

April 28th, 2020

Dear Colleagues

As a concerned group of experts in health equity, we believe that the Province should urgently modify three types of forms in order to facilitate socio-demographic data collection during the COVID-19 pandemic. These forms are: COVID-19 test requisition form; the forms used by Public Health Units to capture the data they need to notify PHO of the details of those who test positive; and, the forms for application and renewal of OHIP cards. At a minimum, the modifications should include questions on race, ethnicity, gender identity, sexual orientation and language. An Indigenous-led group should advance Indigenous questions and Indigenous data governance and management.

The Province should ensure that standardised questions are used for data collection. The Province should ensure that data is collected, analysed and reported to improve the pandemic response and should ensure that the data are accessible so that communities can also analyse them.

The current state of socio-demographic data collection in Ontario's COVID-19 response is poor. Recent news that Toronto Public Health, Peel Public Health, York Region Public Health, and Middlesex-London Health Unit are all expanding their data collection to include race and ethnicity is welcome. Collection of socio-demographic data by all public health units would help the pandemic response, and more systematic forms of data collection would allow a comprehensive picture to be drawn.

It is usual during pandemics to collect data to identify risk factors for infection and risk groups. This helps to understand and monitor the reach and effectiveness of interventions, and to ensure we are making progress towards our goals. Though health services were not mandated to collect data in the legislation linked to the Data Standards for the Identification and Monitoring of Systemic Racism, this does not mean the collection of data by clinicians, institutions, public health or government is illegal. In fact, the need for collection of socio-demographic data including race and ethnicity is included in Ontario's Public Health Standards, it is also considered good medical practice and some hospitals and CHCs are already doing it.

There are many reasons why some parts of our population may be at greater risk from COVID-19 than others. For instance, current political responses have not fully factored in historical social inequalities, as well as the inability of some groups to follow public health guidance due to personal, community or workplace circumstances.

We also know from previous pandemics, such as influenza H1N1, that there can be racial and ethnic differences in infection that require focussed action. Analyses reported that the East and South East Asian populations in Ontario were 3 times, South Asian 6 times and Black populations 10 times more likely to be infected even after a raft of socio-demographic factors were taken into account. Indigenous peoples were also disproportionately impacted by H1N1, representing 30% of first wave hospitalizations and 20% of total mortality.

But this is a new virus and we do not know all the mechanisms which may produce disparities between groups. In Ontario, we have a higher number of positive tests in women and higher risk of hospitalization in men. We have seen outbreaks in older people in long-term care, homeless people in the shelter system and expect people with disabilities living in institutional settings to be at high risk. Some USA cities have reported African Americans are twice as likely to be COVID-19 positive and twice as likely to die. The UK has seen 80% increase rates of infection in Black and Minority Ethnic Groups. In that country 68% of health service staff and all the doctors who have died are racialized. These findings argue strongly that identifying risk groups, and developing strategies to decrease their infection rates is one of the more important next steps in the COVID-19 response.

Socio-demographic data helps us to identify, monitor and develop strategies to address the impacts of COVID-19 within our most marginalized communities. This paper offers some options on socio-demographic collection for the Ontario COVID-19 response from leaders in the field.

Of course, socio-demographic data collection is as good as its implementation and the political will behind it. Past difficulties in implementation in the Canadian context should be taken with a pinch of salt. We have seen things that no-one thought were possible become possible in this pandemic. When there are clear compelling reasons for data collection and analysis, clinicians and public health units are more likely to deliver.

Our COVID-19 response is as strong as its weakest link. If one part of our community is not doing as well as others, then our ability to flatten the curve and keep everyone safe is compromised.

Yours sincerely

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Collection of Sociodemographic Data for COVID-19 Response in Ontario Options for Consideration

Data on socio-demographic variations in COVID-19 testing, incidence, hospitalization and mortalities is urgently needed by health system, social service and community partners to inform situational awareness, immediate action, and the design of targeted supports for marginalized communities. The gold standard for those who are ill, is for socio-demographic data to be systematically collected as part of all patients' health records. CHCs currently do this as do some hospitals. Clinicians and institutions should be reminded that this is good practice.

The purpose of this paper is to outline additional recommendations for provincial socio-demographic data collection in response to the COVID-19 pandemic.

In order to provide a fuller picture of the impact COVID-19 our main recommendation is a three-pronged strategy to augmenting existing data collection forms to include key socio-demographic variables.

A) Modification to include socio-demographic data collection in existing tools

We currently collect, age, sex and postal code data. Postal code data has been used to identify regions and areas most in need. Ontario has accepted that resources may be targeted at more needy areas. Previous pandemics have shown that geography does not give a full picture of need. It does not adequately measure income, socio-economic or risks linked to employment. In addition, some racialized groups, ethnic groups and Indigenous peoples are at increased risk even when area level factors are taken into account. We propose modification of three types of forms:

- I. COVID-19 Virus Test Requisition Form from Public Health Ontario. This information would be collected by the clinician submitting the requisition. Collection at this point is important to ensure the broadest possible capture of the population (positive and negative tests) from all care settings where testing may be ordered (e.g. hospital, assessment centres, long-term care facilities, etc.).
- II. Forms used for input of information into the integrated Public Health Information System on people who have tested COVID-19 positive. This information would be collected by public health professional completing contact tracing protocols. We note that Peel has a pilot scheme which has been collecting expanded data for three weeks, that Toronto Public Health has modernised their CORES system to include socio-demographics in COVID-19 cases, and, that Middlesex-London

and York Region Public Health Units have their own protocols for expanded socio-demographic data collection. The Province should ensure that all public health units collect data in the same way so that they can form a single data set that can be used for analyses.

- III. OHIP registration form. This information would be submitted as part of the form to renew or register for OHIP. While this information may not be collected quickly enough to inform current COVID-19 responses, it could lay the foundation for high quality, representative data to measure inequities at the population-level. This method would ensure the greatest opportunity for individuals to self-identify and would ensure that data is available to the broadest range of stakeholders.

In order to support feasibility of collecting additional information, we propose a minimum list of a streamlined set of questions be asked including race, ethnicity, gender identity, sexual orientation, and language. Race and ethnicity based data will allow us to monitor discrimination, identify and remove systemic barriers, address historical disadvantage and promote substantive equality. The list of questions could be expanded where feasible to collect more accurate socio-economic and socio-demographic data.

We also recommend an Indigenous led, Indigenous specific working group, comprised of First Nations, Inuit, Métis, and urban Indigenous organizational leaders and Indigenous scholars with content expertise to advance Indigenous questions and Indigenous data governance and management.

The modification of these types of forms allow us to collect accurate data which would ensure an optimal COVID-19 response. But, while these data are being collected in sufficient amounts to analyze, we can improve our understanding of disparities by using data we already have.

B) Maximize value of existing socio-demographic data

This includes an analysis of COVID-19 cases stratified by age, sex, and postal code to undertake an area-based analysis of the socio-demographic data collected by the Census or related indices. Postal code could be used to map cases of COVID-19 by geography. In areas of high population density where population size permits, data on COVID-19 patients should be reported at the most granular-level of geography possible (e.g., at the neighbourhood-level in the City of Toronto). Analyses should be quickly and broadly disseminated to communities and health system partners to inform their COVID-19 responses. However, it should be clear that there are limitations to the utility of these analyses.

There is an opportunity to pursue linkage of COVID-19 positive tests or hospitalizations in Toronto to existing socio-demographic data held by CHCs and other primary care organizations. CHC's are currently collecting sociodemographic data and have a data collaboration agreement with ICES. CHC's could then submit their sociodemographic data and COVID-19 data to be analyzed. Data from Ontario's primary care research networks (e.g. the University of Toronto Practice-Based Research Network [UTOPIAN]) are also now linked at ICES, and several members have been collecting sociodemographic data.

It is important to provide researchers with access to the data, and an ability to publicly report analysis on COVID-19 patients, such as linking COVID-19 positive tests or hospitalizations to Immigrant Refugee Citizenship Canada immigrant data base. Given the nature of approval processes through ICES an expedited process to account for use of data around monitoring and surveillance

will be needed that addresses the 1-3 year time-frame for uploads of ICES managed databases. Communities and community based researchers should have access to these data at as granular a level as possible without sacrificing confidentiality. This improves the breadth and quality of analyses available for policy decisions and it improves engagement.

It is vital to ensure that Indigenous-identified COVID-19 data be collected, accessed and used in ways that respect Indigenous data governance principles and guidelines on ethics in research. With respect to ICES data holdings and Indigenous populations there is an existing platform of Indigenous and allied researchers and First nations, Inuit, Métis, and Indigenous health service policy partners that provides a strong basis for moving forwards.

C) Additional considerations

We offer a brief series of recommendations to ensure that sociodemographic data is collected, analyzed, report, and actioned in ways that do not further stigmatize marginalized communities. The Province's Data Standards for the Identification and Monitoring of Systemic Racism offers in depth guidelines.

In brief, the best data are those which are self-reported so that patients are able to self-identify their race and other identities.

The use of the data should also be explained and clarified to ensure patients understand the importance of why it is being collected. In addition, patients should be provided with resources that answer questions around data collection. These resources should be independent of the Ministry, hospital or university.

Training for the data collectors can be useful to ensure that the importance of data collection and the reasons for data collection are clearly understood and so that questions are asked in a consistent, accessible, and purposeful way to ensure quality.

Consultation with communities can be useful on options for not only data collection, but analysis, linkages and reporting, to prevent unintended consequences such as further stigmatization of vulnerable populations. This consultation needs representation from diverse communities to accurately identify and interpret nuances within the data that could lead to improved health outcomes.

Best practice is for data collection to be pursued in parallel with accountability to share how it is used with the communities. There is also a need to ensure that data collection is tied to a meaningful and deliberate plan for acting on that data, including any inequities or gaps that are identified. These plans should be informed and endorsed by the communities for which they directly impact.