McMaster University and the McMaster Children's Hospital are located on the traditional territory shared between the Haudenosaunee confederacy and the Anishinabe Nations, and within the lands protected by the "Dish with One Spoon" wampum agreement.

Toronto is located on the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples and is now home to many diverse First Nations, Inuit and Métis peoples. The City of Toronto is covered by Treaty 13, and the Williams Treaties.

The city of New Orleans is located in the region known as "Bulbancha" a Choctaw term meaning "place of many tongues". It was originally inhabited by the Chitmacha Nation, and prior to 1718 served as a hub for more than 30 Diverse Peoples.
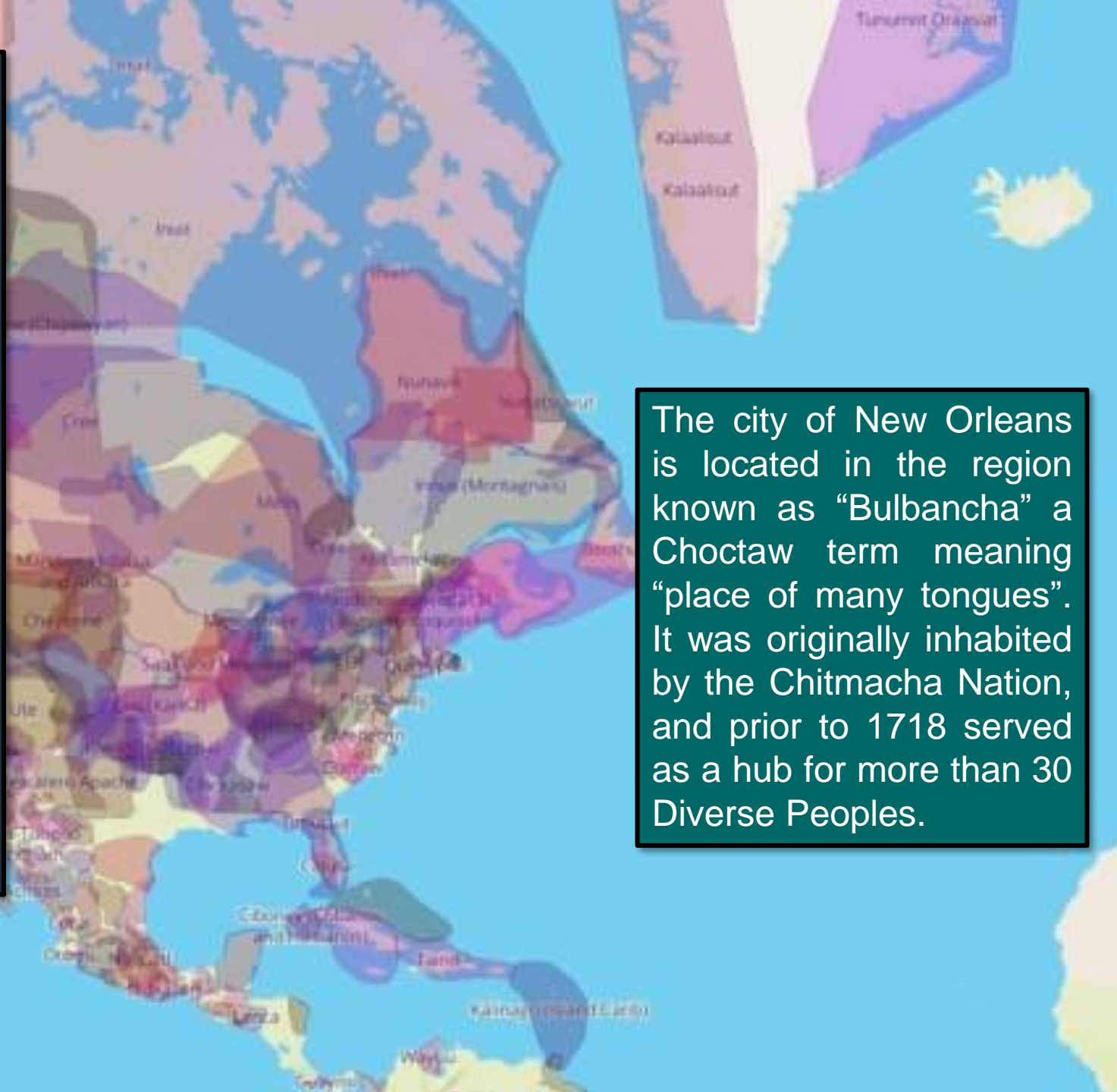
Overview

access acces

Background

Why do we need to collect this information?

What is ACCESS?

Canadian Data Standards

American vs. Canadian Race/Ethnicity Categories

Training for Research Staff

Goal: Consensus Canadian Recommendation for Race/Ethnicity Categorization

Join at
slido.com
#2371541

What sociodemographic information might be potentially sensitive?

What is Potentially Sensitive Sociodemographic Information?

Information including but not limited to:

- Sex
- Gender
- Sexual orientation
- Race
- Ethnicity
- Indigenous identity

- Ability/disability
- Genetic diagnoses
- Family structure
- Finances
- Employment
- Education, Immigration, etc.

Which of the following describes your experience of collecting sensitive sociodemographic data?
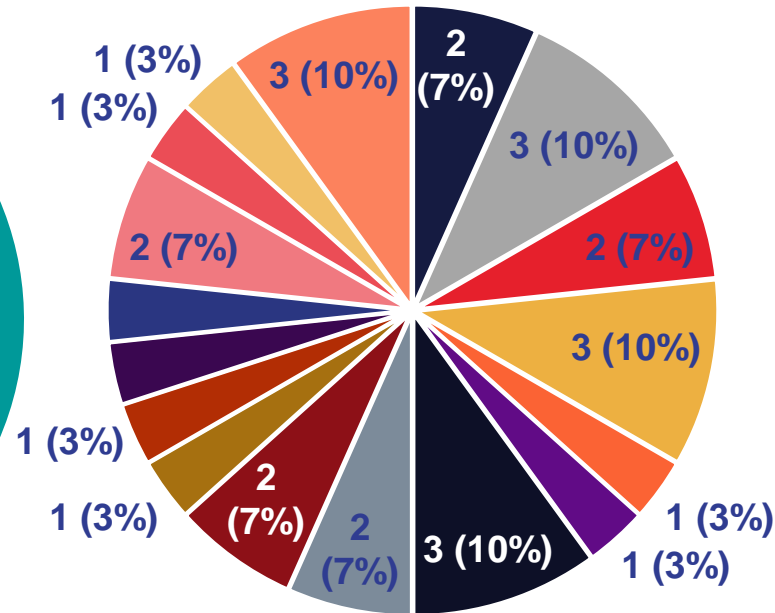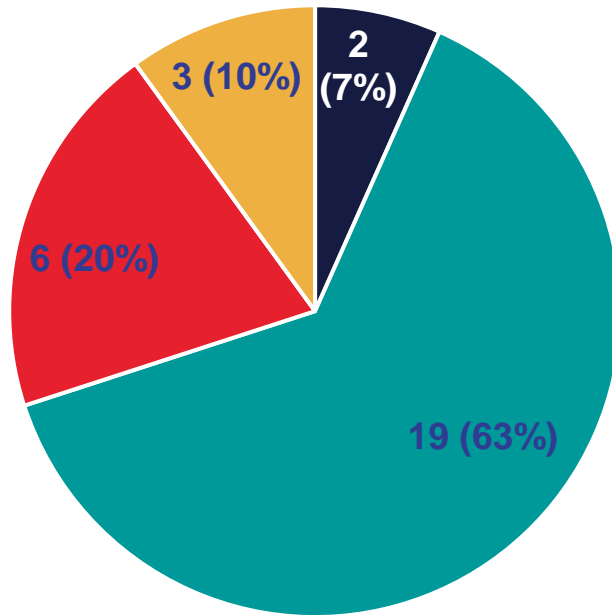
Current Landscape of Collection of Sensitive Sociodemographic Data in Canada
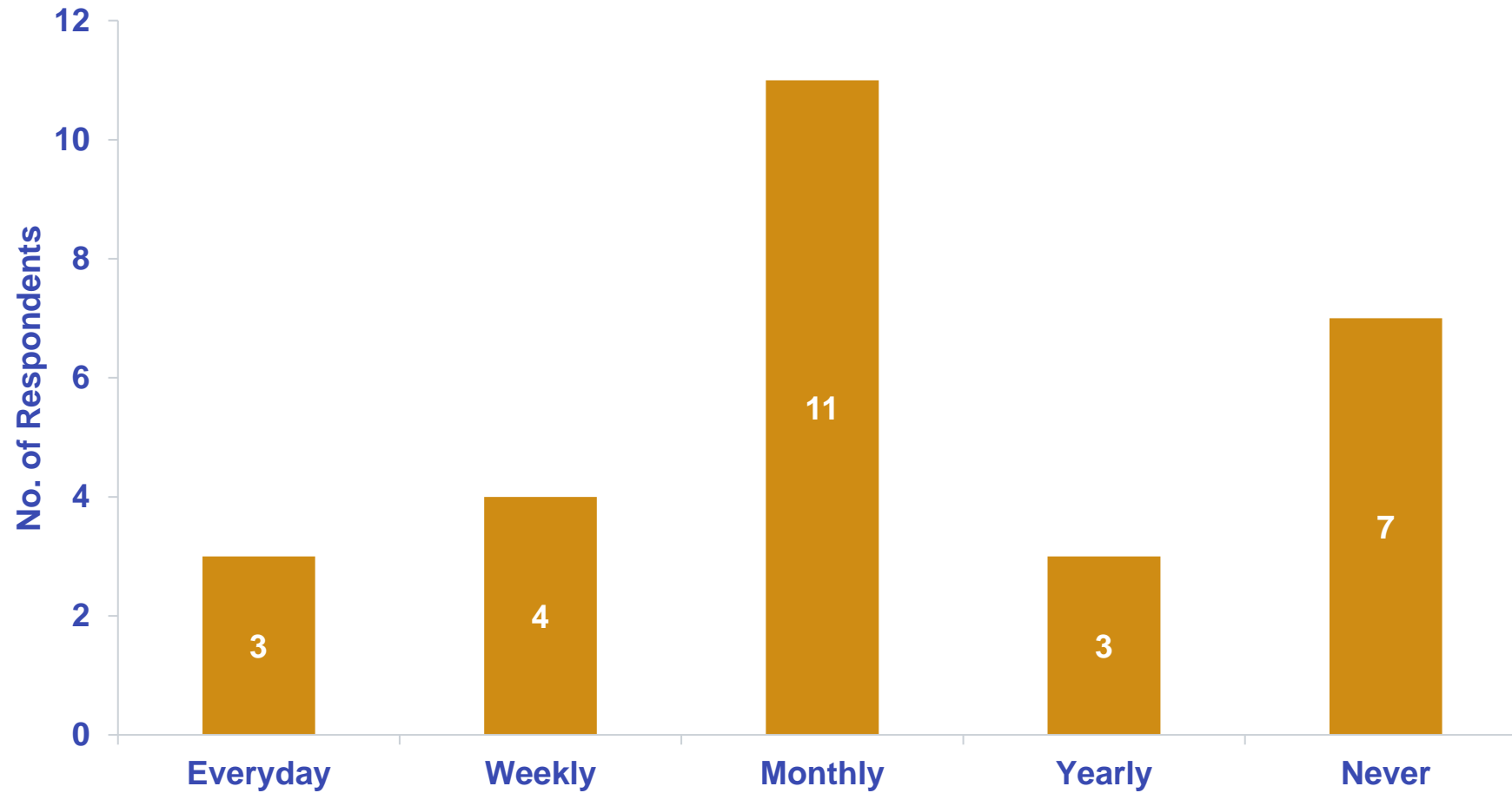
Canadian Survey of Research Staff

o 30 research staff asked about collection of sensitive sociodemographic information

o Surveyed April-May 2024

Who collects this information?
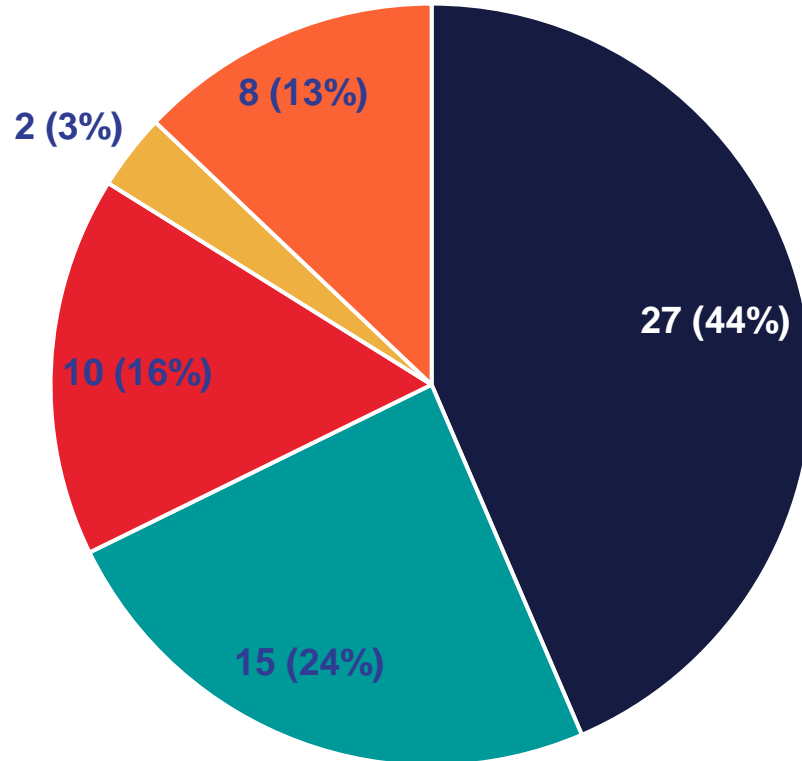
- Clinical team (i.e., physician, residents, fellow, nurses, Social Work, Childlife, etc.) — 27 (44%)
- Clinical Research Nurse — 15 (24%)
- Clinical Research Associate — 10 (16%)
- Other research team member — 2 (3%)
- Self-Reported by patient — 8 (13%)

What type of research training have you completed?
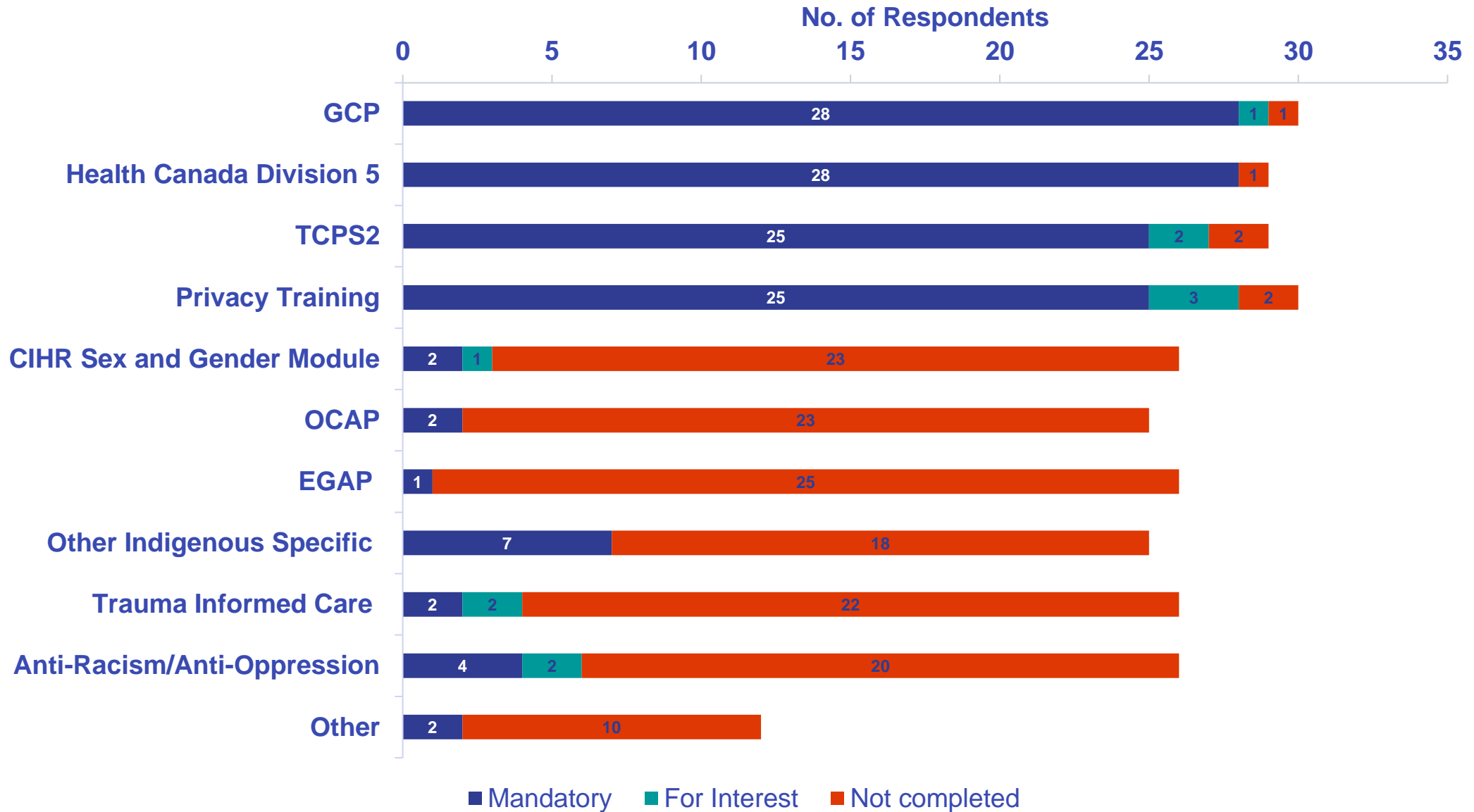
With the training you have received, how comfortable do you feel in asking patients and families for this sensitive information?

Legend:
- Very comfortable
- Somewhat comfortable
- Very uncomfortable
- I do not collect this information
- I prefer not to answer

Pie chart values:
- 1 (3%)
- 4 (13%)
- 10 (34%)
- 2 (7%)
- 13 (43%)
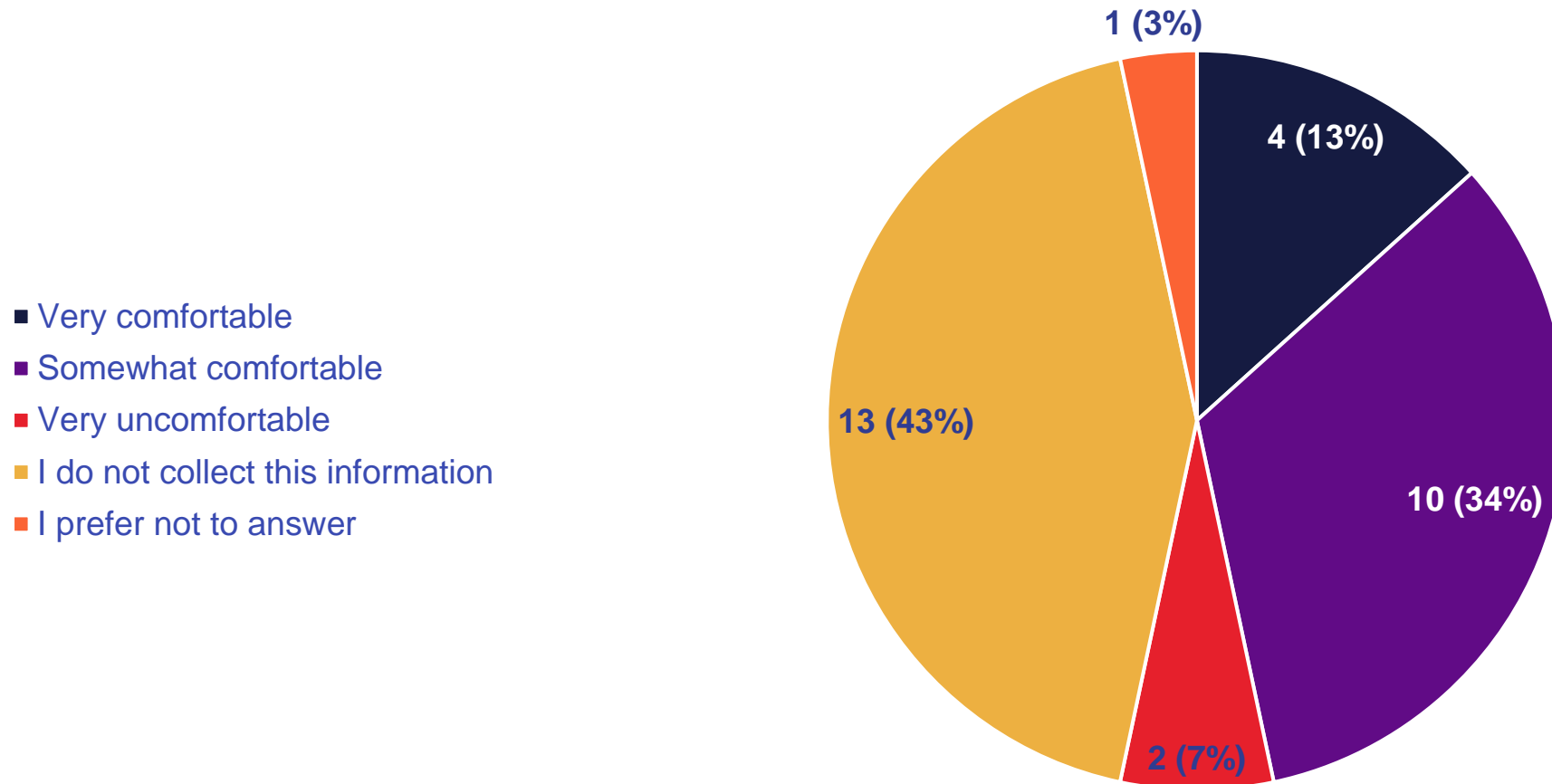
Is this information self-reported?
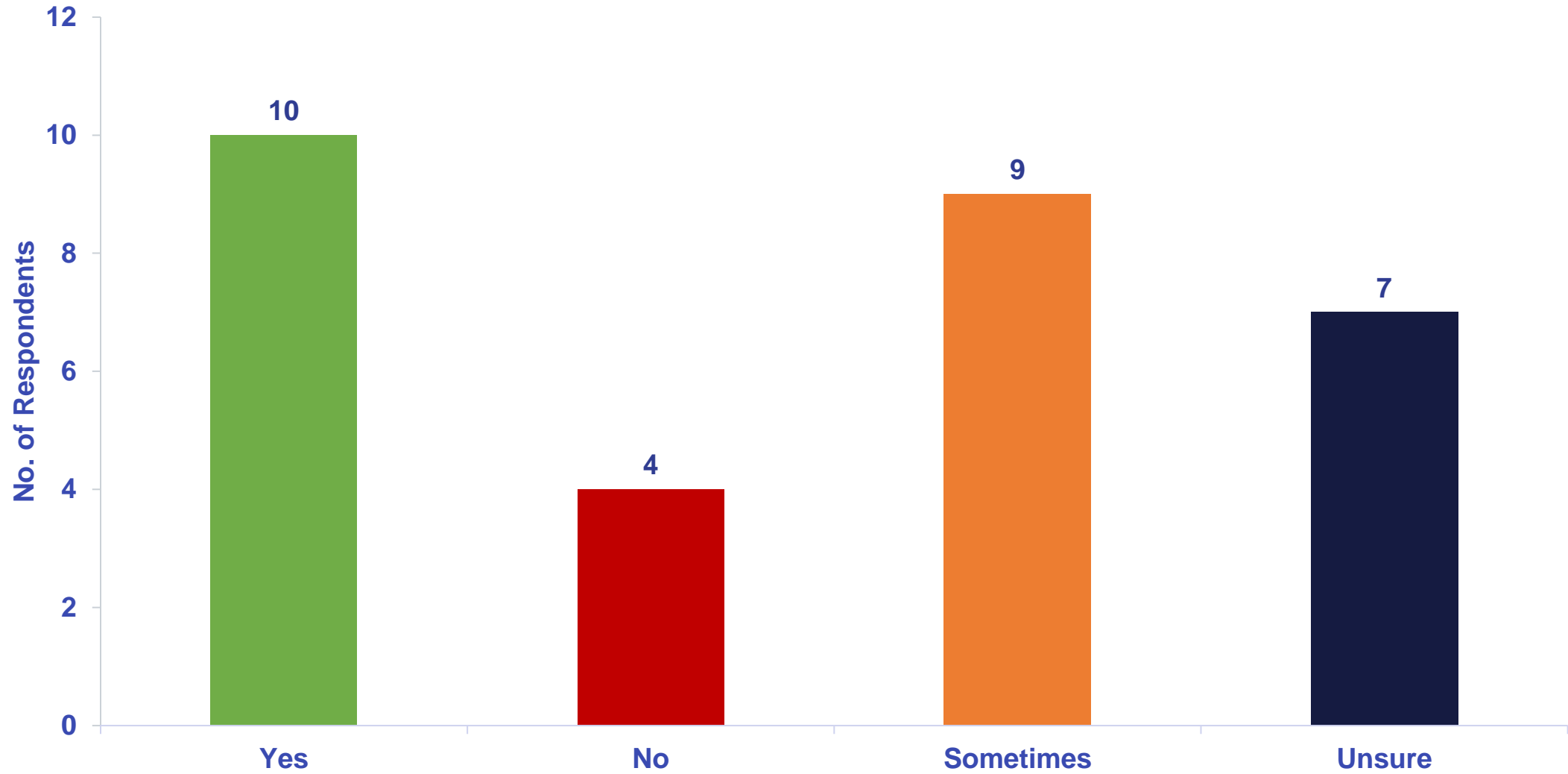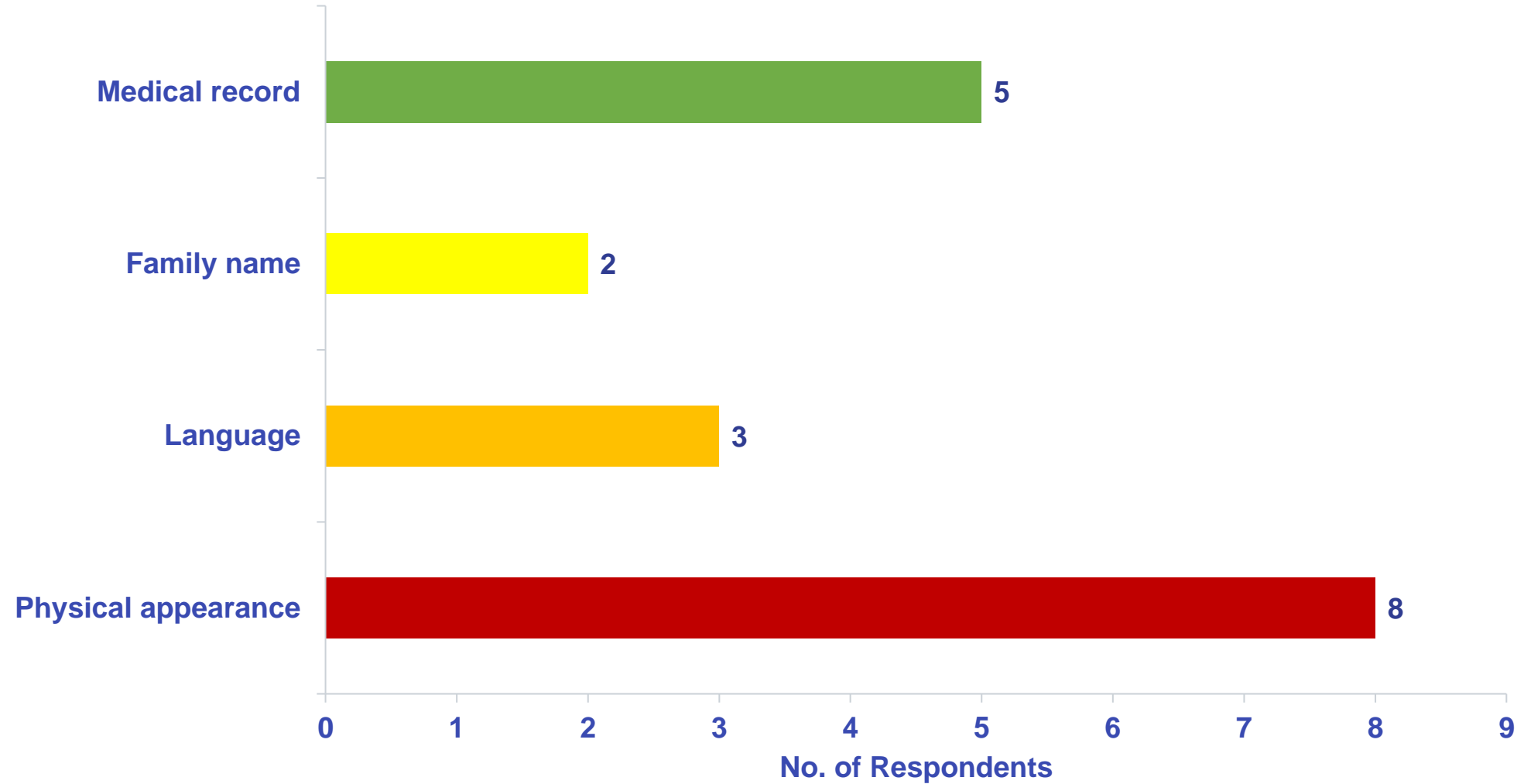
In your experience, how has race-based (and other sensitive socio-demographic) data been collected in research projects in your institution?

(Choose all that apply)

Why is collecting this information important?

Table Exercise

- Introduce yourself to your peers - your name, role and institution
- Then please discuss:
    - If you had access to race/ethnicity and other sensitive sociodemographic information, how would/do you - in your role - use this information to:
        1. Improve patient care on an individual level?
        2. Improve care within the system of your hospital/institution?

        AND…

    - How would you want to access this information?

American Association for Cancer Research Progress Report 2022

Why Do U.S. Cancer Health Disparities Exist?
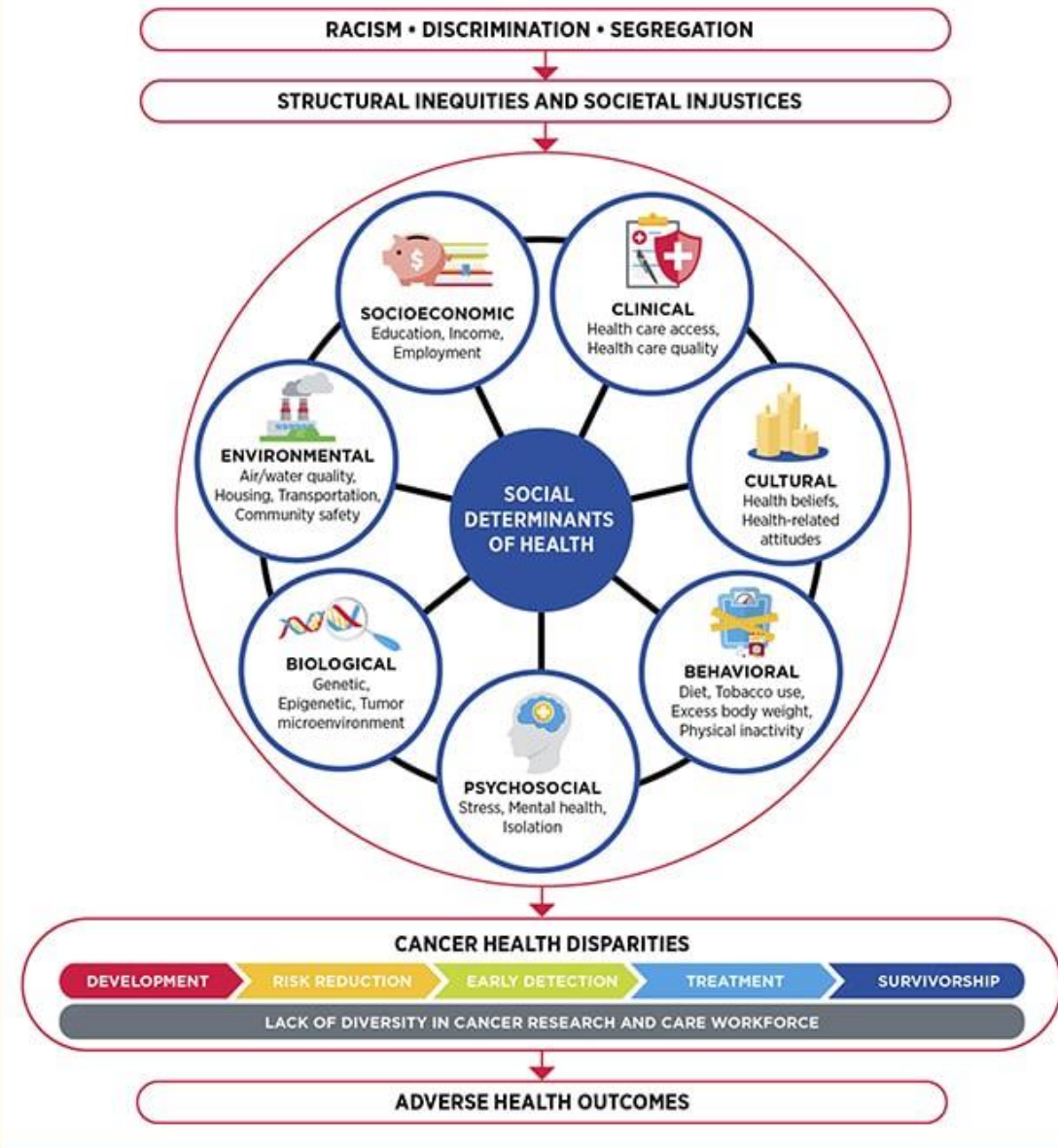
Adapted from *American Association for Cancer Research® (AACR) Cancer Disparities Progress Report 2022*

FIGURE 11

Discrimination Is a Major Barrier to Receiving Quality Health Care
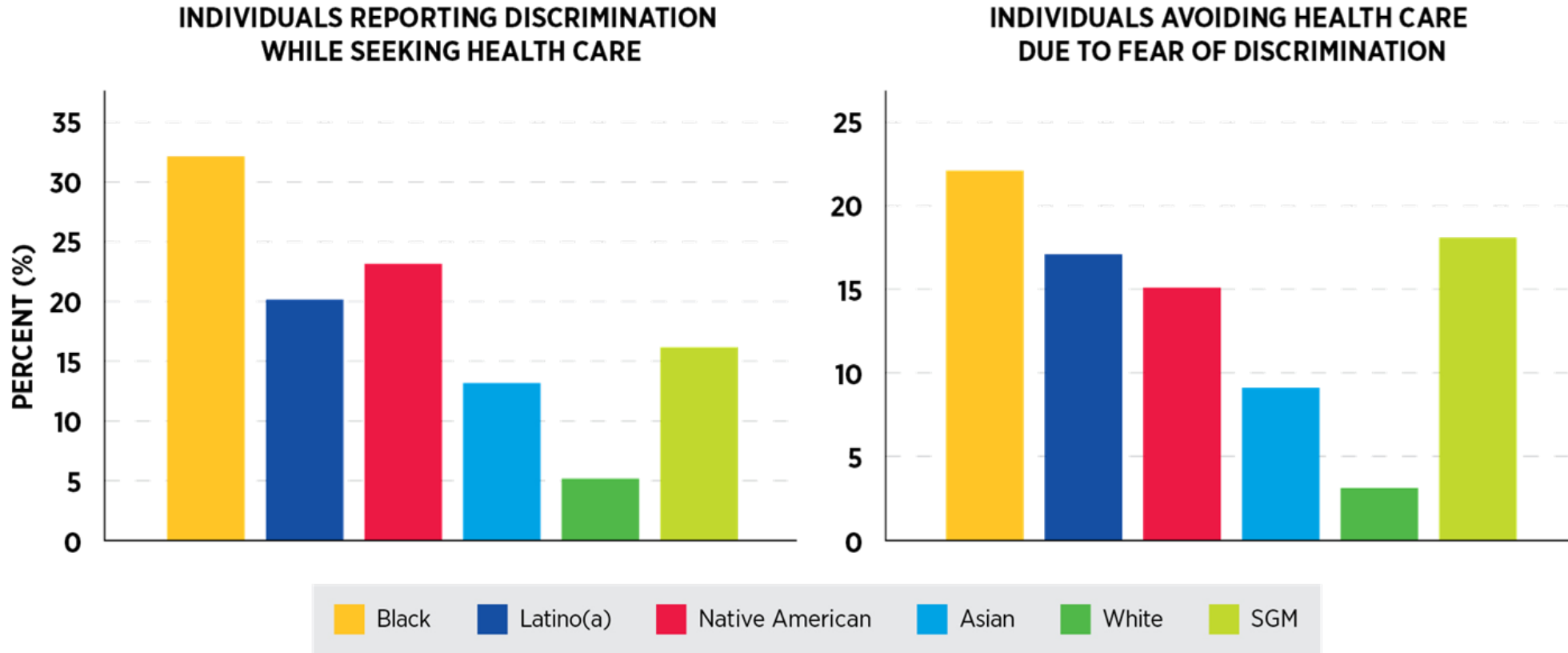
American Association for Cancer Research® (AACR) Cancer Disparities Progress Report 2022

Disparate Childhood Cancer Survival by Race/Ethnicity

ALL 1983-1989

Neuroblastoma (2011)
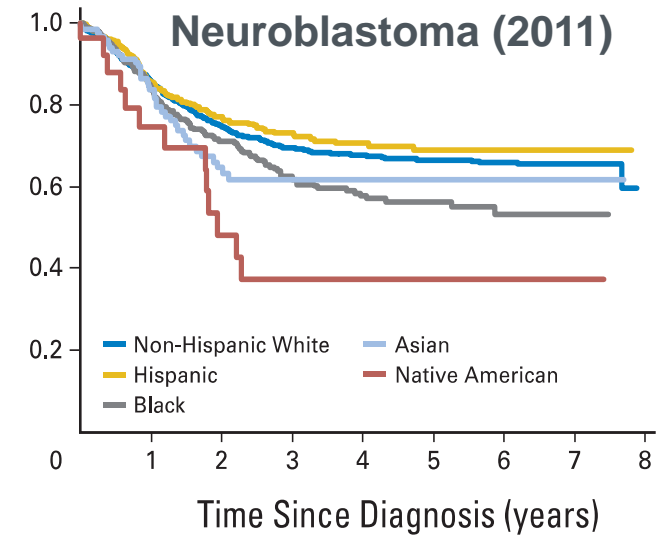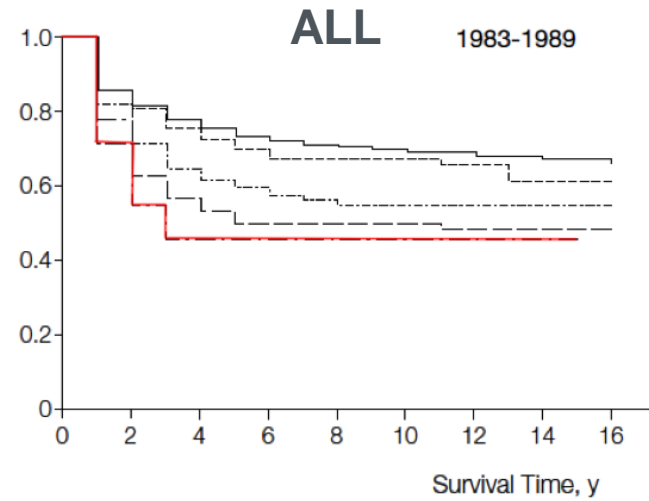
SEER Data 2000-2017 (2022)
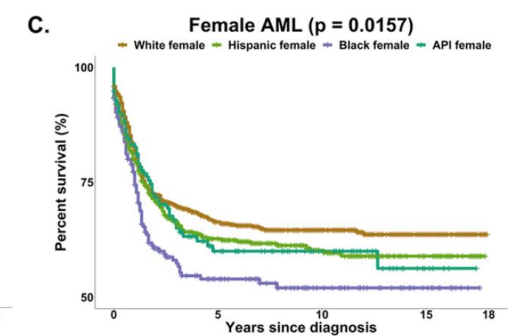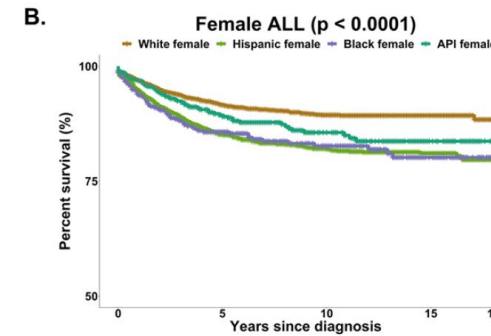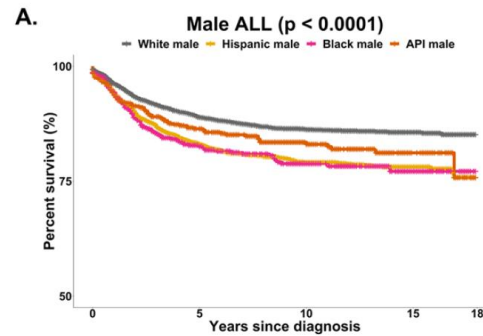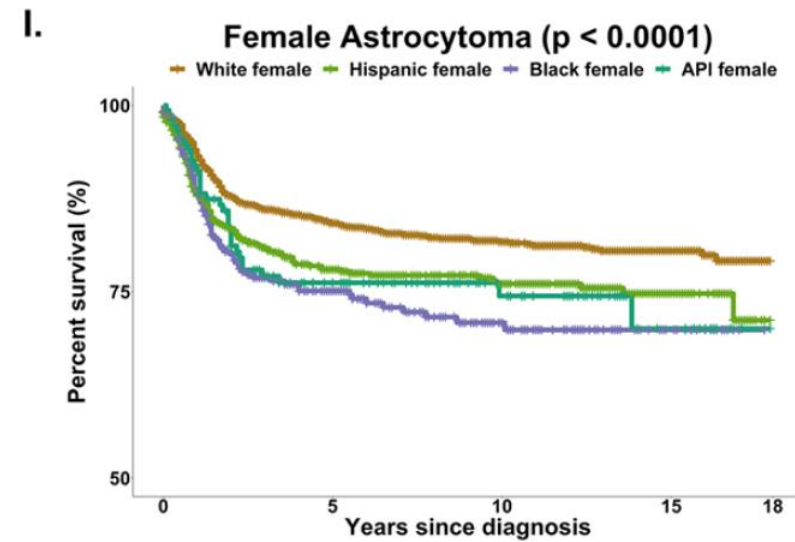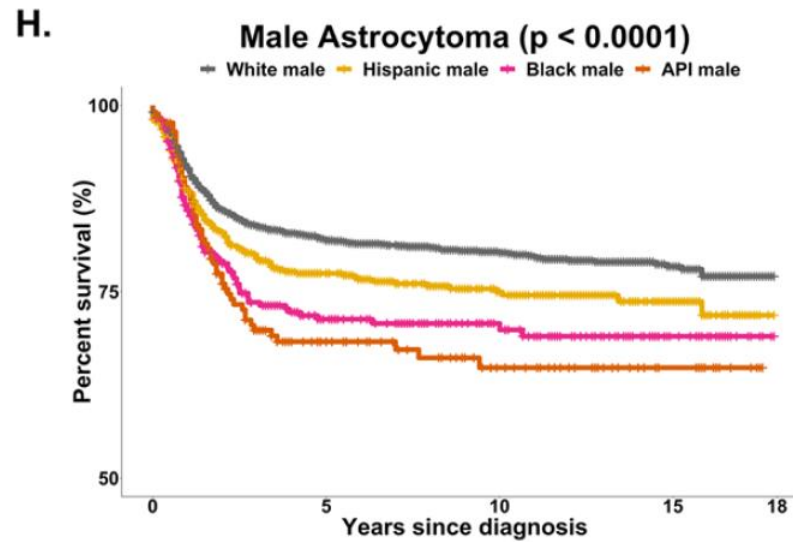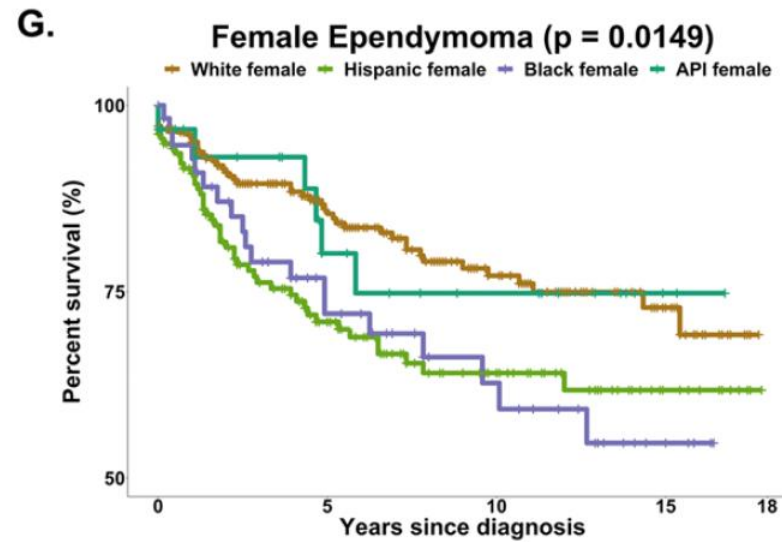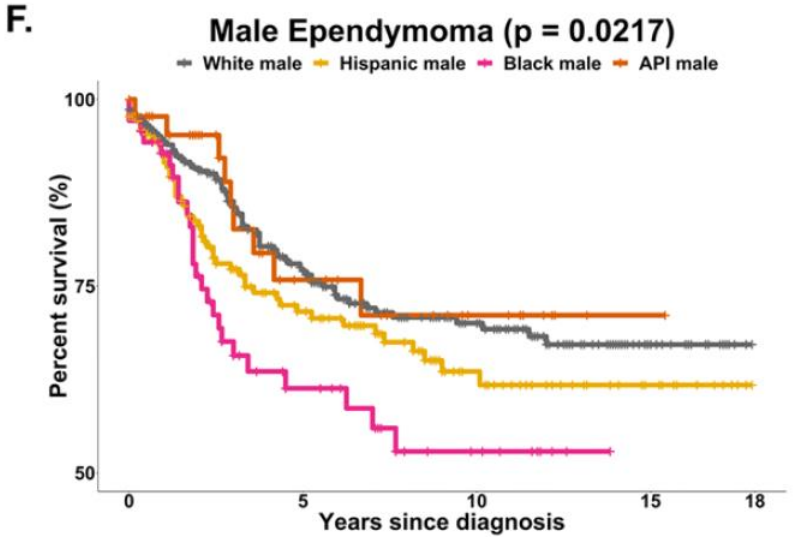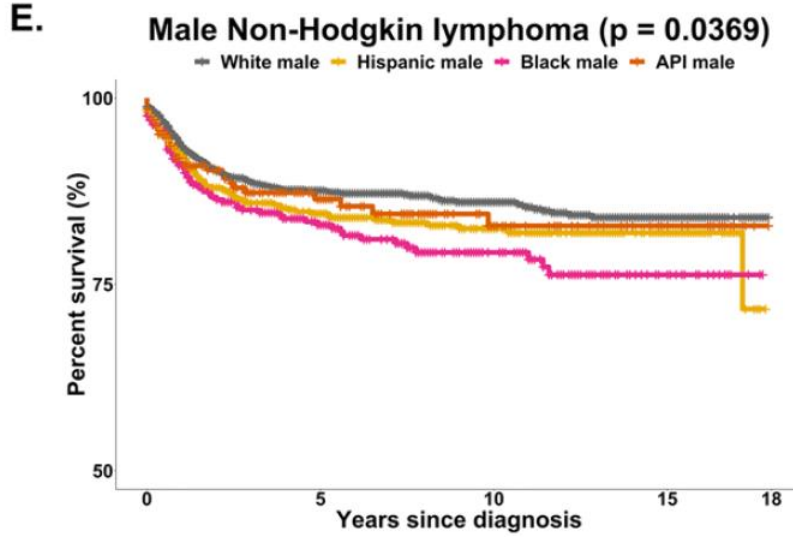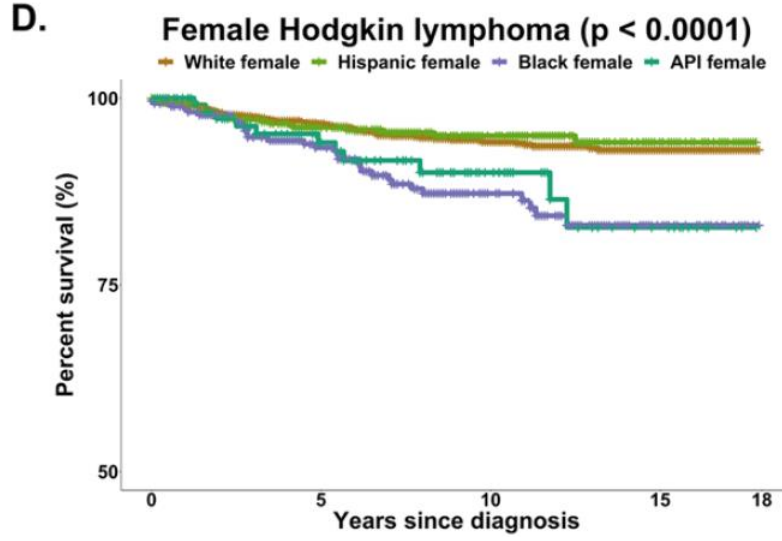
Systematic Review of Low SES & Survival, 2014

NEGATIVE ASSOCIATIONS

POSITIVE ASSOCIATIONS

◆ = Significant
◆ = Non Significant
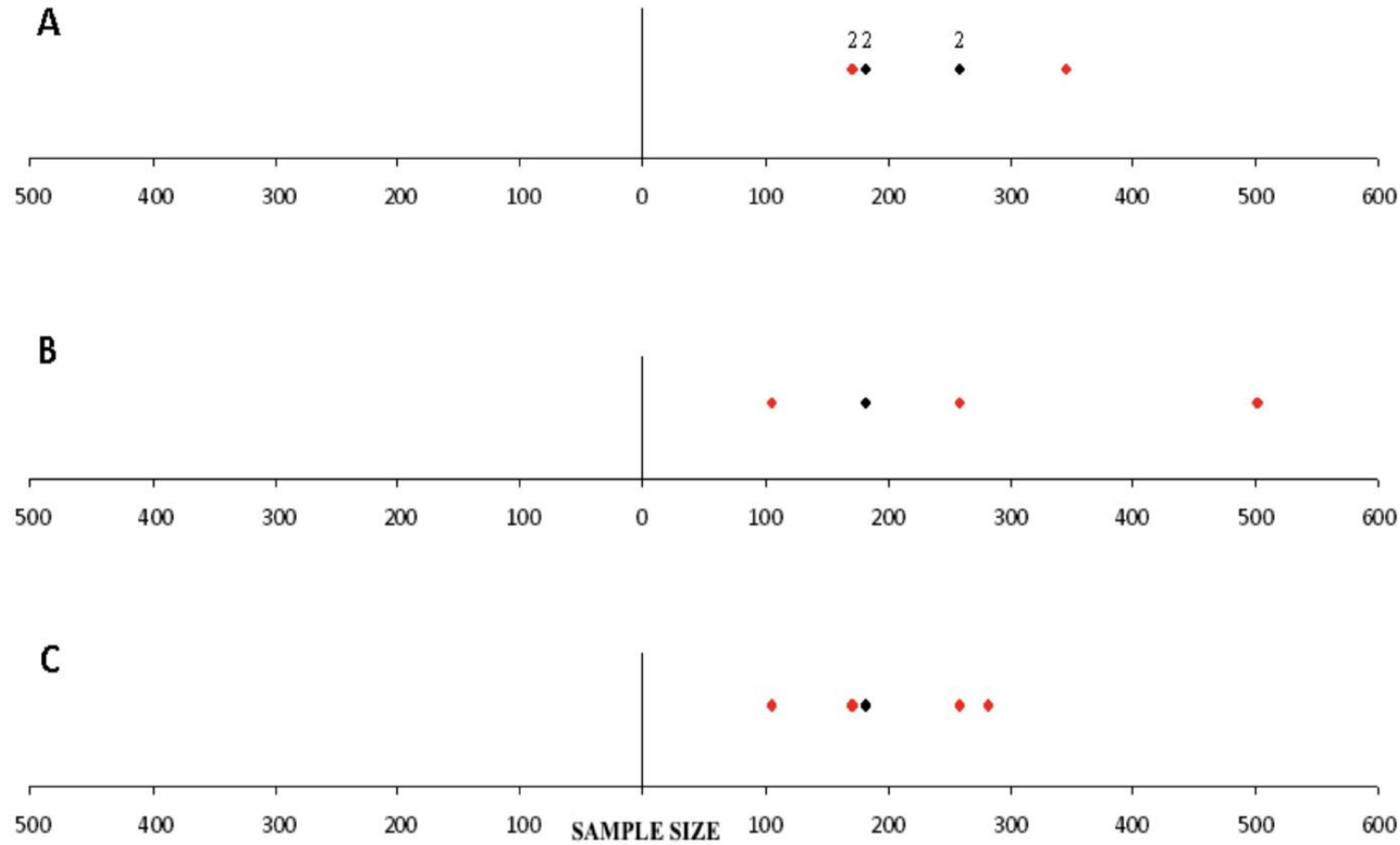
Associations between socioeconomic measures and event-free and overall survival in high-income countries.
A. Ecologic measures B. Measures of material possession, family composition, insurance status, immigrant status, and health care accessibility. C. Measures of education and occupation. D. Measures of income. Positive=lower socioeconomic status associated with inferior outcome; Negative=lower socioeconomic status associated with superior outcome

Financial Hardship in Childhood Cancer Survivors
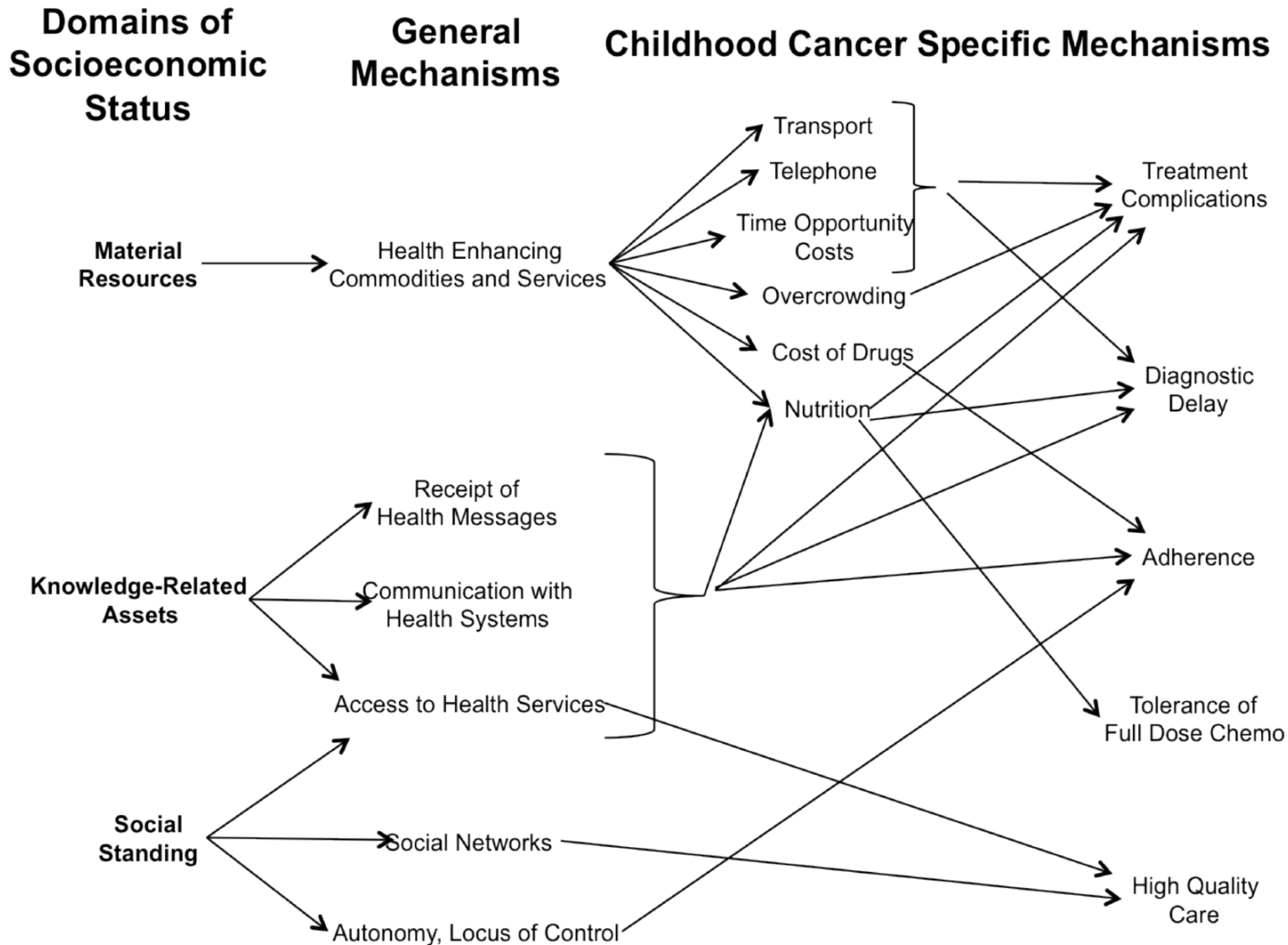
Table 2. Descriptive statistics of area deprivation distribution in survivors and siblings

Distribution measure	Survivors (n = 3475)	Siblings (n = 923)	P^a
ADI quintile cutoff points	16, 31, 47, 67		
ADI quintile, No. (%)			
First, least deprivation	604 (18.0)	203 (23.8)	<.001
Second	605 (18.8)	182 (21.4)	
Third	642 (20.5)	172 (20.2)	
Fourth	656 (20.6)	154 (18.1)	
Fifth, greatest deprivation	705 (22.0)	141 (16.5)	
Disadvantage area, No. (%)			
Low disadvantage area, ADI national rank <50	1976 (61.3)	581 (68.2)	
High disadvantage area, ADI national rank ≥50	1236 (38.7)	271 (31.8)	<.001

[a] Wilcoxon test for continuous variables (testing for medians) or χ^2 test for categorical variables. ADI = Area Deprivation Index.

COG Trial Results

Published Studies Related to Diversity and Health Disparities Using COG Clinical Trial Data from 2013–2023

Disease	Study	COG Study ID	Key Findings Related to Diversity and Health Disparities
ALL	Bhatia, 2014[46]	AALL03N1	6MP adherence during maintenance chemotherapy for ALL lower in Asian Americans and African Americans.
	Gupta, 2022[47]	AALL0331, AALL0232, AALL0434	Boys with inferior EFS and OS of ALL attributable to increased relapses (particularly CNS relapse).
	Gupta, 2023[24]	AALL033, AALL0932, AALL0232, AALL1131, AALL0434, AALL1231, AALL0631, AALL15P1	Black and Hispanic children had inferior EFS in B-ALL. No racial or ethnic disparities in T-ALL.
	Wadhwa, 2023[48]	AALL03N1	Poverty associated with greater hazard of relapse and non-adherence to 6MP during maintenance chemotherapy for ALL.
CNS	Nooka, 2016[49]	Multiple COG and PBTC phase 1 clinical trials	Sex and racial/ethnic groups are mostly proportionally represented phase 1 brain tumor trials. Subgroups of Hispanic children are underrepresented.
HOD	Kahn, 2019[28]	AHOD0341, AHOD0031, AHOD0831	EFS did not differ by race/ethnicity in HOD. Adjusted OS was significantly worse in non-White patients, driven by increased post-relapse mortality.
NBL	Bona, 2021[20]	ANBL0032, ANBL0931	Poverty independently associated with increased risk of relapse and death in children with NBL.
OST	Ilcesan, 2022[50]	AOST0331	No association of poverty, race, or ethnicity with EFS or OS in children and adolescents with OST. Black children had inferior post-relapse survival.

COG Trial Results

RET	Green, 2016[51]	ARET0332	Advanced RET disease associated with non-private insurance, non-White race, and Hispanic ethnicity.
RMS	Munnikhuysen, 2023[52]	D9602, D9802, D9803, ARST0331, ARST0431, ARST0531, ARST08P1	Black and Hispanic patients presented with higher risk features at diagnosis of RMS, no difference in EFS or OS.
Multiple	Bitterman, 2020[53]	Multiple solid tumor clinical trials	Black patients enrolled on COG solid tumor prospective clinical trials less likely to receive proton radiotherapy. No association with SES on proton radiotherapy.
	Faulk, 2020[9]	Multiple	Across COG clinical trials racial and ethnic groups and county-level SES factors were represented proportionally in relation to SEER. AYA and younger patients with solid and CNS tumors were underrepresented.
	Brown, 2022[54]	Multiple	Childhood Cancer Research Network (registry) cases represent 36% of expected childhood cancers diagnosed 2008 to 2015. Enrollment ratios highest in males, non-Hispanic patients, and ages 1–4 years.
	Puthenpura, 2023[26]	Multiple	In patients enrolled in phase 2/3 and phase 3 COG clinical trials, highest rates of loss to follow-up in AYAs, racial and ethnic minority patients, and lower SES.

Abbreviations: 6MP – 6-mercaptopurine, ALL – acute lymphoblastic leukemia, AYA – adolescent and young adult, CNS – Brain tumors, COG – Children's Oncology Group, EFS – event free survival, HOD – Hodgkin lymphoma, NBL – neuroblastoma, OS – overall survival, OST – osteosarcoma, PBTC- Pediatric Brain Tumor Consortium, RET -retinoblastoma, RMS – rhabdomyosarcoma, SES – socioeconomic status

What health inequities exist in pediatric cancer in Canada?

o   What do we measure?

o   How would we know?

Canadian Childhood Cancer Data Sources

Administrative & Billing Data	• Ex: ICES, StatsCan • Difficult patient identification, linkages possible, limited individual socio-demographics
Cancer Registry Data	• Ex: POGONIS, CYP-C • Comprehensive patient enrolment, linkage possible, limited socio-demographics
Clinical Trial Data	• Ex: Children's Oncology Group (COG) • Individual-level data, limited to study questions, only those who choose to enroll
Institutional Data	• Ex: McMaster, SickKids, Alberta Children's, IWK... • Permits detailed analysis, but limited sample size & generalizability

Adapted from: https://ascopubs.org/doi/pdf/10.1200/EDBK_320499

Indigenous Childhood Cancer Outcomes in Ontario
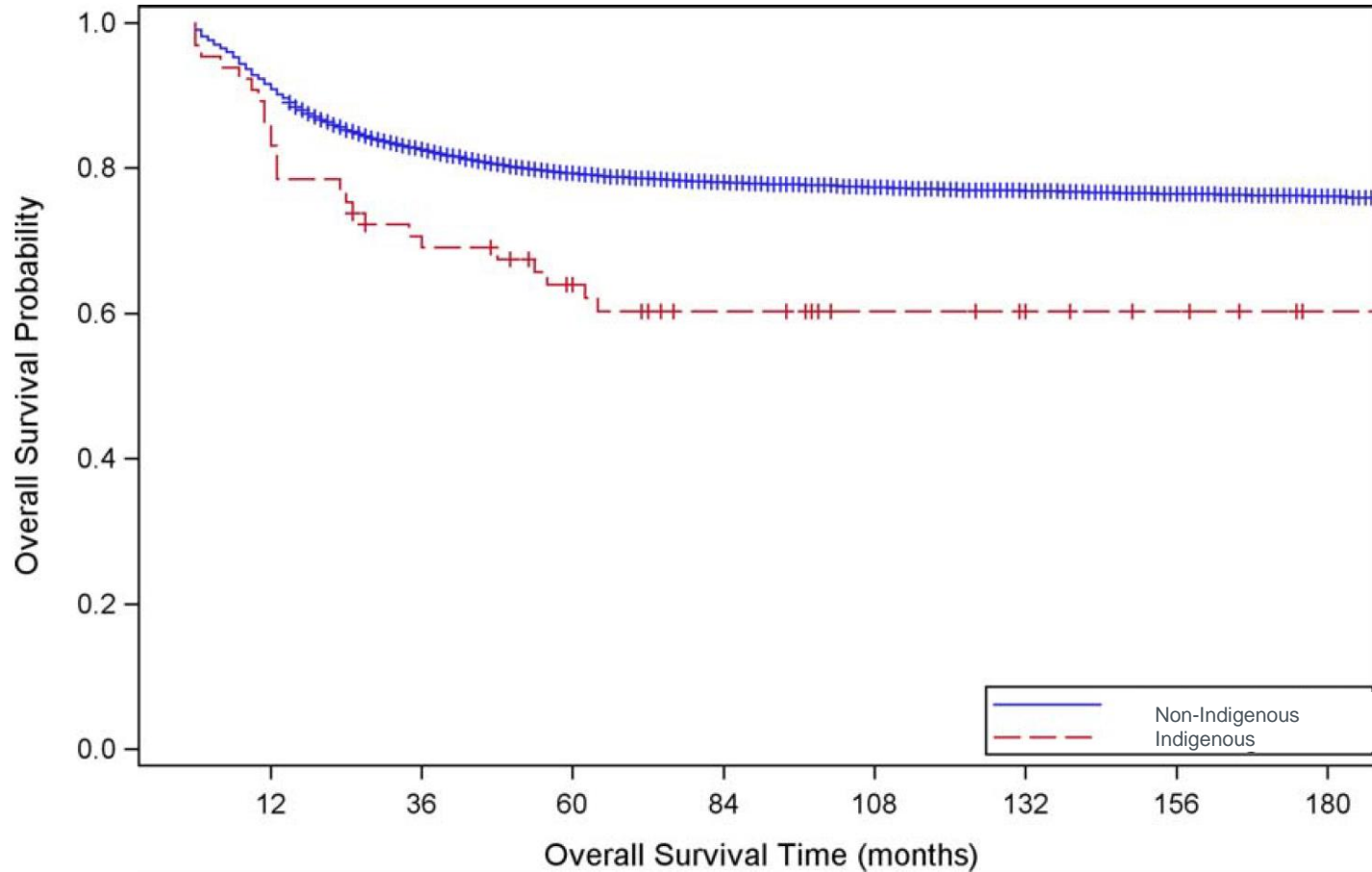
According to Ontario census data, Aboriginal children comprise 2.77% (86,665 of 3127,700) of the population aged ≤19 years.[41] However, in our study, the proportion of children with cancer who were identified as Aboriginal was only 0.62%.

SES and survival in Pediatric ALL in Ontario

Table 3
Univariate and multivariable predictors of event-free survival (N = 1541).

	Univariate			Multivariable		
	HR	95th CI	p	HR	95th CI	p
Socioeconomic variables						
Neighborhood median income quintile						
Q1 (lowest)	Ref	Ref	–	Ref	Ref	–
Q2	1.04	0.70–1.55	0.84	0.93	0.62–1.40	0.69
Q3	1.02	0.68–1.51	0.94	1.03	0.69–1.54	0.89
Q4	1.13	0.77–1.66	0.54	1.09	0.74–1.62	0.68
Q5	1.14	0.77–1.71	0.52	1.09	0.72–1.64	0.70
Immigrant						
No	Ref	Ref	–	Ref	Ref	–
Yes	**0.36**	**0.13–0.96**	**0.04**	**0.33**	**0.12–0.88**	**0.03**
Health care access variables						
Distance from tertiary center						
Short	Ref	Ref	–			
Long	1.05	0.79–1.38	0.76			
Rurality						
Urban	Ref	Ref	–			
Rural	1.15	0.80–1.64	0.46			

CI, confidence interval; HR, hazard ratio; WBC, white blood cell count.
Statistically significant associations are bolded.
 [a] Based on treatment protocol name.

http://dx.doi.org/10.1016/j.leukres.2014.08.017

SES, Distance & Outcomes – Canadian CYP-C Database *

	Event-Free Survival (N=4,162)				Overall Survival (N=4,162)			
	Univariate		Multivariable		Univariate		Multivariable	
	HR (95% CI)	p-value	HR (95% CI)	p-value	HR (95% CI)	p-value	HR (95% CI)	p-value
Socioeconomic Variable – Income Quintile								
1 (lowest)	REF		REF		REF		REF	
2	**0.73 (0.56-0.96)**	**0.02**	0.80 (0.61-1.04)	0.10	0.75 (0.52-1.07)	0.11	0.82 (0.57-1.18)	0.29
3	**0.70 (0.54-0.90)**	**0.007**	0.79 (0.61-1.03)	0.08	**0.67 (0.47-0.96)**	**0.03**	0.79 (0.55-1.13)	0.20
4	**0.65 (0.50-0.85)**	**0.001**	**0.70 (0.54-0.91)**	**0.008**	**0.66 (0.47-0.94)**	**0.02**	0.71 (0.50-1.02)	0.06
5 (highest)	0.79 (0.61-1.01)	0.06	0.85 (0.66-1.09)	0.20	0.75 (0.53-1.05)	0.09	0.80 (0.57-1.14)	0.21
Access to Care Variable – Distance to treating tertiary care center quartile (km)[b]								
1 (shortest)	REF		REF		REF		REF	
2	**0.75 (0.59-0.95)**	**0.02**	0.79 (0.62-1.00)	0.05	0.73 (0.53-1.01)	0.06	0.78 (0.57-1.10)	0.16
3	**0.79 (0.62-0.99)**	**0.04**	0.84 (0.66-1.06)	0.14	0.74 (0.54-1.02)	0.07	0.82 (0.59-1.13)	0.22
4 (longest)	0.82 (0.65-1.03)	0.09	0.89 (0.70-1.12)	0.31	0.88 (0.64-1.20)	0.41	0.93 (0.68-1.27)	0.64

- Solid Tumours
- Work is ongoing, showing similar trends in univariate analyses

Food Insecurity in the McMaster ED

Prevalence of food insecurity (%)
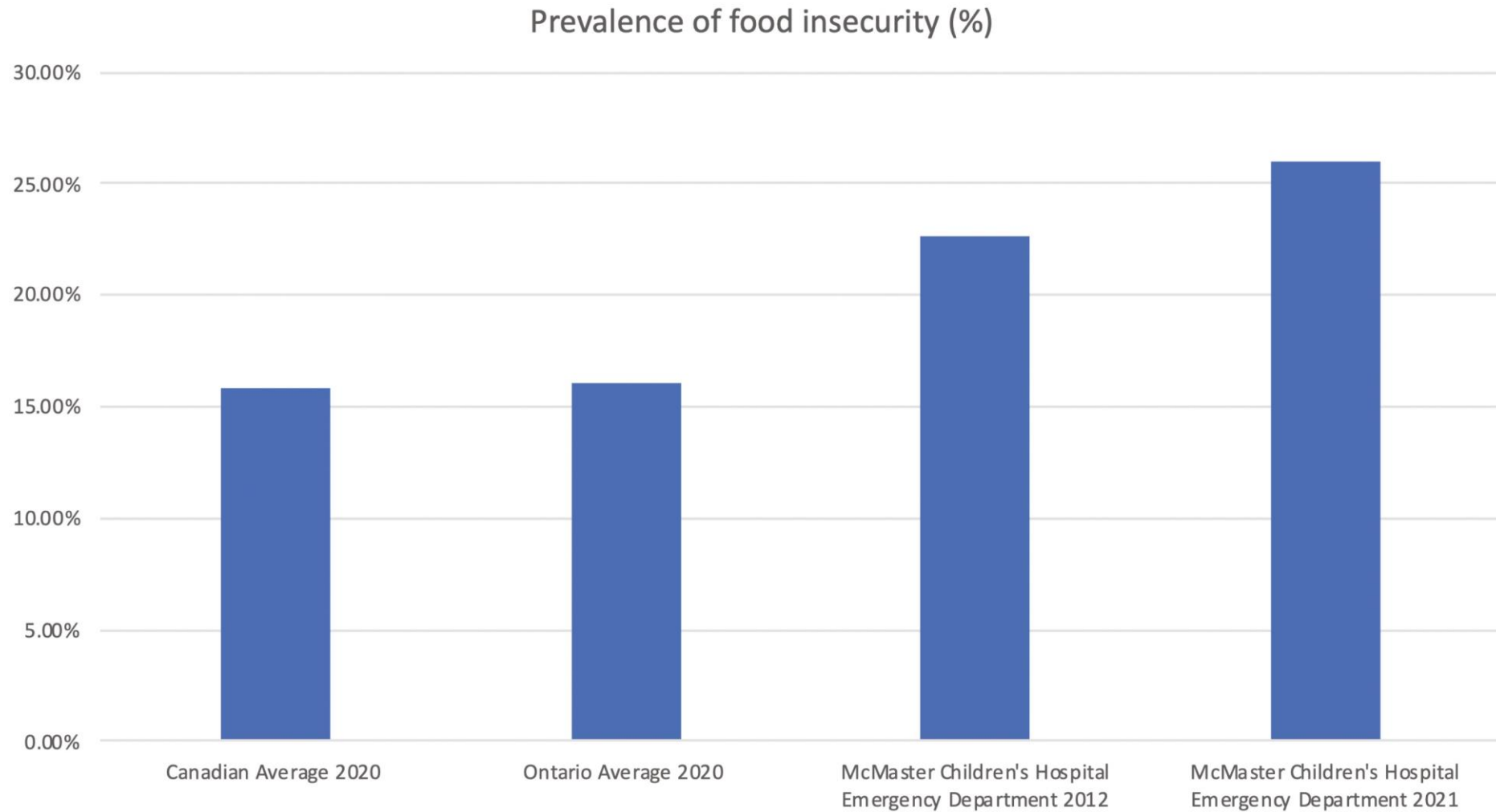
Food Insecurity in the McMaster ED

Table 1. Child health and self-reported household demographic data in relation to food security status

	Food-insecure, n (%)	Food-secure, n (%)	P value
Total families	173 (26%)	492 (74%)	
Child with chronic medical condition	75 (43.4%)	138 (28%)	<0.001
Medical expenses for child causing financial strain (all comers)	96 (55.5%)	71 (14.4%)	<0.001
Child with chronic medical condition and medical financial strain	66/75 (88%)	55/138 (40%)	<0.001
ED visit reason related to child's chronic medical condition	75 (43.4%)	138 (28%)	<0.001
Child with special diet due to medical condition	45 (16.2%)	49 (10%)	NS
Household receiving social assistance	87 (50.3%)	81 (16.5%)	<0.001
Caregiver born in Canada	112 (64.7%)	379 (77%)	0.002
Caregiver Canadian citizen	128 (74%)	434 (88.2%)	<0.001
Caregiver with status other than Canadian citizen[a]	45 (26%)	58 (11.8%)	<0.001

[a]Includes permanent resident, refugee, student visa, work visa or temporary worker, and primary identification as First Nations, Métis or Inuit

Food Insecurity in the McMaster ED

Table 3. Preferred means of in-hospital material support expressed by families experiencing food insecurity

Free or low cost meals provided by hospital	**108 (62%)**
Financial help for child's medical expenses	75 (43%)
Food bank or pantry in hospital	70 (40%)
Access to kitchen in hospital	68 (39%)
Information on local food banks/programs	49 (28%)
Meeting with social worker	48 (28%)
Not needed	5 (3%)

Charting a New Path with ACCESS

MENU ⌄

Canada.ca

Canadian Pediatric Cancer Consortium

From: Canadian Institutes of Health Research

Backgrounder

The $23 million investment in the Canadian Pediatric Cancer Consortium is the largest investment ever made for a Canadian pediatric cancer research project in Canada. The funds for the Consortium come from the $30 million investment in pediatric cancer research announced in Budget 2021.

The Consortium will research all phases of childhood cancer - from prevention to diagnosis to treatment to survivorship. It will address knowledge gaps in pediatric cancer research. Objectives include:

- Establish a foundation for coordinated research in pediatric cancer and knowledge mobilization in Canada
- Improve the research pipeline for the development and further access to drugs for children affected by cancer
- Develop new therapies for childhood cancer
- Train and mentor the next generation of pediatric cancer researchers

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Who is ACCESS?

We are organized into seven research themes and two cross-cutting groups to support all thematic areas.

Cancer Biology – Better understand the biology of pediatric cancers by connecting research efforts, removing barriers and leveraging knowledge and expertise.

Clinical Trials – Develop a national trials infrastructure, improve cross-country trial availability, and build remote access pathways to Canadian studies.

Access to Innovative Therapies & Optimal Care – Improve access to novel therapies, sustainable solutions and better system navigation for pediatric cancer patients.

Regulation, Policy & Economics – Assess health policy and systems to improve on health equity and disparities by promoting evidence-informed policies and programs.

Education & Training – Improve patient involvement in cancer care and research and enhance career development and training opportunities of clinicians and researchers.

Ethics, Legal, Societal Issues & Implementation Sciences – Improve system processes including ethics reviews, data governance, data sharing and patient communication.

Psychosocial & Survivorship – Advance the wellbeing and life quality for patients, survivors and families through prevention and management of cancer treatment side effects.

Knowledge Mobilization Group – Advance information sharing with the research and patient communities to improve uptake of evidence-based knowledge.

Social Justice, Indigenization & Inclusion Committee – Develop guidelines for the inclusion of equity-deserving groups and build expert councils that offer insight on strategic and project direction.

Committee Building

- Self-named: Social Justice, Indigenization & Inclusion
- Included Persons with Lived Experience and those with varied & intersectional identities
- Building stakeholder Networks:
  - Starting with Indigenous Research Circle

Guidelines

- Incorporated best practice guidelines for data on sensitive sociodemographics including race & ethnicity: CMAJ, CIHI, ICES, etc. into an ACCESS Guidance Document.
  - Self-identification
  - Follow governance frameworks – OCAP, EGAP, CARE, etc
  - Meaningful inclusion of PWLE

Foundational Elements

- Created an organizational Equity Statement
- Surveyed the community for diversity & created representative diversity goals
- Reviewing all ACCESS projects for adherence to EDI Guidelines

Education

- Developed several education sessions: Intro webinar for fellows, sessions at AGM on data governance & anti-oppressive practices
- Surveying CRAs for training needs with regard to collection of sensitive sociodemographic data

SJII

ACCESS Equity Statement

ACCESS is a partnership of clinicians, researchers, policy-makers, advocates, patients, survivors and families across Canada. It embeds a patient- and person-centred approach by directly engaging and collaborating with persons with lived experience.

ACCESS is committed to upholding the values of reciprocity, equity and human rights in our work to build a national pediatric cancer strategy. As individual members of ACCESS, we come to this space to share responsibility for creating a diverse and inclusive community that strives to improve pediatric cancer outcomes, while simultaneously working to reduce barriers to treatment and outcome inequities.

ACCESS is committed to addressing systemic inequities, and recognizes systemic oppressions based on but not limited to, Indigenous identity, race, socioeconomic class, gender identity, sexual orientation, immigration status, religion, age, and ability.

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

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.

Mandatory 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)

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.

Putting this into practice …

Background: AALL2131 Proposal to ACCESS

Request was to fund NGS sequencing to allow Canadian sites to participate in a study of Dasatinib +/- Blinatumumab in Ph+ ALL patients

Racial categories based on NCI:

- American Indian/Alaska Native
- Asian
- Native Hawaiian or other Pacific Islander
- Black or African American
- White
- More than one Race

Canadian Categorizations

POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO
FOR KIDS WITH CANCER
FOR NOW, FOR LIFE.

Children's Cancer
& Blood Disorders

access
acces

Based on CIHI

Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

CIHI
ICIS

CIHI Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada

What are important considerations when using or interpreting race and Indigenous identity data?

"The most important consideration when interpreting disaggregated data by race and Indigenous identity is clarity on what is being measured. Disaggregated data is a critical tool that helps make visible the ways in which structural racism, systemic white supremacy and social exclusion both harm Indigenous and racialized peoples and sustain unearned privilege for white settlers. By collecting race and Indigenous identifiers, and ensuring they are used in a good way in partnership with BIPOC [Black, Indigenous and People of Colour] collectives, we can take collaborative actions towards our fully realized health and wellness through evidence-based and self-determined policies, programs, and services."

— Dr. Danièle Behn Smith, Deputy Provincial Health Officer, Indigenous Health, Ministry of Health, Government of British Columbia

Indigenous Identity Data Standard

Table 1 Indigenous identity question and responses*

Question: Do you identify as First Nations, Inuk/Inuit and/or Métis?

Response categories (select all that apply)
Yes, First Nations
Yes, Inuk/Inuit
Yes, Métis
No
Do not know
Prefer not to answer

Note

* The implementation of the Indigenous identity data standard should include data governance agreements, engagement with Indigenous groups, and processes related to culturally safe and appropriate data collection.

Table 2   Race-based question and responses*

Question: In our society, people are often described by their race or racial background. These are not based in science, but our race may influence the way we are treated by individuals and institutions, and this may affect our health. Which category(ies) best describes you? Check all that apply:[†]

Response category	Examples
Black	African, African Canadian, Afro-Caribbean descent
East Asian	Chinese, Japanese, Korean, Taiwanese descent
Indigenous (First Nations, Inuk/Inuit, Métis)[‡]	First Nations, Inuk/Inuit, Métis descent
Latin American	Hispanic or Latin American descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish)
South Asian	South Asian descent (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan)
Southeast Asian	Cambodian, Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent
White	European descent
Another race category *Optional* — please specify: [open text]	Includes values not described above
Do not know	Not applicable
Prefer not to answer	Not applicable

Notes
* The collection of race-based and Indigenous data should involve community engagement to mitigate the risk of harm to individuals and communities, and to ensure the safe and appropriate use of the data.
† Individuals who identify as mixed race can select all categories that apply.
‡ Distinctions-based approaches — that is, separately identifying First Nations, Inuit and Métis Peoples — may be preferred.

Sources
Government of Ontario Anti-Racism Directorate. Data Standards for the Identification and Monitoring of Systemic Racism. Updated November 2021.
Upstream Lab. Screening for poverty and related social determinants and intervening to improve knowledge of and links to resources (SPARK) study. Accessed January 27, 2020.

Race-Based Data Standard

COG Racial & Ethnic Categorizations

CHILDREN'S ONCOLOGY GROUP

Based on NIH

NIH

National Institutes of Health

NIH Definitions (OMB Directive 15)

- **American Indian or Alaska Native.** A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.
- **Asian.** A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- **Black or African American.** A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."
- **Hispanic or Latino.** A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino."
- **Native Hawaiian or Other Pacific Islander.** A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- **White.** A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

COG Registration Information

ASCT2031 Household Sociodemographic Survey

Is your child Hispanic, Latino/a, or Spanish origin?

- No, not of Hispanic, Latino/a, or Spanish origin
- Yes, Cuban
- Yes, Dominican
- Yes, Mexican, Mexican American, Chicano/a
- Yes, Puerto Rican
- Yes, South or Central American
- Yes, another Hispanic, Latino/a or Spanish origin (includes European)
- Other, please specify: _____
- I don't know
- Prefer not to answer

What is your child's race?

- American Indian, Aleutian, Alaska Native or First Nations
- Asian (includes nationalities or ethnic groups originating in the Far East, Southeast Asia, or the Indian subcontinent)
- Black, African American, African, or Afro-Caribbean
- Native Hawaiian, Maori, Other Pacific Islander, or Indigenous Australian
- White, including Middle Eastern
- Other, please specify: _____
- I don't know
- Prefer not to answer

AALL1732 CRF Demographic Questionnaire

Race/ethnicity:

- White/Caucasian
- Black/African American
- Hispanic (check all that apply): Mexican, Mexican American, Chicano, Cuban, Puerto Rican, Other Spanish/Hispanic/Latino (specify) ___
- Asian (check all that apply): Asian Indian (subcontinent), Chinese, Japanese, Korean, Native Hawaiian, Guamanian or Chamorro, Pacific Islander, Filipino, Vietnamese, Samoan, Hmong, Cambodian, Thai, Laotian, Other Asian (specify)____
- Some other race (specify) ____

NCORP Disparities Integration Emphasis Group (DIEG)

NCORP Patient Population Information

1. Please identify the diverse population group (s) that your NCORP Site has the most experience conducting outreach with. (Check all that apply).

   Note: NCORP diverse populations include NIH-designated populations who experience health disparities, e.g., OMB-defined racial and ethnic minority groups; sexual and gender minorities; rural; low socioeconomic status; and other groups underrepresented in research, e.g., older adult; adolescents and young adults (AYA); and patients with Limited English Proficiency.

   American Indian or Alaska Native
   Asian
   Black or African American
   Hispanic or Latino
   Adolescent and Young Adult
   Sexual and Gender Minorities
   Socioeconomically Disadvantaged
   Other underserved (describe, e.g., low health literacy, Limited English Proficiency):
   _____

   Native Hawaiian or Other Pacific Islander
   More than one race
   Other Race/Ethnicity (describe):
   _____
   Older Adult
   Rural

CHILDREN'S ONCOLOGY GROUP

The world's childhood cancer experts

How can we bring these together?

Table Exercise

You are part of a research team implementing a COG clinic trial and must report race to the study using US categories. Your project is also receiving funds from ACCESS and you have been asked to collect race data using appropriate categories for Canadian children.

In your tables, discuss how you would approach this scenario.

Be prepared to report back on:
- Challenges you anticipate
- Approaches/steps you would take

Mapping Race/Ethnicity

Another Consideration - Australia 🇦🇺

Race/Ethnicity Australian Standard
Oceanian
North-West European
Southern and Eastern European
North African and Middle Eastern
South-East Asian
North-East Asian
Southern and Central Asian
Peoples of the Americas
Sub-Saharan African

OCEANIAN

11 Australian Peoples
- 1101 Australian
- Australian
- 1102 Aboriginal
- Australian South
- 1103 Sea Islander
- Torres Strait
- 1104 Islander
- 1105 Norfolk Islander

12 New Zealand Peoples
- 1201 Maori
- 1202 New Zealander

Melanesian and
13 Papuan
- 1301 New Caledonian
- 1302 Ni-Vanuatu
- Papua New
- 1303 Guinean
- Solomon
- 1304 Islander
- Melanesian and
- 1399 Papuan, nec

14 Micronesian
- 1401 I-Kiribati
- 1402 Nauruan
- Micronesian,
- 1499 nec

15 Polynesian
- 1501 Cook Islander
- 1502 Fijian
- 1503 Niuean
- 1504 Samoan
- 1505 Tongan
- 1506 Hawaiian
- 1507 Tahitian
- 1508 Tokelauan
- 1511 Tuvaluan
- 1512 Pitcairn

- 1599 Polynesian

https://www.abs.gov.au/statistics/classifications/australian-standard-classification-cultural-and-ethnic-groups-ascceg/latest-release

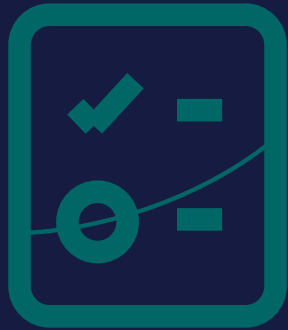What do you think is the best approach to harmonize these categories (current state)?

What do you think is the best way to harmonize these categories (future state)?

If you said other ... what would you recommend?

Data Governance

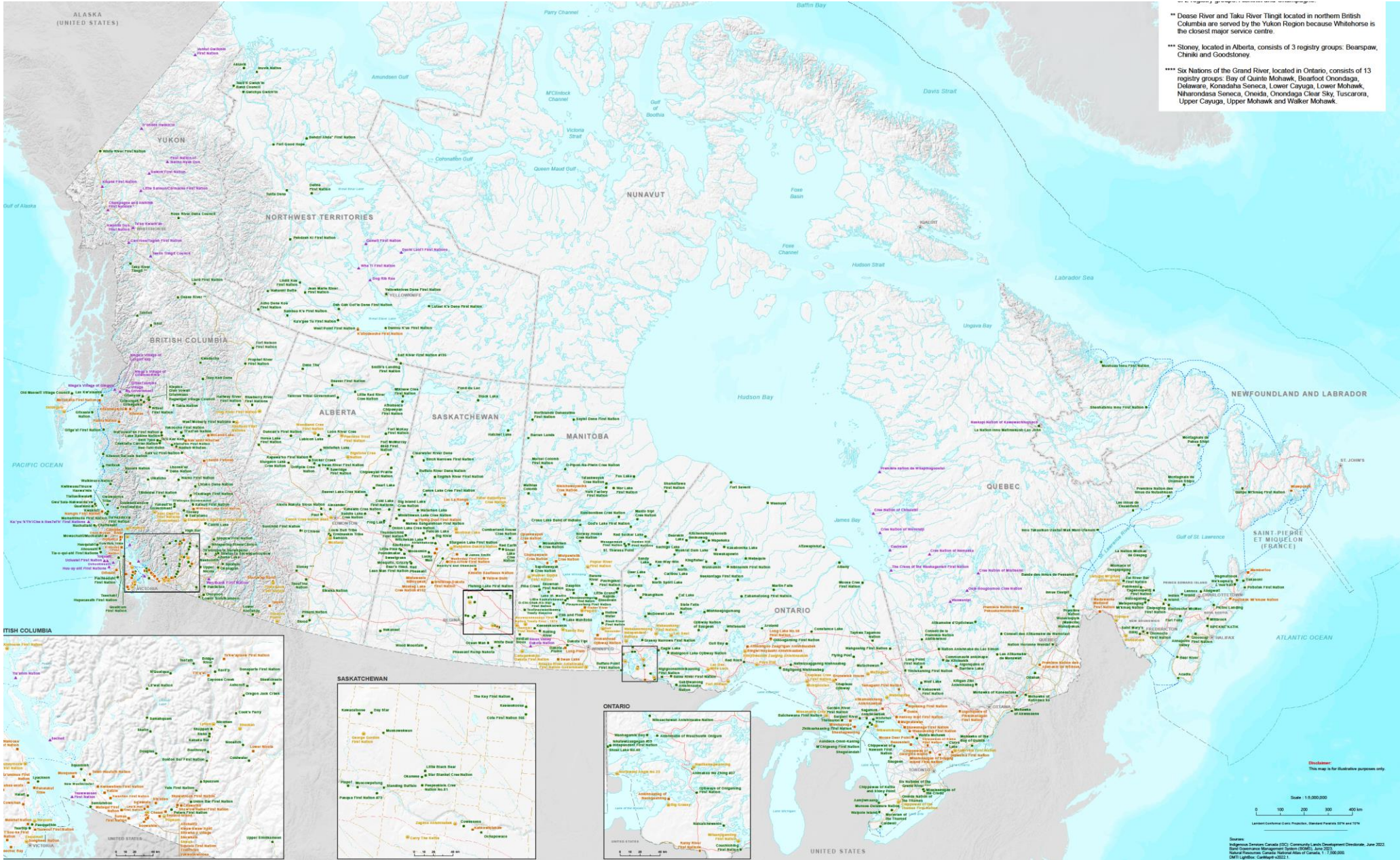What are the ways you have considered data governance? (Choose all that apply)

Ownership refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

Control affirms that First Nations, their communities, and representative bodies are within their rights to seek control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project-from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.

Access refers to the fact that First Nations must have access to information and data about themselves and their communities regardless of where it is held. The principle of access also refers to the right of First Nations' communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

Possession While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.

https://fnigc.ca/ocap-training/

RESEARCH POLICY

I. Purpose

Nipissing First Nation promotes knowledge sovereignty and ethical research that benefits the Nation, its members and is in line with its plans, goals, and aspirations. This policy is intended to guide all research conducted in and about Nipissing First Nation. The policy promotes certainty and clarity and guides the research process.

II. Definitions

Anonymity: The process through which researches protect privacy by not disclosing a participant's identity after information is gathered. A respondent may be considered anonymous when the researcher cannot identify a given response with a given respondent.

Authorship: Refers to the individual(s) that are given credit for reports, journal articles, presentations or products that may emerge from the research study. Authors of a publication are to be listed in order of the significance of their contribution and should include all and only those individuals who have made a significant intellectual or scholarly contribution to the work reported and without whose contribution the work would not be complete. All contributors to the work reported would be recognized regardless of their academic credentials or standing at a university.

Collaboration: A research approach that involves community members in all phases of the project. It seeks a collaborative approach that is equitable for First Nation's involved in the research process from the inception of the research idea to the dissemination and publication of research findings. Collaborative research partnerships should embody a committed vision to working together through any challenges or problems that may arise. Such principals provide a solid foundation for partners to develop a strong and meaningful relationship.

Confidentiality: The researcher is able to identify a person's responses but essentially promises not to do so publically in reporting results from a given study or

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BRITISH COLUMBIA TRIPARTITE FRAMEWORK AGREEMENT ON FIRST NATION HEALTH GOVERNANCE

Made as of the 13th day of October, 2011

Between

HER MAJESTY THE QUEEN IN RIGHT OF CANADA
as represented by the Minister of Health

and

HER MAJESTY THE QUEEN IN RIGHT OF THE PROVINCE OF BRITISH COLUMBIA
as represented by the Minister of Health

and

FIRST NATIONS HEALTH SOCIETY

Endorsed by

FIRST NATIONS HEALTH COUNCIL

National Inuit
Strategy on Research

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INUIT TAPIRIIT KANATAMI

access
acces

Figure 8: *Implementing a coordinated approach to Inuit Nunangat research*

IMPLEMENTING A COORDINATED APPROACH
TO INUIT NUNANGAT RESEARCH
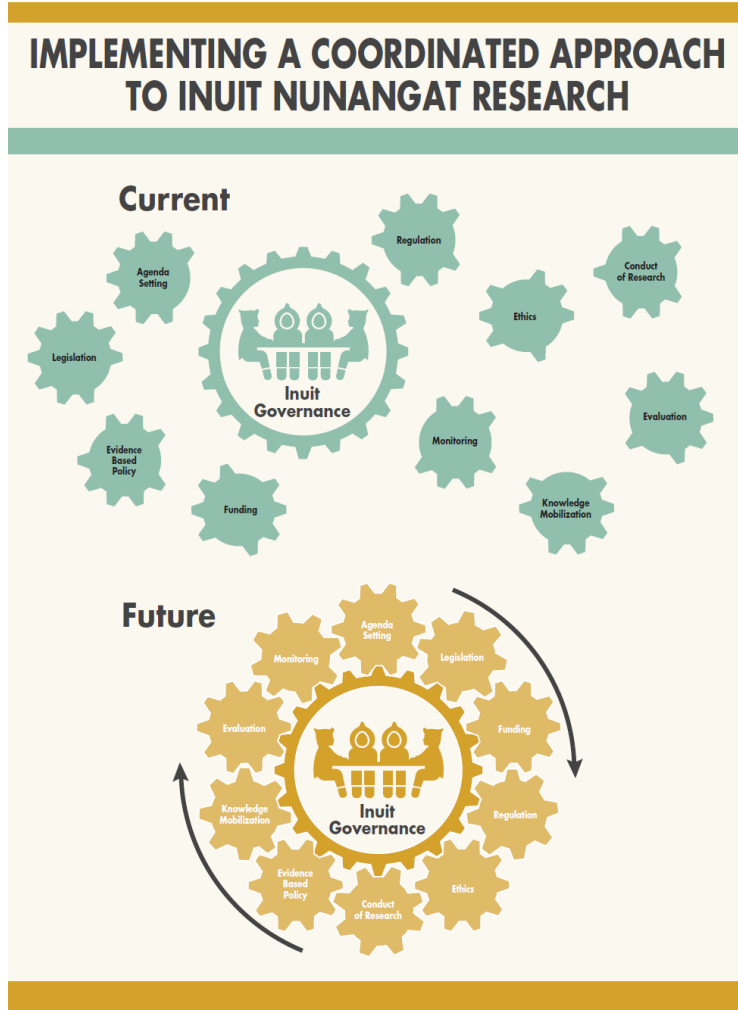
Figure 6: *Using one definition: Inuit Nunangat*

USING ONE DEFINITION:
INUIT NUNANGAT

Figure 1: *Respectful and beneficial research for all Inuit*

RESPECTFUL AND BENEFICIAL
RESEARCH FOR ALL INUIT

Six Principles of Métis Health Research:

Ethical Principles to Guide the Métis Centre in its Work

Think Tank on Métis-Specific Research Ethics

Métis Researchers
Métis Students
Métis Organizations

For more information please contact:
Devin Dietrich, Research Officer, Métis Centre of NAHO. ddietrich@naho.ca

National Aboriginal Health Organization (NAHO)
Organisation nationale de la santé autochtone (ONSA)

Reciprocal Relationships
Building relationships between researchers & communities, while sharing responsibility & benefits, & learning from each other.

Recognize Diversity
Within & between Métis communities; in worldviews; in values & beliefs; in geographic orientation & in politics.

"Respect For"
Individual & collective; autonomy; identity; personal values; gender; confidentiality; practices & protocols.

"Research Should"
Be relevant; benefit all; accurate; accountable; responsible; acknowledge contribution; & protect Métis cultural knowledge.

Safe & Inclusive Environments
Research should be safe for all — youth & Elders; gender & sexual identity; aboriginality; & balance individual & collective.

Métis Context
Understand history, values, & knowledge; advance Métis methodology & include Métis experts; straddle worldviews; & insider-outsider perspective.

www.naho.ca/metiscentre

ENGAGEMENT, GOVERNANCE, ACCESS, AND PROTECTION (EGAP)

A Data Governance Framework for Health Data Collected from Black Communities in Ontario

E ENGAGEMENT
Genuine, cyclical, accessible consultation with communities regarding data collection, management, analysis, and use.

G GOVERNANCE
Community decision-making about engagement processes and data collection, management, analysis, and use, achieved through the establishment of Community Governance Tables.

A ACCESS
The right of communities to access their collective data and to determine who else can access it, along with the capacity building required to enable this right.

P PROTECTION
The safeguarding of all individual rights and types of data, including identifiable, de-identified, and anonymized data.

https://blackhealthequity.ca/

Data collection is one part of embedding equity into research.

What are different ways equity can be embedded into research?

Ongoing Work in the Canadian Sphere

Priority 6

Culturally appropriate care closer to home

Receiving culturally appropriate care close to home is the preferred choice for anyone experiencing cancer. It includes incorporating wholistic approaches to health and wellness and providing equitable access to basic health supports and cancer services.

Priority 7

Peoples-specific, self-determined care

A culturally appropriate approach that addresses the needs of individuals should be offered through Peoples-specific programs and services. This can be achieved through innovative approaches where Peoples-specific leadership is demonstrated through self-determined health programs and services that meet the needs of communities.

Priority 8

First Nations-, Inuit- and Métis-governed research and data systems

First Nations, Inuit and Métis-specific, self-determined data and research are key to understanding access, experience and outcomes in cancer care, and identifying community-led efforts and potential solutions for better outcomes.

Equity, Diversity and Inclusion (EDI) Toolkit

Canadian Cancer Clinical Trials Network

Trial Awareness

Includes templates, research materials, practical strategies and case examples of interventions to improve awareness of clinical trials for underrepresented populations.

Trial Access & Participation

Includes resources, initiatives, remote access programs and culturally sensitive interventions to improve access and participation to clinical trials.

Trial Design

Includes protocol checklists and considerations during trial development to ensure diversity of patient populations are considered.

Increasing Diversity of Clinical Research Teams & Inclusive Hiring Practices

Includes practical strategies tailored to support organization in diversifying their workforce, fostering an inclusive workplace culture, and ensuring equitable hiring procedures are considered.

Guidelines, Education & Training

Includes educational modules, courses and guidelines to support clinical trial staff deliver culturally competent care, address health disparities, and mitigate unconscious bias.

Collection of Race, Ethnicity & Social Demographic Data

Includes standards, guidelines, and practical strategies for collecting data on race, ethnicity, and socioeconomic status.

https://3ctn.ca/equity-diversity-and-inclusion-in-clinical-trials/

Strategic Objective III

- Provide tools and training for healthcare providers to support delivery of medically-safe, culturally-sensitive care.

- Improve the availability of culturally-appropriate education and information for Indigenous children with cancer and their families.

- Establish an advisory table of Indigenous healers and elders with an interest in childhood cancer, and pediatric oncology care providers, and create a prioritized action plan.

Wrapping Up

Acknowledge that collection of sensitive data such as race is work

- But continuing with how we've been collecting in Canada doesn't benefit the pediatric cancer community

Read the ACCESS guidance document on data collection

Advocate for standardized tools at your institution

Ask questions: how is OCAP followed in our institution?