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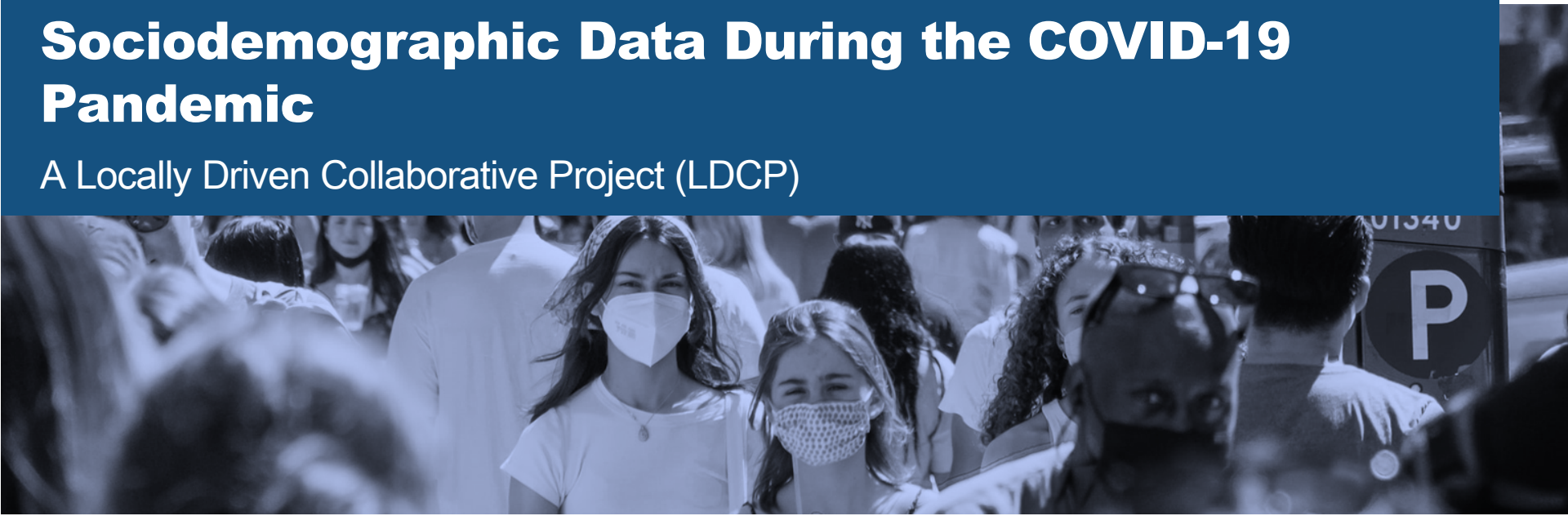
UPSTREAMLAB

Lessons Learned From the Collection of Sociodemographic Data During the COVID-19 Pandemic

A Locally Driven Collaborative Project (LDCP)



September 11, 2023

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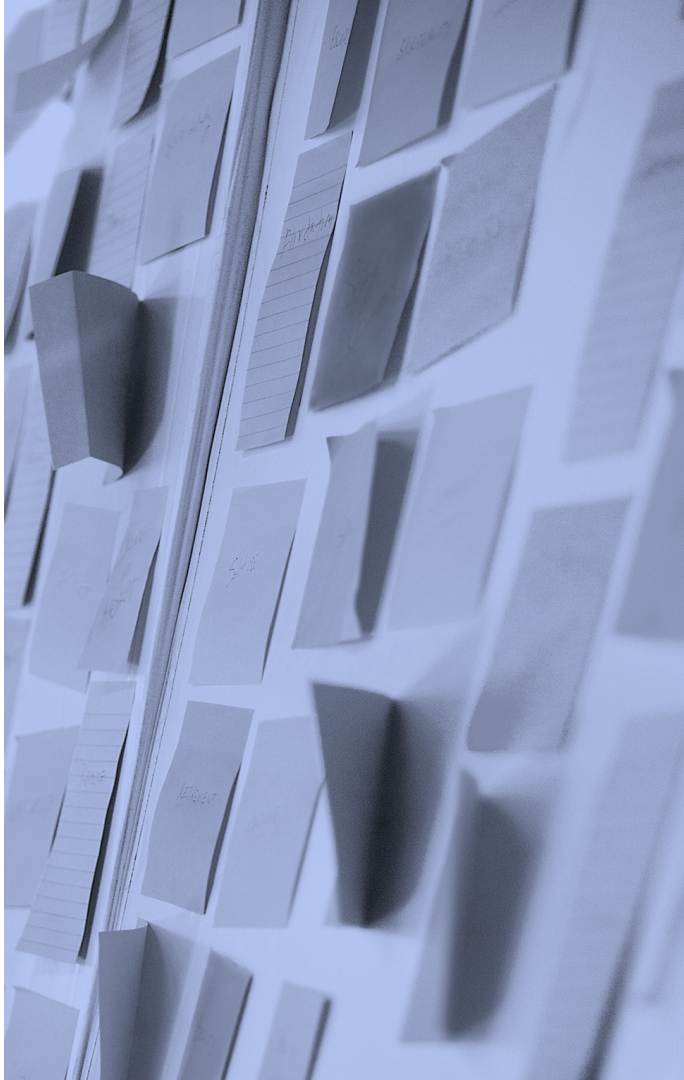
Agenda

- Welcome and opening (5 minutes)
- Presentations (40 min)
- Q&A (13 min)
- Closing (2min)

Moderator: Dr. Reed Morrison, Ontario Public Health



Poll Question #1

What type of organization do you represent?

1. Public Health Unit
2. Community Health Organization
3. Advocacy Organization
4. Academic Institution
5. Provincial or Federal Organization
6. Other (if comfortable can free text reply into chat pod)

Speakers

Peel Public Health
Monali Varia, MHSc, CIC
Director, Public Health Intelligence

Ottawa Public Health
Aideen Reynolds, MPA
Knowledge Exchange Specialist, Epidemiology and Surveillance

Upstream Lab, MAP Centre for Urban Health Solutions, St. Michael's Hospital, Unity Health
Dr. Andrew Pinto, MD CCFP FRCPC MSc
Founder and Director, Upstream Lab

Land Acknowledgement

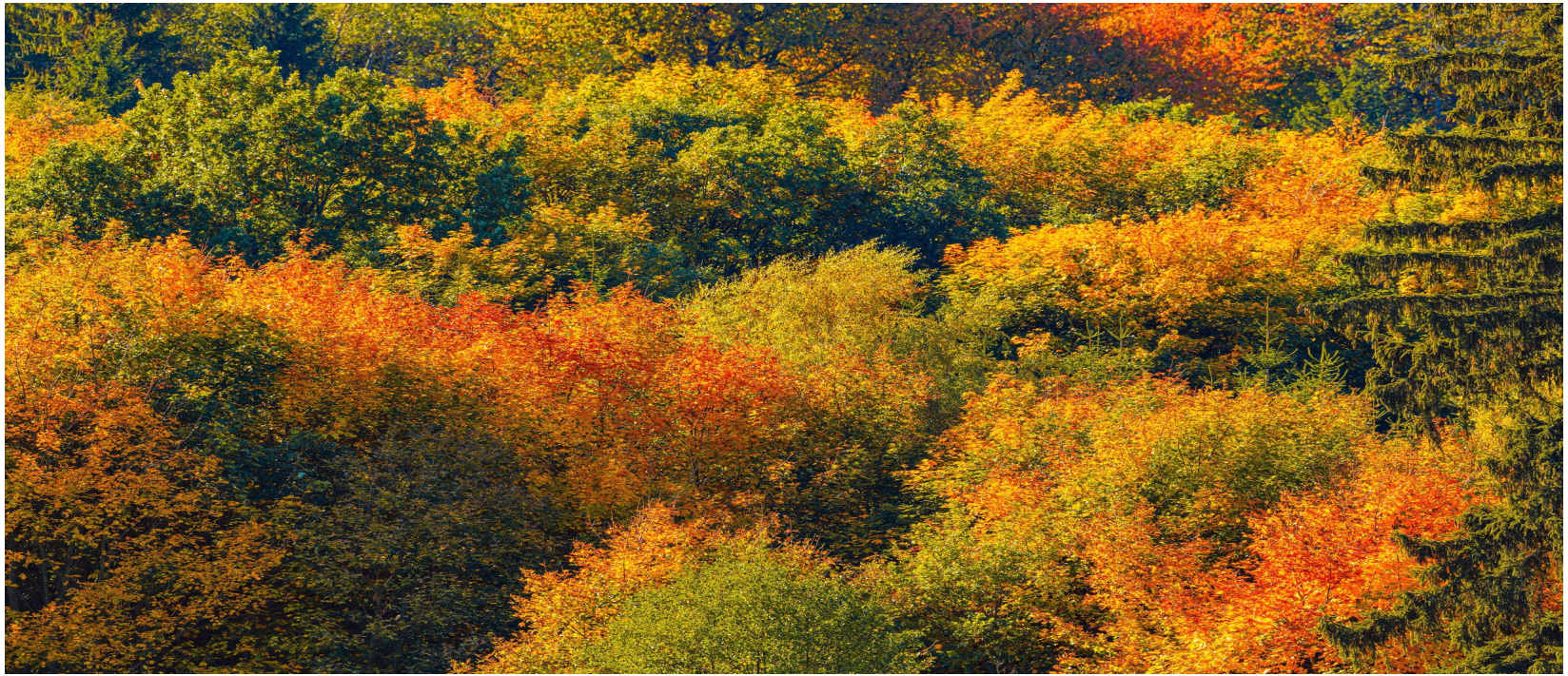


Photo by Petr Ganaj

Disclosures and Conflict of Interest

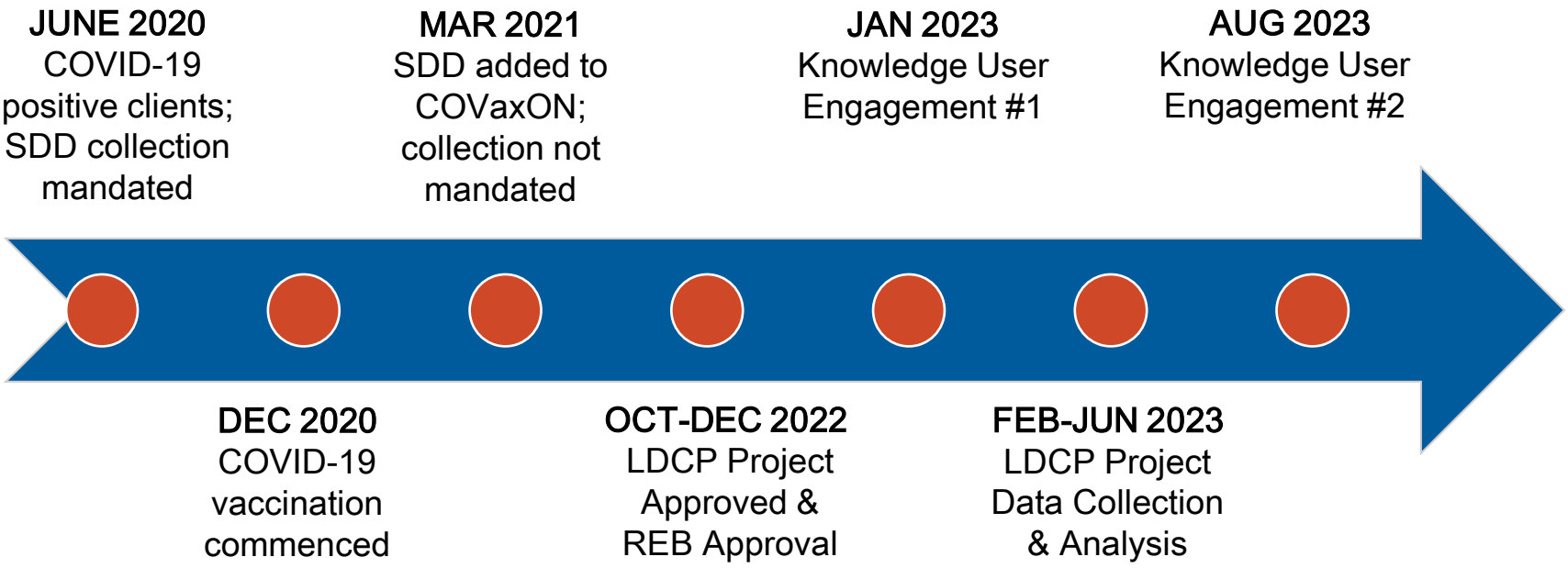
- There are no disclosures or conflict of interests to declare.

Learning Objectives

At the end of this session, you will be able to:

- Understand enablers to sociodemographic data (SDD) collection for PHUs during the COVID-19 pandemic
- Understand barriers to SDD collection for PHUs during the COVID-19 pandemic
- Consider the lessons learned from the application of SDD collection during COVID-19 to support ongoing SDD collection and reporting

Background & Milestones



Knowledge User Groups

Public Health Units	Community Partners	Health System Partners
• Middlesex-London Health Unit • Toronto Public Health	• **Peel:** Roots CS, Indus CS, Wellfort CHS, Punjabi CHS, CMHA Dufferin Peel, Dixie Bloor Neighbourhood Centre • **Ottawa:** Ottawa Local Immigration Partnership, Rideau-Rockcliffe CRC	• Canadian Institute for Health Information • Ontario Health • Ontario Ministry of Health (Indigenous, French Language and Priority Populations Branch) • Statistics Canada

Research Question & Objective

Research Question:

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

Objective:

Identify a set of recommendations for SDD collection based on identified enablers and barriers that PHUs can reference as they scale SDD collection beyond COVID-19-specific activities.

SDD Fields in CCM and COVaxON

- Official Language – English/French
- Language learned during childhood and still understand
- Racial identity
- Ethnicity (COVaxON only)
- Household income
- Number of people in household

Not full suite of sociodemographic data.

Results reflect PHU experience collecting this subset of data.

Methods

- **What did PHUs do?** (survey results; n= 34 PHUs)
  - Survey: Section I: SDD collection in COVID-19 Case Management (CCM)
  - Survey: Section II: SDD collection in COVID-19 Vaccine Clinics (COVaxON)

- **What were PHU experiences of SDD collection?**
  - Two Open-Ended Survey Questions
  - Focus Groups (n=16), and
  - Interviews (n=8)

Methods (2)

Analysis

- **Survey**
  - Descriptive analysis (frequencies) of responses related to collection completeness, and dissemination of SDD
- **Focus groups and Interviews**
  - Inductive and deductive analysis to identify themes

Participants

- Senior management (6)
- Middle management (18)
- Specialist, analyst, epidemiologist (20)
- Frontline staff (20)

Survey Findings
What did PHUs do?

Survey Findings (n=34)

	COVID-19 Case Management	COVID-19 Vaccination
How many collected?	**31 of 34 PHUs** • 24 began June 2020 (mandate + CCM) • 5 began prior to June 2020 • 3 did not collect	**18 of 34 PHUs** • 15 began March 2021 (COVaxON) • 2 began prior to March 2021 • 16 did not collect
Who collected?	Case Managers (PHNs, other) (31 PHUs)	Non-immunizers (13 PHUs)
When collected?	During first client interaction (23 PHUs) or as appropriate for client situation	Prior to vaccination (11 PHUs) or with nurse assessment or post vaccination
Monitored completion?	7 PHUs	8 PHUs
Shared SDD findings?	10 PHUs	2 PHUs
Overall SDD completion rates?	7 PHUs reported 0-25% 13 PHUs reported 26-50% 4 PHUs reported 51-75% completion	16 reported 0-25%

Qualitative Findings

What were the experiences of PHUs in SDD collection?

Enablers

Provincial Direction

Enablers

- Dedicated data system
- Legislative amendments

"…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...That was one success there that enabled us to do that."
(Participant, urban PHU, Epidemiologist-Analyst-Specialist peer group)

Organizational Practices

Enablers

- Support from senior management
- Staff buy-in
- Staff training
- Locally designed and delivered training modalities
- Early locally built data systems
- Virtual assistants

"I … know that our senior management… 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"
(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 train[ing] the staff that was doing this work."
(Participant, Urban health unit, Epidemiologist-Analyst-Specialist group)

Trust, Safety and Care During Staff-Client Interactions

Enablers

- Engagement and explanation of SDD collection contributed to trust building

“What we found is once clients understood why we were collecting the information they were pretty happy to provide it..." **(Participant, Urban Public Health Unit, Senior Management group)**

Learning from Community and other Jurisdictions

Enablers

- Early evidence of inequities from data elsewhere enabled prioritization of SDD collection

"We saw ..information from the US that was presenting information on disparities in COVID…….. We saw …. where migrant workers had disproportionate COVID. We were already hearing anecdotes about race, like certain South Asian population, other PSWs … 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."
(Participant, urban PHU, Senior Management peer group)

Barriers to SDD Collection

Factors Related to Provincial Data Systems

Barriers

- Burdensome to locate and input SDD
- Inability to collect Indigenous identity data in COVaxON

“So, I always remember the early days of CCM not being very user friendly... so, often times we would find that case investigators would miss it, if they weren’t following the procedure step by step…..."

(Participant, urban PHU, Frontline Staff peer group)

Organizational and Logistical Practices

Barriers

- Varying levels of prioritization across all management levels
- Lack of training and support for staff
- Surge periods
- Lack of engagement with local communities

"...Our medical officer of health is a big advocate of it, but … our middle management, it was not a priority for them"
(Participant (interview), urban PHU, Epidemiologist-Analyst-Specialist peer group)

"…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)

Challenges During Staff-Client Interaction

Barriers

- Some vaccine clinics lacked privacy
- Time pressures hindered rapport-building with clients
- Training and discomfort among external staff

"...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..."
(Participant, Rural unit, Epidemiologist-Analyst-Specialist)

Additional Staff Perceptions

Barriers

- Staff discomfort asking some SDD questions (e.g., income)
- Staff lack of understanding of the value of SDD collection

"The challenge I keep seeing over and over is staff and manager pushback... rooted in... implicit bias. I have some staff who were saying, I don't want to answer those questions, so nobody else will..." **(Participant - interview, urban PHU, Epidemiologist-Analyst-Specialist peer group)**

Barriers to Use

Provincial Direction

Barriers to use

- Vaccine-specific data sharing agreements limited PHUs ability to report on vaccination data externally

".. We were explicitly told … 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."
(Participant –Interview, urban, Senior Management peer group)

Organizational

Barriers to use

- Lack of personnel and the absence of a guiding framework impacted PHUs ability to analyze data

“Data is actually sitting there, so it was collected and wasn’t used. So, there’s even just also... 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, …..yet.“
(Participant, rural PHU, Epidemiologist-Analyst-Specialist peer group)

Data Quality Concerns

Barriers to use

- Concerns over data quality/ completeness 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)

Summary

Enablers of Collection

- Provincial direction
- Organizational practices
- Trust, safety, & care during staff-client interactions
- Learning from community and other jurisdictions

Barriers to Collection

- Factors related to provincial database
- Organizational and logistical practices
- Challenges during staff-client interactions
- Learning from community and other jurisdictions
- Additional staff perceptions

Barriers to Use

- Provincial direction
- Organizational
- Data quality concerns

Primary SDD collection as well as data linkages are needed to identify health disparities

The social determinants of health can be used to gain a deeper understanding of the population health needs of communities. Data can be used to examine various health outcomes (e.g., childhood obesity) from the perspective of social determinants of health (e.g., family income, family education level, etc.) and this information helps boards of health identify priority populations. Programs and services tailored to meet the needs of priority populations, policy work aimed at reducing barriers to positive health outcomes, and activities that facilitate positive behaviour changes to optimize health for everyone, are all important components of a program of public health interventions. By assessing the social determinants of health, boards of health have a better understanding of the impact of various social constructs within their communities, and are better able to plan programs and services that can help address health inequities. In some instances, there is sufficient data to demonstrate disparities in health outcomes for populations at the provincial level, such as Francophone and Indigenous communities.

Ontario Public Health Standards: Requirements for Programs, Services and Accountability (gov.on.ca)

Reflections and Implications

- Transformational change requires a burning platform and leadership
- Transformational change is required, but we are steps closer
  - Data collection challenges persist at the local/front line level that calls for centralization and structures to support
  - Need to normalize SDD collection as part of public health practice to ensure we do not inadvertently draw attention away from structural inequities
- There is momentum to build on successes and learnings and expand SDD collection in public health

Recommendations

System-Level

- Include SDD in seminal guidance documents; mandates for PHUs
- Establish a central program of supports
  - Standardize training
  - Build data systems with comprehensive standard suite of SDD
  - Centralize SDD collection efforts (where possible) and explore data linkages across the health care system
- Engage with population groups for data governance (e.g., OCAP; EGAD)
- Provide adequate resources for PHUs to collect, analyze and use SDD

Organization/PHU-Level

- Include SDD collection in organizational strategies
- Engage communities early to plan and implement
- Ensure dedicated resources to support SDD collection, analysis, and use
- Provide staff with comprehensive training before initiating SDD collection
- Provide ongoing support to staff throughout implementation
- Use data to tailor interventions to circumstances, contexts, and needs

What we heard from our Knowledge Users

What we heard:

- SDD collection might be new to PHUs, but it is not a new ask. We need to **acknowledge a history of inaction/insufficient action**.
- **Collection is not enough**. We need to learn about how PHUs used the data too ("the end is equity, not collection in and of itself").
- Collecting disaggregated data comes with risks. Leaders need guidance on the **appropriate trade-off between data, privacy and risk of stigma** but there are frameworks to support this.
- Importance of **standardization** (comprehensive data elements for collection, systems, concepts, etc.) across the health system is critical.
- Need to acknowledge that the **context in which we expanded SDD collection was in an emergency**.

Poll Question #2

How well do these findings reflect your or your organization's experience with collecting SDD?

1. Very well
2. Somewhat well
3. Not sure
4. Not very well
5. Not at all

Next Steps

- Distribution of LDCP deliverables through the COMOH and APHEO listservs
- Posting on PHO's LDCP webpage: https://www.publichealthontario.ca/en/Health-Topics/Public-Health-Practice/LDCP
- Continued engagement with knowledge user groups on ways to advance this work
- Resource guide coming – welcoming feedback

With Gratitude To:

- Health unit participants who shared their experiences with us and our clients, who we are asking for trust in collecting, storing and using personal information for health equity – to improve services for them and for everyone

- Our Knowledge User Groups for sharing valuable insights as we started this project and for their shared commitment to advance this work

- Our LDCP Project Team: Greg Kujbida, Laurie Dojeiji, Ikenna Mbagwu, Joseph O'Rourke, Segun Ogundele, Menna Komeiha, Shilpa Raju, Helen Stylianou, Sydnee Burgess, as well as Margaret Lebold, Dannielle Nicholson-Baker and Geil Astorga

- Public Health Ontario and the LDCP Initiative

Thank you