
FAQ for ICES scientists, staff & trainees

About the Guidance Document and Framework

Where should I direct questions related to the Guidance Document and Framework?

Please direct questions regarding the [Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics at ICES](#) to the Public Engagement and Knowledge Translation Office at ICES (public@ices.on.ca).

If you have specific feedback regarding the contents of the Guidance Document and Framework, please feel free to submit comments using the [continuous feedback form](#). Comments and feedback will be considered for incorporation in future iterations of the document.

Why were the Guidance Document and Framework created?

The [Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics at ICES](#) was created with an aim to promote ICES research and analysis that improves health equity and avoids perpetuating the harm and stigma experienced by racialized communities.

The COVID-19 pandemic disproportionately affected racialized and immigrant communities and contributed to the widespread acknowledgement that not only is race a social construct, but that racism and discrimination reinforce racial inequalities in healthcare and health.

ICES holds data on race, ethnicity, and immigration (i.e., “race and related data”), but these data are limited, and not all are at an individual level or self-reported. Despite a strong desire on the part of ICES staff and the broader ICES science community to use these data appropriately, concerns have been raised by racialized community members and equity experts regarding certain practices related to use of the data. There also is a growing desire to see these data used responsibly, including with engagement with racialized communities. In 2021 the Black Health Equity Working Group released [the Engagement, Governance, Access, and Protection \(EGAP\) framework](#) describing their recommendations for the governance, collection, management, analysis, and use of data from Black communities.

Who should read the Guidance Document and Framework?

This [Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics at ICES](#) outline the key actions ICES is taking toward establishing an anti-racist research agenda and appropriate use of race and related data across the organization. The document is not prescriptive in how the ICES science community should use race and related data, but rather, represents one step in a larger process to improve practice and encourage reflection on research on how racial health inequities have resulted from racism, discrimination, and related social determinants. The shift from ‘race’ to ‘racism’ is one that will look different in each ICES project, and we encourage ICES scientists, staff, and trainees to begin by reviewing the Guidance Document and Framework to understand and appreciate the organizational changes that will be undertaken to help support this shift in perspective.

Does this document provide guidance on the use of Indigenous Data at ICES?

ICES has developed distinct approaches and policies for Indigenous (First Nations, Inuit, and Métis [FNIM]) data governance in partnership with Indigenous leadership organizations, and we work directly with Indigenous

partners to ensure appropriate data use. This work with FNIM partners has highlighted the importance of establishing community-led governance of race and related data. Ultimately, these approaches were critical in informing the Guidance Document and Framework, but, given their distinctness, this Document intentionally does not discuss Indigenous identity or data with Indigenous identifiers. Information on Indigenous data and Indigenous data governance can be found on the ICES [Indigenous Partnerships, Data and Analytics webpage](#).

Does this guidance apply to third party research through Data and Analytic Services (DAS)?

The Guidance Document and Framework will be shared with non-ICES researchers using ICES data, along with information regarding the data holding obligations that relate to the data they are using. If race and related data are used, the project kick-off meeting will include discussion of how the data will be used, interpreted, and disseminated appropriately to minimize harm. ICES staff working on DAS projects will reinforce these requirements at the time of publication and share [applicable ICES resources to support proper reporting](#).

About Race and Related Data at ICES

What data do ICES currently hold related to race, ethnicity, and immigration?

The Guidance Document and Framework include a link to an [inventory of race and related data within the ICES repository](#). This inventory of existing race-related data sources, data elements and the source of the race information (i.e., whether it is self-reported, socially-assigned by a health care provider, or algorithmically-derived) will be updated annually in the ICES data dictionary. Specific considerations for these datasets are beyond the scope of the Guidance Document and Framework, but commonly asked questions about more frequently used datasets are addressed in this FAQ sheet, below.

What are the expectations of scientists and project teams when using race and related data?

We encourage continued use of the data available at ICES with increased attention to:

- Promoting health equity
- Naming and acknowledging racism
- Avoiding misinterpretation, harm, and further stigmatization of identified communities
- Meaningfully engaging members of the communities identified to better contextualize data use and potential findings in a respectful and honest way
- Emphasizing that self-reported data on race and ethnicity are the gold standard but are not always available or feasible

The community-informed principles for appropriate use of race and related data within the Guidance Document and Framework are a starting point for how to apply anti-racist research practices to your ICES project. We have also created a [guide to understanding community engagement](#) as well as an intranet page of other [resources, trainings, and tools related to health equity](#). We encourage scientists and project teams to reflect on their positions, research methods, and ways they can use and report on race and related data appropriately with community needs in mind.

In the analysis and interpretation of any data, consider social determinants of health, systemic/institutional racism, and intersections/interactions between other key disaggregated factors such as sex, income, immigration, recency of immigration, and/or immigrant categories.

What considerations and recommendations are relevant to using IRCC CIC?

IRCC CIC includes variables related to immigration status, country of birth and country of origin. The recommendation is to not use these variables as a proxy for race or ethnicity. Many racialized people in Ontario will not be accurately classified if using country of birth/origin as a proxy for their race or ethnicity. Furthermore, immigrants who landed in other provinces and then moved to Ontario will be in the Registered Persons Database but will not be identified as immigrants.

As such, when reporting on immigration status and country of birth/origin, take care to avoid conflating these variables with race or ethnicity. Consider labelling the “non-immigrant” category “Canadian born/long-term resident”, as the “immigrant” data are only for immigrants and refugees who landed from 1985 onwards. When appropriate, subclassifying “immigrant” classification is encouraged to better contextualize the data: incorporate information on immigration category (e.g., refugee, economic immigrant), socio-demographics (e.g., country of birth/origin, neighbourhood income), and other information (e.g., recency of landing, language).

What considerations and recommendations are relevant to using SURNAMES?

The SURNAMES dataset is derived by applying validated lists of South Asian and Chinese surnames to the raw Registered Persons Database (RPDB), which includes surnames to assign an ethnicity of “South Asian,” “Chinese,” or “general population” to all Ontario residents. The “general population” includes both people with European origins and those from all racial/ethnic groups not identified by surnames. The assignment of South Asian and Chinese surnames represents only a portion of individuals from those ethnic groups and does not capture the totality of religious and cultural groups from these regions. Those using the dataset to identify individuals who are South Asian and Chinese should therefore be aware of the misclassification bias given its positive predictive value (89% for South Asians, 92% for Chinese) and sensitivity values (50% for South Asians; 80% for Chinese).

SURNAMES should used only to define an exposure variable or for cohort formation. Due to its high specificity but low sensitivity, the dataset is not appropriate to define ethnicity as a baseline descriptor or adjustment variable in isolation.

In any reports or manuscripts resulting from these data, research teams should acknowledge that the data provided by the SURNAMES dataset are proxy variables and not self-reported ethnicity data. Research teams should also indicate the sensitivity and specificity of the SURNAMES dataset, that cohorts identified are subsets of certain ethnic communities, and that observations cannot necessarily be extrapolated for entire ethnic groups. Research teams should avoid broad biological or cultural generalizations as explanations for observations using the SURNAMES dataset, as individuals in the cohort identified by the dataset are diverse and can display mixed ancestry, cultural backgrounds, and immigration patterns.

In your analysis and interpretation of the data, consider social determinants of health, systemic/institutional racism, and intersections/interactions between other key disaggregated factors such as sex, income, immigration, recency of immigration, and/or immigrant categories.

What considerations and recommendations are relevant to using CCM?

Race information in CCM was self-reported to Public Health Unit staff and was not mandatory for collection, so is incomplete. Public Health Ontario discontinued collection of race data as of March 31, 2023.

Why are 'self-reported' race data considered the 'gold standard'?

Self-reported race data (i.e., individuals identifying their own race) are generally considered the gold standard. This respects individuals' lived experiences and acknowledges that self-identity can change over time and across contexts. However, there are situations where socially-assigned race (i.e., race classification imposed on a person by others) offers value: it can be an appropriate proxy for experiences of racial discrimination (e.g., differential treatment by care providers). It is important to note that caution should be taken when combining more than one data source on race and ethnicity, even if it is self-reported. For example, national, self-report surveys do not measure one distinct concept and may use a combination of racial, cultural, and ethnic categories as response options. [The inventory of race and related data within the ICES repository](#) identifies which data holdings contain self-reported race data.

May I bring in project-specific data that contain race-related data elements?

Yes. If collecting and/or importing race-related data, ICES recommends adherence to best practices for anti-racist research (as outlined in the Guidance Document and Framework and the ICES intranet page of [resources, trainings, and tools related to health equity](#)).

If external data partners are involved, ICES will adhere to their data governance policies and procedures, as applicable.