



Canadian Collaboration for Child Health: Efficiency
and Excellence in the Ethics Review of Research

Collaboration pancanadienne pour la santé des
enfants: Efficacité et excellence dans la révision
éthique de la recherche

CHEER Webinar Series 2024- 2025

**Empowering REBs: Infusing Research
Oversite with Equity, Diversity, Inclusion,
and Accessibility**

October 29, 2024 12:00 pm EST



Equity, Diversity, Inclusion and Accessibility



Equity is defined as the removal of systemic barriers (e.g., unconscious bias, discrimination, racism, sexism, ableism, homophobia, etc.), enabling all individuals to have equitable opportunity to access and benefit from the program;

Diversity is about the variety of unique dimensions, identities, qualities and characteristics individuals possess along with other identity factors; and

Inclusion is defined as the practice of ensuring that all individuals are valued and respected for their contributions and are supported equitably in a culturally safe environment.

Accessibility is the design of products, devices, services, or environments for people who experience disabilities. It is the opportunity to access programs, services, devices and the environment at the time they are needed without encountering barriers.

Disability

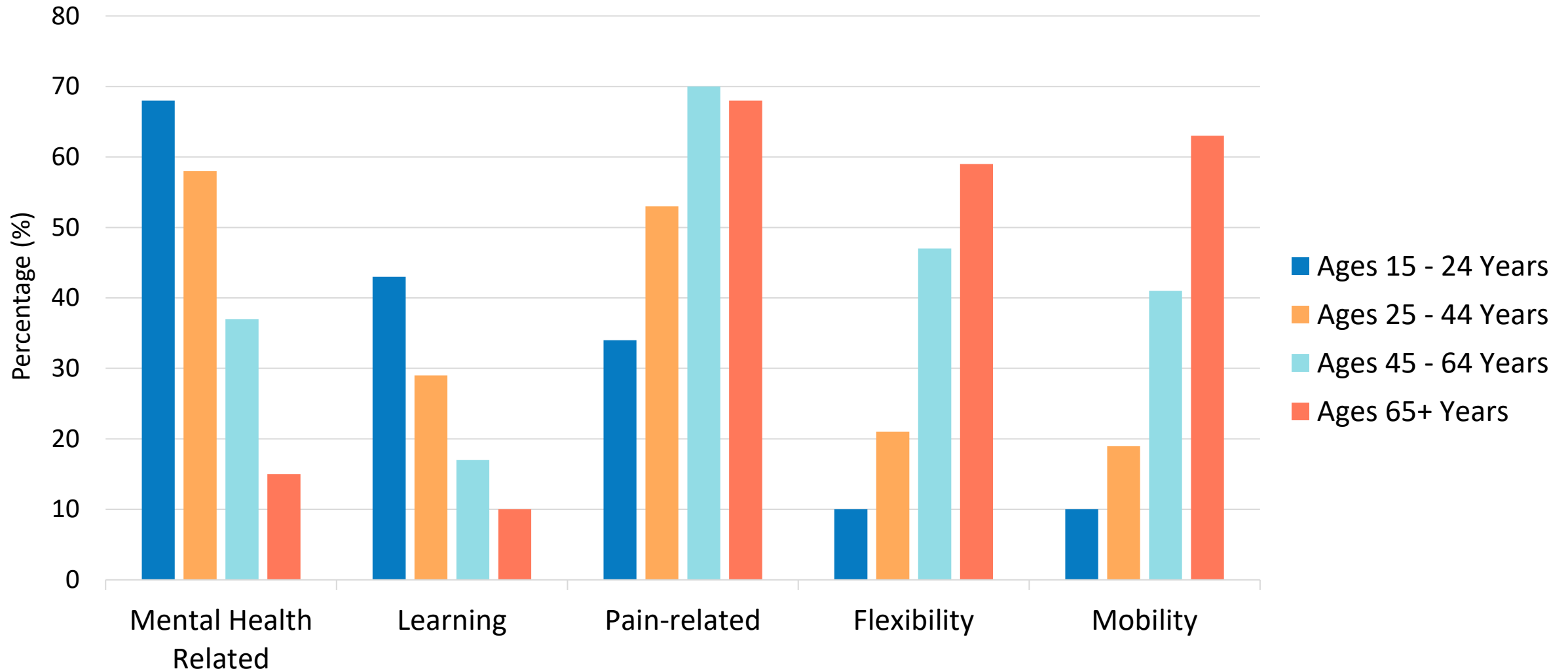


A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).

Disabilities can be visible or invisible and perceived or not perceived by others



Disability Type (%) by Age Group 2022



Barriers of Disability



“Anything physical, architectural, technological or attitudinal, anything that is based on information or communications or anything that is the result of a policy or a practice—that hinders the full and equal participation in society of persons with an impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment or a functional limitation.”

The [Accessible Canada Act](#) (ACA) was passed in 2019 with goal of creating a barrier-free Canada by 2040.

72% of people with disabilities reported that they experienced at least one type of barrier to accessibility because of their condition.

Barriers for Researchers



- ▶ Students and trainees with disabilities may experience early-career barriers
- ▶ People who disclose disabilities can be treated inequitably
- ▶ Disability-tax creates burden for people to provide proof of disability before they arrange accommodation
- ▶ Inflexible deadlines can be a barrier for researchers with disabilities
- ▶ Funding agencies' grant and award policies have excluded accommodations for persons with disabilities



Accessibility for REB Members



Full Board Meetings

- ▶ Make the meeting room accessible (elevators, no environmental hazards)
- ▶ If ordering food, consider dietary restrictions, allergies and sensitivities

Hybrid Meeting Options

- ▶ Use larger font/check documents for accessibility
- ▶ Microphones in the room should be audible to everyone attending virtually
- ▶ Cameras should pick up everyone in the room
- ▶ Name cards should be used

Accessibility for Research Participants



Recruitment and Informed Consent

- ▶ Define all terms and use common words
- ▶ Use larger font/check documents for accessibility
- ▶ Diagrams, other mechanisms for providing information as necessary

Online Research

- Colours should be viewable, especially task buttons and instructions
- ▶ Large font, blank space for surveys
- ▶ Microphones and cameras working for interviews/focus groups, closed captioning

In-Person Research

- ▶ Ask if accommodations of any kind are needed
- ▶ Accessible spaces, elevators, lifts, ramps available
- ▶ If food to be served, any dietary requirements, allergies, sensitivities

Strategies to Increase Accessibility for Meetings



Create a Culture of Sensitivity and Speaking Up!

- ▶ People have invisible, temporary or situational disabilities
- ▶ Be open to disclosure and give individuals the space to let you know their needs on their own terms
- ▶ Enable closed captioning, recording
- ▶ Make accessibility features opt out – not opt in!
- ▶ Make a copy of the presentation materials for people to follow along or review later

Strategies to Increase Accessibility for Meetings



- ▶ Presenters should enable video and center on their face, make sure their face is taking up the majority of the screen
- ▶ Blur or neutralize your background
- ▶ Describe what they look like and what they are wearing
- ▶ Use headphones and a mic
- ▶ Listen and read chat if there are concerns with hearing or seeing
- ▶ Use respectful language

Where People Sit Matters



Set up More Equal Seating

- ▶ In live meetings, physical positions can create a hierarchy of importance.
- ▶ Same for virtual meetings – who has their camera on? Who has camera on?
- ▶ Think about a sharing circle - is everyone visible, equally spread out, able to see and engage with the speaker and each other?
- ▶ Encourage people to sit in a different chair from the last time to shake up habits of the physical dynamic.

Provide alternative ways to share

International Day of Persons with Disabilities



This day aims to increase awareness and promote the rights and well-being of persons with disabilities in every aspect of life



International
Day of
**Persons with
Disabilities**

3 DECEMBER

A Self-reflective Exercise



Imagine the following scenarios:

- ▶ You are picking up your pre-schooler and you need to speak to the teacher about an upcoming appointment that means you need to do pick up earlier than you typically would...
- ▶ You are having dinner in a restaurant, at the table next to you is a couple celebrating their 10-year wedding anniversary...
- ▶ You are an avid tennis player, your coach teaching you a new technique for the perfect backhand serve...

Why is EDIA Needed in Research?

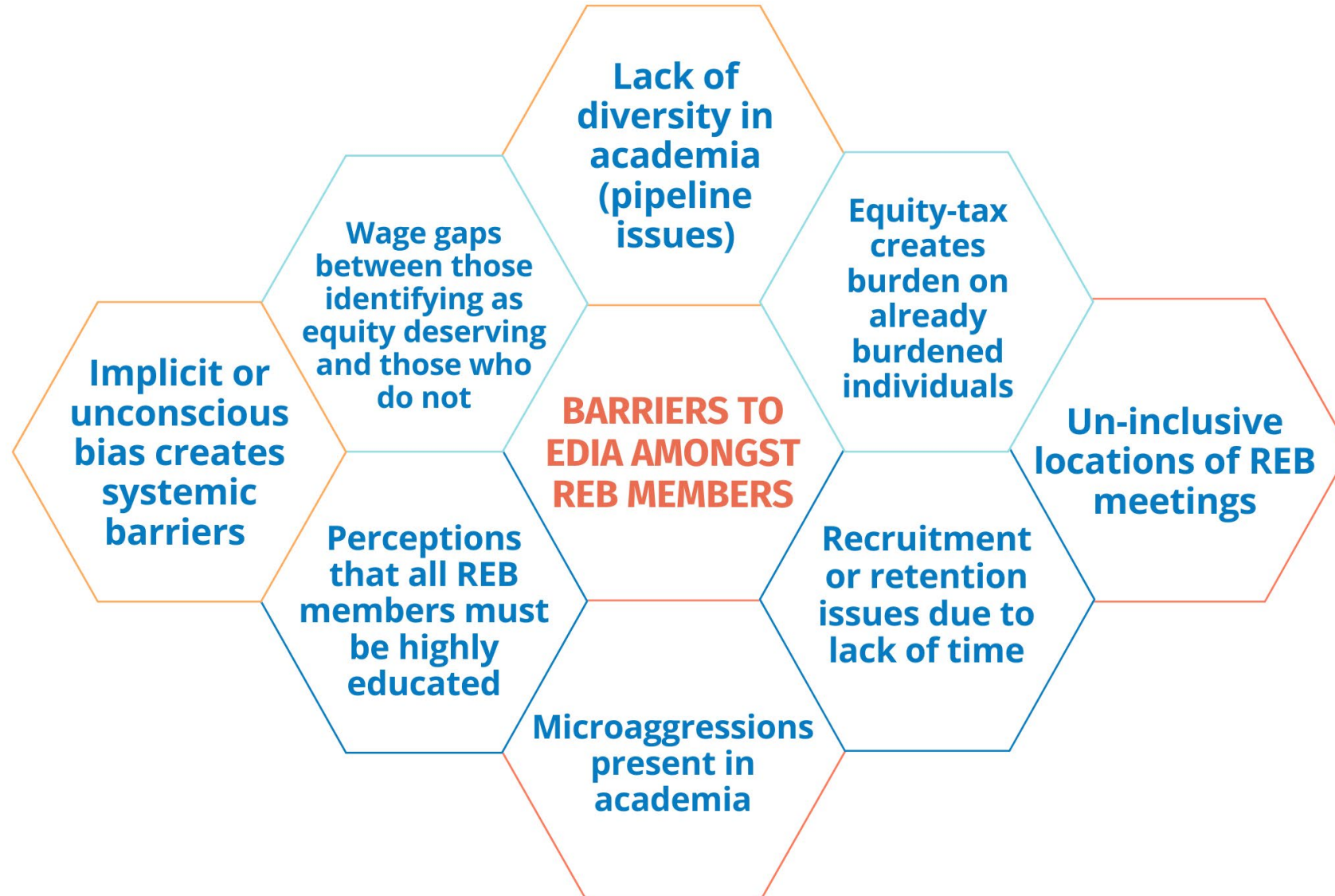


Why is EDIA needed on the REB



- ▶ REB's lacking in diversity may miss salient ethical issues (Churchill et al., 2022)
- ▶ An REB with a diverse membership can provide a more holistic review of research (Anderson et al., 2023, Public Responsibility in Medicine and Research, 2023)
- ▶ Diversity is key to overcoming institutionalized racism (Jonker et al., 2021)
- ▶ Avoid an equity-tax: those from equity deserving groups are not unfairly burdened with the task of solving the EDI question (Drolet et al., 2023)
- ▶ Despite membership being regulated (Tri-agency, December 2022; Health Canada, 2023; U. S. Food and Drug Administration, 2023), diversity amongst the membership is hard to achieve

Barriers to EDIA amongst REB members



Community Members



- ▶ Diversity on the REB is critical to for its function
- ▶ Community member representation of the participant perspective is central to the mandate for the REB
- ▶ Compensation for community members increases equity in research infrastructure (PRIM&R, 2023)
- ▶ Sometimes the community member voice can be lost in the melee of other voices (Anderson et al., 2023)



Facilitators to EDIA amongst REB members



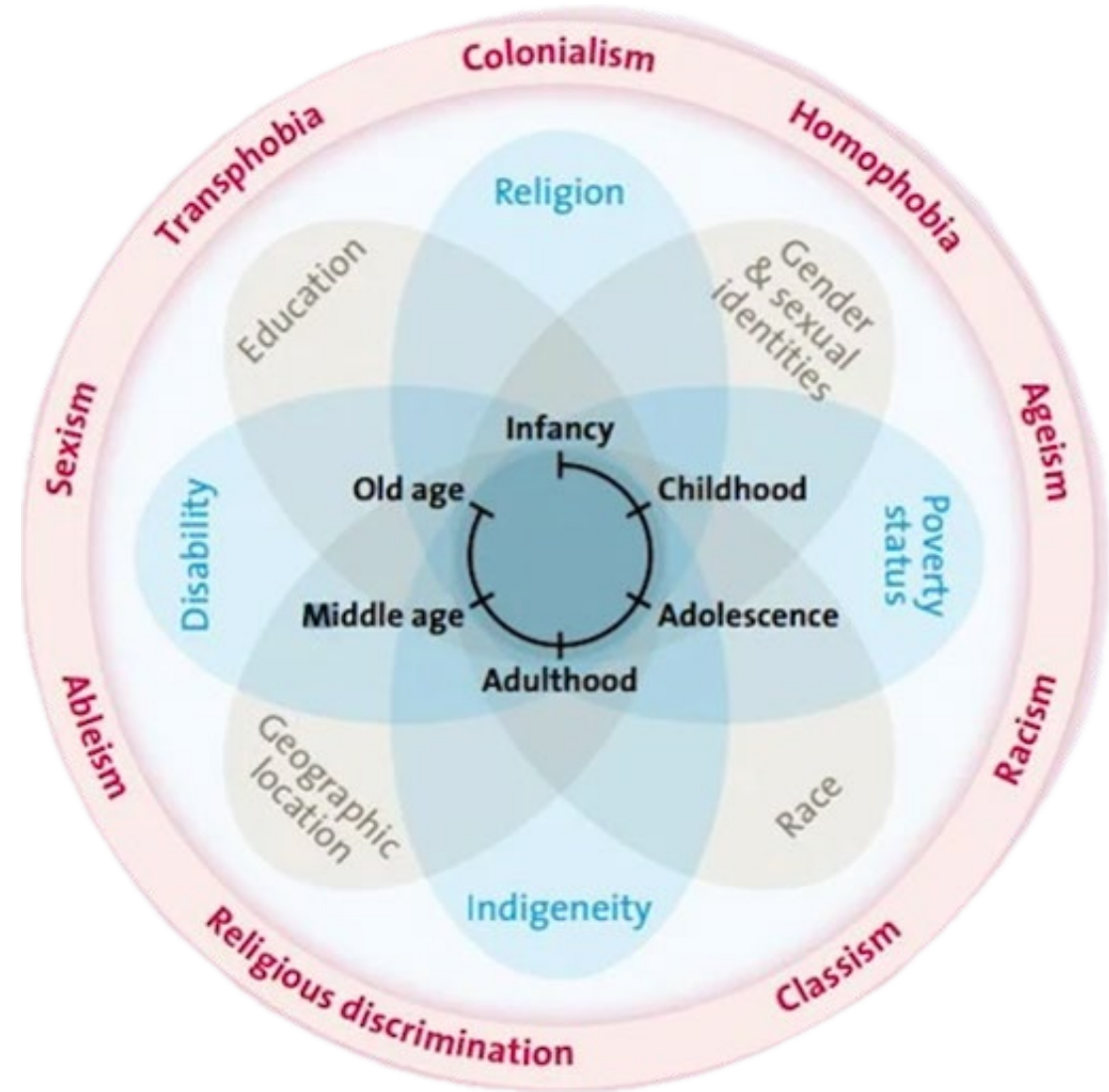
- ▶ Training and educational opportunities
- ▶ Create inclusivity for community members by ensuring their voice is heard
- ▶ Recruit REB members from a diverse pool and use a selection committee to reduce bias
- ▶ Consider compensation
- ▶ Commit to increasing EDIA with an EDIA champion
- ▶ Accommodate part-time REB members, if full time commitment is not feasible

Intersectionality



Apply an intersectionality lens to start breaking down systemic bias

- ▶ We aren't all the same
- ▶ Engagement with stakeholders
- ▶ Training
- ▶ It's ok to be uncomfortable



What is the REB's role in gatekeeping EDIA?

A case study



[Home](#) → [Priority areas](#) → [Equity, Diversity and Inclusion in the Research System](#)

CIHR's commitment to Equity, Diversity and Inclusion in the Research System

The Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council, and the Social Sciences and Humanities Research Council are committed to excellence in research and research training.

Achieving a more equitable, diverse and inclusive Canadian research enterprise is essential to creating the excellent, innovative and impactful research necessary to advance knowledge and understanding, and to respond to local, national and global challenges.

With these goals in mind, the agencies are committed to:

- Supporting equitable access to funding opportunities for all members of the research community
- Promoting the integration of equity, diversity and inclusion-related considerations in research design and practices
- Increasing equitable and inclusive participation in the research system, including on research teams
- Collecting the data and conducting the analyses needed to include equity, diversity and inclusion considerations in decision-making

Through these means the agencies will work with those involved in the research system to develop the inclusive culture needed for research excellence and to achieve outcomes that are rigorous, relevant and accessible to diverse populations.

Related links

- [Systemic Racism in Canada's health research funding system](#)
- [Sex, Gender and Health Research](#)
- [Tri-agency action plan to address systemic barriers and increase equity, diversity and inclusion](#)

Fairness and Equity– TCPS 2 Chapter 2



"Taking into account the scope and objectives of their research, researchers should be inclusive in selecting participants. Researchers shall not exclude individuals from the opportunity to participate in research on the basis of attributes such as culture, language, religion, race, disability, sexual orientation, ethnicity, linguistic proficiency, gender or age, unless there is a valid reason for the exclusion." (Article 4.1)

"Researchers shall disseminate, through publication or otherwise, the analysis of data and interpretation of research results, including those that do not support the research hypotheses. The dissemination shall take place in a timely manner without undue restriction." (Article 4.8)

Community Risks – TCPS 2 Chapter 2



“In assessing risks and potential benefits for specific populations, researchers and REBs should understand the role of the culture, values and beliefs of the populations to be studied. In this regard, REBs may consult ad hoc advisors as needed...

Researchers shall demonstrate to their REBs that they have a reasonable understanding of the culture, values, and beliefs of the population to be studied, and the likely effects of their research upon them.”

Community Risks – TCPS 2 Chapter 2



“As with individual participant risk, community risk may be social, behavioural, psychological, physical or economic. Consideration must be given to the magnitude or seriousness of the harm and the probability that it will occur.

Risks should be assessed from the perspective of the community in consideration of the social, health, economic and cultural context. The onus is on the researcher to engage the community and to minimize the risks of research to participants, the community and to individual members of the community. Research involving communities should be designed such that the potential benefits to the community, and the individuals within it, outweigh the foreseeable risks.”

The Case



- ▶ U of Maryland & Michigan State U depts of Psychology
- ▶ Research goals: to create a comprehensive database of fatal officer-involved shootings (FOIS) that includes officer information as well as victim information
- ▶ Can then determine whether there is a correlation between the race of the officer and the race of the victim
- ▶ Deemed exempt by the University of Maryland Institutional Review Board (IRB)
- ▶ Based on publicly available data (2016)- Washington Post + Guardian databases, newspaper information police department, court documents, internet
- ▶ Exempt research under OHRP regulations receives an administrative review, but not IRB review

RETRACTED



Officer characteristics and racial disparities in fatal officer-involved shootings

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Edited by Kenneth W. Wachter, University of California, Berkeley, CA, and approved June 24, 2019 (received for review March 5, 2018)

Despite extensive attention to racial disparities in police shootings, two problems have hindered progress on this issue. First, databases of fatal officer-involved shootings (FOIS) lack details about officers, making it difficult to test whether racial disparities vary by officer characteristics. Second, there are conflicting views on which benchmark should be used to determine racial disparities when the outcome is the rate at which members from racial groups are fatally shot. We address these issues by creating a database of FOIS that includes detailed officer information. We test racial disparities using an approach that sidesteps the benchmark debate by directly predicting the race of civilians fatally shot rather than comparing the rate at which racial groups are shot to some benchmark. We report three main findings: 1) As the proportion of Black or Hispanic officers in a FOIS increases, a person shot is more likely to be Black or Hispanic than White, a disparity explained by county demographics; 2) race-specific county-level violent crime strongly predicts the race of the civilian shot; and 3) although we find no overall evidence of anti-Black or anti-Hispanic disparities in fatal shootings, when focusing on different subtypes of shootings (e.g., unarmed shootings or “suicide by cop”), data are too uncertain to draw firm conclusions. We highlight the need to enforce federal policies that record both officer and civilian information in FOIS.

officer-involved shootings | racial disparity | racial bias | police use of force | benchmarks

Recent high-profile police shootings of Black Americans have raised questions about racial disparities in fatal officer-involved shootings (FOIS). These shootings have captured public concern, leading in part to the Black Lives Matter movement and a presidential task force on policing (1). Central to this debate are questions of whether Black civilians are overrepresented in FOIS and whether racial disparities are due to discrimination by White officers. However, a lack of data about officers in FOIS and disagreement on the correct benchmark for determining racial disparity in FOIS have led to conflicting conclusions about the degree to which Black civilians are more likely to be fatally shot than White civilians. We address both issues by creating a comprehensive database of FOIS that includes officer information and because a method for testing racial disparities that does

what police departments were involved, and demographic information about civilians. However, even these databases fail to provide information about involved officers, which prevents asking whether certain types of officers are more likely to show racial disparities.*

When officers fire their weapons at civilians, there are three possible outcomes: 1) They miss the civilian, 2) they result in a nonfatal hit, or 3) they result in a fatal hit. Not only do officers miss civilians the majority of times they fire [estimates of hit rates range from 20 to 40% (5, 6)], many shootings do not result in fatalities. Thus, it is important to be clear at the outset that our analyses speak to racial disparities in the subset of shootings that result in fatalities, and not officers’ decisions to use lethal force more generally.

Why should we expect officer characteristics to relate to the race of a person fatally shot? Decades of research from criminal justice have investigated whether officer characteristics relate to the degree of force used by police. Wherein officer race does not typically predict how much force an officer uses (7–11), male and inexperienced officers use more force (7, 8, 10), perhaps due to their use of more aggressive tactics (e.g., initiating more stops; ref. 11). One issue with this research is that it focuses on whether officer characteristics increase the degree of force used, not whether force is used disproportionately by civilian race. Some researchers have proposed that racial disparities in FOIS might be driven by discrimination by White officers (12), but research on this issue is uncommon due to a lack of officer

Significance

There is widespread concern about racial disparities in fatal officer-involved shootings and that these disparities reflect discrimination by White officers. Existing databases of fatal shootings lack information about officers, and past analytic approaches have made it difficult to assess the contributions of factors like crime. We create a comprehensive database of officers involved in fatal shootings during 2015 and predict victim race from civilian, officer, and county characteristics. We find no evidence of anti-Black or anti-Hispanic disparities across shootings, and White officers are not more likely to shoot minority civilians than non-White officers. Instead

The Case



Method:

- ▶ Multinomial regression with civilian race as the outcome and various factors—officer, civilian, and county characteristics—as predictors.
- ▶ What factors predict the race of a person fatally shot by police?



The Case



Results:

- ▶ No evidence for anti-Black or anti-Hispanic disparity in police use of force across all shootings, and, if anything, found anti-White disparities when controlling for race-specific crime. While racial disparity did vary by type of shooting, no one type of shooting showed significant anti-Black or –Hispanic disparity.
- ▶ The uncertainty around these estimates highlights the need for more data before drawing conclusions about disparities in specific types of shootings.

The Case



Findings:

1. As the proportion of Black or Hispanic officers in a FOIS [fatal officer-involved shooting] increases, a person shot is more likely to be Black or Hispanic than White, a disparity explained by county demographics;
2. Race-specific county-level violent crime strongly predicts the race of the civilian shot; and
3. Although we find no overall evidence of anti-Black or anti-Hispanic disparities in fatal shootings, when focusing on different subtypes of shootings (e.g., unarmed shootings or “suicide by cop”), data are too uncertain to draw firm conclusions.

We highlight the need to enforce federal policies that record both officer and civilian information in FOIS.





A study finding no evidence of racial bias in police shootings earns a correction that critics call an opaque half measure”

ARTICLES ▾ FRONT MATTER AUTHORS ▾ TOPICS ▾

LETTER | PSYCHOLOGICAL AND COGNITIVE SCIENCES |

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Making inferences about racial disparities in police violence

Dean Kruse and Jonathan Mumme

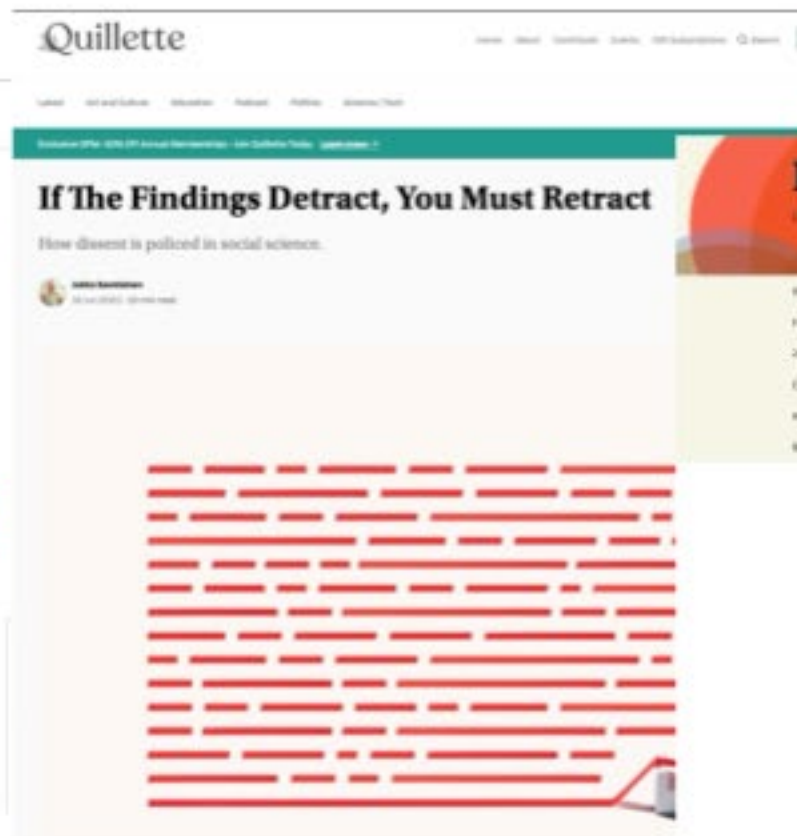
January 21, 2020 | 117 (3) 1261-1262 | <https://doi.org/10.1073/pnas.1919411117>

[VIEW THE ORIGINAL ARTICLE](#) | [VIEW RELATED CONTENT](#) | [THIS ARTICLE HAS A REPLY](#)

84,757 | 34

PDF/EPUB

A recent PNAS study, Johnson et al. (1), investigates the role of race in fatal police shootings. Unlike previous studies which focused on victim race alone, the paper features original data about the race of officers who use deadly force and offers a rare accounting of other shooting attributes that contextualize fatal encounters. Johnson et al. (1) discuss possible “discrimination by White officers” (ref. 1, p. 15877), but conclude racial diversity in police agencies brings limited benefits—a claim cited by major news outlets and in US Congressional testimony, inflaming an already contentious policy debate.



SPSS needs to retract Cesario's False Claims about Racial Bias in Police Shootings

8 June 11, 2020 | 10 views



Outcomes



- ▶ Highly controversial in all domains
 - ▶ Science community
 - ▶ Political right
 - ▶ Political left
- ▶ Researchers responded to backlash
 - ▶ Two separate statements
 - ▶ Both statements acknowledged that the data and results were correct, but conclusions were too generalized
- ▶ Paper was ultimately retracted
 - ▶ Researchers did not want conclusions to be inappropriately used to support an incorrect narrative

Questions



1. Should the IRB have been involved in any part of the study or the controversy?
 - a) Protocol stage
 - b) Analysis
 - c) Dissemination
 - d) Request for retraction

2. Should the researchers have retracted the article?

Concluding Thoughts



- ▶ EDIA is a joint responsibility between the REB, Research Ethics Office, funders, institutions and the public
- ▶ It is important to recognize that inclusion and accessibility are necessary parts of the general population, not only specific research populations and often involve intersectionality
- ▶ Like other ethical principles, there may be the need to consider EDIA concepts from various perspectives
- ▶ Research that focuses specifically on EDIA concepts is also needed

Final Questions



1. What are the roles of the REB, REO, researchers, institutions, funders and members of the public in promoting and enabling EDIA?
2. Should REBs be involved in evaluating EDIA issues beyond what is in TCPS2? If so, how?

Acknowledgements



CHEER Principal Investigators, Co-Investigators, and Collaborators

CHEER Committees:

- Operational Management Team
- REB Advisory Committee
- Patient & Family Advisory Committee
- Strategic Implementation Advisory

Supporters:

- 16 pediatric hospitals/research institutes
- 23 research intensive networks
- Health Canada
- Children's Healthcare Canada

Knowledge Users:

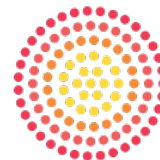


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