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Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics at ICES

Executive Summary



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ICES

V1 06, 2075 Bayview Avenue

Toronto, ON M4N 3M5

Telephone: 416-480-4055

Email: communications@ices.on.ca



Author Affiliations

Laura E. Ferreira-Legere, RN, MScN

Senior Manager, Public Engagement & Knowledge Translation, ICES

Astrid Guttmann, MDCM, MSc, FRCPC

Chief Science Officer and Senior Core Scientist, ICES / Staff Paediatrician, Division of Paediatric Medicine, Hospital for Sick Children / Senior Scientist, Child Health Evaluative Sciences, SickKids Research Institute / Professor, Department of Paediatrics and Institute of Health Policy, Management and Evaluation and Division of Epidemiology, Dalla Lana School of Public Health / Co-Director, Edwin S. Leong Centre for Healthy Children, University of Toronto

Elise Leong-Sit, RD, BSc Dietetics

Public Engagement & Knowledge Translation Officer, ICES

J. Michael Paterson, MSc

Interim Chief Science Officer, ICES / Program Leader, Chronic Disease and Pharmacotherapy Research Program and Core Scientist, ICES / Assistant Professor, Department of Family Medicine, McMaster University / Assistant Professor, Institute of Health Policy, Management and Evaluation, University of Toronto

Michael J. Schull, MD, MSc, FRCPC

Chief Executive Officer and Senior Core Scientist, ICES / Professor and Clinician-Scientist, Department of Medicine, University of Toronto / Senior Scientist, Evaluative Clinical Sciences, Sunnybrook Research Institute / Professor, Institute of Health Policy, Management and Evaluation, University of Toronto / Staff Emergency Physician, Sunnybrook Health Sciences Centre

Sujitha Ratnasingham, MSc

Director, Strategic Partnerships, ICES / Operational Lead, Indigenous Portfolio, ICES

Baiju R. Shah, MD, PhD

Senior Core Scientist, ICES / Scientist, Evaluative Clinical Sciences, Sunnybrook Research Institute / Head, Division of Endocrinology, Sunnybrook Health Sciences Centre / Professor, Department of Medicine and Institute of Health Policy, Management and Evaluation, University of Toronto / Novo Nordisk Research Chair in Equitable Care of Diabetes and Related Conditions, University of Toronto

Marian J. Vermeulen, BScN, MHSc

Senior Director, Research, Data and Financial Services, ICES

Susitha Wanigaratne, PhD, MHSc

Research Fellow, ICES / RESTRACOMP Fellow, Child Health Evaluative Sciences, SickKids Research Institute

Sabella Yussuf-Homenauth, BSc Pharmacy, MPH

Senior Public Engagement & Knowledge Translation Officer, ICES

Bidjinie Coriolan, MScPH

(Former) Public Engagement & Knowledge Translation Officer, ICES

Jenine Paul, BSc

(Former) Manager, Public Engagement & Knowledge Translation, ICES / Principal, Amplify Engagement



About ICES

ICES is an independent, non-profit research institute. As a prescribed entity under Ontario's privacy legislation, ICES is authorized to collect and use healthcare data for the purposes of health system analysis, evaluation and decision support. Secure access to these data is governed by policies and procedures that are approved by the Information and Privacy Commissioner of Ontario. ICES research provides measures of health system performance, a clearer understanding of the shifting healthcare needs of Ontarians and a stimulus for discussion of practical solutions to optimize scarce resources.

The ICES Peoples' Panel

The Peoples' Panel was convened to guide ICES' approach on the use of race, ethnicity and immigration data at an institutional level. Individuals from across Ontario who identified as racialized or who had an interest in how race data are used were recruited through an open call. No experience in health, science or policy was needed. We sincerely thank the members of the ICES Peoples' Panel and the Tamarack Institute and Digital Justice Lab for their contributions to this Document. To access the full Peoples' Panel Report, see Appendix 2.

Acknowledgements

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In March 2023, targeted consultations were undertaken with 13 community representations and equity experts to discuss community-led data governance. These consultations provided detailed recommendations on how to plan for community-led governance of race and related data at ICES, which will be used to guide this work moving forward. We thank those who provided their time and expertise for these discussions.

Peer Review

ICES conducted several rounds of peer review during the development of this Document. We sincerely thank the following groups for their review:

The ICES Internal Committee of Scientists (Appendix 3)
The ICES [Scientific Advisory Committee](#)
ICES Program Leaders and Site Directors
ICES Staff, Scientists and Trainees



...collecting and using race and related data responsibly for health system improvement has been highlighted by communities, human rights advocates, equity researchers and other groups...



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The importance of collecting and using race and related data responsibly for health system improvement has been highlighted by communities, human rights advocates, equity researchers and other groups advocating for anti-racist research. To address these calls to action, ICES consulted with members of the public, external health equity experts, as well as internal staff, scientists and senior leaders to develop a **Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics**.

The aims of this Guidance Document and Framework are to outline organizational strategies to help implement anti-racist and anti-oppressive practices, support appropriate use of race and related data at ICES, prompt scientists and research teams to consider the role of systemic racism and other forms of oppression in perpetuating health inequities and support communities to access impactful research that is responsive to their needs and priorities.

Note on use of the term “race and related data”

The term “race and related data” refers to any data held at ICES that can identify or infer race, including race, ethnicity, or mother tongue. Certain immigration variables are also included under this umbrella term (e.g., country of origin).

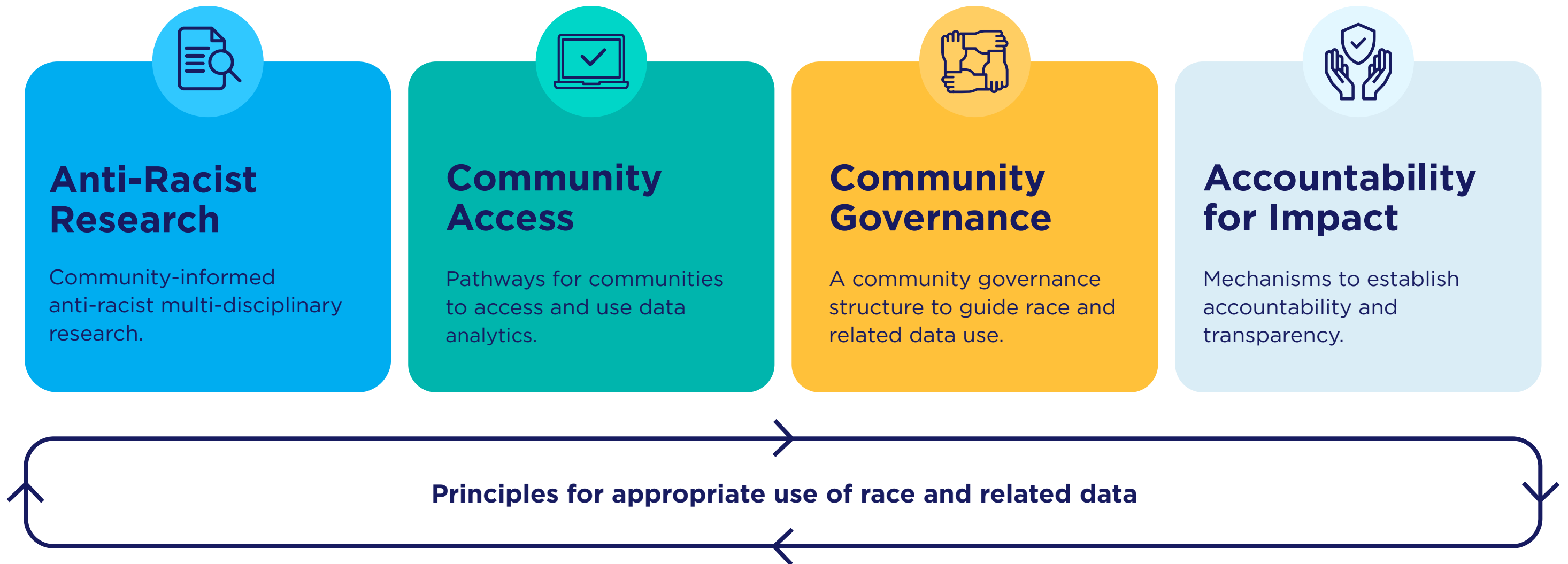
Note on Indigenous identifiers and data

ICES has previously developed distinct approaches and policies for Indigenous data governance in partnership with Indigenous leadership organizations. The Framework below was informed in part by the [ICES Indigenous Data Governance Principles Framework](#), which was initially developed in collaboration with the [Chiefs of Ontario](#) and the ICES Indigenous Portfolio for First Nations data and research. Given the distinct approach of the ICES Indigenous Portfolio work, this Document does not discuss Indigenous identity or data. More information for ICES Scientists on using Indigenous data can be found on the [intranet](#).



Framework to Drive Anti-Racist Approaches to Health Research at ICES*

The *Framework to Drive Anti-Racist Approaches to Health Research at ICES* (The Framework) is organized into four domains. Each domain includes a goal and components that guide ICES' commitment to racial equity in health research. At the foundation of the Framework are the principles for appropriate use of race and related data informed by the Peoples' Panel, a group of over 50 members of the public, which underpin the four core Framework domains.



* The Framework to Drive Anti-Racist Approaches to Health Research at ICES was informed in part by the [ICES Indigenous Data Governance Principles Framework](#), which was developed in collaboration with the [Chiefs of Ontario](#) and the ICES Indigenous Portfolio. The ICES Indigenous Data Governance Principles Framework is a data stewardship model, where Indigenous data are held at ICES but governed by appropriate Indigenous organizations/communities.



Principles for Appropriate Use of Race and Related Data

These overarching principles were established as the foundation of The Framework

We will...

1 Report biases/limitations and engage with equity scholars across many disciplines and communities for appropriate research conduct and contextualization.

2 Discuss racism and evaluate the impact of health policy on racialized populations.

3 Be explicit about the reasons for using race and related data in research and vet research practices with representative community members and health equity experts.

4 Use race and related data to illustrate the impact of racism on health and advance health equity.

5 Engage communities in a respectful way to collaborate on how data are used, interpreted and shared as well as fund research analytics for community-identified needs.

6 Clearly define study limitations and collaborate across disciplines to contextualize studies that use race and related data.

7 Acknowledge that “race” and “ethnicity” are different concepts with no fixed definitions and do not represent genetically distinct homogeneous groups.

8 Integrate self-reflection and positionality throughout the research process.

9 Contextualize research findings by exploring systemic racism and its broader influences on other social and structural determinants of health.

10 Consider the interaction of important social determinants of health such as poverty and education as well as how various forms of discrimination such as racism, sexism and ableism overlap.

DOMAIN 1

Anti-Racist Research



Goal:

Promote community-driven and community-informed anti-racist and multidisciplinary research at ICES.

Domain Components

1.1 Internal Capacity-Building and Community Engagement

Provide education and resources on health equity through tangible tools and consultations with the Public Engagement and Knowledge Translation (PEKT) team. Support research teams with tools and training on planning and conducting meaningful community engagement in an ICES project, including dissemination of results back to community members whose data have been included.

1.2 Broadening Expertise

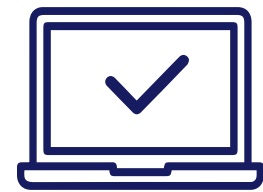
Foster interdisciplinary partnerships and engagement with equity scholars to broaden the science in health equity and promote internal capacity. Provide non-ICES scientists accessing data through Data and Analytic Services (DAS) the same guidance on appropriate use of race and related data at ICES.

1.3 Data Quality Assessment and Data Acquisition

Assess the data quality and controls currently in place through a review and report of the source and validity of race and related variables/algorithms within the ICES repository. Assess the quality and collection of newly acquired data for the ICES repository.

DOMAIN 2

Community Access

**Goal:**

Create pathways for communities and organizations serving racialized communities to access and use data analytics through the Applied Health Research Question (AHRQ) Program.

Domain Components**2.1 Community Awareness and Accessibility**

Use targeted strategies to increase community awareness of pathways to access race and related data analytics through the AHRQ program. Explore additional funding opportunities to support community-driven AHRQs and ensure appropriate resource allocation for projects with a health equity focus.

2.2 Mutual Capacity-Building

Support knowledge users of community-driven AHRQs with context to use race and related data for the purpose of effective knowledge translation to communities they serve. Reciprocally engage in learning with communities on contextualization of their data.

DOMAIN 3

Community Governance



Goal:

Co-design and implement a community-led governance structure at ICES to guide corporate and project-level initiatives involving race and related data.

Domain Components

3.1 Community Governance Structure

Co-design a community governance structure at ICES through consultation with community representatives and develop a mandate that outlines the purpose and goals of this work. Establish a community governance advisory table under this structure to provide corporate and project-level guidance.

DOMAIN 4

Accountability for Impact



Goal:

Create and implement mechanisms to ensure accountability and transparency when using race and related data.

Domain Components

4.1 Knowledge Mobilization

Communicate key findings from ICES research using race and related data clearly and directly to impacted communities. Create opportunities for information sharing and mutual engagement.

4.2 Transparency

Monitor research activities using race and related data to transparently report progress toward meeting the committed actions of the Guidance Document. Establish mechanisms to quantify metrics related to race and related data access and use at project initiation and publication.

4.3 Reporting Mechanisms

Establish reporting mechanisms for community organizations conducting an AHRQ project to provide ongoing feedback on how the process can be improved for accessibility and equity.

This Document is not prescriptive in how scientists should analyze race and related data, but rather is one step in a larger process...



Concluding Remarks

The Guidance Document and Framework outline the key actions ICES is taking toward establishing an anti-racist research agenda and appropriate use of race and related data across the organization. This Document is not prescriptive in how scientists should analyze race and related data, but rather is one step in a larger process to improve data use practice and encourage reflection on how racial health inequities result from social determinants rather than biological differences. The shift from “race” to “racism” is one that will look different in each ICES project.

For questions on the Guidance Document and Framework, we encourage you to connect with the ICES Public Engagement and Knowledge Translation Office (public@ices.on.ca) to discuss how we can assist you.



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