

Commentary

A call to stop extractive health research on South Asian diaspora communities in Canada

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Several major funding awards have been granted to research teams led by White principal investigators to conduct research involving South Asian diaspora communities.¹⁻³ This extractive practice, whereby the composition of the research team does not reflect the study population, is not uncommon and risks becoming worse as funding agencies and academic journals express interest in research examining and documenting the health patterns, practices, and lived experiences of racialized communities.⁴ We discuss why funding agencies need to urgently review their policies regarding the evaluation of research proposals for studies in South Asian populations in Canada, and carefully consider research team composition. Prioritizing the health equity of all racialized groups is necessary.

Research that does not involve representative leadership from South Asian diaspora communities has not been widely challenged or discussed. Researchers untrained in equity study ethnoracial communities for a variety of reasons, including academic self-gain⁵ and may often leave with no sustainable commitment to racial justice in health or foundational knowledge of South Asian communities. The continuation of such research in South Asian communities indicates that researchers and funding agencies have not generalized the lessons learned from the harm inflicted on Indigenous and Black communities.

The expertise and lived experiences of South Asian coinvestigators, collaborators, or community partners are often undermined and ignored by academics who temporarily study a particular community. When South Asian investigators do not lead the research, study findings are open to misguided interpretations that follow colonial bias and false cultural stereotypes, promote experimental bias, and uphold scientific and structural racism.⁶ For example, a study led by non-South Asian researchers concluded that domestic violence was part of the social customs of South Asian culture. This harmful interpretation was published in an academic journal and has been cited; its findings have become part of the stereotypes faced by South Asian people.³ During the COVID-19 pandemic, inequities in morbidity and mortality among South Asian people were incorrectly attributed to harmful stereotypes such as willful disregard of pandemic risk and prohibitions against cultural gatherings despite absence of supporting evidence.⁷ These examples highlight the

Key points

- Institutions have a long history of examining and documenting health patterns and lived experiences of South Asian diaspora communities in Canada that is marked by unequal power relations.
- Most research processes — led by predominantly White academics — have not meaningfully involved South Asian academics in leadership nor meaningfully engaged South Asian communities to reduce health inequities.
- Many South Asian communities regard research, particularly research originating outside their communities, with a certain apprehension and mistrust.
- Research institutes, funding programs, and academic journals should build accountability, ownership, and best practices in research involving South Asian participants to reduce health inequities in Canada.

need for representative leadership and inclusion of research team members from the South Asian diaspora.

Research published with White first and senior authors in leading medical journals, such as *CMAJ*, can misrepresent White academics as experts on South Asian health.^{8,9} This comes at a huge cost to South Asian academics in the highly competitive field of health research. South Asian diaspora communities are heterogeneous with respect to languages, religions, cultures, contexts, migration histories, and lived experiences.¹⁰ Researchers unfamiliar with the rich and diverse Canadian South Asian communities and their histories cannot have a deep understanding of the subtleties and implications of such work. Having research teams that are predominantly led by White researchers perform research on South Asian communities resembles the context of British Raj colonialism, in which South Asian people were exploited during a host of medical experiments, and normalizes extractive research practices.¹¹

Historically, research has seriously harmed Indigenous and Black communities, leading to mistrust of health research among these communities. Similarly, although the communities are different, South Asian diaspora communities have a long history of being over-researched, often using questionable research

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practices and with a lack of transparency, with little to no benefit to communities themselves.¹²

South Asian communities are the largest and fastest growing diverse, visible minority group in Canada.¹³ They have complex and still-emerging patterns of disparities in health determinants, health status, access to health care, experiences with health systems, and morbidity and mortality rates, compared with their White counterparts. These are best appreciated by South Asian researchers who integrate scientific rigour with lived experiences of the nuances of what it means to be South Asian in Canada.

Canadian and tri-agency funding bodies must prioritize meaningful leadership and inclusivity of South Asian people in research teams to ensure that research is ethically conducted to advance South Asian health equity. Previous calls from Indigenous and Black communities toward research justice must extend to all systematically marginalized groups.

Similar to the First Nations Principles of ownership, control, access, and possession (OCAP) and the Research, Evaluation, Data Collection, and Ethics (REDE) Protocol for Black populations in Canada,^{14,15} people who identify as South Asian in Canada must gain control over the collection, analysis, and use of their data. Key to this is the development of principles that reflect the unique historical, spatial, and social complexities embedded in the South Asian diaspora and that do not reinforce stigma and power imbalances in the research process. The experiences of Black and Indigenous communities are different from those of South Asian communities because of their different colonial histories. South Asian community governance tables can be developed to serve as decision-making bodies to build accountability, ownership, and best practices in research processes. Research teams conducting research with South Asian communities must make full efforts to include South Asian leadership, and funding agencies should strive to include South Asian people during the review process.

To dismantle the practices of harmful research on South Asian communities in Canada, major changes are urgently needed. The first stage was to articulate the problem. Now, South Asian communities and academics must be meaningfully engaged in a health research process that acknowledges South Asian people as valuable health research leaders with lived experiences and expertise. This process should build account-

ability, ownership, and best practices in research involving South Asian participants and communities in Canada.

References

1. Award recipients: 2022 research for postpandemic recovery. Ottawa: Social Sciences and Humanities Research Council; modified 2023 Apr. 25. Available: https://www.sshrc-crsh.gc.ca/funding-financement/nfrf-fnfr/special/2022/award_recipients-titulaires_subvention-eng.aspx (accessed 2023 Dec. 15).
2. Crawford J. Cross-cultural development and adaptation of a behavioral survey in public health: an example from a colon cancer screening study with South Asians in Canada. *SAGE Research Methods Cases: Medicine and Health* 2020. doi: 10.4135/9781529741278.
3. Finfgeld-Connett D, Johnson ED. Abused South Asian women in westernized countries and their experiences seeking help. *Issues Ment Health Nurs* 2013;34:863-73.
4. Lett E, Adekunle D, McMurray P, et al. Health equity tourism: ravaging the justice landscape. *J Med Syst* 2022;46:17.
5. Nweke N, Isom J, Fashaw-Walters S. Health equity tourism: reckoning with medical mistrust. *J Med Syst* 2022;46:27.
6. Devakumar D, Selvarajah S, Shannon G, et al. Racism, the public health crisis we can no longer ignore. *Lancet* 2020;395:e112-3.
7. Vohra-Miller S, Brar A, Bannerjee AT. 'It's not Diwali, it's precarious employment and less health care resources.' South Asian medical experts on Brampton's rising COVID-19 cases. *Toronto Star* 2020 Nov. 19. Available: https://www.thestar.com/opinion/contributors/it-s-not-diwali-it-s-precarious-employment-and-less-health-care-resources-south-asian/article_9acfdcea-3e86-5f5a-8ef0-5a7faa58d187.html (accessed 2023 Dec. 15).
8. Creatore MI, Moineddin R, Booth G, et al. Age- and sex-related prevalence of diabetes mellitus among immigrants to Ontario, Canada. *CMAJ* 2010;182:781-9.
9. Yarnell CJ, Fu L, Bonares MJ, et al. Association between Chinese or South Asian ethnicity and end-of-life care in Ontario, Canada. *CMAJ* 2020;192:E266-74.
10. Ghosh S. 'Am I a South Asian, really?' constructing 'South Asians' in Canada and being South Asian in Toronto. *South Asian Diaspora* 2013;5:35-55.
11. Ernst W. Mad tales from the Raj: colonial psychiatry in South Asia, 1800-58. London (UK): Anthem Press; 2010:1-174.
12. Bhopal K. Researching South Asian women: issues of sameness and difference in the research process. *J GenD Stud* 2001;10:279-86.
13. The Canadian census: a rich portrait of the country's religious and ethnocultural diversity. Ottawa: Statistics Canada; modified 2022 Oct. 26. Available: <https://www150.statcan.gc.ca/n1/daily-quotidien/221026/dq221026b-eng.htm> (accessed 2024 May 24).
14. Schnarch B. Ownership, control, access, and possession (OCAP) or self-determination applied to research: a critical analysis of contemporary First Nations research and some options for First Nations communities. *J Aborig Health* 2004;1:80-95.
15. Research evaluation data ethics (REDED) 4 Black lives [home page]. Available: <https://rede4blacklives.com/> (accessed 2023 Dec. 15).

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