survey administration. Specifically, at the end of the survey, respondents were invited to contact the Study Coordinator if they wished to participate in a focus group or a one-on-one interview. The Study Coordinator then provided interested people with a brief description of what their participation would entail and their right to withdraw at any stage. A consent form was attached to email reminders that were sent 24 hours before the scheduled focus group or interview time. At the start of each session, the moderator reiterated informed consent details and answered any questions. Facilitating research staff obtained verbal consent before commencing interviews and focus groups. Participants' identity was masked in the transcripts to ensure anonymity.

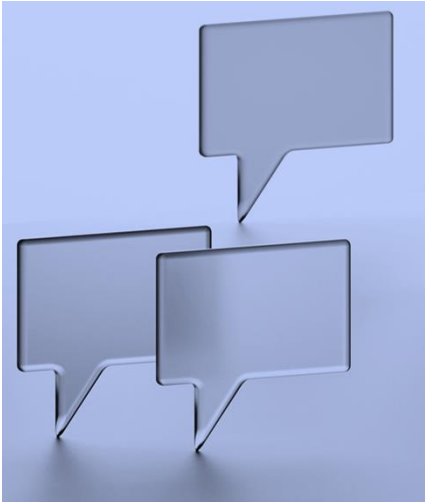
In addition to recruitment through the survey, information about the study and how to enroll was sent to the APHEO and COMOH directories, and Core Team members mobilized existing professional contacts to recruit specific PHUs. Direct contact with individual PHUs proved to be an effective mode of targeted recruitment. For the focus groups, participants were assigned to one of four peer groupings: Senior Management, Middle Management, Specialist/Analyst/Epidemiologist, and Frontline Staff, based on the role(s) they

played in collecting SDD at their respective PHU during the COVID-19 pandemic. This format allowed researchers to capture the unique experiences of each peer group and ensure a diverse representation that included urban and rural PHUs.

The focus groups and interviews were conducted using a semi-structured format. An interview guide containing prompt questions was created prior to the recruitment process (Appendix D). Four variations of the guide were developed to specifically address the unique roles and experiences of each peer group. The sessions ranged in duration from 45 to 80 minutes, while individual interviews had an average duration of 30 minutes. Two facilitators and two note-takers alternated roles as session moderators and annotators. Each session had one facilitator and one note-taker. The semi-structured nature of the sessions allowed the facilitator to adapt the prompts according to the individual experiences or group composition, and to explore new areas of interest as they emerged. Each session began with a broad question to establish rapport and obtain an overall understanding of the group's or individual's experiences with SDD collection. At the end of the sessions, participants were encouraged to share their recommendations to optimize SDD collection.

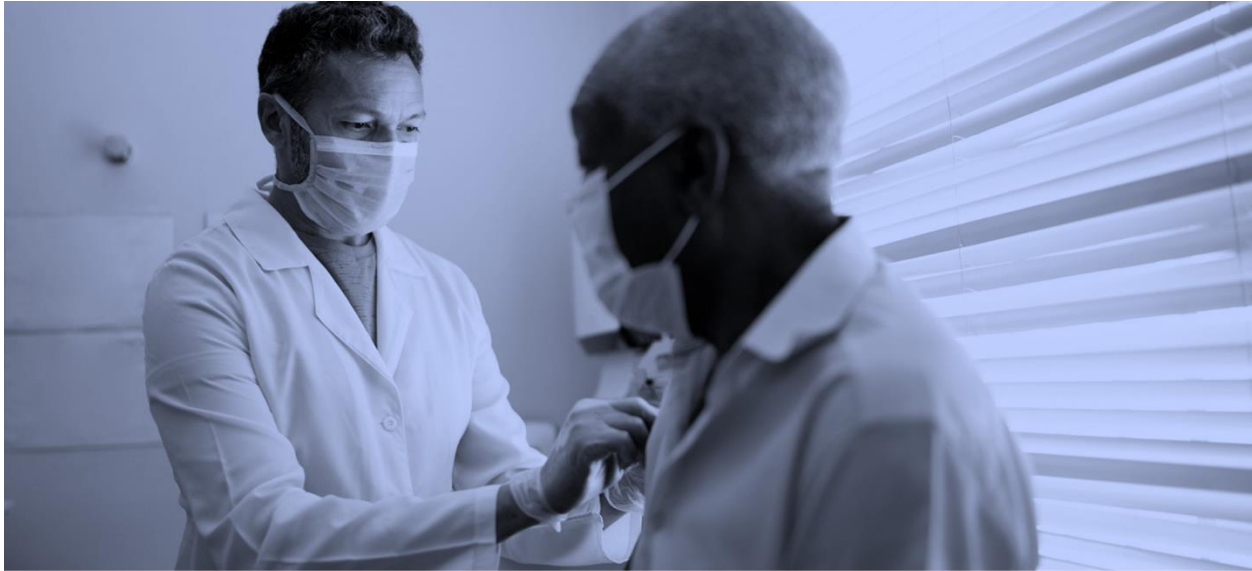
All sessions were audio recorded, and transcription was conducted by a third-party transcription company. Transcribed data were provided to the analysts in the form of Microsoft Word documents in preparation for content analysis.

A codebook was developed in a Microsoft Excel file, and two analytical lenses were applied to the data:



1. An inductive lens, using constant comparison, was applied to each data element to identify new themes arising from the data. This was to capture content generated through broad questions (e.g., what do you think about PHUs collecting sociodemographic information from clients?).
2. A deductive lens, that allowed analyzing the data based on preexisting categories based on previous research ([ref.](#)), was applied by using the themes identified from the open-text survey data analysis (i.e., enablers of SDD collection, barriers to SDD collection, challenges with SDD analysis and use).

To minimize researcher bias (e.g., confirmation bias), each transcript was analyzed by two members of the Core Team - a primary analyst and a secondary analyst (to review and appraise the primary analyst's codes for validity and accuracy). In instances where there were divergent views, a third analyst made the final decision.



Findings

The results of the study from Phase 1 (survey and open text data) and Phase 2 (focus group and one-on-one interviews) are presented in this section. Phase 1 includes an analysis of completed survey submissions from all 34 PHUs in Ontario. Phase 2 results are from the analysis of transcripts from 16 focus groups and eight interviews with a total of 65 individuals.

Phase I: Public Health Unit Survey

SDD Collection and Reasons for Not Initiating Collection

Thirty-one out of 34 PHUs reported collecting SDD during COVID-19 case management. For the three PHUs that did not collect SDD as part of case management, the top two reasons for not initiating collection were lack of training, resources and capacity; and lack of data analysis guidance/framework (Appendix C, Table 1).

Whereas 31 PHUs collected SDD with case management, 18 PHUs or just over half, reported collecting SDD in their COVID-19 immunization clinics. Among the 16 PHUs that did not collect SDD during COVID-19 vaccination, the top reasons included SDD collection not being a provincial requirement; lack of training, resources,

and capacity; and physical infrastructure challenges (Appendix C, Table 1).

Timing of Initiation and Reasons for Early Initiation of Collection

Twenty-four of the 31 PHUs (77.4%) that collected SDD during case management began collecting after the province mandated collection in June 2020. Five PHUs had started collecting SDD before it became mandated (Appendix C, Table 4). Of the 18 PHUs that collected SDD during COVID-19 vaccination, 15 (83.3%) started collecting SDD only after the province included SDD in COVaxON in March 2021; three had started collecting before SDD had been included in COVaxON (Appendix C, Table 9).

Among the five and three respective PHUs that initiated collecting SDD before it became mandated with COVID-19 case management or being added to COVaxON, reasons for early initiation included measuring health disparities was a pre-existing organizational priority; COVID-19 case disparities were being identified in other jurisdictions; community stakeholders' request and expectations; SDD collection was already underway at the PHU; as well as momentum and experience from collecting as part of case management (Appendix C, Table 4).

SDD Collection: Who, When, and How

In the context of COVID-19 case management, all 31 PHUs reported that case managers were the ones who collected SDD from clients diagnosed with COVID-19. Nine health units also selected 'other' and specified: the use of a virtual assistant; contact tracers, students and/or provincial workforce staff for SDD collection (Appendix C, Table 5). When asked about the guidance that PHUs gave staff about when to collect SDD from clients diagnosed with COVID-19, 23 PHUs reported guiding their staff towards collecting SDD during their first interaction, 12 guided to collect during a middle interaction with the client, and seven recommended collection during the final interaction with the client (Appendix C, Table 6). Nine PHUs also selected 'other' and specified that the timing of collection from a client was dependent on an individual client's situation, the establishment of rapport with an individual client, the need to wait for confirmed case follow-up, or guidance to collect during the second interaction with a client.

In immunization clinics, of the 18 PHUs that collected SDD, 13 (72.2%) of the PHUs reported non-immunizers (e.g., data clerks, and volunteers) were the ones who collected SDD. Seven PHUs reported that

immunizers collected SDD and four health units selected 'other' and specified that clients submitted SDD electronically (Appendix C, Table 11). In terms of when or at what point SDD was collected at vaccination clinics, eleven reported collecting SDD before vaccination (at reception/registration), whereas six collected as part of nurse/immunizer assessment and seven during the post-vaccination waiting period (Appendix C, Table 12). The majority of PHUs (14 PHUs; 77.8%) reported entering SDD directly into COVaxON, six collected on paper before entry into COVaxON, and three selected 'other' and specified the use of a survey or other electronic submission process (Appendix C, Table 13).

Monitoring, Analysis and Dissemination

The proportion of clients for whom SDD was collected was lower in COVID-19 vaccination clinics compared to case management. Among the 18 PHUs who collected SDD with vaccination, 16 reported a low level of completion (between 0-25% of clients receiving vaccination). With COVID-19 case management, of the 31 PHUs who collected SDD, 13 PHUs reported that SDD was collected from 25-50% of clients (Appendix C, Table 2).

Of the 31 PHUs who collected SDD with case management, only seven monitored SDD completion rates whereas eight of the 18 PHUs that collected with vaccination monitored SDD completion. (Appendix C, Table 3).

In terms of sharing results from SDD analysis, 10 of the 31 PHUs that collected SDD as part of case management, and only two of the 18 PHUs that collected SDD in their vaccination clinics reported sharing findings from SDD analysis (Appendix C, Tables 8 and 14).

Experience of PHUs with SDD Collection

In two open-ended questions, PHUs were asked to share their experience regarding the collection of SDD as part of COVID-19 case management and vaccination efforts. There were 28 responses to the first question and 18 responses to the second question. The findings from the thematic analysis of the responses are summarized below.

Case Management

Some PHUs had begun collecting SDD **using a locally built system** before the Ministry of Health mandated SDD collection with race, language and income fields added to the CCM database. Locally-built efforts were user-friendly and enabled quick, easy collection.

“*...our PHU began collecting SDOH data/SDD using a locally built data system. In that system, SDOH data fields included a script that could be read by investigators...Data could be entered by selecting check boxes, and the ease of this approach was seen as an important enabler to collecting...The information was displayed on the main investigation page, which provided a visual reminder to the investigator to ask the questions, and the information could quickly and easily be entered, so that it did not interrupt the flow of the investigation conversation.*”
(urban PHU)

Further, the **introduction of the provincial mandate, and associated guidelines and training**, prompted other PHUs to initiate collection and contributed to increased staff comfort in collecting SDD. Having the ability to explain the rationale for collection as well as a script translated into appropriate languages, facilitated collection.

“*...clients were cooperative for the most part and answered questions willingly when the reason for collecting the information was explained to them.*”
(urban-rural PHU)

“*Having a script (including appropriate language) with training was necessary for case managers to collect sociodemographic data to improve staff comfort level when asking these questions. Clients had varying comfort levels in answering questions (e.g., income).*”
(urban-rural PHU)

Many **PHUs developed their own training** and other resources to support ongoing collection. Some PHUs mentioned the use of other modes such as virtual assistants to increase completion, particularly during surge periods when timely case management was compromised and it was difficult to ask for SDD.

Respondents mentioned the **discomfort experienced by staff** when asking clients for their SDD. They also mentioned the lack of capacity to provide ongoing training and support which could have increased understanding of the rationale for collecting this information that may have increased client comfort to provide, particularly race and income for example, which were perceived as uncomfortable for both staff and clients.

“...training sessions were provided to all Case Management staff and managers to support the collection of sensitive SES data...The Health Equity team developed a presentation, tip sheet and FAQ document to support staff learning; content was adapted from Public Health Ontario materials. One of the training sessions was recorded and later incorporated within the new staff orientation pathway.”
(urban PHU)

“...SDD item completeness for those who answered through the Virtual Assistant tool within CCM vs. asked questions by case managers. Especially...given further reduced capacity...the ability to collect this information through case management will be further limited.”
(urban-rural PHU)

“...case managers felt most comfortable collecting this information when it was captured via email through salesforce.”
(urban-rural PHU)

“Many case investigators admitted to not feeling comfortable asking for such personal information (especially about income) during such an emotionally charged time and therefore didn't prioritize the SDD questions when calling a client.”
(rural PHU)

“Case Managers felt uncomfortable asking the questions to clients, which is why it was asked on an infrequent bases at the start of the pandemic and phased out after a few months due to other priorities.”
(rural PHU)

“We had almost all new staff working on case management...we lacked time/capacity to train staff on collecting sensitive information when case counts were surging.”
(urban PHU)

Respondents mentioned the **recruitment of new external staff, who were not previously part of the PHU**, to assist with case management. This presented unique challenges in terms of providing staff with adequate training that will enable them to explain the rationale for SDD collection and establish a trusting rapport in order to request this information from clients.

“*...need for training and support to feel more comfortable and confident in asking SDD questions in culturally humble and safe ways.*”
(urban PHU)

“*Challenges associated with having external groups collecting data for us (e.g., Provincial Work Force - PWF) without the same training or approach as our own staff; sometimes clients felt uncomfortable or pressure...PHU staff were able to ask questions with sensitivity...this can be a difficult conversation.*”
(urban PHU)

During surge periods with high COVID-19 case volumes, **other aspects of case management were prioritized over SDD collection**, resulting in lower collection/completion. In addition, SDD collection in CCM was called “time-consuming” and/or “cumbersome”. Further, SDD is not a ‘provincially-required’ field, but rather, an ‘as possible’ data element. To deal with these challenges, PHUs reported not collecting at all, collecting when possible, or undertaking retrospective collection to collect SDD during lower-case volume periods when they had the time and capacity to do so.

“Due to capacity challenges, our health unit was not able to collect SDD for our cases. We had to routinely modify what was urgent as our health unit was one of the hot spots for COVID-19.”
(urban PHU)

“When cases were low and manageable, the SDD data was collected, but the SDD questions were often identified to be cut when cases surged and priorities in case management had to be set. Without the ability to consistently collect this data, it was not useful to analyze. The questions stopped being asked when we were in surge of cases and could no longer consider them to be a priority.”
(urban-rural PHU)

“During a surge in cases, due to limited capacity, we stopped collection of SDD (as per direction from the Ministry). When capacity increased at a later date, we completed data remediation and attempted to call back cases in order to collect their SDD data.”
(urban-rural PHU)

“There was also a technical burden to case investigators in completing the SDD section in CCM. The database does not allow for the SDD risk factors to all be entered simultaneously. Instead, each one has to be entered separately and each entry requires multiple steps. You select the risk factor, answer the question, add the date, then save and then answer the other 4 questions in the section. Very time consuming.”
(rural PHU)

“The setup for data entry in CCM was onerous for the user with each SDD construct having to be created separately for each client and then the response entered (about 50 clicks through the system, without any notes.”
(rural PHU)

Health units expressed concern about **not being able to collect Indigenous identity data**, and having to explain this to First Nations, Inuit and Metis clients and community partners. This reflects a barrier created by the absence of a field to appropriately capture Indigenous identity data in provincial data systems for COVID-19 case management (CCM) and vaccinations (COVaxON). Some PHUs that had been collecting Indigenous identity data previously in their locally-built systems stopped collecting once SDD fields were added into CCM, of which, Indigenous identity fields were not included.

“*Our health unit raised questions around...indicating Indigenous identity, in light of OCAP. A brief script describing the issue was produced internally and discussions did take place but no further direction or action was [taken].*”
(urban-rural PHU)

Vaccination

Many of the experiences collecting SDD during COVID-19 vaccination clinics were similar to those experienced with COVID-19 case management.

The **time it took to ask for this information, especially during surge periods**, was the main barrier to collecting SDD in vaccination clinics. In some cases, SDD collection was given up completely because the articulated priority was to prioritize high appointment volumes and efficiency.

“*Time was a primary issue in collecting this data in the highly time crunched model of immunization, it would have doubled or tripled the interaction time if completed by the nurse thereby reducing number of vaccines per day.*”
(urban-rural PHU)

Ongoing, consistent training was needed to increase client and staff comfort.

In addition, alternate processes or solutions to collect this information, such as online at the time of registration or as part of pre-registration, were suggested to address time and comfort challenges.

External help was brought in during surge vaccination periods, and the appropriateness of having non-PHU staff and volunteers asking for SDD information was questioned. Also, external staff contributed to ongoing training challenges and potentially increased SDD variability.

Most PHUs collected SDD at client registration during busy clinics, which created **privacy challenges** resulting in discomfort for both clients and staff. Some PHUs developed strategies such as laminated response sheets that clients could point to, to help in these challenging circumstances.

“Some clients felt that it was an invasion of their privacy.”
(urban PHU)

“No staff had training to ask these sensitive questions and they did not feel comfortable.”
(urban-rural PHU)

“Training was needed to increase staff and client level of comfort in asking and answering questions, especially as many staff were new to public health.”
(urban-rural PHU)

“Staff training was needed on how to collect data since many were not experienced in dealing with diverse and vulnerable populations; it was important for them to understand why we are collecting this data.”
(urban PHU)

“Asking volunteers to collect this information may have felt inappropriate. Additionally, speed was a key focus in mass clinics, so check-in process was streamlined as much as possible.”
(rural PHU)

“Questions were asked during registration in open places where other clients may have been in ear-shot. Modifications were made to make it possible for clients to point to responses rather than voice them out loud (e.g., pointing to laminated sheet).”
(urban-rural PHU)

Further, some PHUs reported that **the lack of privacy in COVID-19 vaccination clinics** deemed them inconducive to collecting SDD. Clients were perceived as being apprehensive to provide SDD in vaccination clinics, as people were focused on getting their shots and did not understand the reason for collecting SDD.

As with case management, PHUs noted the **inability to collect Indigenous identity data in COVaxON**, and the discomfort this created with clients and the community, despite having scripts to explain reasons behind its exclusion. Staff reported that this was negatively received by some clients as it was viewed as a form of exclusion and concern about underrepresentation.

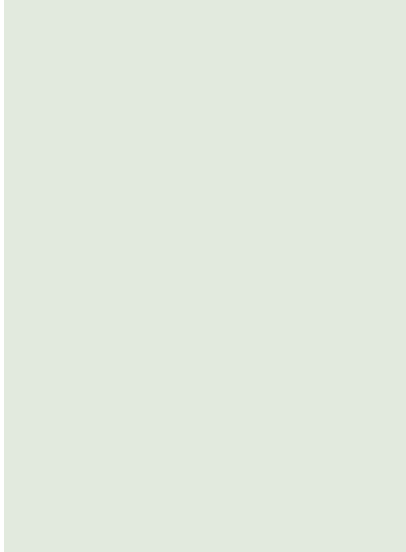
There was also mention of the **inability to analyze and use SDD due to insufficient data** as well as the **lack of a framework or guidance for PHUs to analyze SDD**. Among PHUs that did analyze the SDD collected, some only shared internally whereas others did share summaries with external partners and used the data for planning purposes.

“Clients at times are...reluctant to provide information in public settings, they are also anxious as to what the data is being used for and why it is being collected despite providing them the explanation. Many are concerned about privacy and confidentiality when providing this information, especially in open clinic settings where two immunizer tables are very close together and other clients can hear the client's responses.”
(urban PHU)

“Further, the lack of Indigenous race/ethnicity options on the ministry SDD question made it awkward when working with these populations as it felt as though they were being excluded. Although we had scripts to explain its exclusion, it still created discomfort and confusion.”
(urban PHU)

“Without the ability to consistently collect this data, it was not useful to analyze.”
(urban PHU)

“Although we did analyze sociodemographic data for COVID-19 cases for about a year and was shared internally, the data was never used to engage community partners working with priority populations or target populations for testing, prevention, or to mitigate transmission within our communities.”
(urban-rural PHU)



“
...the response rates were poor, and there were lots of data management challenges...little guidance surrounding how best to analyze these data with regards to collapsing values into meaningful categories. Therefore, we stopped our analysis efforts with plans to go back and analyze the data once there was improved completion, technical guidance and increased analytic capacity.”
(urban PHU)

Phase II: Public Health Unit Focus Groups and Key Informant Interviews

Sixteen focus groups and eight one-to-one interviews with a total of 65 participants were conducted between February 17, 2023, and March 15, 2023.

Participant breakdown by peer group was as follows:

6 Senior management	18 Middle management	20 Frontline staff	20 Epidemiologist-Specialist- Analyst staff
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Participants identified several factors that impacted their ability to collect, analyze and use data. After applying both inductive and deductive analytical approaches, the identified themes were classified into the sub-headings “Enablers of SDD collection”, “Barriers to SDD collection”, and “Challenges with SDD analysis and use”.

Enablers of SDD Collection

Provincial Enablers

The Ministry of Health took two key steps to facilitate the collection of SDD. These included establishing a dedicated data system and legislative amendments to enable the collection of SDD during COVID-19 case management.

Organizational Practices

SDD collection was prioritized in some PHUs, as evidenced by senior management's outright support of the work and efforts to socialize SDD collection across the organization.

Staff were provided with training that highlighted the purpose and value of SDD collection. In addition, early adopters or "champions" of SDD collection were leaned on to support their colleagues in understanding and implementing SDD collection.

“ *Between when the pandemic was declared in March and when they came out with the new system (CCM) in August, not only had they developed a completely new system that allowed for collection of this type of data...but they also amended the legislation to allow for the health protection and promotion act to permit the collection of this type of data as well. So, for a government, that's pretty lightning speed. That was one success there that enabled us to do that.*”

(Participant, urban PHU, Epidemiologist-Analyst-Specialist peer group)

“ *I just do know that our senior management, in making decisions in terms of resource allocation, would have made decisions to help support some of the technological advancements in our region to support the collection of the social determinants of health data. I see that as a way of senior management really facilitating that collection...[they] would provide internal updates, town halls around how vaccination clinic work is going, how CCM work was going. They would have also utilised some of that data, and really been able to help frontline staff see the connection of where I'm collecting information, and how it is being used and applied to make decisions.*”

(Participant, urban PHU, Middle Management peer group)

“ *I think it's really important to have staff buy-in. I think it took a lot of training...in terms of being able to explain why this was done and trained the staff that was doing this work.*”

(Participant, urban PHU, Epidemiologist-Analyst-Specialist peer group)

“ *Then the staff are very engaged, you have SDD champions in some of the clinics. I think that has made a big difference in people embracing it and wanting to ask the questions.*”

(Participant, urban PHU, Frontline Staff peer group)

Trust, Safety and Care During Staff-Client Interaction

Engagement and explanation of SDD collection, both as part of one-on-one conversations with frontline case managers and through community ambassadors, contributed to trust-building and comfort with SDD collection on the part of clients.

Community members understanding the purpose of collection as well as perceiving the environment as confidential and safe, including being able to point to their responses rather than shouting them were enablers of SDD collection.

“ *With the trust-building done beforehand where community ambassadors speak to members of the community, explain context of the service, and some more information about the clinic, then we found clients enter that first check-in point already feeling more comfortable than if they hadn't had that conversation with a trusted member of the community. We know that that did lead to higher data completeness from the trust that had built up beforehand by community ambassadors.*”
(Participant, urban PHU, Senior Management peer group)

“ *What we found is once clients understood why we were collecting the information they were pretty happy to provide it...*”
(Participant, urban PHU, Senior Management peer group)

“ *Sometimes related to privacy, so the client is able to point to the question if they don't want to answer out loud, so we did provide that. Also, the client has the option if there is [sic] any questions that they don't want to answer it's their choice.*”
(Participant, urban PHU, Senior Management peer group)

Learnings from the Community and other Jurisdictions

Early evidence of the pandemic's inequitable impact from other places (e.g., in the USA, experiences of specific communities in Ontario) as well as early insights from the community on the importance of this work enabled PHUs to prioritize and collect SDD.

Barriers to SDD Collection

Factors Related to the Provincial Data Systems

The functionality of the provincial databases (CCM and COVaxON), especially during the early days, was not user-friendly as it was burdensome to locate where the SDD fields were and also to input responses.

On the other hand, there was no Indigenous identity field/option and this did not resonate well with some clients who wanted to provide that information.

“ We saw early on that we had seen information from the US that was presenting information on disparities in COVID, and we started seeing that through our outbreaks. We saw migrant worker-related ... or where migrant workers had disproportionate COVID. We were already hearing anecdotes about race, like certain South Asian population, other PSWs who were ... many of those who came from the Black community. We were hearing a lot of that anecdotally from our community partners, so we made it a priority to really understand and systematically know what was going on, particularly as [our health unit] became a hot spot with higher rates than others across the province, other health units.”
(Participant, urban PHU, Senior Management peer group)

“ So, I always remember the early days of CCM not being very user friendly...in terms of the questions and where they were, it was a whole different, not a module but a different section on that client's page. So, often times we would find that case investigators would miss it, if they weren't following the procedure step-by-step and they didn't have it out in front of them and they weren't going through it as they were on the phone with the client. Because it was a separate part of the case investigation and sometimes it wasn't being done, I think that was more in the early days where not everyone was familiar with CCM.”
(Participant, urban PHU, Frontline Staff peer group)

“ And there was a particular clinic region where there were a lot of Indigenous folks that were coming to get their vaccines, and I remember that questionnaire specifically excluded Indigenous identity under racial and ethnic group because there was insufficient time to have appropriate consultation. But it was rather negatively received in that particular context because it was seen as a form of erasure and not being present. So, while people could fill in their identity through "other", there were a lot of questions being asked as to why Indigenous folks were excluded. And while she was able to provide an educated answer as to why not, there were still

concerns with that approach in that particular community."
(Participant, urban-rural PHU, Frontline Staff peer group)

Organizational and Logistical Practices

In some PHUs, SDD collection was not considered a priority across all levels of management. Participants also highlighted that a lack of training and support resources for staff inhibited SDD collection, especially for new hires. Less time was dedicated to training them because of their demanding workload.

Similarly, some PHUs did not engage with communities early on and this limited not just the collection but other aspects of the work.

“*...Our medical officer of health is a big advocate of it, but it was ... our middle management, it was not a priority for them, and then since they were the ones who were running our pandemic response division at the time, it was not prioritized.*”
(Participant - interview, urban PHU, Epidemiologist-Analyst-Specialist peer group)

“*...There were several public health nurses that were hired, that was the last group presentation I provided...I provided organizational sociodemographic question training across the organization...there was a push that every single staff member was going to get training on how to do case and contact management. So, it was provided widely at that point, but I wouldn't say there was recurring training as new people got onboarded.*”
(Participant, urban-rural PHU, Frontline Staff peer group)

“*...In terms of barriers, not specifically the data collection, but barriers to this work overall, one challenge for us [was] trying to get some better community engagement. To help inform the data collection, the analysis, the communications, the use, because that's, of course, a really important piece of this.*”
(Participant, rural PHU, Senior Management peer group)

Operationally, SDD completeness became more burdensome during surge periods which led PHUs to prioritize questions deemed more important.

Challenges During Staff-Client Interaction

Service providers did not always have sufficient time to build rapport with clients as explaining the purpose and utility of SDD on the spot could take significant time.

Also, sometimes the person receiving care may not have time to respond to the questions, for instance, parents with multiple children answering SDD questions for all of them.

Furthermore, the settings where the services were provided were not always ideal for people to share their SDD, for example, due to a lack of privacy or noise in the background.

“*That’s a great way to say it. And when we had high case numbers, management did say to us, here’s what absolutely should be asked during case management, and here’s what doesn’t have to be asked. And one of those that doesn’t necessarily have to be asked is the sociodemographic data.*”

(Participant, urban-rural PHU, Frontline Staff peer group)

“*Our nurses did a great job at explaining why we gather that information, and how we gather that information, but it did sometimes take a great deal of their time explaining why we were gathering that information that wasn’t part of what they were actually dealing with, with the case and contact management at the time.*”

(Participant, urban-rural PHU, Middle Management peer group)

“*[It is] hard collecting data on children especially in vaccine clinics when people would bring you know, if they have three or four kids. You’re asking them the same question for each of the children and again, it’s the time factor and it’s the anxiety. The kids are already anxious, the parents are anxious. It’s not in a very private area. It’s loud, it’s noisy, it’s not what they’re used to.*”

(Participant, urban-rural PHU, Frontline Staff peer group)

“*And from my personal experience going to vaccine clinics, I’d say the opposite can also be true with the big vaccine clinics where it’s very loud, you have to shout to be heard, and you’re being asked those questions and lots of people can hear your responses. And it creates a similar situation of discomfort, I think both for the public health unit staff member who’s tasked with collecting the information, and the person who’s being asked to respond. And I think that’s probably even more so for people who are in a vulnerable population.*”

(Participant, rural PHU, Epidemiologist-Analyst-Specialist peer group)

Additional Staff Perception

Participants expressed that SDD collection was more difficult to implement when staff members did not recognize its value or comprehend its purpose and utility. Also, staff being uncomfortable asking the necessary questions for fear of being disrespectful to the clients receiving care further complicated SDD collection.

Some of the questions - particularly income ones - were more challenging to elicit feedback from clients than other questions.

“*The challenge I keep seeing over and over is staff and manager pushback, and that is rooted in not seeing the value in it. I think it is also rooted in a lot of unconscious bias...or not even implicit bias. I have some staff who were saying, I don't want to answer those questions, so nobody else will. I was like, yeah, but let's look at yourself, though, some of them are in extreme positions of privilege. I was like...the point of collecting sociodemographic data is to understand who is experiencing inequities, so you're not experiencing the inequity, is what I want to say. There's that element of, yeah, I guess unconscious implicit bias that I think needs to be addressed as well.*”

(Participant - interview, urban PHU, Epidemiologist-Analyst-Specialist peer group)

“*I really think the number one barrier was for the staff who had to ask the information was their feeling ... The unknown that they felt and the discomfort that they felt...they were very sensitive to the clients, especially case and contact when you're calling someone telling them that they have COVID, or they have COVID. So, they wanted to ensure that they were being respectful, and they were being kind to the clients. I think that was the biggest barrier and challenge for them.*”

(Participant - interview, urban PHU, Senior Management peer group)

“*People really don't like the money questions. When you ask them about money, even though we know why it's important and even when you explain that, people still do not feel comfortable answering certain questions.*”

(Participant, urban-rural PHU, Frontline Staff peer group)

Additionally, some participants believed there was no clear distinction between the race and ethnicity elements, and the latter was time-consuming to go through as there were lots of options to choose from.

“...Even maybe some of the health professionals, they don't understand the difference between race and ethnicity, and so that kind of sometimes gets muddled in terms of what is race and what is ethnicity. Also, in terms of the number of options that are available for the ethnicity, I think it may be a challenge because an individual may identify with multiple ethnicities, and scrolling through that entire list where there's 100 options, it may be time-consuming and even frustrating for some of the immunizers to sit there and go through every single option.”

(Participant, urban PHU, Middle Management peer group)

Barriers to SDD Analysis and Use

Provincial-Related

Some participants mentioned that for COVID-19 vaccination, the province mandated to only use for internal purposes and not share externally, and this limited their ability to use the data.

“I think there was lots of barriers in terms of the data systems, the infrastructure. For vaccination, certainly our ability to report on it was hindered by Ministry policy and agreements. We were explicitly told on ... for vaccination, that we can use it for internal purposes, but we are not able to share with external community partners. That hindered our ability to use the data, if we were not able to share it with our community partners. It did form some real discussions, there was animosity from community partners, that we were not able to share the information.”

(Participant - interview, urban PHU, Senior Management peer group)

Organizational

Some participants mentioned a lack of personnel, knowledge, or capability to analyze this type of data.

“ *One of the things we would want to do more, in terms of some analysis of who's not coming. But again, some of our resources are quite...we're limited, there was a lot going on in terms of tracking cases...but some of the other aspects, we didn't have a lot of resources to go on.*”
(Participant, urban PHU, Senior Management peer group)

“ *...Data is actually sitting there, so it was collected and wasn't used. So, there's even just also, I wouldn't say hesitation, but sometimes the uncertainty of even how to use it or report it, or it's not even a part of every process that we do in data analysis, I would say, yet.*”
(Participant, rural PHU, Epidemiologist-Analyst-Specialist peer group)

Concerns Over Data Quality

Some PHUs did not plan to use the data as they believed reliable inferences could not be made from the data due to issues such as low completion rates and small sample sizes.

“ *At this point, we definitely don't have any plans to use the data coming out of CCM or COVax, just from a sociodemographic perspective, just because the data is so inconsistent and hasn't been collected very well.*”
(Participant, urban PHU, Epidemiologist-Analyst-Specialist peer group)

“ *Well, it wasn't representative of anything, and you know, like I said, we didn't collect it all the way through. Some clinics collected it for a bit and then stopped, other clinics didn't do it all. We'd have to analyze it based on a clinic-by-clinic basis. It wouldn't have been useful really to us.*”
(Participant, urban-rural PHU, Frontline Staff peer group)



Implications

For many years prior to the pandemic, there has been an understanding of the importance of collecting detailed SDD in healthcare for health equity monitoring, however, there has been limited success with routine and sustained implementation of SDD collection for variables such as race, ethnicity, and income ([ref. 1](#); [ref. 2](#)).

The data fields discussed in this project represent a subset of the full suite of SDD as recommended to the Ministry of Health by the Association of Local Public Health Agencies ([ref.](#)). The inclusion of language and racial identity data was helpful to identify the disproportionate impact of COVID-19 on racialized communities. However, the omission of other key SDD prevented a more fulsome picture of the impacts of COVID-19 on other equity deserving groups. For example, the impact on Indigenous communities by asking people if they identify as First Nations, Inuit and/or Metis; the impact on immigrant communities by asking whether people were born in Canada, and if not, length of time in Canada; the impact on people with disabilities; on people who are under- or

unstably housed; and on people who identify as 2SLGBTQ+.

In our study of SDD collection by Ontario PHUs during the COVID-19 pandemic, we found significant desire among PHUs to initiate SDD collection, driven by the knowledge that some racialized populations were disproportionately affected by COVID-19. Five health units had initiated SDD collection prior to inclusion of select SDD fields and mandating collection in CCM. Additionally, more than half (53%) of PHUs reported collecting SDD in COVaxON during COVID-19 vaccination, even in the absence of a public health mandate. Although collection in both databases yielded varying levels of data completeness, PHUs were able to use available SDD data to inform community strategies to decrease COVID-19 incidence and severe outcomes.

Several factors at the system-, organization-, community- and client/patient-level played a crucial role in shaping the implementation of SDD collection across PHUs and achieving the outcomes observed. The most commonly identified

reasons for not collecting SDD have implications at both the system and the organizational/PHU level, and are discussed below.

System Level

The system level refers to the broader health system and encompasses policies, regulations, and infrastructure that support the delivery of healthcare and public health services, including the collection of SDD in this case.

For public health programs that are required to use provincial data systems, provincial prioritization and expectations for SDD collection and reporting were articulated by study participants as an area that would facilitate SDD collection. Some PHUs described how the collection of additional SDD such as race, ethnicity and income was not considered mandatory in periods of high COVID-19 activity and/or high vaccine demand in order to ensure that more people received the public health intervention (i.e., case management or vaccination). Similarly, not all PHUs monitored SDD completion rates, particularly in vaccination clinics. Lack of monitoring hindered data quality assessment and limited the usefulness of SDD for analysis and decision-making. It was therefore not surprising that several PHUs reported challenges in analyzing and using SDD due to concerns over data completeness, as well as a lack of guidance or a framework.

Subsequent to this, few PHUs reported sharing findings from any SDD analysis to provide awareness of disparities or inform interventions to reduce case incidence (e.g., targeted testing) or support vaccination. This suggests a missed opportunity to leverage the data for informing public health strategies and interventions.

In the absence of direction to collect SDD and the supportive infrastructure including data systems and data standards, it is not realistic to expect that PHUs will consistently do so themselves even if prioritized locally.

Organization Level

Organizational level factors include the characteristics of specific organizations, in this case PHUs, that affect the implementation of SDD collection. This can include organizational culture, leadership support, workflow processes and training. Overall, lack of training, resources, and capacity were cited in our study as key reasons for not initiating SDD collection or experiencing challenges in its implementation. Lack of staff training among new staff, and the absence of standardized communication strategies to address discomfort and build trust with clients during data collection processes negatively affected staff buy-in to the importance of collecting SDD.

Sustaining Change

Following the introduction of the Omicron variant of concern and significant case surge in late 2021, Ontario's requirement for individual COVID-19 case management (and therefore SDD collection) was discontinued. However, the pandemic lessons learned regarding the importance of SDD collection to identify and address health inequities are not forgotten.

Canada's Chief Public Health Officer, Dr. Theresa Tam, has identified the lack of SDD as a challenge and has committed to pan-Canadian data initiatives to address gaps in an ethical manner ([ref.](#)). Similarly, the Chief Medical Officer of Health's 2022 annual report, *Being Ready*, calls for better provincial infrastructure to routinely collect SDD "to identify communities at risk and

work with them to reduce health inequities” ([ref.](#)).

Federal and provincial prioritization of these systems-level changes will help drive

momentum and will enable Ontario PHUs to scale SDD collection across a broader range of health outcomes.



Methodological Considerations

The Project Team acknowledges limitations that were encountered during the study. Firstly, there were challenges in recruiting participants for the focus groups, resulting in low response rates. To address this issue, the recruitment method was changed to directly contact potential participants through the APHEO directory and through professional networks. This alternative approach proved to be more effective, resulting in a total of 65 participants across the four peer groups, representing a mix of rural and urban PHUs.

Another challenge was ensuring adequate representation across all four peer groups. Senior Management were particularly hard to recruit due to time constraints and schedule conflicts. Thus, Core Team members decided to offer one-on-one

interviews to accommodate as many Senior Management staff as possible. The one-on-one interview invites were also extended to other individuals who were affiliated with PHUs that could not participate in focus group discussions or who had unique roles that were not reflected in prior discussions. This approach allowed for more in-depth conversations and the collection of candid data about experiences with SDD collection.

Despite these challenges, it is important to note that they do not diminish the significance of the results or the validity of the recommendations.



Recommendations

Based on the findings of this research, recommendations for the improvement and scale-up of SDD collection beyond COVID-19 to other public health programs and services are as follows:

System-Level

At the system level, key stakeholders include government bodies, regulatory agencies, and health authorities responsible for establishing standards, allocating resources, and overseeing healthcare and public health service delivery. System-level interventions focus on shaping the overall health system landscape, SDD collection, analysis and use.

It is recommended that provincial health system partners:

- Ground SDD collection and use as part of health equity work by including it in foundational guidance documents (e.g., Ontario Public Health Standards) for PHUs.
- Establish clear mandates for PHUs to collect and use SDD, including having clear targets and measurable outcomes.

- Establish a central program of support including standardized training for SDD collection, guidelines (framework) for SDD analysis and use, and structured opportunities for knowledge exchange across PHUs (e.g., a community of practice).
- Build data systems with a comprehensive, standard suite of SDD with easy-to-navigate fields for efficient data entry.
- Where possible, centralize SDD collection efforts and/or explore data linkages across the health system to minimize duplication and emphasize client-centred approaches.
- Engage with population groups including Indigenous, immigrant and Black communities in Ontario to develop and respectfully apply data governance frameworks in the

collection, analysis and use of SDD (e.g., OCAP, EGAP).

- Provide adequate resources to PHUs to support implementation of SDD collection, analysis and use.

Organizational/PHU-Level

At the organization or PHU level, key considerations include governance structures, leadership, organizational culture, workforce management, and resource allocation. Organizations play a vital role in coordinating care, managing resources, and implementing evidence-based practices.

As provincial levers for SDD collection and use are explored, it is recommended that PHUs:

- Continue and expand the collection of SDD during public health service provision to inform equitable public health interventions.
- Prioritize SDD collection and use by enshrining it in respective organizational strategies and creating an accountability mechanism (including targets and indicators) to monitor the work.

- Engage with communities early to collaboratively plan and implement SDD collection, including discussing the purpose and utility of SDD.
- Use data to tailor interventions to the specific circumstances, contexts, and needs of the communities served.
- Ensure dedicated resources are in place (specifically, people and time) to support SDD collection, analysis and use within the organization.
- Provide staff with comprehensive training before initiating SDD collection. Training should emphasize the purpose and utility of SDD, recognizing that staff understanding the value of SDD and comfort with asking fosters an environment of trust on the part of the client to provide this information.
- Provide ongoing support to staff throughout the implementation process by offering a variety of tools adapted to the specific context, including flexible options for data collection.

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Appendix A: Public Health Unit Survey

Section 1: SDD and COVID-19 Case Management

The section asks about your health unit's SDD collection practices as part of COVID-19 case management.

Did your health unit collect SDD such as childhood language, racial identity and income as part of COVID-19 case management?

- Yes
- No

If no, what factors led to your PHU not collecting these SDD? Select all responses that apply.

- Lack of appropriate data infrastructure
- Staff discomfort
- Lack of training resources/capacity
- Lack of community engagement resources/capacity
- Lack of analysis guidance/framework
- SDD collection not an organizational priority
- Do not know
- Prefer not to answer
- Other, specify:

For approximately what proportion of clients in your region diagnosed with COVID-19 do you have SDD such as childhood language, racial identity and income collected? Select one response.

- 0-25%
- 26-50%
- 51-75%
- 76-100%
- Do not know
- Prefer not to answer

How would you rank the level of completeness of each SDD construct? List the SDD constructs in order of most complete to least complete.

- Official language
- Childhood language
- Racial identity
- Household income
- Household size

When did your health unit initiate SDD collection? Select one response.

- Before Province mandated collection (June 2020)?
- After Province mandated collection (June 2020)?
- Do not know
- Prefer not to answer

If your health unit initiated 'Before Province mandated collection (June 2020)', what were the primary reason(s)? Select all responses that apply.

- SDD collection was already underway at my PHU
- Community stakeholder(s) request
- Measuring disparities in health was a pre-existing organizational priority
- Do not know
- Prefer not to answer
- Other, specify:

Who collected SDD? Select all responses that apply.

- Case Managers (PHNs or other)
- Do not know
- Prefer not to answer
- Other, specify:

What was your health unit's guidance about when to collect SDD? Select all responses that apply.

- During the first interaction with client
- During a middle interaction with client
- During the final interaction with client
- After case closure - e.g., retrospective collection at a later time
- Do not know
- Prefer not to answer
- Other, specify:

Did your health unit monitor SDD completion rates internally (on a regular basis)?

- Yes
- No
- Do not know
- Prefer not to answer

Did your health unit analyze the COVID-19 case management SDD? e.g., descriptive analyses or other?

- Yes
- No
- Do not know
- Prefer not to answer

Did your health unit publish or share findings from any COVID-19 case management SDD analyses?

- Yes
- No
- Not applicable; did not analyze
- Do not know
- Prefer not to answer

Is there anything else you would like us to know about your health unit's experience collecting and using SDD as part of COVID-19 case management?
[open field]

Section 2: SDD and COVID-19 Vaccinations

The section asks about your health unit's SDD collection practices as part of COVID-19 vaccinations.

Did your health unit collect SDD such as childhood language, racial identity and income with COVID-19 vaccinations?

- Yes
- No

If no, what factors led to your PHU not collecting these SDD? Select all responses that apply.

- Not a provincial requirement
- Lack of appropriate data infrastructure
- Staff discomfort
- Physical infrastructure challenges
- Lack of training resources/capacity
- Lack of community engagement resources/capacity
- Lack of analysis guidance/framework
- SDD collection not an organizational priority
- Do not know
- Prefer not to answer
- Other, specify:

For approximately what proportion of clients who received at least one dose of COVID-19 vaccine in your region do you have SDD such as childhood language, racial identity and income collected? Select one response.

- 0-25%
- 26-50%
- 51-75%
- 76-100%
- Do not know
- Prefer not to answer

How would you rank the level of completeness of each SDD construct in COVaxON? List the SDD constructs in order of most complete to least complete.

- Official language
- Childhood language
- Racial identity
- Ethnic origin
- Household income
- Household size

When did your health unit initiate SDD collection? Select one response.

- Before Province included SDD in COVaxON (March 2021)?

- After Province included SDD in COVaxON (March 2021)?
- Do not know
- Prefer not to answer

If your health unit initiated SDD collection 'Before Province included SDD in COVaxON (March 2020), what was the primary reason(s)? Select all responses that apply.

- SDD collection was already underway at my PHU
- Community stakeholder(s) request
- Measuring disparities in health was a pre-existing organizational priority
- Do not know
- Prefer not to answer
- Other, specify:

In which PHU-led vaccination clinics did your health unit collect SDD? Select all responses that apply.

- Mass/community clinics
- Mobile clinics
- Pop-up/neighbourhood clinics
- Do not know
- Prefer not to answer
- Other, specify:

Who collected SDD? Select all responses that apply.

- Immunizers (PHNs; other)
- Non-Immunizers (Data clerks; volunteers)
- Do not know
- Prefer not to answer
- Other, specify:

What was your health unit's guidance about when to collect SDD? Select all responses that apply.

- At reception/registration
- As part of nurse/immunizer assessment
- Post-vaccination waiting period
- Do not know
- Prefer not to answer
- Other, specify:

How did your health unit collect SDD from clients? Select all responses that apply.

- On paper only
- On paper followed by entry into COVaxON
- Directly into COVaxON
- Do not know
- Prefer not to answer
- Other, specify:

Did your health unit monitor COVaxON SDD completion rates internally (on a regular basis)?

- Yes
- No
- Do not know
- Prefer not to answer

Did your health unit publish or share data findings from any COVID-19 vaccination SDD analyses?

- Yes
- No
- Not applicable; did not analyze SDD
- Do not know
- Prefer not to answer

Is there anything else you would like us to know about your health unit's experience collecting and using SDD as part of COVID-19 vaccinations?
[open field]

Appendix B: Public Health Unit Peer Grouping Taxonomy

Table 1: Public Health Unit Peer Grouping Taxonomy

Public Health Unit	Region	StatsCAN Peer Group	Geography
Northwestern Health Unit	Northwest	D	Rural
Thunder Bay District Health Unit	Northwest	C	Urban-rural
Algoma Public Health	Northeast	C	Urban-rural
North Bay Parry Sound District Health Unit	Northeast	C	Urban-rural
Porcupine Health Unit	Northeast	C	Urban-rural
Public Health Sudbury & Districts	Northeast	C	Urban-rural
Timiskaming Health Unit	Northeast	C	Urban-rural
Ottawa Public Health	Eastern	B	Urban
Eastern Ontario Health Unit	Eastern	C	Urban-rural
Hastings Prince Edward Public Health	Eastern	C	Urban-rural
Kingston, Frontenac and Lennox & Addington Public Health	Eastern	C	Urban-rural
Leeds, Grenville & Lanark District Health Unit	Eastern	D	Rural
Renfrew County and District Health Unit	Eastern	D	Rural
Durham Region Health Department	Central East	B	Urban
Haliburton, Kawartha, Pine Ridge District Health Unit	Central East	C	Urban-rural
Peel Public Health	Central East	H	Urban
Peterborough Public Health	Central East	C	Urban-rural
Simcoe Muskoka District Health Unit	Central East	D	Rural
York Region Public Health	Central East	H	Urban
Toronto Public Health	Toronto	G	Urban
Chatham-Kent Public Health	Southwest	C	Urban-rural
Grey Bruce Health Unit	Southwest	D	Rural
Huron Perth Public Health	Southwest	D	Rural
Lambton Public Health	Southwest	C	Urban-rural
Middlesex-London Health Unit	Southwest	B	Urban
Southwestern Public Health Oxford Elgin St. Thomas	Southwest	D	Rural
Windsor-Essex County Health Unit	Southwest	B	Urban
Brant County Health Unit	Central West	C	Urban-rural
City of Hamilton Public Health Services	Central West	B	Urban

Haldimand-Norfolk Health Unit	Central West	D	Rural
Halton Region Public Health	Central West	B	Urban
Niagara Region Public Health	Central West	C	Urban-rural
Region of Waterloo Public Health and Emergency Services	Central West	B	Urban
Wellington-Dufferin-Guelph Public Health	Central West	D	Rural

Source: [Health Region Peer Groups - Working paper, 2018 \(statcan.gc.ca\)](#)

Appendix C: Public Health Unit Survey Results

Table 1. Collection of sociodemographic data (SDD) by Public Health Units (PHUs) during case management and vaccination

Response	Case Management (%)	Vaccination (%)
Yes, did collect SDD	31 (91%)	18 (53%)
No, did not collect SDD	3 (9%)	16 (47%)
<i>Not a provincial requirement*</i>	-	12 (75%)
<i>Lack of appropriate data infrastructure</i>	1 (33%)	6 (38%)
<i>Staff discomfort</i>	1 (33%)	6 (38%)
<i>Physical infrastructure challenges*</i>	-	10 (63%)
<i>Lack of training resources/capacity</i>	3 (100%)	11 (69%)
<i>Lack of community engagement resources/capacity</i>	1 (33%)	5 (31%)
<i>Lack of analysis guidance/ framework</i>	2 (67%)	3 (19%)
<i>SDD collection not an organizational priority</i>	1 (33%)	6 (38%)
<i>Other</i>	1 (33%)	8 (50%)
Do not know	0 (0%)	0 (0%)
Prefer not to answer	0 (0%)	0 (0%)
Total	34 (100%)	34 (100%)

Note: *fields are not relevant/not asked for case management; responses are not mutually exclusive and may add up to more than 100%. The proportions for reasons under 'no' are out of the numbers of PHUs who responded they did not collect.

'Other' includes: need time to develop infrastructure, clinical capacity, limited resources and training, logistics, lack of time.

Table 2. Proportion of SDD collection for clients diagnosed with COVID-19

Response	Case Management (%)	Vaccination (%)
0-25%	7 (23%)	16 (89%)
26-50%	13 (42%)	0 (0%)
51-75%	4 (13%)	0 (0%)
76-100%	2 (6%)	0 (0%)
Do not know	4 (13%)	2 (11%)
Prefer not to answer	0 (0%)	0 (0%)
Missing	1 (3%)	0 (0%)
Total	31 (100%)	18 (100%)

Table 3. Internal monitoring of SDD completion rates

Response	Case Management (%)	Vaccination (%)
Yes , internal monitoring was completed	7 (23%)	8 (44%)
No , internal monitoring was not completed	24 (77 %)	10 (56%)
Do not know	0 (0%)	0 (0%)
Prefer not to answer	0 (0%)	0 (0%)
Total	31 (100%)	18 (100%)

Table 4. Case management: Initiation of SDD collection

Response	Case Management (%)
Before province mandated collection (June 2020)	5 (16%)
<i>SDD collection was already underway at my PHU</i>	1 (20%)
<i>Community stakeholder(s) request</i>	2 (40%)
<i>Measuring disparities in health was a pre-existing organizational priority</i>	5 (100%)
<i>Other*</i>	1 (20%)
<i>Do not know</i>	0 (0%)
<i>Prefer not to answer</i>	0 (0%)
After province mandated collection (June 2020)	24 (77%)
Do not know	1 (3%)
Prefer not to answer	0 (0%)
Missing	1 (3%)
Total	31 (100%)

Note: responses are not mutually exclusive and may add up to more than 100%. The proportions for reasons under 'before province mandated collection' are out of the numbers of PHUs who responded they began collection before the mandate.

'Other' includes: identified case disparities in other jurisdictions.

Table 5: Case management: Collector of SDD

Response	Case Management (%)
Case Managers (PHNs or other)	31 (100%)
Other*	9 (29%)
Do not know	0 (0%)
Prefer not to answer	0 (0%)
Total	31 (100%)

Note: responses are not mutually exclusive and therefore may not add up to 100%.

*'Other' includes: virtual assistant, case investigators, contact tracers, students, provincial workforce staff.

Table 6. Case management: PHUs guidance about when to collect SDD

Response	Case Management (%)
During the first interaction with the client	23 (74%)
During a middle interaction with client	12 (39%)
During the final interaction with client	7 (23%)
Other*	9 (29%)
Do not know	0 (0%)
Prefer not to answer	0 (0%)
Total	31 (100%)

Note: responses are not mutually exclusive and therefore may not add up to 100%.

*'Other' includes: dependent on client situation, confirmed case follow-up, timing was dependent on client rapport, second interaction.

Table 7. Case management: Health unit analysis of SDD collected

Response	Case Management (%)
Yes, SDD was analyzed	18 (58%)
No , SDD was not analyzed	12 (39%)
Do not know	0 (0%)
Prefer not to answer	1 (3%)
Total	31 (100%)

Table 8. Case management: Health unit shared findings from SDD analyses

Response	Case Management (%)
Yes, findings were shared	10 (32%)
No , findings were not shared	18 (58%)
Not applicable, did not analyze SDD	3 (10%)
Do not know	0 (0%)
Prefer not to answer	0 (0%)
Total	31 (100%)

Table 9. Vaccination: Initiation of SDD collection

Response	Vaccination (%)
Before province included SDD in COVaxON (March 2021)	2 (11%)
<i>SDD collection was already underway at my PHU</i>	1 (50%)
<i>Community stakeholder(s) request</i>	1 (50%)
<i>Measuring disparities in health was a pre-existing organizational priority</i>	2 (100%)
<i>Other*</i>	1 (50%)
<i>Do not know</i>	0 (0%)
<i>Prefer not to answer</i>	0 (0%)
After province included SDD in COVaxON (March 2021)	15 (83%)
Do not know	1 (6%)
Prefer not to answer	0 (0%)
Total	18 (100%)

Note: responses are not mutually exclusive and may add up to more than 100%. The proportions for reasons under 'before province included SDD in COVaxON' are out of the numbers of PHUs who responded they began collection before the province included SDD in COVaxON.

*Other includes: momentum, community expectations, and experience from collecting as part of case management.

Table 10. Vaccination: Vaccination clinic types for SDD collection

Response	Vaccination (%)
Mass/community clinics	15 (83%)
Mobile clinics	10 (56%)
Pop-up/neighbourhood clinics	12 (67%)
Other*	6 (33%)
Do not know	1 (6%)
Prefer not to answer	0 (0%)
Total	18 (100%)

Note: responses are not mutually exclusive and may add up to more than 100%.

*Other includes: momentum, community expectations, and experience from collecting as part of case management.

Table 11. Vaccination: Collector of SDD

Response	Vaccination (%)
Immunizers (PHNs; other)	7 (39%)
Non-Immunizers (Data clerks; volunteers)	13 (72%)
Other*	4 (22%)
Do not know	1 (6%)
Prefer not to answer	0 (0%)
Total	18 (100%)

Note: responses are not mutually exclusive and therefore may not add up to 100% .

*Other includes: clients submitted responses electronically.

Table 12. Vaccination: Clinic location for SDD collection

Response	Vaccination (%)
At reception/registration	11 (61%)
As part of nurse/immunizer assessment	6 (33%)
Post-vaccination waiting period	7 (39%)
Other*	3 (17%)
Do not know	2 (11%)
Prefer not to answer	0 (0%)
Total	18 (100%)

Note: responses are not mutually exclusive and therefore may not add up to 100% .

*Other includes: clients submitted responses electronically.

Table 13. Vaccination: Method of SDD collection

Response	Vaccination (%)
On paper only	1 (6%)
On paper followed by entry into COVaxON	6 (33%)
Directly into COVaxON	14 (78%)
Other*	3 (17%)
Do not know	0 (0%)
Prefer not to answer	0 (0%)
Total	18 (100%)

Note: responses are not mutually exclusive and therefore may not add up to 100%.

*Other includes: online survey using REDCap, iPADS/QR code linked to a survey not connected to COVaxON.

Table 14. Vaccination: Health unit shared findings from SDD analyses

Response	Vaccination (%)
Yes , findings were shared	2 (11%)
No , findings were not shared	13 (72%)
Not applicable, did not analyze SDD	2 (11%)
Do not know	0 (0%)
Prefer not to answer	1 (6%)
Total	18 (100%)

Appendix D: Focus Group Interview Guide

Core Questions

1. What do you think about PHUs collecting sociodemographic information from clients?
 - **Optional facilitator prompts:**
 - Should SDD collection be universal (i.e., collected in all client interactions)?
 - What concerns do you have?
 - What are your unanswered questions about collecting SDD?
2. What strategies, resources or supports did you or your PHU use to increase data completeness?
 - **Optional facilitator prompts:**
 - Timing of collection in process flow?
 - Who asked? E.g., Nurse, data clerk, other?
 - Staff training?
 - Messages of encouragement/endorsement from leadership?
 - Community partnerships?
 - Development of policies and procedures?
 - Sharing examples with staff of how SDD has been used to inform response?
 - Information for clients on why we're collecting the information?
3. What were some challenges or barriers you or your PHU faced during SDD collection implementation?
 - **Optional facilitator prompts:**
 - Data infrastructure challenges (e.g., CCM, COVaxON)?
 - Staff pushback?
 - Time pressures?
 - Client perspective/experience?
 - Indigenous population documentation challenges
 - Representation of hard-to-reach populations
 - Privacy and data retention concerns (client and/or staff)
4. In the same vein, how did you or your PHU use the SDD that was collected?
 - **Optional facilitator prompts:**
 - (In case SDD was not used) provisional uses of SDD
 - To target care to specific cultural groups
 - To adapt programs
 - To build community partnerships
5. What were some challenges or barriers you or your PHU faced in using SDD?
 - **Optional facilitator prompts:**
 - Community related barriers
 - Collector related barriers
 - Organizational barriers

6. Do you have suggestions for how PHUs could improve their experience and success with collecting and using SDD from clients?
 - **Optional facilitator prompts:**
 - Improved accessibility?
 - Enhanced collection prompts?
 - Data system changes/improved user experience?
 - Enhanced community and client engagement?
 - Provincial data sharing/linkage?

7. How will you or your PHU's experience and/or lessons learned from SDD collection and uses (if any) through the COVID-19 pandemic be applied within your PHU for other programs and services?
 - Optional facilitator prompts:
 - Potential future uses
 - End goals
 - The effects of SDD collection on the local communities
 - Programs and services evaluation (in light of collected SDD)

8. What is needed from provincial stakeholders (e.g., Ministry of Health, Public Health Ontario) for PHUs to be successful in collecting and using SDD from clients for other public health services?
 - **Optional facilitator prompts:**
 - Resources or supports needed for staff and/or client/community?
 - Provincial data sharing/linkage?
 - Revisions to the Ontario Public Health Standards (OPHS) and or *Health Protection and Promotion Act* (HPPA)?
 - Support networks/community of practice?

9. Are there any themes that have not been discussed, but should be?

Do you have any closing comments or recommendations in relation to the collection of SDD within PHU or for public health practice in general?