Exploring barriers to living donor kidney transplant for African, Caribbean, and Black communities in the Greater Toronto Area, Ontario: a qualitative study protocol

Research Team Positionality Statements

Ghazaleh Ahmadzadeh

I have over three years of experience working as a clinical research assistant with the Kidney Health Education and Research Group and over two years of experience as a qualitative research analyst in the same group. Although my experiences may aid in my understanding and interpretation of the data, I would like to acknowledge my standpoint as a non-Black, first-generation female post-secondary student, and an Iranian immigrant. I acknowledge that my positionality will influence the interpretation of the data and I will make an active effort to identify and address my biases and existing assumptions and mitigate their impact on the study as it evolves.

Ranie Ahmed

Born to parents of Ethiopian descent, Ranie Ahmed is a 22-year-old Muslim living in Toronto, Ontario. He completed his Honours Bachelor of Science at the University of Toronto and is currently a graduate student interested in equitable access to healthcare and the importance of community engagement in the research process. He joined the Kidney Health Education and Research Group in 2021 as a summer research student and is grateful to have the opportunity to conduct research that will contribute to the improvement of health outcomes of marginalized populations.

Lydia Angarso

In every space I enter, I am confronted with challenges because I am a Black woman. Throughout my life, I have not progressed from one stage to another without encountering anti-Blackness. I believe the greatest issue in achieving health equity in the Canadian healthcare system is the constant neglect of the voices of marginalized groups, which I am very aware of having grown up amongst low-income, refugee families belonging to various ACB communities. For this reason, I chose to get involved with the project as a form of giving back to my communities. The experiences which will be elicited may align with my own personal experiences; and sometimes, there will be no alignment and I will challenge my own assumptions of the experiences of self-identified Black individuals in healthcare.

Shilpa Balaji

As an Indian-born Canadian female studying medicine in Toronto, my background and experiences shape my perspectives and understanding of the world around me. Having lived in the greater Toronto area for 15 years, I have been exposed to diverse cultures and communities, which has allowed me to gain a broader perspective on issues of social justice and equity. My interest in kidney transplant began at a young age as I was raised by my grandfather who lived with kidney failure. I have engaged with transplant-related work and research for eight years, which helped me see first-hand the underrepresentation of racialized groups in transplant utilization. This motivated me to engage in this qualitative research study exploring the barriers to living donor kidney transplant for African, Caribbean, and Black communities. I hope that I can work towards breaking down these barriers in my future career as a physician to ensure equal access to life-saving treatments for all patients.

My identities of being a first-generation immigrant and a woman of colour, and having been a part of my grandfather's journey with kidney failure, will help me understand and connect with the study participants to some degree. However, given my identity as a healthy non-Black person without firsthand understanding of the unique social experiences and oppression that the study participants may face, I acknowledge my position as an outsider to this community and the biases and privileges that I bring into this research. All my different identities and their intersectionality impact the way I approach, interact with, and interpret my research.

Priscilla Boakye

I had my PhD education and training focusing on critical approaches to healthcare research and qualitative inquiry. Theoretically, I situate my research within Black feminist thought, intersectionality, and critical race theory. From these theoretical standpoints, understanding lived experience is central to meaning-making and knowledge creation from those impacted by racial and systemic oppression. I recognized and acknowledged my standpoint as a Black scholar. I do not associate directly with ACB members who access LDKT, but as a Black woman I am consciously aware and understand how racial inequality such as racism and discrimination may contribute to inequitable access to LDKT services and impact on care outcomes.

Beth Edwards

I am a qualitative health researcher, born and raised in Halifax, Nova Scotia. Growing up, I learned about the story of "Africville," a predominantly Black community that was neglected by the city of Halifax which resulted in inhabitable living conditions. Africville was destroyed and its residents were relocated against their will to other parts of Halifax and beyond. My personal connections to the African Nova Scotian community and subsequent education in both public health and critical qualitative research bolstered my commitment toward exploring and understanding how structural factors (such as anti-Black racism) influence the everyday lives and experiences of marginalized individuals and communities. However, as a healthy, white, educated, middle-aged woman, I recognize that I hold a certain amount power and privilege in society. In my work, I actively seek to amplify the voices and centre the perspectives and experiences of those often underrepresented in health research. My positionality will inform all aspects of my participation in this study and will need to be carefully considered and challenged, particularly as I engage in data generation, analysis and interpretation, and dissemination of study findings.

Jagbir Gill

Jagbir Gill is a transplant nephrologist at St. Paul's hospital in Vancouver, British Columbia and a researcher with the University of British Columbia. He conducts clinical research on issues relating to inequities in access to kidney transplantation in Indigenous populations and racialized communities, transplant tourism, transplantation in the elderly, and delayed graft function. As the son of immigrants from India and member of a visible minority community, he understands racial inequities and how it impacts access to care, but as a male physician he also recognizes his privilege and how these intersectionalities form his worldview.

Carl E. James

Carl E. James is the Jean Augustine Chair in Education, Community and Diaspora in the Faculty of Education at York University. In his research, he examines the educational, employment and health experiences of racialized Canadians, noting the ways in which race – as it intersects with gender, class, citizenship and other identity constructs – mediates their accessible and equitable opportunities and attainments in the society. In doing so, and informed by his education in Sociology, and his interdisciplinary interests, he aims to speak to notions of decoloniality, equity, inclusion, and social justice for racialized and marginalized people; and thereby move us beyond the essentialist, generalizing, universalizing, and homogenizing representations that account for the lived realities of racialized Canadians – and Black people and youth in particular.

Lydia-Joi Marshall

Lydia-Joi Marshall is a Caribbean-Canadian person of African descent immigrated from the UK. Her academic background in biology and human genetics is shaped through North American Institutional thought at Western University in London, Ontario and Howard in Washington DC. As an able-bodied, neurotypical, English-speaking researcher, she has the privilege to be invited to discuss the impacts of anti-Black racism in health and academia. As a Black community member, mother, partner, and world citizen her views are shaped by moving through this society with these labels.

Istvan Mucsi

Istvan Mucsi (he/him) is a clinician investigator and transplant nephrologist at the Multi-Organ Transplant Program and Division of Nephrology at the University Health Network in Toronto. His current research focuses on understanding and reducing barriers and disparities in access to kidney transplantation and living donor kidney transplantation and assessing the impact of psychosocial distress on clinical outcomes of kidney transplant recipients. He acknowledges his position as a white, male physician and, as such, recognizes that he is a person of usually unacknowledged power and privilege and that his education and training in science and medicine have conditioned him to look at the world in a particular way.

Paula Neves

Paula Neves (she/her) is a white woman currently living in Toronto, traditional territory of the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples. Paula immigrated to Canada with her family at an early age and identifies as Portuguese-Canadian. Her experience as an allophone newcomer informed her career and academic interests and focus on access and equity issues in the delivery of health and social services. Paula holds undergraduate degrees in languages and social work, a Master’s in public administration, and a PhD in Health Policy, Management and Evaluation from the University of Toronto.

Princess Okoh

Princess Okoh is a recent immigrant to Canada and is currently completing her Master's in Medical Science at the University of Toronto. She has experience working with vulnerabilized populations as a medical doctor, which led to her interest in research exploring health inequities. She identifies with the critical social paradigm due to a combination of educational and lived experiences. Her work and interests are shaped by the work of many critical scholars and activists rooted in critical theories, intersectionality, Black feminism, and decolonization.

Emma Rogers

I am a white, middle-class woman from Toronto, Ontario. Prior to my involvement in this particular study, I had been working as a research assistant with the team for two years. As a result, I had a basic understanding of the physical and psychosocial impacts of kidney disease. I also had previous experience analysing focus group data of white patients with kidney failure and their experiences with the Canadian healthcare system. The experiences shared in these focus groups affirmed by beliefs regarding the inclusivity of our healthcare system.

I initially found my immersion in this work to be surprising and sometimes shocking. The experiences of ACB community members in Canada acquired appeared so drastically different from mine. However, as I have become more immersed in the study, I have come to terms with the fact that my positive experiences in Canada are not necessarily universal. This realization allows me to approach the research through a different lens, but does not change the fact that many of the experiences I will hear about will be unfamiliar to me and challenge my understanding of the healthcare system in Canada.