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David Braley Primary Care Research Collaborative

Race in Medical Research

Watch a recording of the session here

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@McMasterFamMed

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Family Medicine

Race in Medical Research

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DARe Group
Differential Attainment REsearch

Land Acknowledgement

Acknowledgements

Today's Agenda

1. Describe the historical contexts of race, racialization, and racial hierarchies within social structures
2. Recognize how medical research has impacted racialized people + communities
3. Describe race as a measurable research construct
4. Applying a Critical Race Theory lens to the conduct and critical analysis of medical research

Reflection

What is your earliest memory of when you became aware of the colour of your skin/race?

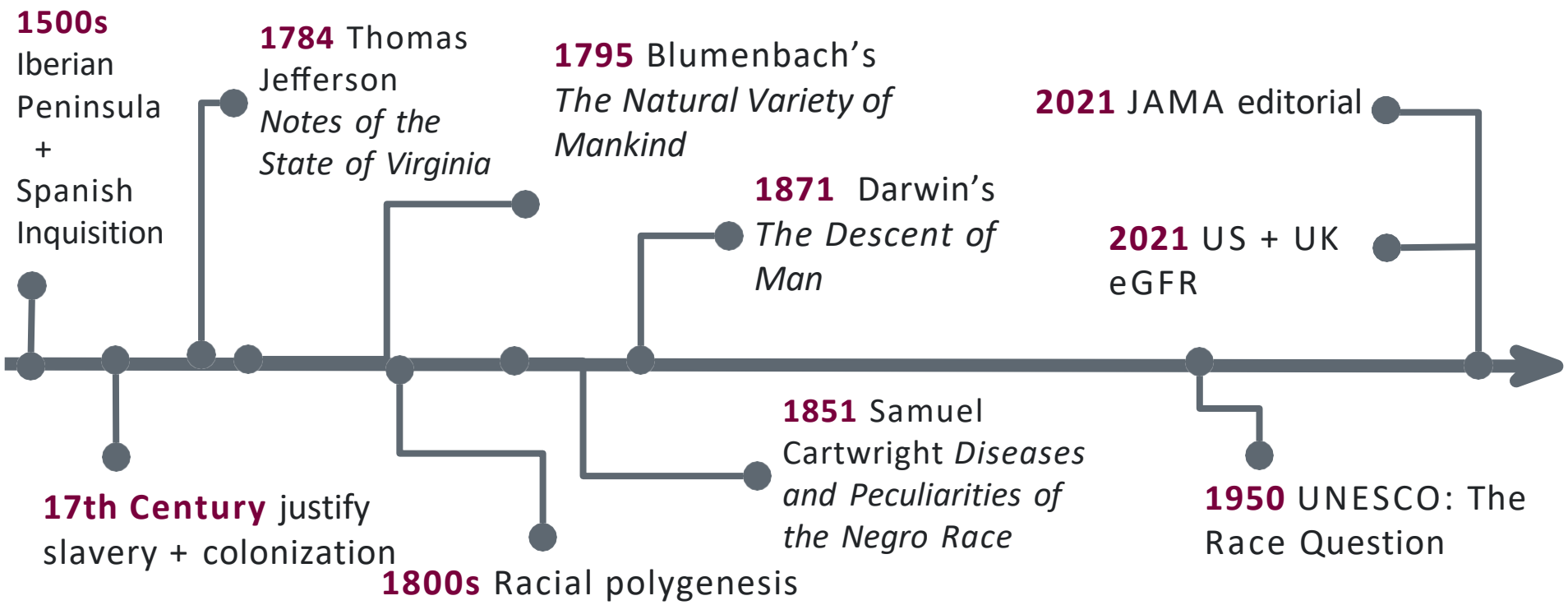
Historical contexts of race theory

Why talk about history?

Race exists *because* of racism
Racism is grounded in history

History is the foundation on which we construct our racial identity.

The Pseudoscience of Race in History



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(James + Burgos; UNESCO; Gama et. al.; Flanagin et. al.; Delgado et. al.)

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What does the evidence say (…now)

NOT Biology - Historically we've changed *who is legally white*

NO evidence of biological differences between races

- Studies continue to find more genetic variations *within* races than *between* them
- **NOT a proxy for scientific measurements** in clinical research
- Complexity in **categorizing participants who are mixed race**.

Racial differences in disease prevalence or outcomes **more likely reflect the impacts of racism** (e.g. toxic stress and racism within health care delivery).

Flanagan et. al. (2021); Vyas et. al. (2020); Braun et. al. (2007)

Race is a social *construct.*

Race

> **socially constructed** and **self-defined,** reflecting a self-identity **formed through cumulative personal experiences** and **built on the foundation of inherited narratives.**

Encompasses:

- **Legacy of racial trauma,** colonialism, prejudice, discrimination and deep pain are **inherited and passed on** from our ancestors through story-telling, verbal history, and upbringing.
- **Lived experiences** of racism, prejudice, discrimination, disadvantage, within racialized communities.

Inheritance in Racial Identity Formation

- My maternal grandmother grew up in Bombay, down the street from the Watson Hotel:

  “Dogs and Indians not allowed”

- My mother and her family immigrated to Canada in 1965

  Civil Rights Act (1964), Selma marches (1965), Loving vs Virginia (1967)

- My grandmother stopped wearing saris within a few years of immigrating from repeated “othering” experiences
- My uncle used to wake up early in the morning to wash off “Paki” spray painted on their garage door, before my cousins woke up.

You will never be one of them

Racialization

> The **dynamic** process of **social interactions** that reinforce these narratives of racial trauma and highlight an individual's perceived race as inferior to the dominant social group, **maintaining historic power differentials and racial hierarchies**.

Racialized peoples identify with these processes, as they are **socialized** within the White-dominated culture of the western world.

Menezes et. al. (2022)

“A mouse born in a stable doesn’t make it a horse.”

The colour of my skin gives everyone the right to question my citizenship

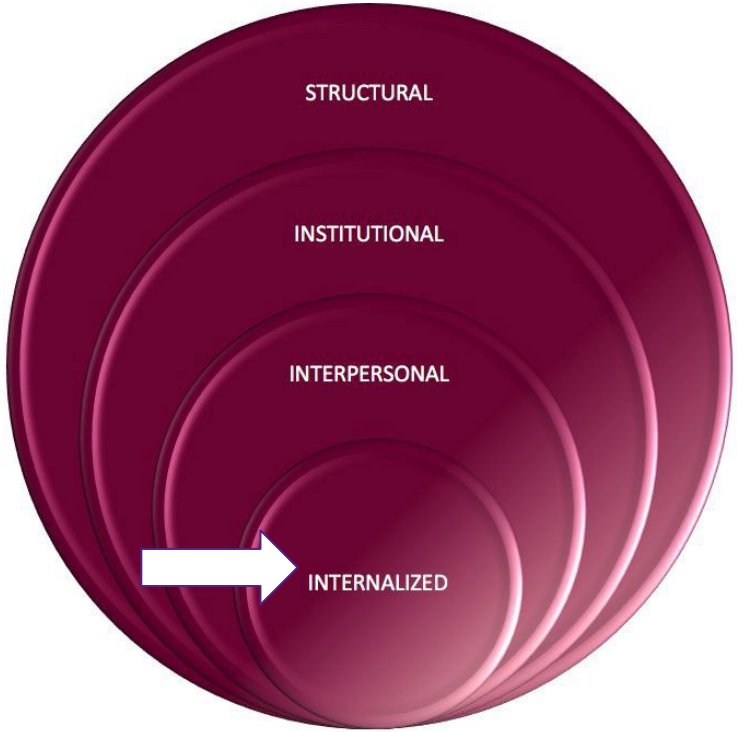
How does racialization impact us?

Not mutually

exclusive

(Nonyel 2021, Jones 2000)

How does racialization impact us?

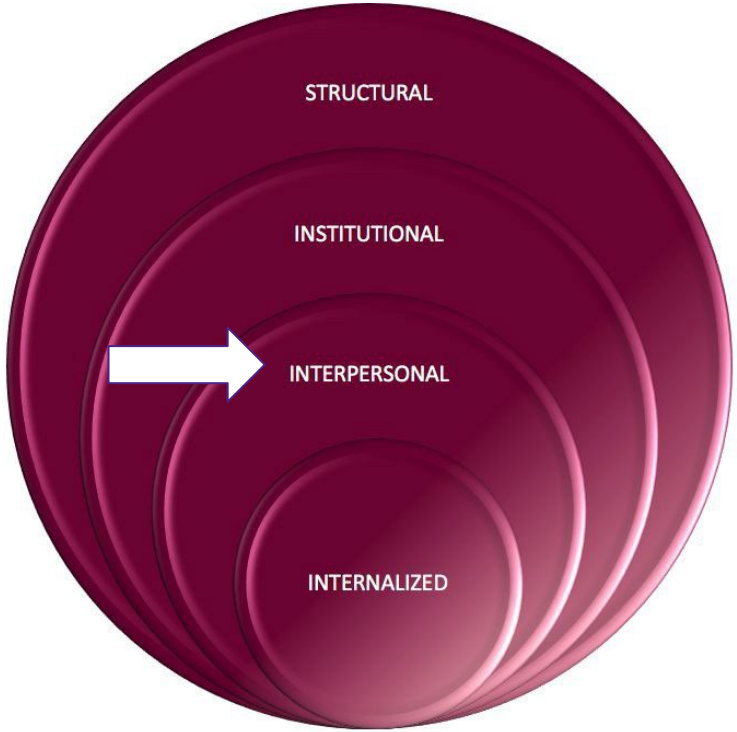


"the acceptance by members of stigmatized races of negative messages about their abilities and intrinsic worth"

e.g., lack of self-efficacy, helplessness, poor sense of belonging, stereotype threat

(Peek 2010)

How does racialization impact us?



"prejudice (differential assumptions about the abilities, motives, and intentions of others according to their race) and discrimination (differential actions) toward others according to their race"

e.g., microaggressions, social isolation, heightened visibility, othering, tokenism

(Peek 2010; Solomon 2021)

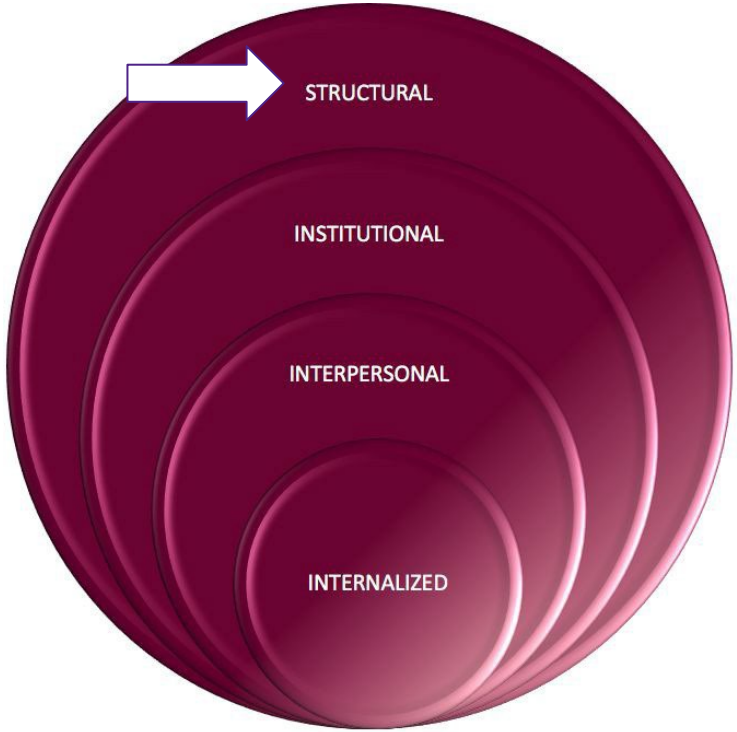
How does racialization impact us?

"system-wide discrimination, either deliberately or indirectly, against specific groups of people."

e.g., disparities in admission and grading/assessments, minority tax

(Purnell 2021; Teherani 2018)

How does racialization impact us?



"mechanisms by which societies foster discrimination through systems of employment, housing, education, income, healthcare, and criminal justice that reinforce discriminatory beliefs, values, and distribution of resources"

e.g., inadequate policies/oversight, amplification cascade

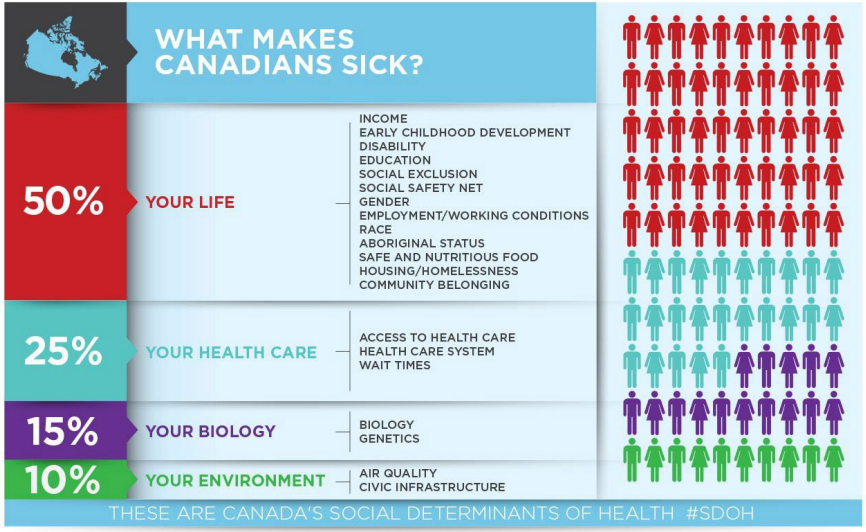
(Peek 2010; Teherani 2018)

Health and wellbeing is experienced in the reality of the social context we live in.

It is impacted by our socially constructed identities (including race).

Social Determinants of Health (SDoH)

Non-medical factors that influence health outcomes. **Social**, **political** and **economic** factors in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.



York University; Canadian Observatory on Homelessness/Homeless Hub

Health Equity and SDoH

There are differences between population groups that are **systemic, causing persistent and widening gaps** between those with the best and worst health and well being.

> *Health equity is defined as the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically*

Why should we measure race?

We measure race to measure the impacts of racism.

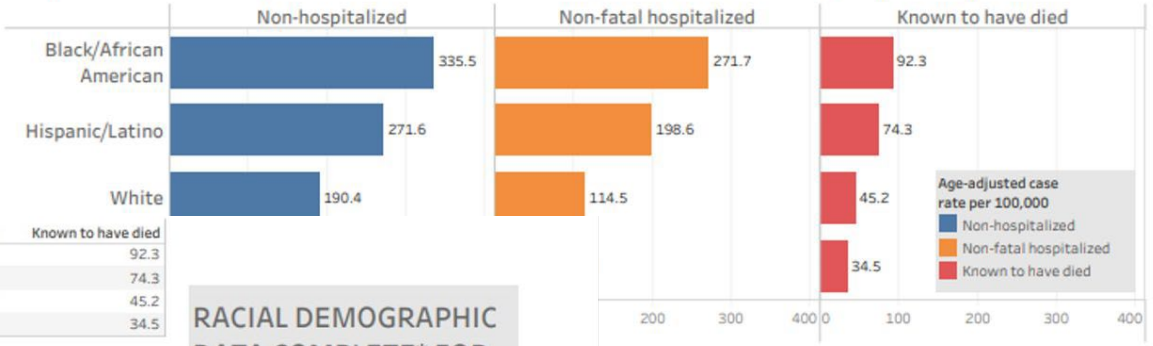
Current Sociodemographic data collection and use

- Long history of researchers advocating for the collection of race-based and socio-demographic data to better understand disparate health outcomes and barriers to equitable care at the population-level
- The COVID 19 pandemic shed light on underlying social inequities and spurred more action by government, standards communities, academics and community organizations

https://www.healthcommons.ca/blog/engaging-communities-in-your-data-collection-initiative

COVID-19 Morbidity + Mortality

hospitalized cases, and patients known to have died 100,000 by race/ethnicity group as of April 16,2020



	Race Ethnicity	Non-hospitalized	Non-fatal hospitalized	Known to have died
Age-adjusted case rate per 100,000	Black/African American	335.5	271.7	92.3
	Hispanic/Latino	271.6	198.6	74.3
	White	190.4	114.5	45.2
	Asian	95.1	82.2	34.5
Count of cases	Black/African American	6,742	5,766	1,999
	Hispanic/Latino	6,701	4,740	1,696
	White	5,900	3,953	1,861
	Asian	1,308	1,132	463
Percent of known race/ethnicity	Black/African American	32.6	37	33.2
	Hispanic/Latino	32.4	30.4	28.2
	White	28.6	25.4	30.9
	Asian	6.3	7.3	7.7

RACIAL DEMOGRAPHIC DATA COMPLETE* FOR

24% of cases

72% of hospitalizations

88% of deaths

All data are preliminary and subject to change. Data are derived from the Bureau of Communicable Disease Surveillance System as of April 16, 2020.

* The vast majority of cases are reported by labs, and race/ethnicity information is often missing because it is not received on the test requisitions from providers.

- Data on persons who identify as American Indian/Alaska Native, Native Hawaiian/ Pacific Islander, or other race are not shown. Hispanic/Latino includes people of any race.
- The rate of non-hospitalized and hospitalized cases shows patients not known to have died. The three categories shown are mutually exclusive.

Chowkwanyun M, Reed A.

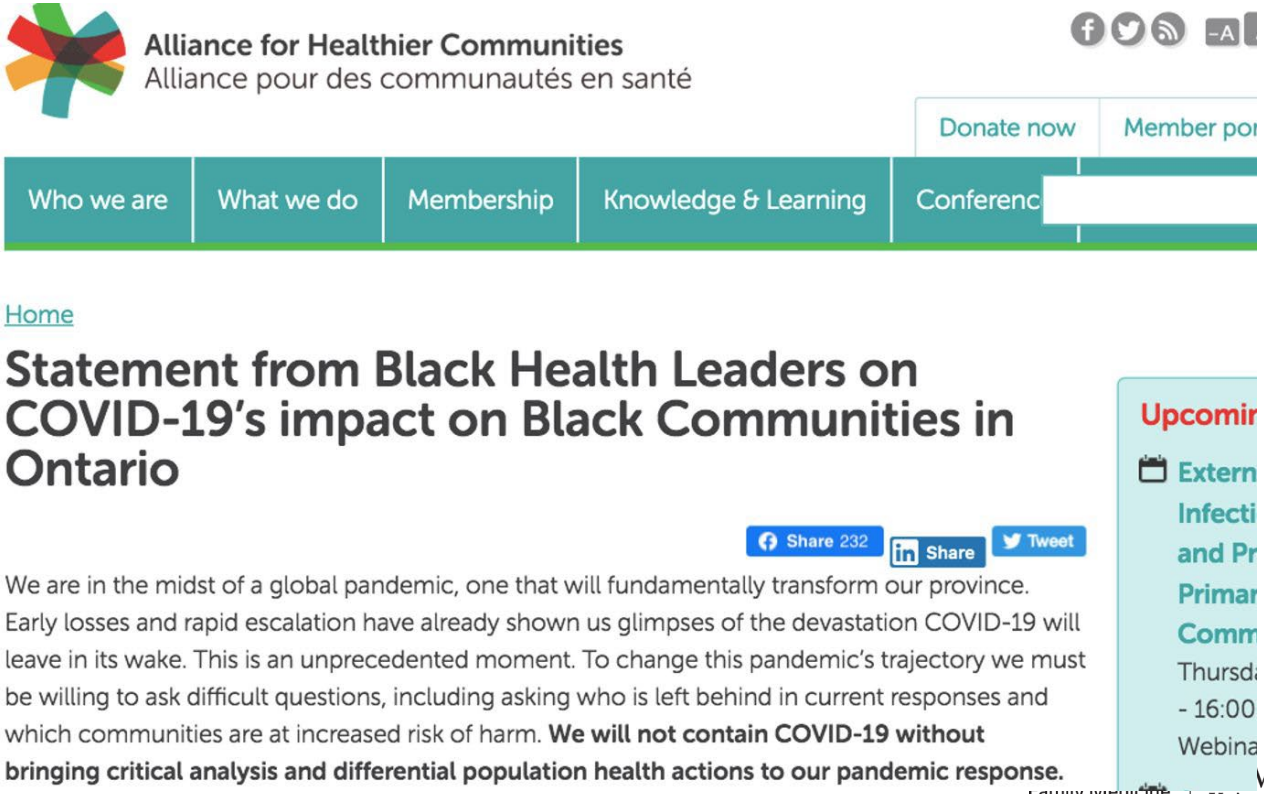
Racial Health Disparities and Covid-19- Caution and Context.

NEJM. May 2020. DOI: 10.1056/NEJMp2012910

- Caution against blaming racial disparities in health solely on biological differences
- **Blaming differences on behavioural patterns reinforces racial stereotypes**– ex. Black people described as unhygienic/ vice ridden to explain the higher rates of TB in Black communities in the 20th century [1]
- Granular data highlights racialized neighbourhoods as problematic – **what does this mean for the future? Demolition? Repressive surveillance?**
- These ”racial issues” are **not just the concern of racialized individuals**

1. Roberts SK. Infectious fear: politics, disease, and the health effects of segregation. Chapel Hill: University of North Carolina Press, 2009.

Canadian Calls to Action



https://www.allianceon.org/news/Statement-Black-Health-Leaders-COVID-19s-impact-Black-Communities-Ontario

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Complexities of Race in [outdated] Medical Algorithms

Box 1. Grace's Dilemma

"What should I do with my Cape Verdean patient?" insists Grace, a third-year medical student. "The clinical protocol for hypertension requires me to identify his race but I don't know how. Is he black or white? This man immigrated to the US at a young age. Is he now African American or should I consider his health needs from the perspective of his immigrant status?" The data on response to therapy seem to suggest that hypertension in blacks is somehow special, implying a separate genetic factor for blacks. But the enormous national differences in hypertension rates do not support this argument. African Americans suffer at rates 3.5 times those of Nigerians living in Africa, although African Americans experience only 0.75 the rates of Germans in Germany [79]. Which category matters more for Grace's patient, country of origin or social status in the adopted nation?

From Braun et al. (2007)

HOW should we measure race?

UN Best Practices: race, ethnicity, and Indigeneity

***UN Principles and Recommendations for Population and Housing Censuses* (United Nations, 2017).**

1. Separate race, ethnicity, and indigenous status categories
2. Include multiple response options to allow people to identify more than one ethnic affiliation
3. Include an 'Other' response option to allow people to self-identify in their own words
4. Design data collection methods that allow people to self-identify and not be assigned to a category based on socially constructed notions of identity
5. Including categories for 'none' or 'refused' should be allowed

Canadian Language

"Visible Minority Persons"

- Employment Equity Act (1995)
- Non-Indigenous persons "non-Caucasian in race and non-White in colour."
- Not comparable to *any* international metric or standard, NOT race

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

JAMA August 17, 2021 Volume 326, Number 7

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

> terminology, usage, and word choice are **critically important,** especially when describing people and **when discussing race and ethnicity**. Inclusive language supports diversity and conveys respect. **Language that imparts bias toward or against persons or groups based on characteristics or demographics must be avoided.**

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

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- Ancestry or genetic data provides more useful information on health and genetic risk of disease

- When reporting results that include racial or ethnic disparities, provide balanced, evidenced based discussion on the implications of these findings in the context of racism

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

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- Explain **how race was measured**, justify the **classification**
- Justify ***why race-based data was collected***
- *Specific* racial categories preferred over collective terms
- ***List racial categories in alphabetical order***
- *Race **AND** ethnicity* not *race/ethnicity*
- *Racial terms are not nouns, eg. Asian participants* not Asians
- Capitalize the first letter of each racial term *(Black* not black)

Editorial

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

Box 1: Guidance for the reporting of race and ethnicity in *CMAJ* research articles

Articles being considered for publication in *CMAJ*'s Research section should adhere to the following guidelines:

1. *CMAJ* encourages the collection, analysis and reporting of data on the race and ethnicity of research participants, in order to provide evidence regarding health effects, disparities and inequities experienced by different racial and ethnic groups.
2. *CMAJ* strongly encourages representation, as study partners, co-investigators and authors, of people from racial and ethnic groups affected by the health context being studied, especially for studies that explore racism, race and ethnicity as determinants of health.
3. Authors should explain the purpose and relevance of collecting, analyzing and reporting data on race or ethnicity in their study and what race and ethnicity represent in the context of the research question.
4. Authors should report race and ethnicity together with other demographics of the study population.
   a) Race and ethnicity should be listed together with other variables collected and analyzed in the Methods section.
   b) Race and ethnicity should be reported together with other demographic variables in a table and summarized at the beginning of the Results section.
5. As race and ethnicity are inherently social constructs, studies that analyze race and ethnicity should endeavour to explore their effects in the context of other sociodemographic variables and structures.
6. In the Methods section, authors should describe how race and ethnicity of study participants was determined and by whom (e.g., "Study participants self-identified their race from 12 categories provided in the 2019 version of the Canadian Community Health Survey …").
   a) Authors should explain whether race and ethnicity were self-identified by study participants or identified by others, providing justification if self-identification was not used.
   b) Authors should state whether options that participants could select to indicate their race or ethnicity were open-ended or based on fixed categories, listing the categories available, if applicable, and whether participants were allowed to identify as belonging to more than 1 racial or ethnic group.
   c) If race and ethnicity categories were determined or constrained by external factors (e.g., government legislation), or were originally collected for a purpose different from the purpose of the study being reported, authors should explain this.
7. 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.
   a) Studies that seek to test genetic hypotheses require collection, analysis and reporting of genetic data.
   b) Although genetic or biological predispositions to certain diseases may track with specific racial and ethnic groups, researchers should not exclude otherwise eligible participants from other groups capable of developing the disease, as doing so may worsen under-recognition of the disease in such groups.
   c) Race-based algorithms (e.g., "corrected" creatinine clearance for Black people) should not be used, as such "race corrections" typically oversimplify, creating the potential for inequity and harm.
   d) Exceptionally, in contexts where genetic characteristics travel very closely with race and ethnicity (e.g., the association between skin pigmentation and vitamin D levels), the rationale and validity of treating race and ethnicity as biological surrogates must be clearly explained and justified.
8. Authors should comment on how their social position and identity, including race and ethnicity and their intersection with other factors, might have influenced data collection, analysis and interpretation, and how the researchers addressed power relations throughout the research process.
9. In the Interpretation section, for studies that highlight associations of race and ethnicity with health outcomes, authors should discuss how their findings illustrate the intersection of race and ethnicity with other sociodemographic factors in the health context being studied, the role of structural racism in this context and how this might be addressed.
10. Authors must use appropriate, precise and respectful language to describe study participants and avoid the use of terminology that might stigmatize participants.
    a) Terms that imply a hierarchy among races (e.g., "non-White") should be avoided and preferred terms (e.g., "under-served" or "under-represented" populations, "historically marginalized groups") used instead, as contextually appropriate.
    b) Listing of racial and ethnic groups in tables should be ordered based on an empirical rationale rather than one that implies a hierarchy (e.g., "White" should not automatically be listed first).
    c) Naming racial and ethnic categories as specifically as is appropriate to the study context is preferred over use of collective categories (e.g., "Indian" would be suitable in the context of some research questions, but in other contexts, "Punjabi" and "Malayali" could be more relevant; "Asian" is usually too generic to be sufficiently informative).
    d) It is acceptable to pool racial and ethnic groups for analysis when necessary and appropriate, but authors should explain and justify the manner in which this is done and ensure that the individual racial and ethnic groups within each category are identified.
    e) Racial and ethnic terms should be used in adjective form rather than in noun form (e.g., "Hispanic people," not "Hispanics").
    f) Names of racial, ethnic or tribal groups should be capitalized.
    g) Authors should use preferred contemporary names for racial and ethnic groups (e.g., White, not Caucasian).
    h) As preferred names for racial and ethnic groups may vary and may change over time, authors should be guided as much as possible by the preferences of study participants as to their expressed identity.

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Race-Based Data Collection in the US

- NIH-funded research requires racial identities of participants
- All participants must be classified into one of 6 categories (as defined by the US Office of Management and Budget Directive No. 15):

❏ American Indian or Alaska Native
❏ Asian
❏ Black or African American
❏ Native Hawaiian or other Pacific Islander
❏ White
❏ Hispanic/Latino

*Intent of this practice was to ensure clinical trials are racially inclusive

From Braun et al. (2007)

CIHI 2022

> Race-based and Indigenous identity data is **vital for the identification and monitoring of health inequalities that stem from racism,** bias and discrimination, and to inform interventions **to improve equity in health care access**, quality, experience and outcomes.

CIHI, (2022)

CIHI 2022

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

Key Concepts

Data Governance:

The overall administration, through clearly defined procedures and plans, that assures the availability, integrity, security, and usability of the structured and unstructured data available to an organization. (AHIMA, 2020)

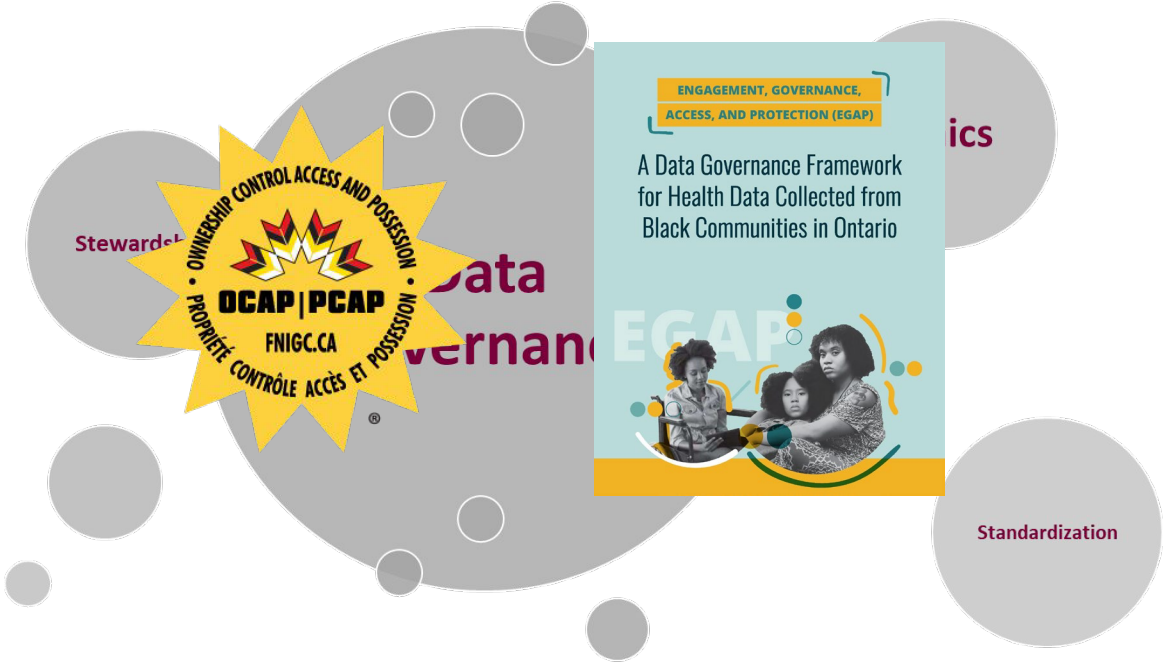
Data Stewardship:

The active management of data and processes so data can be used as a consistent, secure and organized asset that meets policies and standards.

Data Standardization:

Use of agreed upon terms, codes, processes to collect complete, structured and meaningful data

Data Management



WHO should research racialized people?

Privilege, Power, and Social Structures

Any measure of social disadvantage is the result of differentials in power.

- Privilege = to hold power.
- Can apply to *any* equity seeking group
- The *researchers* and the *researched*

Racism is the result of historic and ongoing social systems and structures of racial inequities.

We cannot address racism, nor improve the lives of racialized peoples, without addressing the social structures within which it functions.

The privilege of being “the researcher”

The people with the most expertise and insider knowledge of what it means to be racialized are **racialized people.** Negating this continues to uphold systems of oppression.

Allyship requires us to work to **“build insight among others in positions of privilege, and *mobilize in collective action* under the leadership of people on the bottom [of social hierarchies].”**

Critical Race Theory (CRT)

Contemporary legal thought lead by pioneering Black + racialized legal scholars,[1] → Racism ***"structures how society functions"*** [2]

> **...challenges the ways in which race and racial power are constructed and represented in American legal culture and, more generally, in American society as a whole.**

1. Understand how white supremacy operates, examining social structures and racial power
2. *Change* it.

[1] **For further reading, see the works of: Robert Cover, A Leon Higginbotham, Jr., Derrick Bell, Jr., Kimberlé Crenshaw**

[2] Douglas et. al., , 2022; Crenshaw, 1995

Applying CRT to Medical Research

- **Ingrained nature of race + Racism**
- **Importance of Narrative and Counter-Narrative**
- **Interest Convergence**

Applying these principles as a researcher

Framework for CRT in Medical Research

Researching the self
Researching the self in relation to others
Engaged reflection and representation
Shifting from self to system

(Milner, R. Race, Culture, and Researcher Positionality: Working Through Dangers Seen, Unseen, and Unforeseen. *Educational Researcher,* 2007.)

Framework for CRT in Medical Research

Self	Researchers cannot work for the emancipation/ to solve the problems with and on behalf of others, until they are emancipated themselves. **Ask:** *What is my racial or cultural heritage? How do I know?* *What is the historical landscape of my racial or cultural identity and heritage? How do I know?* *What racialized or cultural experiences have shaped my research decisions, practices, approaches, epistemologies, and agendas?*
Self in relation to Others	
Engaged Reflection + Representation	
Shift Self → System	

Framework for CRT in Medical Research

Self	Power is relational. Understand the tensions inherent in your own interests + power in relation to the people + communities under study **Ask:** *In what ways do my participants' racial and cultural backgrounds influence how they experience the world? How do I know?* *How do I negotiate/ balance my own interests and agendas with those of my participants? How do I know?*
Self in relation to Others	
Engaged Reflection + Representation	
Shift Self → System	

Framework for CRT in Medical Research

Self	Both researchers' and participants' voices, perspectives, narratives and counternarratives are represented in interpretations + findings.
Self in relation to Others	
Engaged Reflection + Representation	
Shift Self → System	

Framework for CRT in Medical Research

Self	Contextualized + ground your views taking into account the broader historical, political, social, economic, racial, cultural realities. Consider policy, institutional, systemic, and collective issues. **Ask:** *What systemic and organizational barriers and structures shape the community and people's experiences, locally, and more moradly? How do I know?*
Self in relation to Others	
Engaged Reflection + Representation	
Shift Self → System	

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(Milner, 2007)

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Applying these principles as a consumer of research

Be Critical of Race in Research

How was the data collected and <u>why</u>:

- *Why was race included? Did the researchers justify its inclusion? Were any other data on social determinants of health collected?*
- *How was race defined? How was race measured? (Self-defined/ defined by the researchers)*
- *What were the categories used to classify race? Were there categories appropriate for the study population? Did the researchers justify the categories used?*

What was the relationship between the racialized participants and the research team?

- *Were racialized or Indigenous people consulted/included in the research team?*

Be Critical of Race in Research

How are the study findings presented and reported?

- *Did the publication follow the JAMA or CIHI guidance of race-based data in research?*
- *What were the assumptions made about race? (e.g. biology of race)*
- *How were the results interpreted? Were the impacts of racism considered? If there were racial differences in the study findings, did the paper assume a biological cause?*

How could this study influence racialized patients/ communities?

- *How could these results impact the health of racialized communities?*
- *How could this impact the care you provide to your racialized patients?*
- *What assumptions do you make about your patient when you apply this evidence?*
- *Were there any differences between the racial make-up of the study population and the population you serve? Can these findings be generalized? What could be the impact of generalizing these findings to all racialized populations?*

Further learning

PBS free interactive e-modules: **What is Race?**

https://www.pbs.org/race/001_WhatIsRace/001_00-home.htm

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