A time to act: Anti-racist paediatric research

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Abstract

Research offers the potential for new treatments, programs and services, and underlies decisions about funding that can have profound implications for people’s lives. When racism in research is not addressed, children and their families will be unjustly impacted by systemic discrimination, exclusion, and inequity. With a growing acknowledgement that racism is a social determinant of health, and as COVID-19 reveals staggering racial disparities, we believe now is the time for intentional anti-racism initiatives throughout the research ecosystem to prevent further harms in patient care and the lives and futures of children. We aim to highlight this need for justice, and conclude with a series of practical recommendations, ranging from the collection and use of race-based data, to equity, diversity, and inclusion (EDI) education, to mentorship opportunities.

Keywords: Anti-racist research; Ethics; Racism; Social determinant of health

History reveals the devastating impact that racism has had on racially marginalized people, and the history of research is no exception. The Tuskegee Study of untreated syphilis in African-American men (1) and the nutrition experiments in Indigenous children in Canadian residential schools (2) are just two stark reminders of how the prioritization of the pursuit of knowledge over the welfare of marginalized, vulnerable people can cause untold harms. While there is now an abundance of research ethics regulation, policy and guidance in place to prevent research harms of this magnitude, racism has continued to permeate the research ecosystem, often contributing to the health disparities that exist among racialized groups (3).

The past several months have witnessed anger boil over with cries for justice and an end to racism at an unprecedented level. There has been an explosion of anti-racism statements, initiatives, working groups, task forces, commitments, policies, and curricula as organizations of all kinds, including the Canadian Paediatric Society, articulate a response to racism. This is good, provided the voices of those who have long been marginalized are prioritized and included in ways that go beyond being tokenistic and patronizing. We dare to hope that we are poised on the precipice of real change.

The COVID-19 pandemic has laid bare staggering racial disparities that should alarm all of us, and that point to racism as a social determinant of health (4). It has driven home the fact that something we can do nothing about—the colour of our skin—has a direct connection to the likelihood of being a COVID-19 statistic. Early data compiled by Toronto Public Health revealed that 83% of COVID-19 cases occurred in racialized people; Black people represent 21% of cases in Toronto, even though they represent just 9% of the city’s population. Through connecting with marginalized communities, we learn that Black and Indigenous people avoid interacting with the health care system, mostly due to experiences with racism and biases (5). This reality will have grave consequences for the well-being of those communities during a pandemic. This ‘syndemic’ (6,7), COVID-19 paired with mounting calls to address systemic racism, has led to federal funding agencies for...
health research such as Canadian Institutes of Health Research (CIHR) to pledge a commitment to becoming anti-racist so as to eliminate race-based health disparities. Dr. Michael Strong, President of CIHR committed to ‘pushing against the barriers that create inequities in our society, in an effort to strengthen our health research community and improve the health of all Canadians’ (8). While we commend this commitment, funding is just one piece of the research ecosystem that requires an anti-racist agenda.

As members of the Research Ethics Board (REB) of an academic teaching hospital for children and youth living with disabilities, our mandate is to advance ethical research through the application of the ethical principles of respect for persons, concern for welfare, and justice (9). The children and families we serve face systemic discrimination, stigma, and exclusion on a regular basis, through unequal access to education, employment, housing, research, and health care services, in ways that people without disabilities do not. These injustices are not unlike those experienced by racialized groups, with multiple intersectionality occurring between and within social identification constructs and disability (10). Given that research offers the potential for new treatments, programs and services, and may underlie decisions regarding policies and funding that fundamentally affect people’s lives, an understanding of systemic racism and a commitment to ending it are crucial.

Our work to eliminate barriers that create inequities for people with disabilities has taught us that this will require dismantling the structural racism embedded in research and health care. A REB is uniquely positioned to impact child health in dramatic ways. As REBs strive to fulfil their mandate of advancing the ethical principles of respect, promotion of welfare and justice, we dare to add another mandate, to accomplish anti-racist paediatric research over the next decade. As such the following recommendations must be adopted:

1. Scrutinize how race will be used in research. While collecting data about ancestry for specific genetic disorders and interventions may offer value, conflating ancestry and race risks further stigmatizing people through racial-profiling in medicine (11). Such racial profiles can lead to the creation of inaccurate health care algorithms that wrongly assume that race is a biological construct, when it is in fact a label shaped through social and political influences.

2. Require education about the history of racism within research and health care, and about Black and Indigenous health disparities, and racism as a social determinant of health. These should be integrated into curricula for all researchers, health care providers, and funders.

3. Engage in critical thinking about research design, recruitment, and data collection. The integration and consideration of how racism is correlated with health outcomes through research design and hypotheses should be evident in all research protocols submitted for review. The engagement of researchers from marginalized and racialized groups in the co-creation and co-design of research will minimize the perpetuation of racism. Researchers should be challenged and supported to recruit a diversity of research participants, and ensure that all data collection tools are equity, diversity, and inclusion (EDI) sensitive.
4. Ensure that REB membership reflects the diversity of the communities that they serve to ensure that this ethical review and approval of research does not result in the perpetuation of additional race-based harm and privilege. This will require learning and dialogue about EDI as it related to the review and approval of research.

5. A national call by CIHR for REBs to understand that EDI considerations are embedded in the three core ethical principles of research ethics, and be equipped and committed to advancing anti-racist research.

CONCLUSION

There is much work ahead of us if we are to eliminate the vast societal injustices that currently exist. This is the work of non-performative allies, and it must be intentional. With so much at stake, this work cannot wait. We invite you, as members of the research ecosystem, as those committed to the care of children, to take up this call.

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