Sociodemographic Data Collection (SDD) Locally Driven Collaborative Project: A Public Health Unit Resource Guide for Implementing and Scaling Primary SDD Collection Beyond the COVID-19 Pandemic

Purpose

This resource has been developed based on the research findings of the "Lessons learned from the collection of sociodemographic data during the COVID-19 pandemic" Locally Driven Collaborative Project (LDCP) (2022/2023). It is intended to support public health units as they consider starting or expanding SDD collection and use within their organizations. Please refer to Public Health Ontario's LDCP webpage for a detailed final report on the research.

The following steps follow a general sequential order; however, the process is not linear nor unidirectional. A health unit may find itself starting at a different step and/or revisiting previous steps. Some steps may require more time than others.

1. **Confirm and demonstrate organizational commitment to SDD collection through senior leadership championing.**

Consider:
- Establishing SDD collection and use as an organizational priority to support equity measurement and quality improvement.
- Including SDD activities in PHU Annual Service Plans and Budgets, strategic plans, operational plans, etc.; ensure adequate, dedicated resources for SDD collection, analysis and use.
- Developing organizational policies and procedures for SDD collection, storage, analysis, and use.
- Communicating clear goals and objectives for the collection of SDD; namely, to better understand who is accessing programs/services, to modify programs/services to address the unique needs of clients/populations, and to collaborate with and engage communities to advance health equity.

2. **Review existing resources and evidence for SDD collection.**

Consider:
- Lessons learned and evidence for SDD collection and use from healthcare settings (e.g., We Ask Because We Care, Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres).
- Guidance for engaging equity-deserving groups (e.g., National Collaborating Centre for Determinants of Health) and data governance considerations for SDD collection

and use (e.g., First Nations Principles of Ownership, Control, Access, and Possession – OCAP® and the Black Health Equity Work Group's Engagement, Governance, Access, and Protection framework - EGAP).

- Refer to list of resources in the Appendix.

3. Determine what specific PHU programs/services would benefit from SDD collection.

Consider:
- SDD collection at an individual level is one tool, but not the only tool, for assessing and monitoring health inequities. Understanding how the data will/could be used is one way to determine if SDD is the right tool.
- What are the key questions driving SDD collection? Is SDD needed to answer the key questions?
- What does currently available evidence/data say about populations most affected by the health issue or program/service – locally, provincially, nationally?
- Starting within a select program area (or areas) supports capacity building and continuous quality improvement as SDD collection practices evolve and advance to other areas.

4. Engage early and ongoing with key community partners (e.g., community leaders, advocacy groups, and members of equity-deserving groups represented in the data) to discuss the rationale for SDD collection and use to learn about the SDD constructs that matter most to their communities.

Consider:
- Existing relationships with communities, particularly unique equity-deserving groups.
- Reviewing best practice approaches for engaging equity-deserving groups.
- How the community partners would like to see ongoing engagement from collection through to dissemination and use.
- Seeking to understand community information needs, preferences and concerns about the collection and use of SDD.
- Identifying opportunities to build trust and communicate about the importance of SDD collection and use for equity measurement and quality improvement.
- Engaging with key community partners to discuss and interpret preliminary analysis findings.
- Fulfilling commitments to key community partners by sharing findings from data analyses in the appropriate format and location. This may or may not include public reporting.

5. **Engage early with internal staff/teams to build capacity and comfort to collect this information from clients as part of public health practice and service delivery.**

Consider:
- Change management strategies such as internal SDD champions to drive the work forward and build team buy-in.
- Developing staff/team engagement surveys to assess knowledge of the importance of SDD and level of comfort collecting this information from clients.
- The potential role, based on community feedback, of community partners in championing and supporting SDD collection with staff.
- Documenting and sharing examples of how SDD has been analyzed and used for program decision-making.

6. **Determine how SDD will be collected for the identified PHU programs/services.**

Consider:
- What specific SDD or data fields will help to answer the key questions?
- For what aspects of the program/service will SDD data be collected (e.g., will all clients be asked within a program/service, or only a subset of clients)?
- The context within which the SDD will be collected and any options or accommodations that might be needed for collection (e.g., verbally, electronically, on paper; practitioner-led or client-led).
- What point in the service workflow makes best sense to collect SDD?
- Where/how will the data be captured (e.g., existing data system, secure webform; and, is the data stored securely?)

7. **Explore data governance frameworks and consider their application to ensure responsible, non-stigmatizing data collection and use.**

Consider:
- Establishing processes for early and ongoing engagement with First Nations, Inuit, Métis, Black, immigrant and/or other communities to ensure data governance principles are respectfully applied.
- The participation of community/population groups in SDD analysis and/or interpretation, particularly for dissemination of findings and/or recommendations emerging from the data.
- Exploring the need for data sharing agreements with community/population groups (as needed).

8. **Develop and implement a data completeness and quality monitoring plan.**

Consider:
- Establishing percent completion targets during a given timeframe.
- Regular sharing of completion rates with staff/teams who are collecting SDD to inform opportunities for process improvements, and to motivate ongoing collection efforts.

- Engaging staff to identify enablers and barriers to collection and explore opportunities to improve data completeness and quality (e.g., standing meetings or SDD community of practice).

9. Develop and implement a data analysis and reporting plan.

Consider:
- What is needed for analysis (e.g., data definitions, comparators (Census or other), frequency/timing for analyses, analysis notes for data fields).
- Existing guidance for stratified analyses (e.g., Canadian Institute for Health Information equity stratifier guidance).
- What proportion of the population are captured in the data? Is it representative of the population? Who is/isn't reflected in the data?
- Other types of analysis including disaggregation and intersectionality (e.g., gender-based, race-based, immigration, housing).
- A standard process for summarizing key findings/key messages and the use of inclusive language.
- Reviewing data reporting guidelines to address the needs of small populations.
- Engaging community partners to inform analysis, interpretation, and key findings (see step 4).
- Identifying affected or over-represented community groups and engaging prior to public sharing of findings and key messages to ensure messaging is not deficit-based nor contribute to mistrust (see step 4).

10. Train staff and leaders on SDD collection.

Consider:
- Building on the work to engage staff, develop training that emphasizes the purpose and utility of SDD. If staff and leaders understand the value of SDD, they will feel more comfortable and recognize their role in fostering an environment of trust on the part of the client to provide this information.
- Emphasizing the importance of informed consent for clients to provide SDD. If clients understand the rationale for collecting, they may be more likely to provide the information.
- Emphasizing the importance of humility and creating safety in collecting SDD. This may include guidance and/or training provided by representatives of local equity-deserving groups (e.g., locally-relevant history, how best to create safety in asking the SDD questions).
- Ensuring ongoing and adequate training for SDD collection and use, particularly for newly hired staff.

11. Provide ongoing support to staff and clients to safely collect this information.

Consider:
- Offering a variety of tools throughout the implementation process that are adapted to the specific context (e.g., visual aids (posters), laminated response sheets in multiple languages as appropriate, frequently asked questions with rationale for each data construct).
- Physical space(s) to ensure client and staff safety and privacy for SDD collection.
- Creating ongoing opportunities to gather feedback about asking SDD questions and collection, to support continuous quality improvement efforts.

APPENDIX

The list of resources below should be considered a starting point and is not intended to be exhaustive.

Data Standards & Data Collection Resources
- Learning Exchange: Discussion on local socio-demographic data during COVID-19 - PHO Rounds
- Data Collection Resource: Introducing Race, Income, Household Size, and Language Data Collection: A Resource for Case Managers - PHO
- Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada - CIHI
- We ask because we care - Toronto Public Health/St. Michael's Hospital/CAMH/Mount Sinai Hospital
- Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospital and Community Health Centres - Sinai Health System
- Data Standards for the Identification and Monitoring of Systemic Racism - Ontario Anti-Racism Directorate
- Association of Local Public Health Agencies Correspondence: Standardized Collection of Sociodemographic Data - alPHa
- Facilitators and barriers of sociodemographic data collection in Canadian health care settings: a multisite case study evaluation | International Journal for Equity in Health | Full Text (biomedcentral.com)

Data Governance Resources
- The First Nations Principles of OCAP - First Nations Information Governance Centre
- Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities in Ontario - Black Health Equity Working Group

Community Engagement Resources
- Engaging Communities in your Data Collection Initiative – Health Commons Solutions Lab
- Let's Talk: Community engagement for health equity | National Collaborating Centre for Determinants of Health (nccdh.ca)

Data Analysis Resources
- Measuring Health Inequalities: A Toolkit - CIHI
- Gender-based Analysis Plus (GBA Plus) - Women and Gender Equality Canada

Change Management Resources
- The 8 steps for leading change - Kotter