

DATA COLLECTION RESOURCE

Introducing Race, Income, Household Size, and Language Data Collection: A Resource for Case Managers

Purpose

This document provides information to support case managers' use of new integrated Public Health Information System (iPHIS) fields for the collection of socio-demographic data from individuals who test positive for COVID-19; socio-demographic variables include race, income, household size, and language. This resource includes a sample script that can be used for data collection, tips for case managers, frequently asked questions, as well as background information. It should be used in conjunction with other relevant guidance documents (e.g., iPHIS User Guides), organizational policies, and legislation.

Experience in a Canadian health setting suggests that people are open to answering socio-demographic questions if they understand why the data are being collected and that providing the information will not negatively impact treatment or access to services.¹

Data collection tip

- Ask questions on race, income, household size, and language toward the end of your conversation or interaction since you will have started building a rapport with the client.

Script

Why we are asking

As part of Ontario's provincial management and response to COVID-19, [name of Public Health Unit] is collecting information on race, income, household size, and language from people who test positive for COVID-19 or are considered a probable case. There are five questions so this should only take a few additional minutes.

Collecting this information will help us monitor and understand which communities are being impacted by COVID-19. With this information, we will be able to:

- Respond to specific community needs; and
- Better plan public health programs and other services and supports.

I'm happy to answer any questions you may have. If you choose not to answer these questions it will not affect your access to services.

Questions

RACE²

The first question is about race. In our society, people are often described by their race or racial background. For example, some people are considered “White” or “Black” or “South Asian.”

Which race category best describes you? Select all that apply from the options I will read out:

[Additional instructions for interviewer: You can use ‘description/examples’ when clients need guidance or help]

| Race categories | Description/examples |
|-----------------------|--|
| Black | African, Afro-Caribbean, African-Canadian descent |
| East/Southeast Asian | Chinese, Korean, Japanese, Taiwanese descent Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent |
| Latino | Latin American, Hispanic descent |
| Middle Eastern | Arab, Persian, West Asian descent, e.g. Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish, etc. |
| South Asian | South Asian descent, e.g. East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean, etc. |
| White | European descent |
| Another race category | Another race category (Optional: allow write-in response) |
| Do not know | |
| Prefer not to answer | |

Data entry instructions: Please see the COVID-19 iPHIS Data Entry guide³

INCOME⁴

Income can come from various sources such as from work, investments, pensions or government. Examples of income include your pay, Employment Insurance, Social Assistance, Child Tax Benefit and other income such as child support, spousal support (alimony) and rental income.

1. What was your total household income before taxes in 2019? Select one from the list of income ranges I will read out:

[Additional instructions for interviewer: Clients should include all members of the household in the total and can use a rough estimate if it helps with the response]

- 0 - \$29,999
- \$30,000-\$49,999
- \$50,000-\$69,999
- \$70,000-\$99,999
- \$100,000-149,999
- \$150,000 or more
- Do not know
- Prefer not to answer

We also know that income is impacted by the number of people supported by that income. The more people, the more stretched the income will be. So as part of asking about your income⁴, can you let us know...

2. Including yourself, how many family members live in your household?

- _____(people)
- Do not know
- Prefer not to answer

Data entry instructions: Please see the COVID-19 iPHIS data Entry guide³

What we know (information for the interviewer):

- These wider income ranges increase client comfort by improving their sense of privacy while providing us with information we can use in many ways, such as identifying poverty and comparing income groups.
- Capturing a numerical response for income will allow us to compare health outcomes based on income ranges, a significant goal of these data collection activities.

LANGUAGE⁵

We know that language barriers can impact people's experiences when accessing health services and other programs. In order to understand language profiles of our clients/patients, we are going to ask you two questions on language.

1. **What is the language that you first learned at home in childhood and still understand?**

- Drop down list of languages already in iPHIS
- Do not know
- Prefer not to answer

2. **In which of Canada's official languages, English or French, are you most comfortable?**

- English
- French
- Both English and French
- Neither
- Do not know
- Prefer not to answer

Data entry instructions: Please see the COVID-19 iPHIS Data Entry guide³

What we know (information for the interviewer):

- Research on the impact of language barriers provides compelling evidence about its negative impact on client/patient experience, on care provision, and on outcomes⁶
- In Ontario, research has found that language barriers can pose a significant issue for healthcare in multiple municipalities particularly as immigration continues to increase⁷

Frequently Asked Questions by Clients

Q1. Is it legal for me to be asked me these questions? Isn't it racist?

Yes, it's legal. The data are collected under the authority of the *Personal Health Information Protection Act* (PHIPA).⁸ We know from research in Canada and other places that we cannot fully understand people's health without knowing more about who they are.

Q2. Who will see my information? How will my privacy be protected?

Access to this information is protected by privacy legislation; specifically, the Personal Health Information Protection Act, 2004 (PHIPA). This information is used by the local public health unit and also reported to the Ministry of Health and Public Health Ontario as per Ontario Regulation 569 of HPPA. Data will be stored in a secure government data centre and will only be used and disclosed as permitted or required by law. Any information reported publicly will be combined with information from many other people and all personal or identifying information (i.e., information that could identify your own answers) will be completely removed.

Q3. What does race/ income/language have to do with COVID-19 infection?

Race, income, and language impact communities in all areas of life. These areas include day-to-day interactions (such as in providing health care) and structures (such as the impact of colonialism on health systems that exclude Indigenous practices). For example, in Ontario neighbourhoods with higher ethnic concentrations have higher percentage of confirmed positive COVID-19 tests and over twice the hospitalization rate compared to those with lower ethnic concentration.

With more data we will be able to understand and track what is happening here in Ontario and be in a better place to address it.

Q4. Why are you asking me 'how many family members live in your household'? What does it mean?

We know that information on income alone will not tell us enough about the ability to afford medication, daycare, food, and other essentials. That's because supporting more people with a certain income makes it harder to ensure everyone has the essentials they need. Looking at household number is a very common way to calculate the number of people being supported by the reported income. We acknowledge this still does not capture some issues, such as individuals supported outside the household with this income.

Q5. How will you use this information?

Our first goal is to understand what is currently going on with regard to COVID-19 risk and race, income and language, so collecting information from you and others will help us form that picture. This information will allow us to assess who is at higher risk for COVID-19 infection and severe disease based on factors such as race and income. This information will also help us put services and supports where they are needed most and work on addressing the inequities that lead to increased risk. Ultimately we can do more of what is working, and less of what is not working.

Q6. What if this information is used to discriminate against me? Or to stereotype my community?

We know that these concerns are important and reflect the experiences of many communities. They are also the reason we are collecting this information. Individual privacy will be protected by privacy legislation, specifically the *Personal Health Information Protection Act, 2004*. When we are using and analyzing this information, the goal will be to use a human rights approach to understand the results and highlight the impacts of discrimination and racism.

Q7. Why aren't you collecting data on Indigeneity or Indigenous identity?

To address health inequities faced by Indigenous Peoples, the Ministry continues to work with Indigenous partners to identify whether and how collecting information about Indigenous identity will lead to meaningful change in program and service delivery and health outcomes.

References

1. Pinto AD, Glattstein-Young G, Mohamed A, Bloch G, Leung F-H, Glazier RH. Building a foundation to reduce health inequities: routine collection of sociodemographic data in primary care. *J Am Board Fam Med.* 2016;29(3):348-55. Available from: <https://doi.org/10.3122/jabfm.2016.03.150280>
2. Ontario. Legislative Assembly. *Data standards for the identification and monitoring of systemic racism.* Order in Council 897/2018. Available from: <https://www.ontario.ca/page/anti-racism-data-standards-order-council-8972018>
3. Ontario Agency for Health Protection and Promotion (Public Health Ontario). COVID-19 iPHIS data entry guide. Toronto, ON: Queen's Printer for Ontario; 2020.
4. Wray R (DGL Consulting), Agic B (Centre for Addiction and Mental Health), Bennett-AbuAyyash C (Mount Sinai Hospital), Kanee M (Mount Sinai Hospital), Lam R (Toronto Public Health), Mohamed A (St. Michael's Hospital), et al. We ask because we care: the Tri-Hospital + TPH health equity data collection research project report [Internet]. Toronto, ON: Mount Sinai Hospital; 2013 [cited 2020 May 8]. Available from: http://www.mountsinai.on.ca/about_us/health-equity/measuring-health-equity/we-ask-because-we-care-complendum-september-2013/index.html
5. Statistics Canada. Table A: language characteristics: concepts, questions asked and surveys in which they are found [Internet]. Ottawa, ON: Her Majesty the Queen in Right of Canada; 2015 [archived; cited 2020 Jun 29]. Available from: <https://www150.statcan.gc.ca/n1/pub/91-549-x/2013001/t/tbla-eng.htm>
6. Bowen S. The impact of language barriers on patient safety and quality of care: final report prepared for the Société Santé en français [Internet]. Ottawa, ON: Société Santé en français; 2015 [cited 2020 Jun 29]. Available from: <https://www.reseausantene.ca/wp-content/uploads/2018/05/Impact-language-barrier-qualitysafety.pdf>
7. Sears J, Khan K, Ardern CI, Tamim H. Potential for patient-physician language discordance in Ontario. *BMC Health Serv Res.* 2013;13:535. Available from: <https://doi.org/10.1186/1472-6963-13-535>
8. *Personal Health Information Protection Act, 2004, SO 2004, c 3, Sched. A.* Available from: <https://www.ontario.ca/laws/statute/04p03/v34>

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