

# Best Practices in the Use of Routinely Collected Race, Ethnicity and Immigration Data

**Susitha Wanigaratne, PhD**

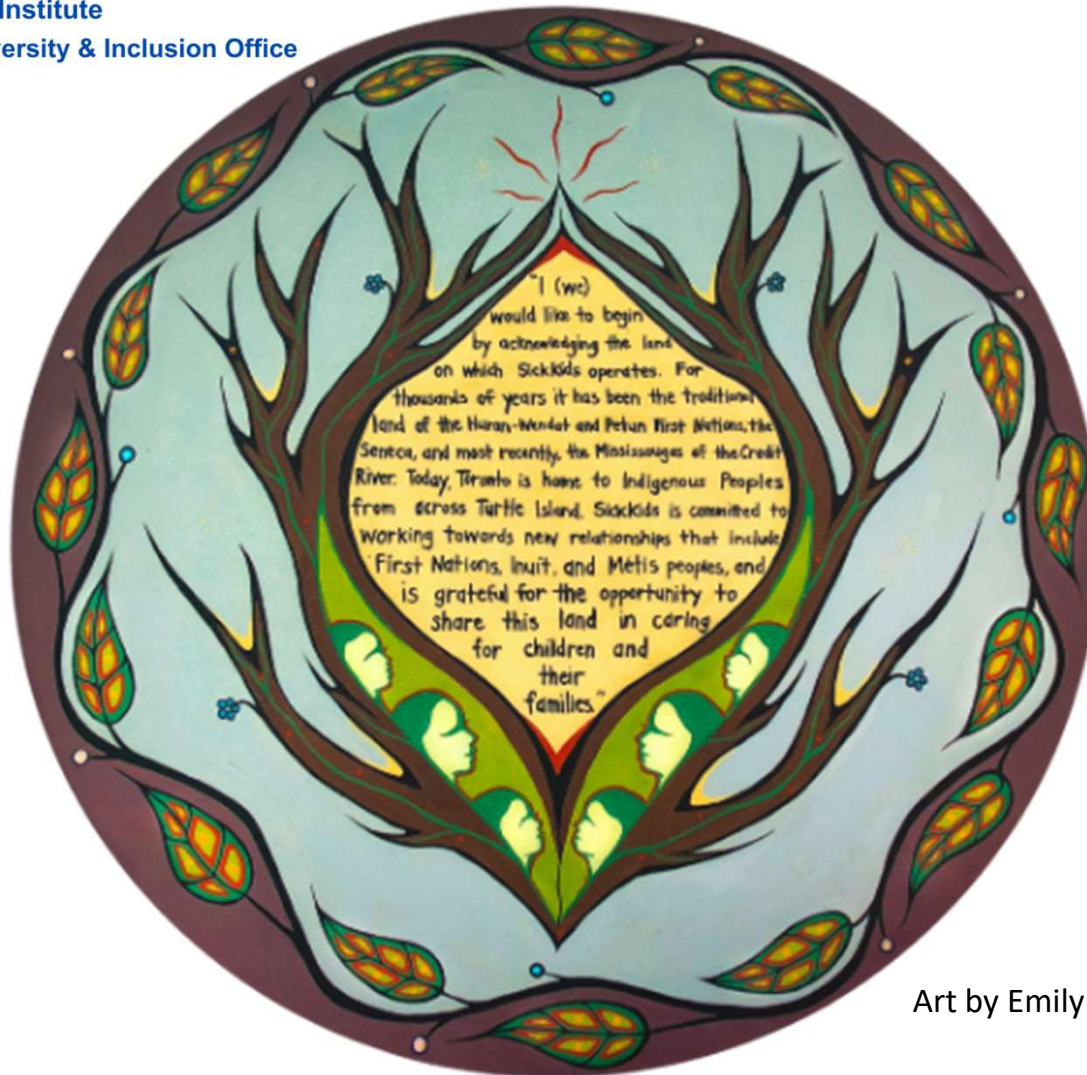
Social Epidemiologist & Senior Research Associate,  
Edwin S.H. Leong Centre for Healthy Children  
Fellow, ICES (formerly the Institute for Clinical Evaluative Sciences)

Diversity & Inclusion in Your Research Design Workshop  
April 18, 2023



Edwin S.H. Leong Centre for Healthy Children  
UNIVERSITY OF TORONTO





Art by Emily Kewageshig

## Leong Centre Vision & Mission



Edwin S.H. Leong Centre for Healthy Children  
UNIVERSITY OF TORONTO

**Call to Action:** Of 38 high income countries, **Canada ranks 30<sup>th</sup>** for child well-being (mental well-being, physical health, and academic and social skills).

Source: UNICEF Innocenti, 'Worlds of Influence: Understanding what shapes child well-being in rich countries', Innocenti Report Card 16, UNICEF Office of Research – Innocenti, Florence, 2020.

**Vision:** Harnessing interdisciplinary research to promote the **flourishing** of every child and family.

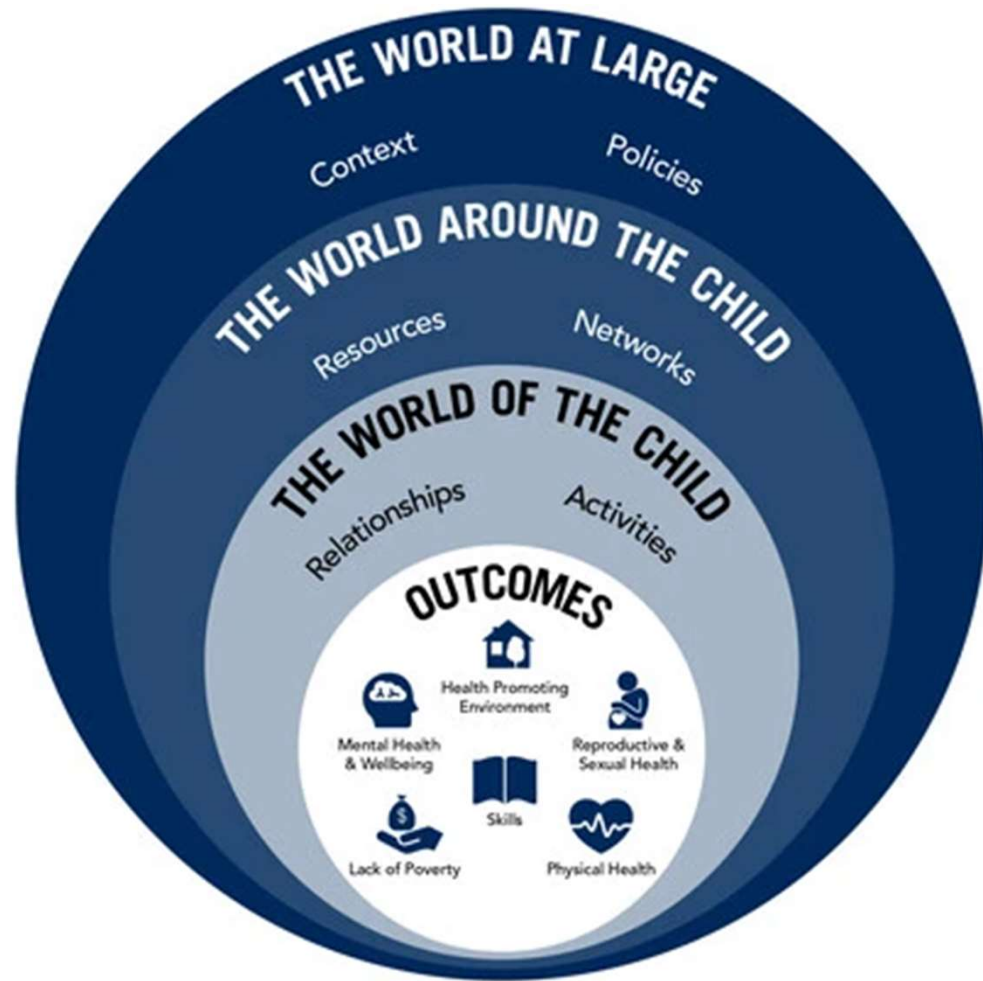
**Mission:** Through funding vehicles and the recruitment of endowed Chairs who are leaders in their respective fields, three core research programs will be established:

1. Data Science for Child Health Equity
2. Child Policy Research
3. Child Health Intervention



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# Leong Centre's Conceptual Framework for Child Flourishing in Canada



# Stay in Touch



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## Website



<http://leongcentre.utoronto.ca>

## Twitter



@LeongCentre

## Newsletters



February 2021

Vol. 2, Issue 1

A Message from Astrid & Eyal

A year ago the Leong Centre launched, and we began embarking on a journey to fulfill the Centre's vision of "harnessing interdisciplinary research to promote the flourishing of **every** child and family." Despite the challenge of launching a research centre in the middle of a global pandemic, the Leong Centre's focus on addressing inequities in childhood is more important than ever before.

*"Not everything that is faced can be changed; but nothing can be changed until it is faced."*

— James Baldwin

This past year has provided a striking reminder of the injustices of structural racism, income inequality and other social determinants of health. These forces are continuing to impact the opportunities of children and youth to flourish.

## Member Events



The Leong Centre is pleased to share these upcoming events from our members. **Have an update to share?** Please submit updates, news and events to [leong.centre@sickkids.ca](mailto:leong.centre@sickkids.ca).

### COVID-19 Vaccination and Child Health

Fraser Mustard Institute for Human Development Policy Bench  
February 19th, 2021  
10am – 12pm EST via Zoom (link provided upon Eventbrite registration)



The Fraser Mustard Institute for Human Development Policy Bench invites you to join an **online interdisciplinary panel discussion on vaccination of children in the context of the COVID-19 pandemic**.

This webinar will bring together experts from the domains of medicine, social work, and public health to offer perspectives on issues surrounding COVID-19 vaccination that are relevant to children's health and development, followed by a moderated discussion period.

Panelists will explore:

- Key considerations for the implementation of novel COVID-19 vaccines in children

Become a member to access funding and stay up-to-date!  
<https://leongcentre.utoronto.ca/content/membership-application>



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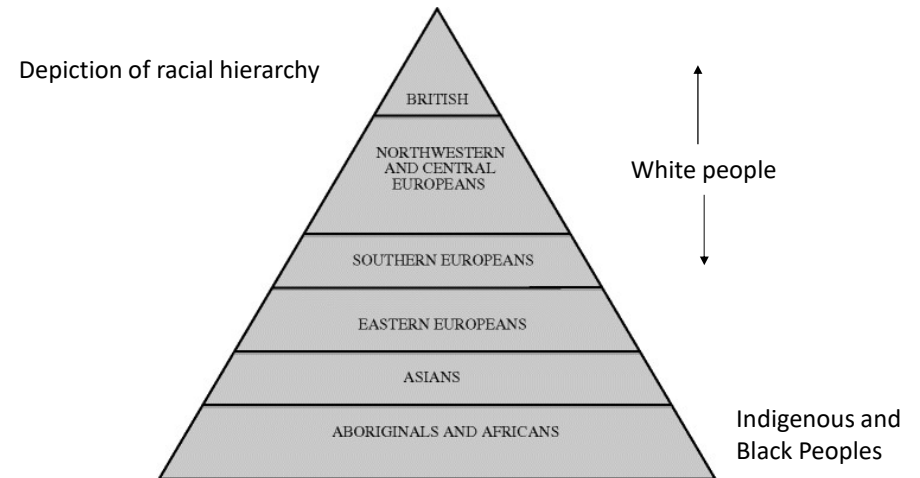
# Overview of Best Practices

## Thinking about & Using Race/Ethnicity in your Research

- Race is an idea invented by people
- Ethnicity relates to shared cultural-group membership
- Race ≠ genetic ancestry, implications for research & clinical decisions
- Racism is a structural & social determinant of child/youth health
- Discrimination and xenophobia impacts health and health service use among immigrants
- Read & follow guidance on responsible use of race, ethnicity, immigration data

# Race is a Social Construct

- An idea developed by societies, categorizes people based on physical features like skin colour, hair texture.
- Has no measurable scientific (biological, genetic) basis.
- Organizes humanity into a hierarchy of power and value, where greater value is assigned, and power is held by those closest to Whiteness.
- Constructs differences between groups which have significant consequences for people's lives (i.e., in access to the SDOH).



# Ethnicity is a Social Construct



- A multi-dimensional concept referring to community belonging and a shared cultural group membership.
- Related to characteristics such as language, religion, geographic origin, nationality, cultural traditions, ancestry and migration history.
- Like race, has no scientific basis.



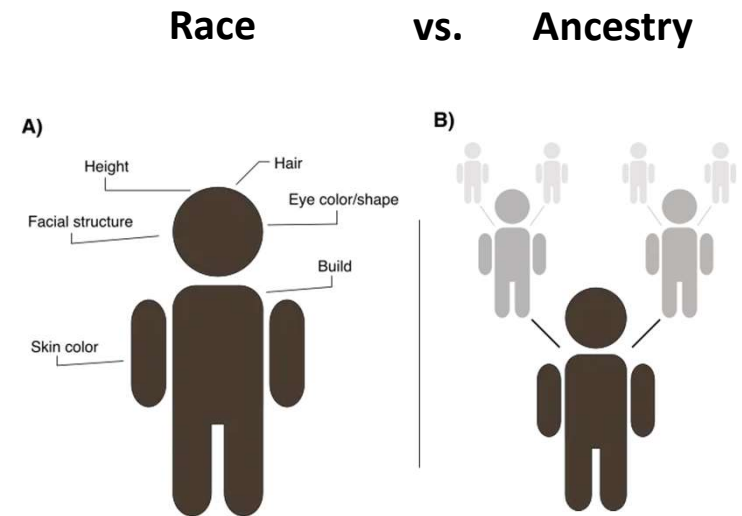
# Race ≠ Genetic Ancestry (1)

## Ancestry

Subset of paths through the human family tree by which people inherit DNA from specific ancestors, a historical process.

Ancestry DOES NOT include:

- categorization by populations or groups
- context describing individuals (apart from their genealogical connections) e.g., labelling individuals with geographical or cultural info

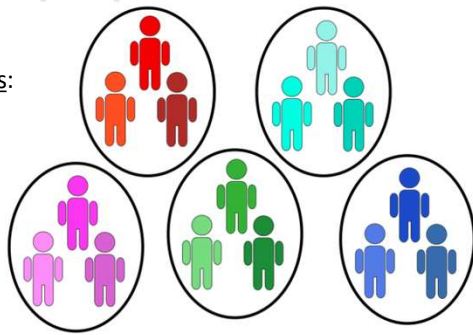


# Race ≠ Genetic Ancestry (2)

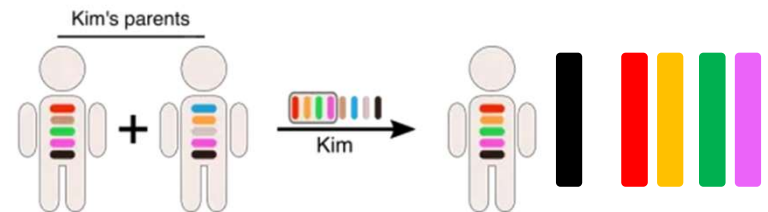
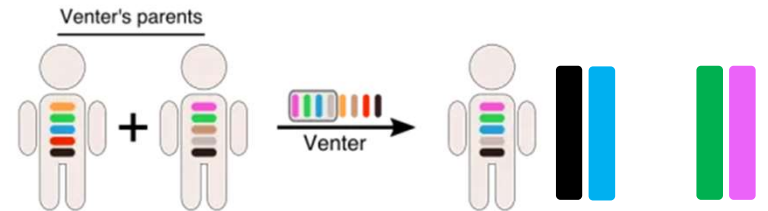
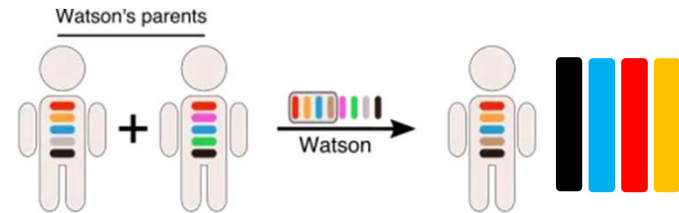
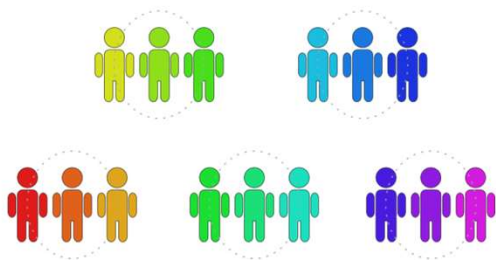
A) Popular conception of genetics and "5 races"

Ancestral categories:

- African
- European
- Asian
- Oceania
- Native American



B) Actual genetic variation - Ancestry is continuous rather than discrete



## Getting genetic ancestry right for science and society

We must embrace a multidimensional, continuous view of ancestry and move away from continental ancestry categories

By Anna C. F. Lewis, Santiago J. Molina, Paul S. Appelbaum, Bege Dauda, Anna Di Rienzo, Agustin Fuentes, Stephanie M. Fullerton, Nanibaa' A. Garrison, Nayanika Ghosh, Evelyn M. Hammonds, David S. Jones, Eimear E. Kenny, Peter Kraft, Sandra S.-J. Lee, Madelyn Mauro, John Novembre, Aaron Panofsky, Mashaal Sohail, Benjamin M. Neale, Danielle S. Allen

SCIENCE 15 APRIL 2022 • VOL 376 ISSUE 6590

*“continued reliance on continental ancestry is likely to exacerbate medical stereotypes about individuals and groups, contribute to health disparities rather than addressing them, and reify (mis)understandings of race as biological.”*

## Use of Race in Pediatric Clinical Practice Guidelines

A Systematic Review *JAMA Pediatrics* August 2022 Volume 176, Number 8

Courtney A. Gilliam, MD; Edwin G. Lindo, JD; Shannon Cannon, MD; L'Oreal Kennedy, DNP, CNM, ARNP;  
Teresa E. Jewell, MLIS; Joel S. Tieder, MD, MPH

Table 1. Included Clinical Practice Guidelines by Categories

Category	No.
<b>Positively impact health inequities</b>	
No. (%)	45 (35.7)
Race used to describe health disparity	18
Race used to describe inclusivity	7
Establishing representative committee structures	2
Recommending cultural humility	14
Describing geographic risk	4
<b>Negatively impact health inequities or perpetuate structural racism</b>	
No. (%)	73 (57.9)
Normalizing the majority group (centering whiteness)	15
→ Conflating race as a biological risk factor	23
→ Conflating race with negative stereotype	8
→ Conflates race, ethnicity, and genetic risk	7
→ Establishing testing or treating thresholds or using racial coefficients	20

### Best Practice for CPGs:

- Race should not be described as a risk factor for disease pathology.
- Race should not be used as a co-efficient to establish a testing or treatment threshold (incl. algorithms).
- Highlight racism as a social determinant of health.

### Best Practice for Research:

- Race-corrected clinical algorithms should not be used or developed.

# Racism, not Race, Impacts Health



- A cultural and structural system that assigns value and grants opportunities and privileges based on race
- Exists in all aspects of society
- Contemporary racism is pervasive, often subtle and ordinary
- Functions on multiple levels and through various forms to create and reinforce beliefs, prejudices and stereotypes, and to normalize discriminatory practices

## DEFINITIONS AND EXAMPLES OF DIFFERENT LEVELS OF RACISM

EXAMPLES OF LEVELS OF RACISM	INTERNALIZED RACISM <sup>10,12,18</sup>	INTERPERSONAL OR RELATIONAL RACISM <sup>10,12</sup>	SYSTEMIC RACISM <sup>10,12,21</sup>
<p><b>Definition</b></p>	<p>The “mastery and ownership”<sup>18</sup>, p 2125 of attitudes, beliefs and actions that reflect White supremacist ideologies into one’s interactions.</p>	<p>Racism expressed between people, assaults on dignity and social status (microaggressions<sup>19</sup>), racial slurs, verbal or physical assaults, individual discriminatory behavior.</p>	<p>Policies and practices within private and public institutions such as racialized and colourblind norms, regulations and standard ways of operating that lead to racially biased outcomes and experiences.</p>
<p><b>Examples</b></p>	<p>White people are socialized to act in ways which reflect a belief in their inherent superiority to racialized peoples.</p> <p>Racialized people failing to support each other’s leadership, especially when it challenges White privilege and racism.</p>	<p>Indigenous people denied treatment or access to hospital care based on negative stereotypes and assumptions of service providers.<sup>20</sup></p>	<p>The Indian Act continues to officially define who is “Indian” through criteria that have not been endorsed by Indigenous peoples.<sup>10</sup></p> <p>Racialized Canadians earn only 81.4 cents for every dollar earned by White Canadians.<sup>22</sup></p>

A systematic review of studies examining the relationship between reported racism and health and wellbeing for children and young people

Social Science & Medicine 95 (2013) 115–127

Naomi Priest<sup>a,\*</sup>, Yin Paradies<sup>b</sup>, Brigid Trenerry<sup>a</sup>, Mandy Truong<sup>a</sup>, Saffron Karlsen<sup>c</sup>, Yvonne Kelly<sup>d</sup>

- 121 empirical quantitative studies, most studies published after 2006
- most cross-sectional, conducted in the United States, 12-18 years old
- African Americans, Latino/a, Asian populations
- Mental health outcomes, behavioural problems, well-being and pregnancy and birth outcomes
- Lack of longitudinal studies, limited validated exposure instruments, poor conceptualization and definitions of racial discrimination



Research Institute  
Equity, Diversity & Inclusion Office

POLICY STATEMENT Organizational Principles to Guide and Define the Child Health  
Care System and/or Improve the Health of all Children

American Academy  
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

2019

## The Impact of Racism on Child and Adolescent Health

Maria Trent, MD, MPH, FAAP, FSAHM,<sup>a</sup> Danielle G. Dooley, MD, MPhil, FAAP,<sup>b</sup> Jacqueline Dougé, MD, MPH, FAAP,<sup>c</sup> SECTION ON  
ADOLESCENT HEALTH, COUNCIL ON COMMUNITY PEDIATRICS, COMMITTEE ON ADOLESCENCE

“Racism is a social determinant of health that has a profound impact on the health status of children, adolescents, emerging adults, and their families.”

“Pediatrics as a field has yet to systematically address the influence of racism on child health outcomes and to prepare pediatricians to identify, manage, mitigate, or prevent risks and harms.”



*Annual Review of Developmental Psychology*  
**Effects of Racism on Child Development: Advancing Antiracist Developmental Science**

Iheoma U. Iruka,<sup>1</sup> Nicole Gardner-Neblett,<sup>2</sup> Nicole A. Telfer,<sup>3</sup> Nneka Ibekwe-Okafor,<sup>4</sup> Stephanie M. Curenton,<sup>4</sup> Jacqueline Sims,<sup>4</sup> Amber B. Sansbury,<sup>5</sup> and Enrique W. Neblett<sup>6</sup>

<sup>1</sup>Department of Public Policy, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA; email: iruka@unc.edu

<sup>2</sup>Department of Psychology, University of Michigan, Ann Arbor, Michigan, USA

<sup>3</sup>Department of Psychology, University of Maryland, Baltimore County, Baltimore, Maryland, USA

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<sup>5</sup>College of Education and Human Development, George Mason University, Fairfax, Virginia, USA

<sup>6</sup>School of Public Health, University of Michigan, Ann Arbor, Michigan, USA

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Annu. Rev. Dev. Psychol. 2022. 4:109-32

First published as a Review in Advance on August 26, 2022

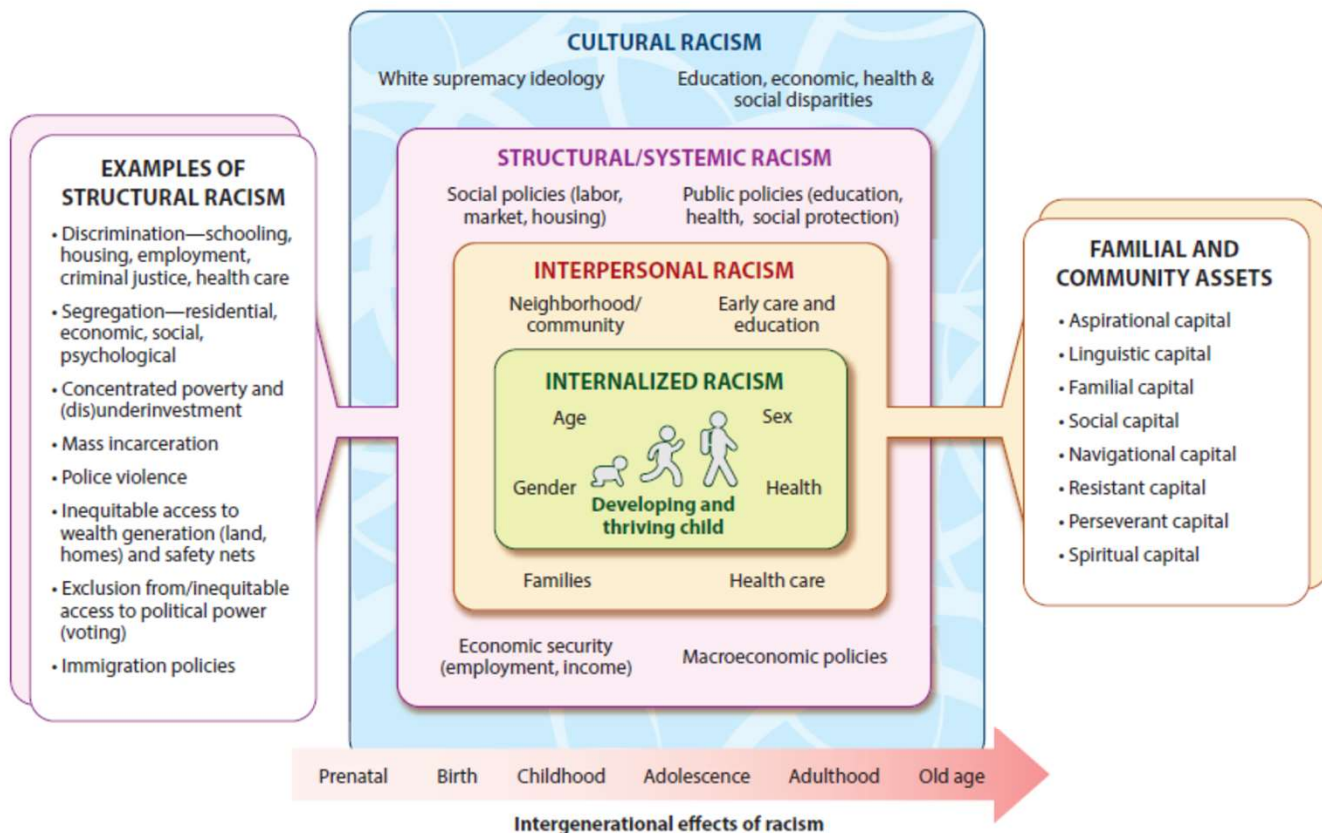
The Annual Review of Developmental Psychology is online at devpsych.annualreviews.org

**Keywords**

racism, child development, antiracism, Black, minoritized, racial equity

**Abstract**

Racism, a multidimensional system of oppression and exclusion, is part



**Figure 1**

Racism + Resilience + Resistance Integrative Study of Childhood Ecosystem ( $R^3$ ISE). The  $R^3$ ISE integrative model is a conceptual framework examining how different forms of racism, such as cultural and systemic racism, impact children's healthy development and the moderating role of family and community cultural assets. Note that vicarious racism and some other forms of racism are not pictured.

# Global Spotlight in the Lancet, March 2023

## Racism, xenophobia, and discrimination: data disaggregation is a complex but crucial step to improving child health



*\*Delan Devakumar, Srivatsan Rajagopalan, Kathleen L Strong, Jennifer Requejo, Theresa Diaz, Lu Gram, Robert Aldridge, Sarah L Dalglish*

Published Online  
March 30, 2023  
[https://doi.org/10.1016/S0140-6736\(23\)00618-9](https://doi.org/10.1016/S0140-6736(23)00618-9)  
For the WHO Health Inequality Monitor see <https://www.who.int/data/inequality-monitor>

Racism, xenophobia, and discrimination are major determinants of child health, leading to poor health among affected children at every stage of their life, with potential intergenerational implications.<sup>1,2</sup> Poor health outcomes for children might arise directly from interpersonal forms of violence and abuse, but also

The disaggregation of data makes health inequities visible that would otherwise be masked, allowing for an intersectional approach to designing policies and programmes. Regular tracking of disaggregated data can also help to hold decision makers to account in making progress towards increased equality and inclusivity. However, child health data are infrequently disaggregated in ways that can spotlight inequalities among children who face racism and discrimination, and action is insufficient on this crucial health issue.

Health indicators, when presented as an average, can hide disparities between groups. If child health indicators could be disaggregated by categories of minoritisation (such as caste, ethnicity, Indigeneity, migratory status, race, religion, and skin colour<sup>1</sup>), it would enable better quantification of disparities between groups of children, and improve understanding of the effect of racism on child health, encompassing both individual acts of interpersonal racism and upstream structural racism. This information can in



## **Xenophobia as a determinant of health: an integrative review**

**Shazeen Suleman<sup>1,3</sup> · Kent D. Garber<sup>2</sup> · Lainie Rutkow<sup>1</sup>**

“Attitudes, prejudices and behaviour that reject, exclude and often vilify persons, based on the perception that they are outsiders or foreigners to the community, society or national identity”

- Experienced by migrants around the world
- affects individual health - mental health, social stress
- Barriers to accessing health services

## What is Routinely Collected Data?

- Data collected for purposes other than research or without specific a-priori research questions developed before collection
- Examples
  - Electronic health records
  - Health administrative data (OHIP, hospitalizations etc)
- Race and ethnicity data are not often collected with health data
- Some organizations have data governance structures which allow them to link health data with race, ethnicity and immigration data

# Race and Ethnicity Variables in Routinely Collected Data in Canada (1) (not exhaustive)

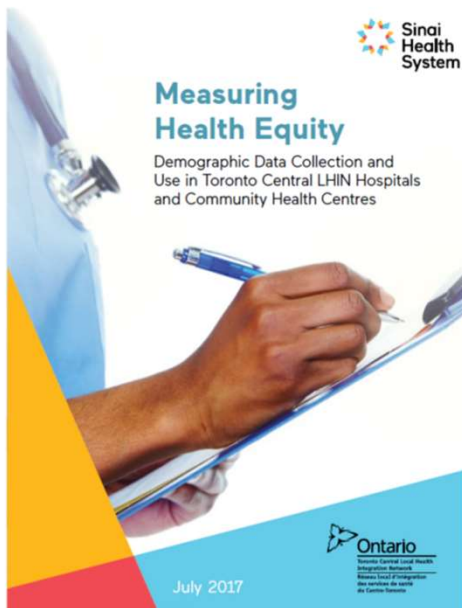
Hospitals and Community Health Centres  
(Toronto Central LHIN), 2013

Data collected in healthcare settings

“Racial Group” (listed alphabetically)

1) Asian – East; 2) Asian - South; 3) Asian – South East 4) Black – African; 5) Black – Caribbean; 6) Black – North American; 7) First Nations; 8) Indian – Caribbean; 9) Indigenous/Aboriginal; 10) Inuit; 12) Latin American; 13) Metis; 14) Middle Eastern; 15) White – European; 16) White – North American; 17) Mixed.

“Language” (dimension of ethnicity) – 34 options



# Race and Ethnicity Variables in Routinely Collected Data in Canada (2)

## Statistics Canada, Research Data Centres

- population-based health administrative databases linked to...

Statistics Canada Census:

“Visible Minority”, defined by the Employment Equity Act - persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour.

- Black, Chinese, Japanese, Korean, South Asian, Arab, West Asian, Filipino, Southeast Asian, Latin American.

“Indigenous identity”, Indigenous peoples of Canada defined in the Constitution Act, 1982

- First Nations, Metis and/or Inuk (Inuit), Registered or Treaty Indians (registered under the Indian Act), membership in a First Nation or Indian band.

“Ethnic and cultural origins”

- pages of response options and opportunity to write-in response

# Race and Ethnicity Variables in Routinely Collected Data in Canada (3)



ICES - population-based health administrative databases linked to...

## Statistics Canada data

- Ecological measures of % visible minority, % recent immigrant in small census areas (ON-MARG)

## Immigration Refugee Citizenship Canada Database

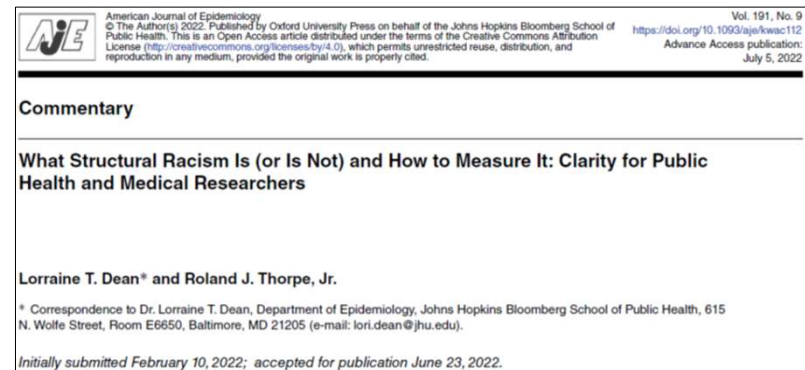
- Mother tongue (dimension of ethnicity)
- Country of Birth/Citizenship (not necessarily race or ethnicity, some geographies perhaps correlated with one or both)

## Canadian Community Health Survey (Statistics Canada)

- “Visible Minority Status”
- Indigenous Identity

# Collecting your own data? Measuring Racism & Discrimination

- Everyday Discrimination Scale
- Major Experiences of Discrimination Scale
- Work Discrimination Scale
- Heightened Vigilance Scale
- Structural Racism → →





# Journal & Organizational Guidelines on the Use and Reporting of Race & Ethnicity

HEALTH AFFAIRS FOREFRONT

RELATED TOPICS:

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## On Racism: A New Standard For Publishing On Racial Health Inequities

[Rhea W. Boyd](#), [Edwin G. Lindo](#), [Lachelle D. Weeks](#), [Monica R. McLemore](#)

JULY 2, 2020

10.1377/forefront.20200630.939347

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



EDITORIAL

JAMA August 17, 2021 Volume 326, Number 7

## Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals

Annette Flanagan, RN, MA; Tracy Frey, BA; Stacy L. Christiansen, MA; for the *AMA Manual of Style* Committee

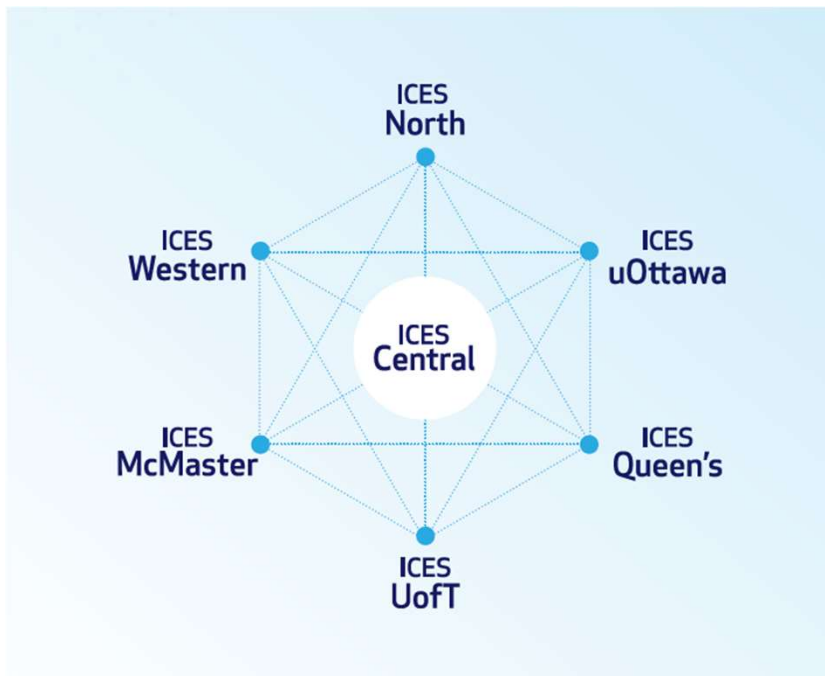
## CMAJ's new guidance on the reporting of race and ethnicity in research articles

Matthew B. Stanbrook MD PhD, Bukola Salami RN PhD

■ Cite as: *CMAJ* 2023 February 13;195:E236-8. doi: 10.1503/cmaj.230144

# Anti-Racist Approaches to Research at ICES

## Ontario-wide research network of 7 sites



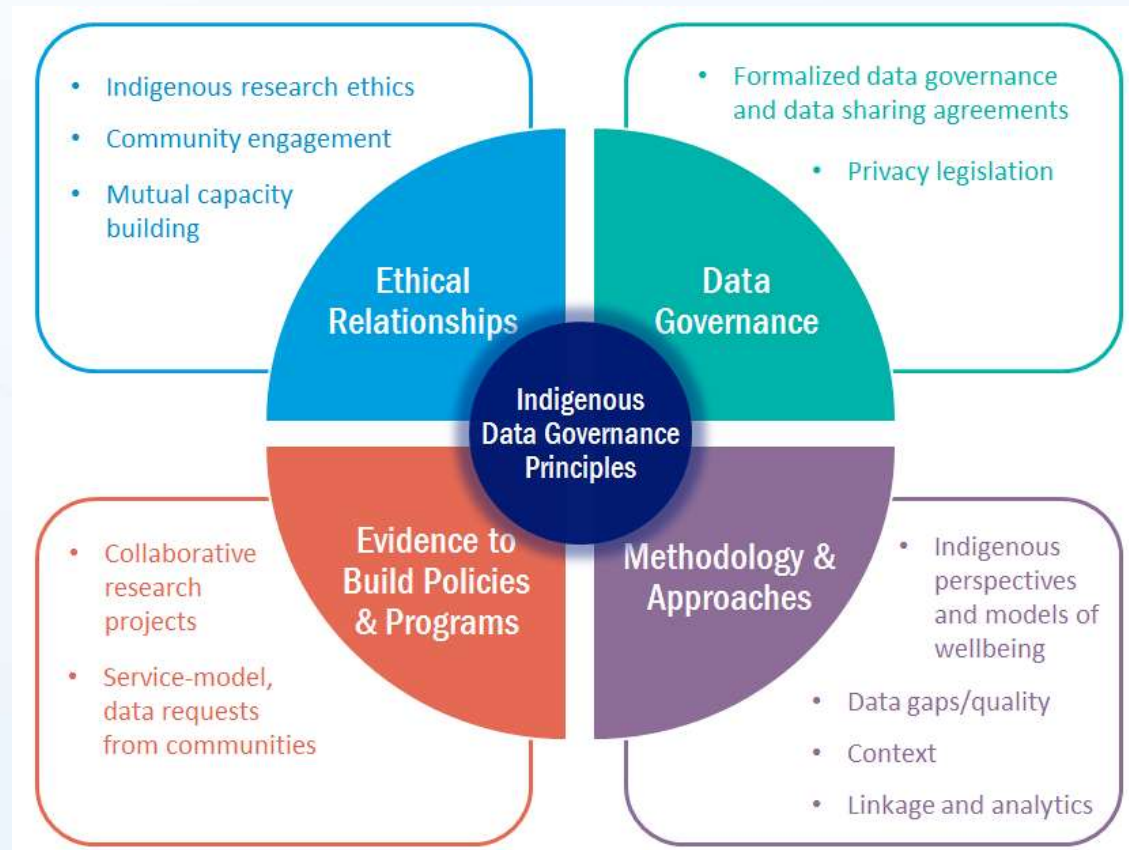
An independent, not-for-profit research organization founded in 1992 as the Institute for Clinical Evaluative Sciences

Governed by a volunteer board of directors

Guided by a scientific advisory committee and a public advisory council

A trusted steward of the health records of over 20 million Ontarians, including past and present health card holders

# Framework for working with First Nations data at ICES



- Initially developed with the Chiefs of Ontario

## Anti-Racism

“...is a process, a systematic method of analysis, and a **proactive course of action** rooted in the recognition of racism, including systemic racism.

Anti-racism ***actively seeks to identify, remove, prevent, and mitigate*** racially inequitable outcomes and power imbalances between groups and change the structures that sustain inequities.”

-Ontario Anti-Racism Directorate Data Standards Glossary

# How systemic racism can shape the research to action pipeline



*Persistent or increased racial inequities* in service delivery, quality of care and health outcomes are captured by data systems.

## Data Collection

Administrative data are collected by systems and organizations (and people employed by them) that reflect prevailing social and structural conditions.

Service delivery, quality of care, health outcomes

## Research

Use, interpretation and findings



Status quo maintained or policies implemented which worsen racial inequities in health outcomes, service delivery or quality of care.

## Policy and Decision-Making

Biased and racist Interpretation or misinterpretation of findings, and sometimes even the absence of interpretation, shapes policies and decision-making.

# How research can be used to combat systemic racism



*Reduction in racial inequities* in service delivery, quality of care and/or health outcomes are captured by data systems.

**Data Collection**

Administrative data are collected by systems and organizations (and people employed by them) that reflect prevailing social and structural conditions.

**Service delivery, quality of care, health outcomes**

**Research**  
Use, interpretation and representation of data



Anti-racist policies and decisions aim to reduce racial inequities in service delivery, quality of care and/or health outcomes.

**Policy and Decision-Making**

Researchers recognize and point to the influence of system racism in their study findings (being anti-racist), ideally leads to anti-racist policies and decision-making.

# Key elements of building the Anti-racist research framework



## LEARNING

Learning and reflecting on scientific/medical racism.



## COLLABORATION

Working closely with the ICES community, government and other data institutes.



## EXPERT ADVICE

Consulting with equity and race experts and community organizations for guidance.



## ENGAGEMENT

Seeking community input to understand and align with their priorities.

# Framework and Guidance to drive Anti-racist Approaches to Research at ICES





# Summary of Best Practices

## Thinking about & Using Race/Ethnicity in your Research

- Race is an idea invented by people
- Ethnicity relates to shared cultural-group membership
- Race ≠ genetic ancestry, implications for research & clinical decisions
- Racism is a social determinant of child/youth health
- Discrimination and xenophobia impacts health and health service use among immigrants
- Read & follow guidance on responsible use of race, ethnicity, immigration data

**“The beauty of anti-racism is that you don’t have to pretend to be free of racism to be anti-racist. Anti-racism is the commitment to fight racism where you find it, including in yourself. And it’s the only way forward.”**

– Ijeoma Oluo, author of  
“So You Want to Talk About Race”

**Thank-you!**

**Questions/Comments**

**[susitha.wanigaratne@sickkids.ca](mailto:susitha.wanigaratne@sickkids.ca)**

***Interested in community engagement in research??***

**Next DIY Research Design talk - Tuesday May 2, 12-1pm**

**“Tools of Togetherness: Designing & Planning a Community-Engaged Research Project.”**

**Priscilla Medeiros, PhD Knowledge Mobilization Specialist, Leong Centre**