



## **ACCESS Guidance Document on Collection and Use of Sociodemographic and/or other Potentially Sensitive Data**

### **Purpose**

The intent of the document is to:

1. Outline the processes and recommended best practices concerning the collection, management, and use of potentially sensitive sociodemographic data within ACCESS activities.
2. Set clear expectations for data considerations across ACCESS projects inclusive of each stage of their development and implementation.
3. Provide resources and educational materials for the ACCESS community.

### **Rationale**

Research shows that children from underserved and marginalized sociodemographic groups have poorer cancer outcomes and experiences. To document these disparities and build responsive programs to bridge these gaps, we need to collect potentially sensitive sociodemographic information. Children and families can and have been harmed by the inappropriate collection, use, distribution, and analysis of this information. To date, there has not been a standardized process nor guidance on how to collect this data within the Canadian childhood cancer space. ACCESS endeavours to lead work to address this gap starting with this guidance document.

### **Principles**

This guidance document supports the ACCESS Equity Statement and key values of:

- Patient/Survivor and Family Centeredness
- Collaboration
- Anti-Oppression
- Innovation and Excellence
- Accountability

### **Processes for the Collection of Potentially Sensitive Information**

Where ACCESS projects are collecting and reporting potentially sensitive sociodemographic information (including but not limited to sex, gender, sexual orientation, race, ethnicity, Indigenous identity, ability/disability, genetic diagnoses, sociodemographic information, etc.), researchers, health care professionals and teams **must adhere to the following items**:

1. This information **must be self-reported** (by the patient themselves if they have the capacity to do so, or by caregivers/guardian, when appropriate)
2. When this information is categorized (for example, in race or ethnicity fields), the project **must use Canadian standardized and current data fields** (current recommendation:

CIHI Race-based Data Standard [Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada \(cihi.ca\)](#)). If this is an international study, the participants **must be presented with Canadian appropriate data field options** that can be mapped to the international options at a minimum.

3. The individuals tasked with collecting this information **must receive appropriate training**. Determination of appropriate training will depend on which data elements are being collected as part of the project. Please see list of training resources below.
4. Sensitive data **may not be abstracted, collected, nor included for/from any participant who has declined consent to share their information**.
5. Data governance of sensitive information **must be in alignment with ACCESS principles and other accepted Canadian guidelines**, as they are developed. Please see resources below.

Projects with ACCESS will be reviewed at the funding and publication stages to ensure adherence to these elements to the extent feasible.

### **Best Practice Guidance**

Standard and emerging best practices are listed below. We encourage all members of the ACCESS community to consider these at all stages of project development and implementation.

- All ACCESS research and associated projects will strive to collect patient-level sociodemographic data for the purposes of identifying and subsequently decreasing health inequities in the pediatric cancer community.
- When asking patients and families for potentially sensitive sociodemographic information, the rationale for why you are doing so, how it will be used and who will have access to this information should be explicitly outlined.
- The method of data collection should be documented and standardized amongst the research team, and in alignment with current best practices.
- As race and ethnicity are inherently social constructs, they should not be presented as an independent surrogate for biological or genetic variation, or genetic ancestry. For more information about this, please refer to [CMAJ's guidance on the reporting of race and ethnicity in research articles](#) editorial.
- Research teams will aim to include representation (as study partners, co-investigators and authors) from persons with lived experience, as well as those from diverse backgrounds affected by the health conditions being studied and analyzed. This becomes more essential as the depth of the exploration of the effects of sociodemographic variables are considered. Inclusion of diverse partners can help study teams avoid harms through how questions are asked, ensure diverse patients and families feel as comfortable as possible providing this potentially sensitive information, consider results in the context of lived experiences that may be imperceptible to outsiders, and add perspective to analyses and reporting that avoids perpetuating stereotypes.

### **Mandatory Training Resources:**

These resources **must be reviewed by project teams** as a first step in including equity into projects:

- CMAJ Guidance on reporting – as we expect research teams to adhere to these principles as much as feasible: <https://www.cmaj.ca/content/195/6/E236>
- ACCESS Education Session entitled ‘Incorporating anti-oppressive practices into the care of children with cancer in Canada’ presented by Stacey Marjerrison and Caroline Wai (video): [2023-11-01 CPCC Education Session - SJII.mp4](#)
- Presentation from the 2023 ACCESS Annual General Meeting entitled ‘Applying an Equity Lens to Pediatric Cancer in Canada’ presented by Caroline Wai (video): [AGM - Applying an Equity Lens to Pediatric Cancer in Canada.pdf](#)

Where projects include data on the following elements, at a minimum, at least the first listed training resource must be reviewed, and the others highly recommended:

- First Nations, Inuit and Métis Identity:
  - [The First Nations Principles of OCAP® - The First Nations Information Governance Centre \(fnigc.ca\)](#)
  - [CARE Principles — Global Indigenous Data Alliance \(gida-global.org\)](#)
  - Inuit Qaujimajatuqangit Principles – [Guidelines for Research Involving Inuit](#) (2010)
  - Manitoba Métis principles of ownership, control, access and stewardship – [Principles of Ethical Métis Research](#) (2011)
  - [Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada \(cihi.ca\)](#)
  - [San'yas Indigenous Cultural Safety Online Training \(sanyas.ca\)](#)
  - [Indigenous Relationship and Cultural Awareness Courses | Cancer Care Ontario](#)
  - [Indigenous Canada | University of Alberta \(ualberta.ca\)](#)
- Race and Ethnicity:
  - Engagement Governance, Access, and Protection (EGAP) Principles: <https://blackhealthequity.ca>
  - [Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada \(cihi.ca\)](#) – includes widely accepted Canadian race and ethnicity categories.
  - [Webinars on racism, anti-racism and racial equity | National Collaborating Centre for Determinants of Health \(nccdh.ca\)](#)
- Sex and Gender:
  - CIHR Sex and Gender training modules: [Home | CIHR-IRSC \(cihr-irsc-igh-isfh.ca\)](#)

### **Additional Project-Dependent Resources:**

These resources may be necessary depending on your project:

- ICES Guidance documents, which contain information on how to incorporate, analyze and report on your project with an equity lens: <https://www.ices.on.ca/health-equity-at-ices>
- [NCCIH - National Collaborating Centre for Indigenous Health > Home > EXTERNAL RESOURCES > Resource Library](#)
- POGO Indigenous resources, which contain further suggestions and resources on Indigenous health considerations: <https://www.pogo.ca/education/indigenous-resource-guide/>.
- [Introduction to health equity \[Online course\] | National Collaborating Centre for Determinants of Health \(nccdh.ca\)](#)
- City of Toronto Data for Equity Strategy: Includes questions, how-to (e.g., consent, ordering of questions, suggested core and optional SD questions beyond race and Indigenous identity): <https://www.toronto.ca/legdocs/mmis/2020/ex/bgrd/backgroundfile-158052.pdf>
- Adapted/evolved questions from the We Ask Because We Care Tri-Hospital + TPH pilot on socio-demographic data collection: <http://torontohealthequity.ca/wp-content/uploads/2013/02/Measuring-Health-Equity-Demographic-Data-Collection-Use-in-TC-LHIN-Hospitals-and-CHCs-2017.pdf> .
- Considerations for patients under 18: <http://torontohealthequity.ca/wp-content/uploads/2017/08/Collecting-Demographic-Data-from-Hospital-Patients-under-18.pdf>
- Health Equity Sample training modules: <https://torontohealthequity.ca/training/>
- Nipissing University Research on Indigenous Data Collection: <https://www.nipissingu.ca/departments/indigenous-initiatives/research>
- The Nunatsiavut Research Centre's Government Research Advisory Committee [Nunatsiavut Government Research Advisory Committee – Nunatsiavut Research Centre](#)
- The Manitoulin Anishinabek Research Review Committee: [Research Ethics \(noojmowinteg.ca\)](#)
- The Six Nations Research Ethics Policy [Conducting Research at Six Nations](#)
- The Canadian Cancer Clinical Trials Network (3CTN) EDI Framework and Toolkit <https://3ctn.ca/equity-diversity-and-inclusion-in-clinical-trials/>
- Ontario Health Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics (for PDF of report, please contact the ACCESS Secretariat).