# ICES Peoples' Panel

## SUMMARY REPORT

Principles and Recommendations for Community-Driven, Anti-Racist Use of Race, Ethnicity and Immigration Data at ICES

OCTOBER 2021

## About ICES

ICES is an independent, not-for-profit research institute made up of a community of research, data and clinical experts. We work with Ontario's health-related data and aim to inform health system policy and planning to improve the health of all Ontarians. Our organization receives core funding from the Ontario Ministry of Health.

## What do we do?

ICES leads cutting-edge studies that evaluate health care delivery and outcomes. Since 1992, the Ontario government has entrusted ICES with securing and analyzing its residents' health information. Our researchers access a wide range of health-related data, including population-based health surveys, anonymous patient records, and clinical and administrative databases. ICES is recognized as a leader in maintaining the privacy and security of health information. Our mission is translating data into trusted evidence that makes policy and health care better and people healthier.

## ICES Sites

The ICES network is spread across seven sites in Ontario, which includes universities and academic health science centres. These sites enable scientists to access ICES data holdings from remote locations, while promoting closer connections with local organizations and communities.

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Reference: ICES Peoples' Panel. *Principles and Recommendations for Community-Driven, Anti-Racist Use of Race, Ethnicity and Immigration Data at ICES. Summary Report*. Toronto: ICES; October 2021

# Overview

For many years, racialized communities, equity organizations and health equity experts have been asking that race data be collected and used in a responsible, community-driven manner. However, race and ethnicity data have not been routinely collected in Canada’s heath care system in the past, limiting the ability to examine racism as a determinant of health. In 2020, the interest and calls from community leaders and public health experts intensified due to the disproportionate impact of COVID-19 on racialized, ethnic and immigrant communities. Several public health units in Ontario, including Toronto, Peel and London-Middlesex, began collecting race data with their COVID-19 positive cases in an effort to address health inequities in their pandemic responses. The Ministry of Health later mandated the collection of race data in relation to all COVID-19 positive cases and vaccine recipients in Ontario.

As the focus on the need for race and ethnicity data increased in Ontario and more widely, the importance of collecting and using these data in a responsible manner has been highlighted by communities, human rights advocates, equity researchers and groups advocating for an anti-racist approach. Though these data are limited, ICES’ data repository contains race or race-related variables that can be accessed for research projects and ICES is likely to receive more of these data from the Ministry of Health and other data partners in the future. In addition, concerns have been raised about certain practices related to the use of immigration data held at ICES and algorithms created to assign race and ethnicity variables in research.

Several health and research institutions in Ontario have existing race data standards or are in the process of developing them. One group of health equity experts called the Black Health Equity Working Group created the EGAP (Engagement, Governance, Access and Protection) Framework to provide guidance on the governance of health data collected from Black communities. The EGAP framework has influenced the work of many Ontario-based groups involved in health equity initiatives.

Over the past year, ICES has been on a journey to learn and reflect on the use of race, ethnicity and immigration data in ICES research and respond to these calls and requests. This work has evolved to be about more than data; instead, we aim to leverage ICES’ role as data steward and research institute to address systemic racism in health care and promote health equity. ICES’ 2020/21 strategic plan redefines our vision towards “improved health and health care for everyone through world-leading research and analytics” to demonstrate that health equity is foundational to our work. ICES recognizes the global and national impact of colonization and the role of data in decolonizing health research and dismantling systemic racism. The Indigenous Portfolio at ICES has built partnerships with communities and governance organizations to guide Indigenous data governance and our learnings have provided inspiration for how to approach this work. As such, ICES is developing a framework to guide the appropriate use and governance of race and ethnicity data in health research and support an anti-racist research agenda.

## The Peoples' Panel

ICES worked with the Tamarack Institute and the Digital Justice Lab to lead a Peoples' Panel on how race and ethnicity data should be used for health data research. Through this Peoples' Panel, ICES sought to hear directly from members of the public, specifically those who identify as racialized, to understand their priorities and values for how these data are used and interpreted. ICES is striving for community-driven and community-informed anti-racist use of race, ethnicity and immigration data. The Peoples' Panel was ICES' initial step towards community engagement in the development of the framework.

Panelists shared what matters most to them about the use of race, ethnicity, and immigration data. They provided feedback and refined a series of guiding principles for how race and related data should be used in research. The Peoples' Panel also generated recommendations for specific scenarios related to ICES' processes for data acquisition, access, use and interpretation and how these data should be used to better support communities, reduce health inequities, and not perpetuate racism or anti-immigration sentiments.

The outcome of the Peoples' Panel, and what is outlined in this summary report, is a set of principles and recommendations that will contribute to the creation of an ICES Race and Ethnicity Data Framework. The Peoples' Panel's principles and recommendations have formed the foundation of ICES' internal and external dialogues to develop the framework and are one key input along with other health equity and community consultations. ICES' internal team has begun to reflect on how to best address the recommendations in the organization's policies and operations.

## DEFINITIONS

### Race

Race is a term used to classify people into groups based principally on physical traits (phenotypes) such as skin colour. Racial categories are not based on science or biology but on differences that society has created (i.e., "socially constructed"), with significant consequences for people's lives. Racial categories may vary over time and place and can overlap with ethnic, cultural or religious groupings.

### Ethnic groups

Refers to a person's ethnic or cultural origins. Ethnic groups have a common identity, heritage, ancestry, or historical past, often with identifiable cultural, linguistic, and/or religious characteristics.

### Systemic racism

Systemic racism consists of organizational culture, policies, directives, practices or procedures that exclude, displace or marginalize some racialized groups or create unfair barriers for them to access valuable benefits and opportunities. This is often the result of institutional biases in organizational culture, policies, directives, practices, and procedures that may appear neutral but have the effect of privileging some groups and disadvantaging others.

*Definitions provided by Ontario Anti-Racism Directorate*

# About the ICES Peoples' Panel

### What is a Peoples' Panel?

A Peoples' Panel is a group of people composed of members of the public, brought together to discuss, investigate, or decide on a particular matter. This Peoples' Panel was convened to guide ICES' approach on the use of race, ethnicity and immigration data at an institutional level. For the ICES Peoples' Panel, diverse individuals from across Ontario were recruited through an open call. We sought out people who identified as racialized and who had an interest in how race data is used —no experience in health, science or policy was needed. Participants were compensated.

### Peoples' Panel Process

The Peoples' Panel met weekly for five weeks starting on March 17, 2021. These sessions were hosted on the Zoom platform together with a virtual whiteboard platform called Mural.

**Session 1 – Wednesday, March 17, 6:30-8:30pm**

Orientation and introduction to the use of health data at ICES

**Session 2 – Wednesday March 24, 6:30-8:30pm**

What principles should govern the use of race and ethnicity heath data at ICES?

**Session 3 – Wednesday March 31, 6:30-8:30pm**

Use-Case Scenarios: How might these principles be implemented in each phase of the data pipeline?

**Session 4 – Wednesday April 7, 6:30-8:30pm**

Peer feedback session on use-case scenarios and generation of recommendations.

**Session 5 – Wednesday April 14, 6:30-8:30pm**

Finalizing recommendations on the use of race and related data for health data research at ICES

### Level of Influence and Outputs

Topics being discussed were still at the formative stage at ICES. The Peoples' Panel was convened early in this process to advise and inform ICES's work and research.

The two key outputs from this Peoples' Panel are community-supported principles and scenario-based recommendations to guide the ethical and appropriate conduct of studies using race, ethnicity, and immigration data.

*Please note that ICES has a dedicated Indigenous portfolio which guides Indigenous data governance.*

### Peoples' Panel Member Profile

**26** identify as Black (e.g., African, Afro-Caribbean, African-Canadian descent)

**17** identify as South Asian (e.g., East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean)

**6** identify as East/Southeast Asian (e.g., Chinese, Korean, Japanese, Taiwanese descent; Filipino, Vietnamese, Cambodian, Thai, Indonesian)

**4** identify as Indigenous - First Nations, Métis, Inuk/Inuit

**4** identify as Latino (e.g., Latin American, Hispanic descent)

**3** identify as Middle Eastern - Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish)

**7** identify as White (European descent)

**27** currently work in the healthcare system

### Facilitation Team

**Jenine Paul,** Manager, Public Engagement and Knowledge Translation, ICES

**Bidjinie Coriolan**, Public Engagement and Knowledge Translation Officer, ICES

**Lisa Attygalle**, Consulting Director, Community Engagement, Tamarack Institute

**Nasma Ahmed**, Director, Digital Justice Lab

# Principles

ICES is developing overarching principles as a core component of their Race & Ethnicity Data Framework to guide the ethical and appropriate conduct of studies using race, ethnicity, and immigration data. These principles are intended to reflect community voices, literature and best practices for how race and related data should be used in research.

The following principles were initially formed based on a literature review conducted by members of the ICES Race & Ethnicity Data Framework team. They were then put forward to the Peoples' Panel for their feedback through two rounds of modifications. The principles below are now considered to be community-informed and are organized based on values that were defined by the Peoples' Panel. These principles will continue to evolve and will influence ICES' framework and the activities and approaches for how race and related data are used in research.

*In the following principles, the term "race data" is used to simplify the text and refers to race and related data, including race, ethnicity, and immigration data **

## Transparent and Representative Data Collection

- Data collected by the health care system can reflect healthcare providers' and society's biases. Health differences reported in race data can be interpreted in ways that do not represent the complex experiences of those most affected. When conducting research using these data, scientists must be rigorous in understanding and reporting how these biases and limitations shape data collection, analysis and reporting.

## Access and Control of Data

- Race data can be misused and abused to cause both individual (interpersonal) and community or group harm (via institutions and governments). Communities identified in the study must be made aware of this research and be granted access to the data. They must be engaged in the research process in a way that is meaningful and respectful to them, so they have a say on how the research question is framed and how their data are used, interpreted, and shared.

## Well-Informed Research Process

- Race and ethnicity are different concepts with no fixed definitions. The meaning of racial or ethnic categories reported can change depending on the location, time, and context of data collection, and from person to person. Scientists must use categories that are meaningful to the outcomes and experiences being explored in their research and provide clear definitions and limitations for them.
- Racial categories do not represent genetically or biologically distinct homogeneous groups. Research should never suggest that race is the cause or a risk factor for ill health, as this is not only inaccurate and not supported by scientific evidence but reinforces outdated notions of racial hierarchy or superiority. Health is harmed because of the interpersonal and structural racism experienced throughout many domains of life. Race is only a proxy for racism and researchers using race variables must report them as such.

## Data used for Positive Impact

- Systemic and interpersonal racism impact people's health. We have a responsibility to integrate race data in our research to demonstrate health inequities when appropriate.
- Researchers must use race data in health research with a clear objective of dismantling racism, ending various forms of discrimination, and finding solutions to improve the health of the groups or communities that are represented in these data.

## Contextualization and Accountability

- Reporting differences in health between racial or ethnic categories is never enough. Researchers must clearly explain that these differences occur because of the systemic racism and discrimination experienced by certain communities or groups.
- When examining health differences by race or ethnicity, researchers must analyze and describe the potential overlap of many forces of oppression where possible, such as racism, sexism, ableism, etc.
- Scientists must question the default use of the majority group or white category as the "norm" or "standard" against which other racial groups are compared, and when it is used as the reference, be explicit about the reasons why. The way racial or ethnic categories are compared in research must be vetted for each specific project with consultation from representative community members and health equity experts.
- Researchers must acknowledge and state their own position of privilege, their context expertise or lack thereof, and the potential for personal biases to influence their interpretation of race data.

# Recommendations

## For ICES’ Institutional and Research Processes

The second key output of the Peoples’ Panel was recommendations to guide ICES’ use and governance of race, ethnicity, and immigration data both at the overarching institutional level and at a research project level. These recommendations will be a primary input to guide the creation of the Race & Ethnicity Data Framework.

Peoples’ Panel members were divided into small groups and each group was assigned one of six topics within the research processes to focus on. Groups met for two of the five sessions to discuss issues, ask questions, and get feedback from peers. They then used this input to put forward recommendations for each scenario. Final recommendations were shared with the larger group for further feedback, and members also individually provided a final round of feedback on these recommendations through a post-panel survey. Recommendations that have been updated based on the survey comments have been identified with an asterisk.

The six topics included:

**Institutional-level research processes**
(Things done by ICES’ corporate teams)

**1.**
**Data acquisition and sourcing**

Process by which ICES receives data from external sources, such as the Ministry of Health, government databases, or disease registries.

**2.**
**Accountability**

ICES is accountable to the provincial government and the Ontario public. Our policies, practices and procedures for using data must be reviewed and approved by the Office of the Information Privacy Commissioner of Ontario.

**3.**
**Data Disclosure**

Process by which ICES shares data and/or analytics with investigators external to ICES, which include public sector organizations or private sector companies and researchers.

**Project-level research processes**
(Things done by the researcher and project team)

**4.**
**Data access and approvals**

Access to ICES data repository by our scientists is a process that is administered on a project-by-project basis. Scientists need to apply for and justify the data they are requesting.

**5.**
**Research Initiation, Analysis, & Interpretation**

Defining the research question and outcomes, using specific datasets and research methods, analyzing, and assigning meaning to the data, and determining the conclusions, significance, and implications of the findings as it relates to the research question.

**6.**
**Sharing Research Findings & reporting**

Considering target audiences who might benefit from the research and communicating with those audiences to facilitate research uptake in decision-making and practice.

# 1. Data Acquisition & Sourcing

## Overview

Data acquisition and sourcing is the process by which ICES receives data from external sources, such as the Ministry of Health, government databases or disease registries. Typically, research data collection can involve a variety of methods including interviews, questionnaires, assessments, or surveys. At ICES, this process happens differently because most of our projects use data generated much earlier, at the point of health service delivery or government surveys. ICES does not actually collect data but receives them from others.

Rather than collecting data, project-specific datasets are created by pulling together and linking data from different sources and databases. Because of that, the data that ICES receives may include race, ethnicity and/or immigration data in various formats, and we have no control over the format in which we receive the data.

Scenarios for data acquisition & sourcing include:

1. Approximating race & ethnicity categories
2. Self-reported vs. assigned race & ethnicity data
3. Linking data to fill in missing race or ethnicity variables
4. Actively acquiring race & ethnicity variables
5. Varying quality of data sets
6. Responding to limitations & gaps

## Approximating Race & Ethnicity Categories

**To understand concerns around using data as proxies, like surname or country of birth, for approximating racial or ethnic classifications in research studies.**

Scenario: Historically, ICES did not always have race or ethnicity data to demonstrate inequities in health outcomes or services to certain populations. In some cases, researchers chose to use other information like last name or country of birth to approximate race categories. For example, if someone was born in India, researchers would assume that they were of the race category "South Asian".

What are your concerns related to using other data, like surname or country of birth, to approximate racial/ethnic classifications? Are there any situations where this would be acceptable or not acceptable?

**Peoples' Panel Recommendation:**

**ICES should not use proxies such as last name or country of origin to approximate racial or ethnic classification. The only exception would be if a community specifically requests the use of these proxies to answer a research question pertaining to their population, in which case ICES can use the data for analysis with a clear disclaimer.**

**Level of agreement:**

**80%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Self-Reported vs. Assigned Race & Ethnicity Data

**Considerations for when race data is self-reported (individuals reporting their own race), assigned (providers or researchers assigning a race to individuals based on appearance or perceptions), or from unknown sources.**

Scenario: ICES does not collect data but receives data from other sources. In some circumstances, organizations that collect data may ask individuals their race, which we call “self-reported” race data. In other instances, doctors or health care providers may “assign” individual's a race category based on appearance and perceptions. For example, in the cardiac care registry, they historically had a race-related variable that was filled in by the patients’ doctor or cardiologist. Whether the doctor asked the individual to identify their race is unknown.

What should be considered when race is self-reported vs assigned? How should we treat those data differently? What if the source is unknown (as in ICES cannot tell from the dataset if the data was self-reported or assigned)?

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**Peoples’ Panel Recommendation:**

**ICES should avoid using assigned data categories and should treat unknown data sources as if they were assigned. ICES could use assigned race data only for research projects intending to investigate perceived notions of race on health outcomes.**

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**Level of agreement:**

**51%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.3/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Linking Data to Fill in Missing Race or Ethnicity Variables

**Considerations required when filling in missing race or ethnicity variables by linking data sources together, where a race or ethnicity value might be missing in one dataset but present in another.**

Scenario: We know that some individuals choose not to disclose their race when it is asked of them during data collection. Specifically, Black and South Asian individuals tend not to provide these data compared to individuals of other races, likely due to historical misuse and misrepresentation of these data to cause harm. However, ICES may be able to link several data sources to fill in missing race categories, for example if it is provided in one data set and not another.

What are your concerns related to filling in missing race or ethnicity variables by linking data, where a race value is missing in one data set but is present in another?

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**Peoples' Panel Recommendation:**

**ICES can link datasets only if it ensures that race categories collected in either dataset were collected in a similar manner. ICES should be conscious of datasets that contain ambiguous categories or lump together multiple racial or ethnic categories and how those are represented in linked data (e.g., 'visible minority' or 'people of color').***

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**This recommendation was updated based on comments received in the post-Panel survey.*

| Level of agreement: | Level of importance: |
|---|---|
| **66%** | **4.5/5** |
| of respondents STRONGLY agree with this recommendation | Is the average level of IMPORTANCE respondents give to this recommendation |
| *n=41* | *n=41* |

## Actively Acquiring Race & Ethnicity Variables

**To understand whether ICES should actively seek out acquiring data that includes race and ethnicity variables, and under what circumstances it should do so.**

Scenario: Currently, ICES does not seek out obtaining race and ethnicity data, but instead receives it passively when it is already collected in other databases like the census and surveys. However, ICES does actively work with Immigration, Refugee and Citizenship Canada to receive immigration data and even discuss how it should be used.

Should ICES actively seek out acquiring data that includes race and ethnicity variables? Are there specific circumstances when we should acquire data? Are there specific circumstances when we should NOT acquire the data?

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**Peoples' Panel Recommendation:**

**ICES can actively collect race or ethnicity data while ensuring the data it receives is of high quality (e.g., self-reported data, clear race/ethnicity categories, consistent data collection methods).**

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**Level of agreement:**

**73%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Varying Quality of Data Sets

**To assess and determine the variability in quality and range of race and/or ethnicity variables coming to ICES.**

Scenario: Not all race, ethnicity and immigration data are collected the same way or with the same variables. Each data set that ICES receives which contains these variables could be of a different quality. For example, some race variables may be self-reported whereas others may be assigned by the healthcare provider, and some race variables may contain a combination of both race and ethnicity categories.

What should be used to assess and determine the quality of race and/or ethnicity variables coming to ICES?

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**Peoples' Panel Recommendation:**

**ICES should identify how data was collected (self-report vs. assigned) & prioritize self-reported data as the gold standard. ICES researchers should recognize the data limitations they are working with (e.g., categories mixing race and ethnicity variables) and report these limitations in their work. ICES should ensure that researchers also report self-locations and potential biases.**

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**Level of agreement:**

**71%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Responding to Limitations and Gaps

**To address gaps and limitations (e.g., missing race values or populations not being represented) of various data sets at the point of data sourcing.**

Scenario: Although most of ICES data is population-level and would contain data from all individuals in Ontario, some data sets that are brought in from other sources do have limitations or gaps, based on how the data were collected or where the data are coming from. For example, a data set may not contain representative samples of all races that access their service as some individuals may choose to not share their race and/or ethnicity. In other cases, certain populations may not be visible in the data because they do not access services provided by the provincial health system, such as people experiencing homelessness.

How should these data gaps and limitations be considered and addressed by ICES at the point of data sourcing?

**Peoples' Panel Recommendation:**

**ICES should obtain information from the data source about what the intentions were behind the collection of race data and ensure that these intentions align with the aims of the study. ICES should be transparent with whose data is represented and whose is not and consider if the data that is available is enough to make a conclusion. Where gaps are identified, ICES researchers should consider what action they can take (funding or advocacy) for more inclusive data collection.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**80%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Summary for Data Acquisition & Sourcing

**The Peoples' Panel recommended that:**

- Researchers do not use surname, country of birth, language or other variables as proxies for race, unless it is specifically requested by community
- ICES actively seeks out acquiring race data only if the data meets defined quality standards
- ICES requests data providers supply information on race data collection methodology, history and purpose to determine data quality and usability
- ICES is transparent about who is represented or not represented in the data received
- Researchers considers what actions need to be taken for more inclusive data collection when gaps are identified
- ICES establishes self-reported race data as the gold standard
- ICES evaluates the quality of race data before any data linkage and use is approved
- ICES prevents use of assigned race data unless it is used to study racial discrimination, and considers any race data of unknown origin as assigned

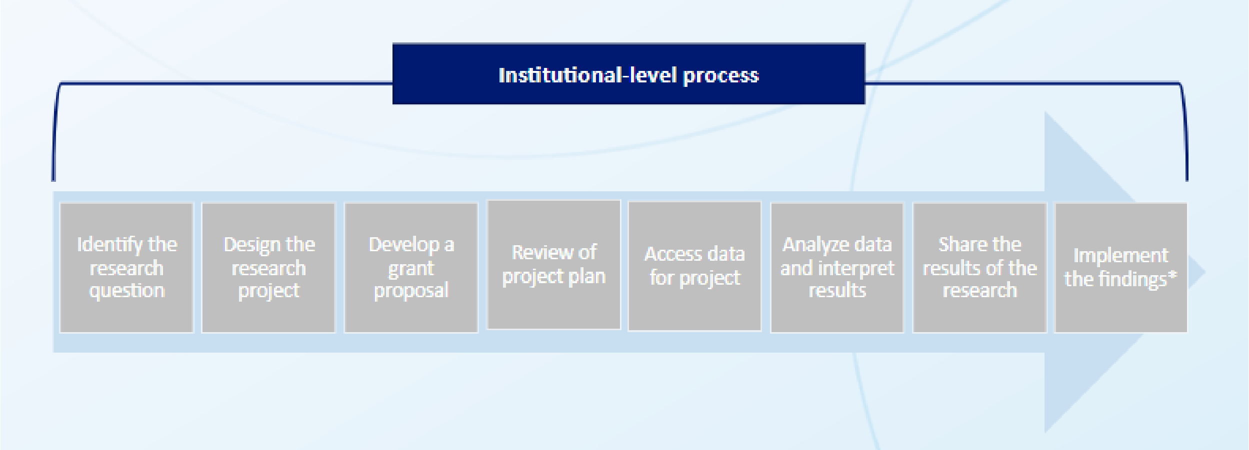
# 2. Accountability

## Overview

ICES is accountable to the provincial government and the Ontario public. Our policies, practices and procedures for using data must be reviewed and approved on a regular basis by the Office of the Information Privacy Commissioner of Ontario. There are currently no additional or specific accountability measures related to race, ethnicity, and immigration data.

Scenarios for accountability include:

1. Accountability measures
2. Levels of accountability
3. Tracking progress
4. Ownership of large population-level data sets
5. Understanding of history, systemic racism and race data by researchers



## Accountability Measures

**To determine who ICES is accountable to (the community, public, health care service providers, government, health care users) for its use of race and ethnicity data.**

Scenario: ICES is accountable to the Government of Ontario through our legislative mandate and regulatory requirements for how we acquire and use these data, and through this the Ontario public who provide the data we use.

How should ICES approach accountability for the use of race and ethnicity data? Who should ICES be accountable to, and to what degree - for example, is it the community, public, health care service providers, government, health care users?

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**Peoples' Panel Recommendation:**

**ICES should create a governance or overseeing body, with appropriate representation from community members and subject matter experts, to guide researchers in their use and reporting of race and ethnicity data. ICES should implement clear criteria in order for researchers to access data (e.g., training, disclosure statements, agreeing to community practice guidelines, participation in community of practice, etc.). Research findings should be accessible to the public. ICES should also consult with a community governing body, separate from ICES, on data usage and study findings. This body should have equal power in saying who can access data.**

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**Level of agreement:**

**73%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Levels of accountability

**To understand the level of accountability each party – ICES, researchers, data providers – should uphold to ensure race data is used appropriately.**

Scenario: ICES only has partial control over how researchers use these data in their projects, as they are the ones interpreting the data and publishing the findings. ICES can implement checkpoints, balances, and policies for data use and release, but the conducting of the research project is at the discretion of the researcher.

Where does accountability lie for the appropriate use of these data? Is it with ICES, the researcher, the data provider, or a combination? Do each have distinct or complementary roles to play?

**Peoples' Panel Recommendation:**

**All parties stewarding the data should be accountable to a governing body (an entity separate from ICES and composed of community members and subject matter experts guiding the use and reporting of race data at ICES) with appropriate members of this body engaged during all phases of the research process. ICES should take an active leadership role in building guidelines for all access and engagement mechanisms surrounding race and ethnicity data. The governing body should uphold these guidelines. ICES can engage with funders to create some accountability structures that ensure that researchers adhere to community practice guidelines and work with the community governing body.**

**Level of agreement:**

**71%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Tracking Progress

**To understand what targets (key performance indicators and metrics) ICES should aim to achieve related to its use of race and ethnicity data.**

Scenario: ICES uses metrics and key performance indicators to track its progress on certain commitments and activities. Should ICES develop targets related to the Race and Ethnicity Data Framework, and if so, what measures would demonstrate progress? For example, should ICES have targets related to the number of projects using race/ethnicity data, the number of community-led projects, or the number or projects specifically focused on impacting health system outcomes to address systemic racism?

**Peoples' Panel Recommendation:**

**Community groups should be engaged to help define what metrics would be authentic to them to demonstrate progress. Once these metrics are defined, annual audits (qualitative and quantitative) should be conducted in consultation with community groups to ensure continued alignment with their needs and interests. A qualitative outcome could be meeting with a community group yearly and asking if research had a positive impact on their population. ICES should measure the quality of research that uses race and ethnicity data, not just the quantity.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**61%**

**of respondents**
**STRONGLY agree with this**
**recommendation**

*n=41*

**Level of importance:**

**4.5/5**

**Is the average level of IMPORTANCE**
**respondents give to this**
**recommendation**

*n=41*

## Ownership of Large Population-Level Data Sets

**To understand what effective data ownership is for population-level data sets and identify authority figures or individuals that can speak on behalf of a group or community.**

Scenario: At ICES we use large, population-wide data sets that are collected through the healthcare system. What does ownership of data mean to you with regards to population-level data sets? What would be an example of how effective data ownership is done? Who can speak to ownership of data on behalf of an individual or a community?

**Peoples' Panel Recommendation:**

**Community should be considered the true owners of the data. They should be actively engaged as members/contributors of the governing body (an entity separate from ICES and composed of community members and subject matter experts guiding the use and reporting of race data at ICES). Capacity should be built within communities so that members can actively participate in the use and governance of their data, for example through representation in data sharing agreements. External organizations should request permission to use these data.**

**Level of agreement:**

**61%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Understanding of History, Systemic Racism and Race Data by Researchers

**To understand what minimum amount of understanding and training ICES researchers need to acquire and demonstrate in order to use race and ethnicity data.**

**Scenario:**
In order to be accountable, a degree of understanding of history, systemic racism and race data is required by researchers who use these data appropriately. What is the minimum amount of understanding or training that researchers should have? What should researchers learn about or demonstrate an understanding of in order to use these data? Should all researchers be required to do some level of training?

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**Peoples' Panel Recommendation:**

**All ICES researchers should complete community-recommended or endorsed training, with appropriate credit or compensation and with a demonstrated understanding or evaluation. Researchers should also disclose the intent behind their use of race and ethnicity data as part of their submission to the governing body (an entity separate from ICES and composed of community members and subject matter experts guiding the use and reporting of race data at ICES) before data access is issued. Researchers should disclose their biases and limitations of knowledge and lived experience in their submission to the governing body, in their final report, and in any published findings.**

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**Level of agreement:**

**78%**

**of respondents
STRONGLY agree with this
recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE
respondents give to this
recommendation**

*n=41*

## Summary for Accountability

**The Peoples' Panel recommended that:**

- Researchers complete community-endorsed training on race data use and demonstrate understanding
- ICES implements a community governance body with appropriate representation and clear criteria to help determine how data is used and reported by researchers
- Researchers disclose their intention for using race data as part of their data access request to the governing body
- Researchers state their biases, limitations of knowledge and lived experience in their submission to the governing body, in the final report and in any publications
- Research findings be made accessible to the public
- The governing body holds all parties accountable and is engaged in every phase of the research process
- ICES builds guidelines for all data access and community engagement mechanisms surrounding race data
- ICES enables community representatives to be members of the governing body and build capacity for them to participate in the use and governance of race data
- ICES, in collaboration with community groups, develops metrics with pertinent targets and measures quality, and not just quantity, of research using race data

# 3. Data Disclosure

## Overview

Data disclosure is the process by which ICES shares data and/or analytics with investigators external to ICES, which include public sector organizations or private sector companies and researchers.

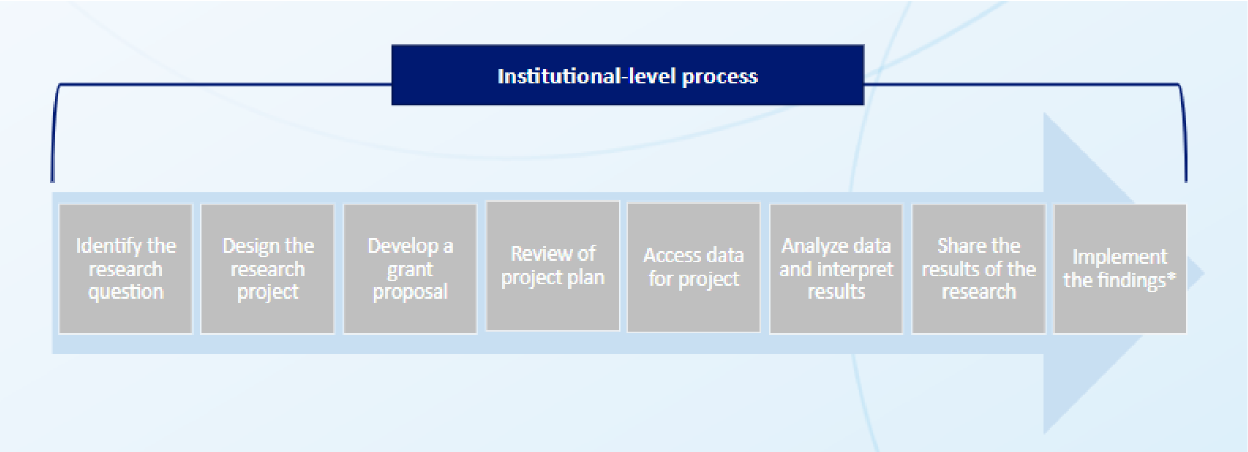
Publicly funded, not-for-profit organizations can submit a request to ICES to obtain and analyze ICES data to answer a research question. We work with requestors to design a research-ready data extract from our data repository while meeting all privacy standards.

Requestors can access the data extract, perform analyses, and create reports. Private sector companies and researchers cannot access individual-level data but can request analytic services. ICES performs the analyses and generates the results report based on their specifications. We can also facilitate linkage of existing clinical trial data with administrative data holdings to assess long-term outcomes among trial participants.

Formal agreements with data providers define the way that ICES uses and safeguards data. These agreements also confirm the legislative authority for data sharing. Race, ethnicity, and immigration data can be requested by external partners to perform analyses or create reports.

Scenarios for data disclosure include:

1. Data Disclosure to External Organizations
2. Analysis for Government Organizations
3. Analysis for Not-For-Profit and Community Organizations
4. Analysis for Private Companies



## Data Disclosure to External Organizations

**To determine what requirements ICES can ask of external organizations requesting analytic services that include race data, and how to navigate external practices or guidelines on race data use when providing data or analyses to other organizations.**

Scenario: ICES provides data and analytics services to external organizations, like government organizations, not-for-profit and health care service providers. In most cases, they ask ICES to use our data to conduct an analysis about a service they provide or a community they serve.

When ICES provides analysis to external organizations, and they have their own practices related to race data use, to what degree should ICES' principles and framework influence the way they use the data? For example, if a public health unit is requesting an analysis and they already have their own race-related equity practices in place, are they still required to abide by ICES' framework? How can we determine if their approaches are acceptable?

---

**Peoples' Panel Recommendation:**

**External organizations should, at minimum, meet the standards of the ICES' framework. Other organizations may have more stringent equity practices than ICES to but not less in order for ICES to provide services to them. Each organization should offer a clear rationale and purpose for using the data. ICES should ensure that the organization uses and handles the data appropriately. ICES should also involve communities impacted by the data use and its interpretation.**

---

**Level of agreement:**

**66%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.5/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Analysis for Government Organizations

**To determine what responsibility ICES has when providing analytic services to government organizations providing data they collected themselves that contain race, ethnicity, or immigration variables.**

Scenario: In some cases, government organizations, like the Ministry of Health or Health Quality Ontario, collect data but do not have the analytic power to clean, code and analyze them. ICES research teams provide them with these services so they can use the data they collect.

When a data provider, like the Ministry of Health, requests analyses using the data they have provided, and it contains race and ethnicity variables, what is ICES' responsibility for how these data are used and interpreted? Should we request anything from them before conducting these analyses, given they collected the data?

**Peoples' Panel Recommendation:**

**ICES should require protocol documents from the organizations or agencies that clearly describe how data being provided was collected, what methods were used, how these data should be analysed and interpreted, to offer contextual information on data quality, meaning, and limitations. ICES' role can be to provide guidance and best advice on the appropriate data use and collection.**

**Level of agreement:**

**68%**

**of respondents**
**STRONGLY agree with this**
**recommendation**

*n=41*

**Level of importance:**

**4.5/5**

**Is the average level of IMPORTANCE**
**respondents give to this**
**recommendation**

*n=41*

## Analysis for Not-For-Profit and Community Organizations

**To understand what processes or commitments ICES can ask of community organizations or groups that represent a racialized community when they request data analyses or results on their population.**

Scenario: Not-for-profit and community organizations can ask ICES to conduct analyses for them using our data repository to improve their services or understand their population. For example, an organization providing health services to South Asian women or Black youth might approach us to provide them with analyses.

When ICES is providing data analyses/results to community organizations or community groups that are representing their own community, what processes or commitments do they need to make about using these data?

**Peoples' Panel Recommendation:**

**ICES should require community groups to follow the framework with anti-racist and anti-oppressive lens. ICES should be proactive and supportive in ensuring communities can access and use the data for their own benefits and in a way that works for them. ICES should share resources such as data strategies to help organizations develop their research objectives and approaches.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**61%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Analysis for Private Companies

**To know what requirements ICES can ask of private companies requesting access to generalized analyses of ICES data that includes race, ethnicity, or immigration variables.**

Scenario: In some instances, ICES does provide analyses to private companies such as pharmaceutical companies through a specific and restricted pathway. They are not able to see the raw data itself; they only have access to the generalized analysis. The research question they asked ICES is publicly posted and the results of the study are posted within a year.

If a private company, like a pharmaceutical company, requests the use of data that includes race and ethnicity variables, what requirements should ICES ask from them for how they will use the data?

**Peoples' Panel Recommendation:**

**ICES should demand that private companies abide to the framework's minimum requirements and demonstrate how they do so. ICES should request the following information: their source of funding, the client or customer base being targeted, who is excluded and why, partnerships with other organizations, other third party of interest, and how the results will be applied. ICES should confirm that private companies' research objectives align with community needs and priorities and that the research outputs will benefit the communities of interest. ICES should actively communicate the types of analysis performed for private companies to increase general awareness of health data use. ***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**63%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Summary for Data Disclosure

**The Peoples' Panel recommended that:**

- Private companies provide information about their source of funding, target market, partnership, exclusion criteria and rationale, and demonstrate how their research is aligned with community needs and priorities before they obtain data analytics containing race data
- ICES develops strategies to actively disseminate research outputs performed for private companies to the communities impacted
- ICES proactively offers resources to support community organizations in accessing and using data
- Data providers, such as government agencies, provide documentation on data quality including how the data was collected, by what methods and how it should be analyzed and interpreted
- ICES offers guidance to data providers on appropriate data use and collection methodology
- External organizations meet the ICES Framework' standards and give a clear rationale and purpose when seeking to use race data held at ICES
- ICES involve communities impacted by the data use and interpretation

# 4. Data Access & Approval for Research

**Overview**

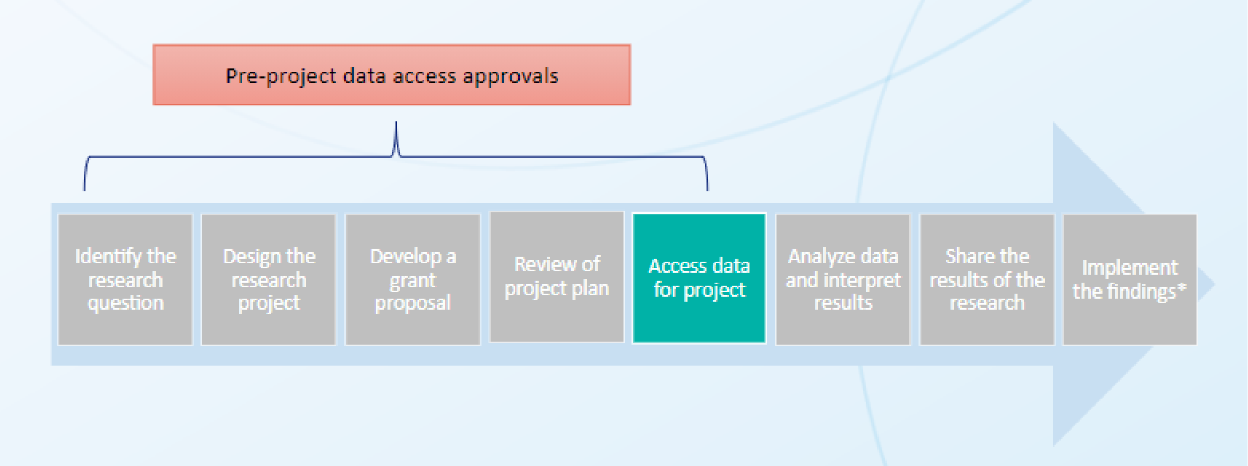
Access to ICES data repository by our scientists is a process that is administered on a project-by-project basis. Scientists need to apply for and justify the data they are requesting.

Researchers can access health data on individuals on our secure servers after it is desensitized (personal identifiers are removed) and once data quality is confirmed.

There is currently no specific or separate approval process for accessing race and ethnicity data and a very limited approach for accessing immigration data.

Scenarios for data access & approval for research:

1. Approving Projects Involving Race, Ethnicity and Immigration Data
2. Determining Appropriateness of Use of Data
3. Data Governance
4. Different Use of Race, Ethnicity and Immigration Data
5. Linking Data



## Approving Projects Involving Race, Ethnicity and Immigration Data

**To understand what parameters to consider and processes to implement for approving access to race data for research projects at ICES.**

Scenario: ICES has a series of checkpoints at the initiation of a project, including a grant review, privacy review, and data set creation plan. Typically, ICES does not “approve” projects, but instead reviews them for issues or concerns, as it is not usually our place to say a project cannot or should not be done.

In the case of a project using these data, should there be an approval process for access to race, ethnicity and immigration data? Who can act as approver? What should be approved?

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**Peoples’ Panel Recommendation:**

**ICES should require research projects using race data to comply with a set of criteria such as representation of the communities being studied on the project team. ICES should also provide tools and best practice to work with these data. ICES could delegate the authority to an equity review panel that can request revisions when a proposal is flagged as problematic, racist, or propaganda.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**63%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.8/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Determining Appropriateness of Use of Data

**To understand what criteria should be used to evaluate whether a research project is using race data appropriately.**

Scenario: It is often discussed that these data need to be used “appropriately”, however it is not clear what is deemed appropriate or inappropriate. For example, some argue that research should always use these data if they exist, as a way to demonstrate that health is impacted by systemic racism. On the other hand, others say it is inappropriate to use these data as they often perpetuate harm to racialized communities.

What criteria should be used to determine if a project using these data is appropriate or inappropriate?

**Peoples’ Panel Recommendation:**

**ICES should follow principles of equity and inclusion. ICES researchers should engage with community members to ensure the project is a research need and that it will be beneficial to them. Any research application looking to use race data should integrate critical reflection and critical race theory and should require scientists to name their biases. Examples of biases could be provided in the application for clarity and education.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**66%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Data Governance

**To understand what role communities can have in data governance of race and ethnicity data (determining who can access data and for what reasons), and who can represent a community.**

Scenario: In research, we refer to the rules dictating data access (who can access data and for what reasons) as data governance. ICES' data governance approaches are controlled by various elements including legislation, privacy and cybersecurity practices, policies and procedures. In some cases, data governance can include community input for who should access the data for each project.

What role should the community have in determining access to race and ethnicity data? How do we define who can represent the community?

**Peoples' Panel Recommendation:**

**Ideally, communities should have autonomy and governance over their own data. ICES should consider its role in establishing community governance. ICES researchers should partner with community organizations or representatives who are trusted, well known, and considered subject matter experts by the communities of interest.***

**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**63%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.4/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Different Use of Race, Ethnicity, and Immigration Data

**To understand how ICES can approach projects that have race data as a key focus compared to projects where race data is just a small component, and to determine if ICES should encourage the use of race data as a component in studies.**

Scenario: Research projects can use race and ethnicity data in different ways. Some projects have racial inequity or immigration as the key focus, where the purpose is to look at how health outcomes or services differ across racial groups or immigrant populations. However, other studies just use race or ethnicity as one variable in a study amongst several others.

How should projects that have race, ethnicity and/or immigration data as a key focus be treated compared to projects where it is just a small component? Should we encourage the use of race, ethnicity and immigration data as a component in studies?

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**Peoples' Panel Recommendation:**

**ICES researchers should approach any project using race data, regardless of the extent of race data in the research, with a foundational anti-oppressive and critical understanding, and include this context in the research products. Researchers should avoid comparative conclusions when too few variables result in limited or insufficient evidence.**

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**Level of agreement:**

**59%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.5/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Linking Data

**To understand what risks and benefits should be considered when linking race data to other datasets.**

Scenario: When scientists at ICES access data, they request a series of datasets that they then link together to perform their analyses. Data being linked can be general health records, immigration data, data containing race and ethnicity variables, and neighbourhood data like education and income.

What considerations should be made when linking race and ethnicity data with other data? What do you see as some benefits of linking data that include race and ethnicity variables? What about risks?

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**Recommendation:**

**Unique considerations are needed for communities who have had their data used in a harmful way in the past. When linking race data to other datasets, scientists should state what assumptions are being used and avoid oversimplification of data categories (e.g., ethnicity variables being distinct from race).**

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**Level of agreement:**

**63%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Summary for Data Access & Approval for Research

**The Peoples' Panel recommended that:**

- Research projects comply with a set of criteria, such as community representation in the project, to be granted access to race data
- ICES provides tools and best practices around the use of race data and appoints an equity review panel to evaluate race-related projects flagged as concerning or biased
- Researchers engage with representative community members to conduct race-related research
- Researchers reflect on their personal biases and integrate critical reflection and critical race theory in their work, regardless of the extent of race data being requested
- Researchers state the assumptions being used when linking data sets that contain race data
- Researchers avoid comparative conclusions when data is limited or insufficient
- ICES establishes a community governance approach

# 5. Research Initiation, Analysis and Interpretation

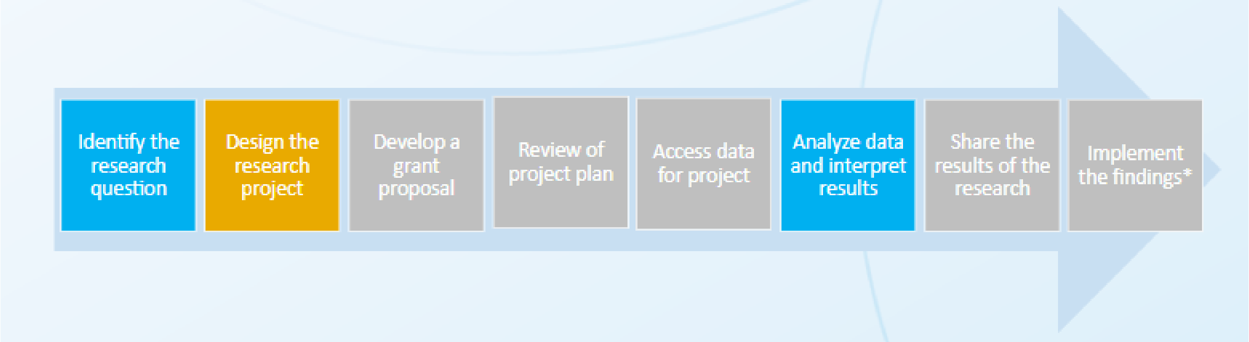
## Overview

This involves defining the research question and the outcomes to look at, conducting the research using specific datasets and research methods, analyzing and assigning meaning to the data, and determining the conclusions, significance, and implications of the findings as it relates to the research question.

At the moment, there is no formalized processes that dictate how ICES scientists use race, ethnicity, and immigration data in their projects.

Scenarios for research initiation, analysis, and interpretation:

1. Identifying the Purpose of the Research
2. Engaging Community Members in Research
3. Contextualization
4. Neighbourhood-Level Analysis



## Identifying the Purpose of the Research

**To determine what rationale or processes ICES researchers should include when conducting projects that use race data to ensure research projects will "do no harm".**

Scenario: The initiation of a research project is when the project team determines the purpose of their study, their hypothesis and the outcomes they would like to look at in their study. This is the key point when the researcher decides the intention of their study.

What should researchers consider before initiating a project that uses race, ethnicity and immigration data? Should projects provide rationale for using these data, and if so, what should this rationale include? What should be included at this stage of the research project to ensure that the project results will "do no harm"?

**Peoples' Panel Recommendation:**

**Scientists should complete a 'pre-opt' checklist, along with an associated checklist on how the research proposal will be evaluated, to rationalize their use of race and ethnicity data. This checklist should contain clear definitions of race and ethnicity and ICES should participate in creating a consensus view of race and ethnicity definitions amongst ICES's ecosystem and major community stakeholders.**

**Level of agreement:**

**63%**

**of respondents**
**STRONGLY agree with this**
**recommendation**

*n=41*

**Level of importance:**

**4.5/5**

**Is the average level of IMPORTANCE**
**respondents give to this**
**recommendation**

*n=41*

## Engaging Community Members in Research

**To understand how community members should be engaged during the development of research questions, data analysis and interpretation, and to identify who can act as community representatives.**

Scenario: At the point of initiating the project, a researcher will create a "research question" which is the problem they want to solve by looking at the data. For example, a research question could be "How many Ontarians have diabetes, where do they live and how many of them are taking insulin?" The research question is the foundation of the project and shapes the rest of the process. After this point, the research team will receive the data they need and do an analysis to answer that question, and then interpret the results of the analysis. Throughout this process, there is an opportunity for community members to be included and provide input into the project.

How should community members be engaged during the development or framing of research questions? What about during analysis and interpretation of the data? Who can represent the community?

**Peoples' Panel Recommendation:**

**ICES researchers should work with community liaisons or community scholars that can help lead research supported by the community of interest. These representatives should be context experts of the community of study. Researchers should make a community plan as a requirement of the research vetting process, and this plan needs to be vetted and accepted by the community liaison, key stakeholders and ICES. ICES should ensure compensated roles for community representatives. ICES should also develop specific community guidelines on how to engage and ensure that research teams using race data are diverse.***

**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**71%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Contextualization

**To understand what type of context is necessary to include alongside research using race data in order to position or interpret it appropriately.**

Scenario: When scientists at ICES conduct a research project, they request a series of datasets to link together in order to perform their analyses. Data being linked can be general health records, immigration data, sociodemographic data (like race and ethnicity variables), and neighbourhood data (like education and income). These types of data can provide helpful context to show the impact of systemic racism. Researchers can also include other literature and stories from community members to provide further information to the study.

What type of context is necessary to include alongside research using race, ethnicity and immigration data to position or interpret it appropriately (i.e., immigration, job status, income, historical context, systemic oppression, information about systemic racism, etc.)?

**Peoples' Panel Recommendation:**

**Scientists using race data should conduct a comprehensive literature review and append non-traditional sources of information if possible (e.g., cultural base, experiential, spoken word, literature by BIPOC communities or experts). ICES should create a public research funnel/pipeline that indicates the stage of all proposals using race data, with their evaluation or score in display. This research funnel and submissions should be transparent to the public and communities (via a permission process). ICES should also create guidelines for how researchers and media communicate race-related research findings.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**61%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.4/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Neighbourhood-Level Analysis

**What to consider when demonstrating ethnic diversity at the neighbourhood-level in research projects, and inevitably connecting a health trend to the diversity or "concentration" of immigrant or racialized populations residing in the area.**

Scenario: In some situations, data can be used to define ethnic diversity of a population at the geographic level, like a neighbourhood or area. For example, there is a standard measure to determine the "ethnic concentration" of a neighbourhood, which uses the proportion of visible minorities and immigrants residing in that area. The neighbourhood can then be labelled as having high or low ethnic concentration and that information can be connected to other measures. In a study for instance, it was shown that neighbourhoods with a 'high ethnic concentration" in Ontario also had high rates of positive COVID-19 cases. This doesn't necessarily mean that immigrants and racialized individuals had COVID-19, but the neighbourhood they live in had many positive cases, which can lead to problematic interpretations. What are concerns that arise for neighbourhood-level characterizations like this one? What should be considered when analysing and interpreting data with similar measures?

**Peoples' Panel Recommendation:**

**All neighbourhood-level research requires the highest level of scrutiny. ICES should mandate a community-based review for any research project making neighbourhood-level characterizations to confirm that objectives align with community priorities and research outputs will be beneficial to communities impacted prior to publishing the results. ICES should also create a tier data access system where research scrutiny increases for projects with heightened data sensitivity. ***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**73%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Summary for Research Initiation, Analysis, and Interpretation

**The Peoples' Panel recommended that:**

- Research projects making neighbourhood-level characterizations that can infer the racial background of communities of interest undergo a community-based review
- ICES designs a tier data access system where research scrutiny increases for projects with heightened data sensitivity
- Researchers collaborate with community liaisons and scholars and provide a community engagement plan when conducting studies using race data
- ICES establishes guidelines around community engagement and encourages diversity in research teams
- Researchers complete a checklist to validate their use of race data and submit a community engagement plan before initiating a project
- ICES participates in creating a consensus view of race and ethnicity definitions amongst its stakeholders
- Researchers conduct a comprehensive literature review, including non-traditional sources, to interpret race data appropriately
- ICES creates a publicly available research pipeline and guidelines for public or media communications of race-related research findings

# 6. Sharing Research Findings & Reporting

## Overview

Sharing of research findings and reporting involves considering target audiences who might benefit from the research and communicating with those audiences to facilitate research uptake in decision-making and practice.

Sharing research findings can take many forms, such as publishing a manuscript in a scientific journal, issuing a newspaper editorial, distributing public-facing materials, presenting at conferences, etc.

How research studies containing race, ethnicity, and immigration data are shared and disseminated is at the discretion of scientists.

Scenarios for sharing research findings & reporting:

1. Sharing Research Outside of Academia
2. Preventing Problematic Interpretation
3. Interpretation of Research at the Local Level
4. Requirements for Accurate Representation
5. Community Involvement

## Sharing Research Outside of Academia

**To understand what aspects ICES scientists should consider when sharing research results and findings with communities, and to determine who specifically these findings should be communicated to.**

Scenario: At the completion of a research project, the analyses are typically summarized into a manuscript that is peer reviewed and published in an academic journal for other researchers to read and use. However, these traditional avenues of sharing research findings are notably not easily available or accessible to people outside of the research community, such as members of the public, policy makers and community organizations who could make use of them. Research findings containing race and ethnicity data could help improve health care for racialized communities, or support community organizations when rallying for more funding to serve their population.

How should research results and findings be shared with the community? Who should these findings be shared with?

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**Peoples' Panel Recommendation:**

**Research reports should be free and easily accessible to all communities, including availability in different languages. Reports should be shared with policy makers, different stakeholders, and media sources, including community-based media. The community that was engaged in the research process should also collaborate in the dissemination strategy (e.g., in writing reports, posting on social media platforms, and organizing meetings or community gatherings).***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**66%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.8/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Preventing Problematic Interpretation

**To understand what actions to consider when results show poor outcomes for a specific racial, ethnic or immigrant community in order to prevent harm when these data are released publicly, and to determine what disclaimer or engagement strategies should be adopted to warn populations of interest of those outcomes.**

Scenario: When research findings that include outcomes by race are published, they become publicly available and open to public interpretation. In some cases, studies show that a specific racial or ethnic group has poor outcomes, which can be picked up by the media and individuals which use them to push hateful or racist narratives.

When data are being shared that shows poor outcomes for a specific race, ethnicity or community, what should ICES do to prevent harm before these data are released publicly? How should the community be engaged or warned of those outcomes?

**Peoples' Panel Recommendation:**

**When reporting poor outcomes for specific racialized groups, researchers should precede findings with proper context and limitations. Researchers should validate these findings with the community of interest to inform the potential interpretation of the results and ensure that there is no associated negative connotation. Scientists should also revisit the research question and tools used to ensure that the research process was comprehensive.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**68%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.8/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Interpretation of Research at the Local Level

**To address concerns that arise when researchers release reports at the neighbourhood level that can connect a poor health outcome to a specific racial or ethnic community, even when this community was not explicitly mentioned in the reporting.**

Scenario: In some instances, although race and ethnicity data are not being explicitly mentioned, it is evident from the neighbourhood or area being investigated that a specific racial or ethnic group is represented by the poor outcome. For example, with data on COVID-19 by neighbourhood, a study showed that neighbourhoods in Peel and Toronto, which were known to have large populations of Black and South Asian individuals, had very high cases.

What concerns arise with sharing reports that can connect an outcome to a specific community base at the neighbourhood level?

**Peoples' Panel Recommendation:**

**Findings should be contextualized and not generalized to prevent further stereotyping. Reports should provide clear justification related to the findings including potential impacts and its relationship to the social determinants of health. Scientific tools should be configured properly and be inclusive.**

**Level of agreement:**

**66%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Requirements for Accurate Representation

**To determine what specific contextual information (such as collection methods, definitions, data source, etc.) should be required in reports and manuscripts that include race data.**

Scenario: Since many of the race and ethnicity variables are collected in different ways, with different categories and reporting structures, each study using these data may have a slightly different representation of race.

What contextual information is needed when reporting findings related to race, ethnicity, and immigration data (e.g., collection methods, definition, data source, historical context of race data being used, etc.)?

Is there specific language or sections that should be required in reports and manuscripts that include race, ethnicity and immigration data? How should researchers address limitations and gaps in data?

**Peoples' Panel Recommendation:**

**ICES should ensure that data collection methods align with supported standard practice such as the Ontario Human Rights code. Researchers should acknowledge race and ethnicity as a social and political construct within the report. Authors should state their personal biases in relation to the research.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**71%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.7/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Community Involvement

**To understand how to involve community members in the finalization of findings and sharing of analyses, and who from the community should be engaged at that stage.**

Scenario: When publishing research findings, the final product is open to interpretation from public users. This public narrative will often impact the uptake of that evidence for decision-making. Members of racialized or ethnic communities are often not involved when research findings are being shared publicly.

How should community members be involved in the finalization of findings and sharing of analyses? Who can represent the community at this stage?

**Peoples' Panel Recommendation:**

**ICES researchers should build relationships with community members who are well connected and engaged with their community to help share findings. These community members should be representative of the diverse experiences and perspectives that exist within the community of interest. Researchers should avoid involving partisans or politicians in the finalization of the findings unless this has been sanctioned by the community representatives.***

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**This recommendation was updated based on comments received in the post-Panel survey.*

**Level of agreement:**

**66%**

**of respondents STRONGLY agree with this recommendation**

*n=41*

**Level of importance:**

**4.6/5**

**Is the average level of IMPORTANCE respondents give to this recommendation**

*n=41*

## Summary for Research Findings & Reporting

**The Peoples' Panel recommended that:**

- Researchers validate findings that show poor outcomes for specific racialized groups with the community of interest to inform the interpretation of results and revisit research questions and methodology to ensure they are comprehensive
- Research reports be free of charge and easily accessible to communities and shared with policy makers, media sources, and other relevant stakeholders
- Communities engaged in the research process collaborate in the dissemination strategy
- ICES verifies that data collection methods in any project align with supported standard practice for race data
- Researchers acknowledge race and ethnicity as a social and political construct and reflect on their personal biases in their reporting
- Reports include a full contextualization of findings that includes social determinants of health as well as potential impact of study conclusions
- Researchers connect with diverse, well connected community representatives to advise on how best to share findings while avoiding partisan voices or politicians in this process

# Race & Ethnicity Data Framework

These outputs from the Peoples' Panel are being used to inform the creation and implementation of the ICES' Race & Ethnicity Data Framework.

During Phase 2 — scheduled for July-October 2021 — the Peoples' Panel recommendations will be shared with the ICES' Internal Committee, a group of ICES scientists and experts with experience with race data and health equity guiding the implementation of the framework, for their review and endorsement. The Peoples' Panel process will also be shared with the broader ICES community of staff and researchers to discuss and understand ICES' role and work in building equity and addressing racism.

ICES has begun working with other equity experts and community organizations representing racialized individuals to discuss key pillars of the framework. ICES intends to host consultative sessions with these organizations in Fall 2021 to understand how to support community access and use of data and co-develop appropriate processes to do so.

ICES anticipates that a draft of the Race & Ethnicity Data Framework will be ready for further consultation in Fall 2021. This draft will be shared with the Peoples' Panel for reference and to gather feedback. Implementation of some recommendations from within the framework have already begun, with further implementation happening through 2022.