BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2023-073176
Article Type:	Protocol
Date Submitted by the Author:	24-Feb-2023
Complete List of Authors:	Edwards, Beth; University Health Network; University of Toronto Marshall, Lydia-Joi; Black Health Alliance Ahmadzadeh, Ghazaleh; University Health Network; University of Toronto Ahmed, Ranie; University Health Network; University of Toronto Angarso, Lydia; University Health Network; University of Toronto Balaji, Shilpa; University Health Network; University of Toronto Okoh, Princess; University Health Network; University of Toronto Rogers, Emma; University Health Network; University of Toronto Neves, Paula; University Health Network Boakye, Priscilla; Toronto Metropolitan University Gill, Jagbir; The University of British Columbia James, Carl Everton; York University Mucsi, Istvan; University Health Network; University of Toronto
Keywords:	Health Equity, Adult nephrology < NEPHROLOGY, End stage renal failure < NEPHROLOGY, Renal transplantation < NEPHROLOGY, Chronic renal failure < NEPHROLOGY

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

Authors: Beth Edwards[1*], Lydia-Joi Marshall[2*], Ghazaleh Ahmadzadeh[1], Ranie Ahmed[1], Lydia Angarso[1], Shilpa Balaji[1], Princess Okoh[1], Emma Rogers[1], Paula Neves[3], Priscilla Boakye[4], Jag Gill[5], Carl Everton James[6], Istvan Mucsi[1]

[1] Multi-Organ Transplant Program and Division of Nephrology, University Health Network, University of Toronto, Toronto, Ontario, Canada
[2]Black Health Alliance, Toronto, Ontario, Canada
[3]Centre for Living Organ Donation, University Health Network, Toronto, Ontario, Canada
[4]Daphne Cockwell School of Nursing, Toronto Metropolitan University, Toronto, Ontario, Canada
[5]Division of Nephrology, Department of Medicine, University of British Columbia, Vancouver, British Columbia, Canada
[6]Jean Augustine Chair in Education, Community & Diaspora, Faculty of Education, York University, Toronto, Ontario, Canada

* Co-first authors, contributed equally

Author for correspondence: Dr. Istvan Mucsi
Academic Degree(s): MD, PhD, FRCPC, FASN
Affiliations: Multi-Organ Transplant Program and Division of Nephrology Department
University Health Network
Address: 585 University Avenue, MARS Building, Floor 9 Room 9062
Toronto, Ontario, M5G 2N2, Canada
Phone: 416-340-4084
Fax: 647-689-3070
E-mail: Istvan.mucsi@utoronto.ca

Abstract (word count = 295/300)

Introduction

Living donor (LD) kidney transplant (KT) is the best treatment option for many patients with kidney failure as it improves quality of life and survival compared to dialysis and deceased donor KT. Unfortunately, LDKT is underused, especially among groups marginalized by race and ethnicity. African, Caribbean, and Black (ACB) patients are 60-70% less likely to receive LDKT in Canada compared to White patients. Research from the United States and the United Kingdom suggests that mistrust, cultural and generational norms, access, and affordability may contribute to inequities. To date, no Canadian studies have explored the beliefs and behaviours related to LDKT in ACB communities. Research approaches that utilize a critical, community-based approach can help illuminate broader structural factors that may shape individual beliefs and behaviours.

In this qualitative study, we will investigate barriers to accessing LDKT in ACB communities in the Greater Toronto Area (GTA), to enhance our understanding of the perspectives and experiences of ACB community members, both with and without lived experience of chronic kidney disease (CKD).

Methods and analysis

Hospital and community-based recruitment strategies will be used to recruit participants for focus groups and individual interviews. Participants will include self-identified ACB individuals with and without experiences of CKD and nephrology professionals. Collaboration with ACB community partners will facilitate a community-based research

approach. Data will be analyzed using reflexive thematic analysis and critical race theory. Findings will be revised based on feedback from ACB community partners.

Ethics and dissemination

This study has been approved by the University Health Network Research Ethics Board UHN REB file #15-9775. Study findings will contribute to the co-development of culturally safe and responsive educational materials to raise awareness about CKD and its treatments and to improve equitable access to high quality kidney care, including LDKT, for ACB patients.

Strengths and Limitations

Insert 5 bullet points only relating specifically to the methods.

- Community-based approach to study design fosters relationships between academic and community partners.
- Theoretically-informed data analysis goes beyond documentation of health inequities.
- Reflexive data analysis examines biases and challenges assumptions of the research team.
- Inclusion of diverse participant perspectives, e.g. gender, age, representation from diverse ACB communities, patients, healthcare professionals, and community members without lived experience of kidney disease.
- Community partners were not involved in the initial phases of study design.
- Not all ACB communities will be represented.

Introduction (word count = 3954/4000)

Living donor kidney transplant (LDKT) is considered the best treatment from a medical perspective for many patients with kidney failure who require kidney replacement therapies (dialysis or kidney transplant [KT]). [1] LDKT is associated with better quality of life, graft survival, and life expectancy compared to dialysis [1-7]. LDKT is also associated with shorter wait times compared to deceased donor KT (DDKT). [1] LDKT is underused internationally and in Canada, [8] especially among groups marginalized by race and ethnicity. [9, 10] Specifically, African, Caribbean, and Black (ACB) patients are 60-70% less likely to receive LDKT in Canada compared to White patients. [10-12] ACB communities represent 4.6% of the population of Canada and include generations of Canadians, recent immigrants from Africa or the Caribbean, individuals of Afro-Indigenous origin, and diasporic ACB communities who identify with various ethnic and geographic regions. [13, 14] While these are diverse communities based on countries of origin, immigration status, religion, and culture, they may all face systemic anti-Black racism both within and outside the healthcare system. [15]

Discrimination against ACB individuals remains deeply entrenched and normalized in Canadian institutions, policies, and practices. [16] For example, a landmark police report revealed that ACB individuals in Toronto are overrepresented among victims of police use of force. [17] The COVID-19 pandemic further unveiled systemic anti-Black racism and long-standing inequities faced by ACB communities in Toronto. [18-22] ACB Canadians experience higher incidence of diabetes and hypertension compared to the general population. [23, 24] This may be related, in part, to the stress associated with discrimination and anti-Black racism and can contribute to higher rates of chronic kidney disease (CKD) in this population. [23, 24]

In the United States (US) and the United Kingdom (UK) studies have shown that mistrust in physicians and the healthcare system, cultural and generational norms, access, and affordability substantially limit accessing KT and LDKT among ACB patients. [25] [26] [27] [28] Although these studies provide valuable insights, we cannot directly extrapolate these findings to Canada because there are fundamental differences in the social, environmental, and healthcare systems between Canada, the US, and the UK.

Despite the repeatedly documented inequities in access to KT and LDKT, no academic research studies have been conducted in Canada to explore and understand the factors that influence beliefs and behaviours around KT and LDKT in ACB communities. For example, respect for death-related rituals and rites and concern about the religious permissibility of KT may create hesitation among Muslim Canadians, which comprise an increasing proportion of ACB communities in Canada. In addition, individuals may prefer directed donation to members of their community as a result of experiences of racism, oppression, and systemic mistrust. [29] Moreover, individuals may feel alienated from the healthcare system due to its dominantly Eurocentric approaches that privilege biomedical care with little consideration for socio-environmental conditions influencing health outcomes. Such topics are best explored using qualitative research methods.

A better understanding of the perspectives and experiences of ACB patients and families, healthcare professionals (HCPs), and community members will facilitate the tailoring of information and clinical pathways to the needs of ACB patients.

Aims

The purpose of our study is to identify barriers to accessing LDKT in ACB communities in the Greater Toronto Area (GTA), Ontario. The objectives of the study are to explore study participants' perspectives on and experiences with the health and kidney care system, CKD, kidney failure and its treatments, particularly LDKT, to deepen our understanding of the perspectives and experiences of ACB community members, both with and without lived experience of kidney disease. Ultimately, we wish to generate knowledge to inform the co-development (with ACB community partners) of culturally safe and responsive educational materials to raise awareness about CKD, kidney failure and its treatments, and to improve equitable access to the best kidney care for ACB patients.

Methods and Analysis

Study Design

We will conduct an exploratory, qualitative study including focus groups and individual interviews with self-identified ACB individuals both with and without lived experience of CKD.

Setting and context

ACB individuals with lived experience of CKD who previously participated in quantitative research conducted by our team and indicated their interest in participating in focus groups or interviews will be invited to participate in this qualitative study. We previously conducted a cross-sectional study to assess psychosocial and ethnocultural barriers to accessing LDKT among patients with CKD. All ACB patients referred for pre-KT assessment from various renal programs across the GTA, as well as potential KT candidates treated with maintenance dialysis from renal programs at the Toronto General Hospital, St. Michael's Hospital, Humber River Hospital, or Scarborough General Hospital were eligible to participate in the study. Of these, any individuals who indicated interest in participating in focus groups or interviews will be contacted by a member of the qualitative research team and invited to participate in the current study. Collaboration with our community partner, Black Health Alliance (https://blackhealthalliance.ca/), a community-led registered charity that works to improve the health and well-being of ACB communities, will facilitate recruitment of individuals with no connection to CKD. [30]

Sample and recruitment

We have chosen to speak with individuals from three groups of participants, whom we anticipate may have unique perspectives on CKD, kidney failure, and kidney replacement therapies such as LDKT: individuals with lived experience with CKD, general community members, and nephrology professionals (e.g. physicians, nurse practitioners, nurses). All three groups may have shared experiences of racialization, but we feel that our classification, that considers their relationship with CKD and kidney care, may shape their perspectives. Purposive and snowball sampling will be used to recruit study participants. Study recruitment has been impacted by the COVID-19 pandemic and its effects on in-person data collection, the disproportionate burden on ACB communities, and the increased workload of HCPs. The pandemic has had a detrimental impact on the ability to recruit study participants and conduct in-person focus groups. Additionally, the increased burden on ACB communities and HCPs as a direct result of the pandemic resulted in further recruitment challenges. As a result, we ceased in-person data collection soon after the pandemic started and will conduct virtual data collection via telephone and MS Teams until we can safely resume in line with recommendations of participating hospitals and community partners.

Individuals with lived experience with CKD

Individuals who self-identify as members of ACB communities with lived experience with CKD (e.g. individuals with kidney failure, waitlisted for KT, KT recipients, family members, living donors, and individuals undergoing living donor evaluation) will be invited to participate in focus groups and/or individual interviews. We aim to hold 5-6 focus groups with 6-8 participants per group.

ACB community members with no lived CKD experience

We will also invite self-identified ACB community members with no known lived experience of kidney disease to participate in the study. We aim to hold 5-6 groups with 6-8 participants per group. The rationale for speaking with this group is that anyone may be considered a potential living donor therefore it is important to understand their perspectives and experiences regarding CKD, kidney transplant, and organ donation.

Healthcare professionals (HCPs)

Finally, we will interview 8 -10 nephrology professionals who self-identify as ACB community members. We have chosen to interview HCPs individually since it can be challenging to coordinate focus groups with this particular participant group.

The inclusion criteria for all three participant groups are as follows: self-identified members of ACB communities, ≥18 years of age, able to speak and understand English. The exclusion criteria are as follows: unwilling or unable to provide informed consent and, in the case of the second group (individuals with lived experience of CKD), dementia or significant mental delay/challenge as identified by the individual's healthcare team. Study recruitment will occur via hospital-based methods, such as the posting and distribution of flyers and in-clinic study recruitment efforts. The research team will also collaborate with community partners and a community engagement specialist (LJM) with close ties to ACB communities, who will utilize established connections to extend personal invitations to participate in the study. Study recruitment will benefit from the established and trusted relationships that both our community partners and community engagement specialist have with diverse ACB communities.

Potential study participants will be approached by a member of their healthcare team (in the case of the first participant group) or a community host known to the community engagement specialist (e.g. community leader, social influencer) in the case of the second participant group. The community host will be a trusted individual who will act as a liaison between the community engagement specialist and the study participants. The host will help to plan, organize, and schedule the groups, answer questions, and assist with practical matters at the time of the focus group. For the third participant group, potential participants will be identified by study co-investigators and contacted by a research team member.

Once potential study participants have agreed to learn more about the study, they will be connected to a qualitative team member who will provide further details, answer questions, and address any concerns about the study.

Information regarding the study and invitations to participate will be distributed in person, as well as via existing communication channels of our community partners, such as: direct person-to-person contact through phone, in-person communication, and online messaging platforms such as e-mail, Facebook Messenger, and WhatsApp; informational sessions with interested groups who request the opportunity to hold a focus group during regularly scheduled meetings; and connecting to new community groups and partners to inform them of the opportunity to participate in the study. In an attempt to maximize the diversity of the sample, we will connect with various ethnic groups within ACB communities, including: Jamaican; Haitian; Somalian; Nigerian; Ethiopian; Ghanaian; West Indian; and Sudanese. Consideration will also be given to ensure representation across age, immigration status, religion, gender, and geographic region in the GTA.

Theoretical Framework

This study was not initially designed in collaboration with ACB community partners; however, as a result of discussions with the community engagement specialist and other collaborators, the study evolved from a more traditional institution-driven approach to one that is informed by the principles of community-based participatory research (CBPR) to guide data collection, data analysis, and dissemination of study findings. [31] [32]

CBPR is a research paradigm which integrates education and social action to improve health and reduce health disparities. [31] CBPR focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts. [32]

Critical race theory (CRT) [33, 34] will be used during data analysis to understand how the experience of "race" or, more accurately, racialization influences the perspectives and experiences of study participants regarding accessing or considering healthcare and specifically, kidney care and LDKT. The term "racialization" emphasizes the complex historical, social, and political processes that result in unequal power distribution between groups. The term "racialized" refers to individuals in groups that are socially and politically constructed as distinct from the "reference" group or the one holding the majority of the economic, social, and political power. Racialized individuals face implicit or overt bias, micro- and macroaggression, racism, and discrimination, including during their interactions with the healthcare system. These experiences and interactions are also related to health inequities. [35-38] Critical race research and interventions in the health sector must go beyond merely documenting disparities and instead seek to uncover the causes of health disparities; how racialization shapes disciplinary conventions; and how knowledge is produced within the existing, biased frameworks, in order to better understand and to challenge the existing power hierarchies. [39] Accordingly, we will draw upon four tenets of CRT in our data analysis:

Racial Consciousness

The research team will approach the analysis with the knowledge that race and racialization are salient realities that shape the lived experiences of members of ACB communities both within and outside of the healthcare system. This racial consciousness is also informed by an understanding of anti-Black racism specifically as prejudice, attitudes, beliefs, stereotyping, and discrimination that is directed at people of African descent and rooted in the unique history and experience of colonization, enslavement, and its continued complex impact and legacies. [40] [41]

Social, geographical, and temporal location

The research team will bear in mind that Canada's race relations are greatly informed by the existence of a particular type of racism often dismissed because of the country's identity as being "polite", "friendly", and "tolerant." While Canada prides itself on its ethos of multiculturalism, discrimination against ACB individuals remains deeply entrenched and normalized in Canadian institutions, policies, and practices. [16] Until relatively recently, public opinion was that racism did not exist in Canada; however, the murder of George Floyd, an unarmed African American man, by a White police officer in the United States in 2020 prompted worldwide protests, the rise of the Black Lives Matter movement [42], and an increasingly open public discourse about the enduring existence of anti-Black racism in Canada. As Marie-Claude Landry, the Chief Commissioner of the Canadian Human Rights Commissions stated, "It is time for all Canadians to acknowledge that anti-Black racism is pervasive in Canada. In fact, the belief that there is little to no racism in Canada is in itself a barrier to addressing it." [43] Indeed, Canada has a long history of systemic racism including colonialism, the trans-Atlantic slave trade, the Indian Act, Residential Schools, and more.

Power Relations and Processes

The research team will also approach this analysis with an understanding of how race, racism, and racialization manifest both within and outside of institutional settings, and how individual, institutional, and systemic racism are interlinked, as well as produced and reproduced within broader social structures and systems.

Counternarratives as valid data

Lastly, the research team will acknowledge, respect, and validate the experiences of ACB communities shared during interviews and focus groups as valid sources of data that serve to disrupt existing institutional perspectives.

Elements of CRT will be employed in the analytical process to expose and challenge the mechanisms by which racism produces inequities in access to healthcare in general and to LDKT, specifically. Ultimately, we will seek to centre the multiple and diverse lived experiences of the study participants in order to disrupt ideas that may be commonly taken for granted by the healthcare system regarding the inequitable access to LDKT experienced by ACB communities in the GTA.

Research Team

The research team consists of a diverse group of individuals from different ethnocultural backgrounds (including ACB communities) and varying degrees of educational and professional training and experience, which confer power and privilege in numerous ways. Please see Appendix A for positionality statements from all co-authors. The community engagement specialist and the qualitative lead will conduct all focus groups and interviews, with support from community partners and qualitative research team members.

Data Collection

Focus groups and interviews

Informed consent and demographic information (see Appendices B and C) will be obtained from study participants prior to their participation in focus groups and interviews. Participants will be given the opportunity to ask questions and obtain assistance in completing consent forms and demographic questionnaires. In addition to the hospital environment, focus groups and interviews will also be held in community locations. If necessary, virtual (MS Teams) or telephone options will be offered. For in-person focus groups, food incorporating the culture of the participant group will be provided, when possible, to foster a comfortable atmosphere for participants and to support ACB-owned businesses. When necessary, childcare, language translation (for words or short phrases), and accommodation for specific meal observances will be provided. Support and resource materials will be available to participants after focus groups or interviews as necessary. Due to the sensitive nature of the research, it is a priority of the research team to create both a psychologically and culturally safe environment for participants. We will also aim to respect community norms around meetings, meaning that focus groups can be conducted in conjunction with existing meetings. Study participants will be provided with $30 honoraria as a token of our appreciation.

Focus group/interview discussion guide

Semi-structured focus group/interview guides (see Appendices D and E) were developed by the research team based on clinical experience, literature review, and discussion with community partners. Focus groups were originally focused on perspectives of kidney disease, treatment options for kidney failure, and experiences of kidney care. Revisions to the focus group guide resulted in the addition of an introductory discussion about ethnic identity, health, and the Canadian healthcare system. This is particularly important for the general community focus groups, since the majority of these participants will have no direct connection to kidney disease or transplant. The focus group moderators will then guide the discussion into topics related to kidney disease, kidney transplant and LDKT, and organ donation. Moderators will ask open-ended questions designed to explore the participants' views on the topics of interest and stimulate discussion and group interaction among participants.

As is common in qualitative research, not all questions will be asked the same way, in the same order during each focus group or individual interview and participants will be encouraged to take the discussion in different directions if desired. Moderators and interviewers will be responsible for maintaining the flow and focus of the conversations, while enabling study participants, as experts in their own lives and experiences, to speak about topics they deem relevant and important.

Focus group moderator/interviewer training

To prepare for focus group moderation, the primary focus group moderator (the community engagement specialist) and additional co-moderators (representatives from community partner organizations and research students) have been provided with focus group training by the qualitative research lead (BE). The community engagement specialist and community partners have also provided the qualitative research team with information and resources on conducting culturally safe research with ACB communities. For example, although it is common for a focus group moderator to interrupt a study participant dominating the conversation in order to give all participants the opportunity to speak, interrupting a participant, particularly a community elder, may be viewed as rude and could erode trust between the research team and the focus group participants. Focus group co-moderators will be responsible for note-taking, asking follow-up questions, and assisting with language translation if necessary. Regular debriefing regarding data collection will occur between the qualitative team and the community engagement specialist throughout the duration of the study. All focus groups and interviews will be audio recorded, transcribed verbatim, verified, and de-identified for data analysis. Hard copy data will be stored in locked filing cabinets at the University Health Network (UHN) and electronic data will be stored on secure UHN servers. Data management and analysis will be facilitated by the use of NVivo 12 software (QSR International) designed to assist with the storage, organization, and analysis of qualitative data.

Data Analysis

Data will be analyzed using reflexive thematic analysis (RTA) [44] [45] which results in the development of themes that are reflective of the data as a whole. The goal of this approach is to move from a detailed, descriptive level of analysis to a broader, more thematic level. Data analysis will begin in conjunction with data collection and will be informed by the tenets of CRT. Data collection will cease when the research team determines that the study sample holds enough information power, meaning the volume and quality of the data are sufficient to address the research objectives. [46, 47] The reflexive aspect of RTA is particularly relevant due to the diversity of our team and effects of our varying social positions on data interpretation. [48] We wholeheartedly view this as a strength, rather than something to be mitigated, and will actively engage in reflexivity exercises throughout the analysis to account for how our individual subjectivities influence study findings. [48]

We will also be fortunate to have continuous input from our community engagement specialist and community partners throughout the duration of the study, which will include both formal team presentations as well as informal discussions during analytical sessions and other meetings. The research team has participated in anti-racism and anti-oppressive training. Finally, we will regularly engage in discussions regarding power relations, as they arise in research partnerships between community organizations and academic institutions such as universities and hospitals.

RTA is also deemed a suitable choice of analytic method due to its strong grounding in qualitative philosophies, as well as its alignment with applied qualitative health research. The process of RTA consists of six phases: (1) familiarization, (2) generation of initial codes, (3) construction of themes, (4) review of potential themes, (5) naming and defining themes, and (6) production of the final report. [44] [45] Emerging ideas will be discussed in diverse, expanding circles, i.e. research seminars, community town halls. We will actively seek feedback as our analysis progresses to ensure the rigour and trustworthiness of the study and its findings.

Patient and public involvement

Both patient and community partners have been involved in study design and will be involved in study conduct as described above. We will adhere to the principles of community-based research principles to facilitate a collaborative, equitable partnership that fosters co-learning and capacity-building among all partners, with the goal of generating knowledge that will benefit everyone involved. Patient and community partners will be asked to review and disseminate study findings. Importantly, we will seek advice from patient and community partners on how and where to disseminate study findings beyond the traditional academic routes such as conferences and publications.

Ethics

Ethical approval for this study was obtained from the University Health Network Research Ethics Board (UHN REB #15-9775) and from the ethics boards of participating hospitals (#2016-011-M; #16-249; #NEP-18-016). All study procedures will be conducted in accordance with the standards of the UHN REB and the 1964 Helsinki declaration and its later amendments. No study procedure will begin until the study participant has provided informed consent and participants can leave the study at any time and for any reason without any consequences. Data will be stored in a de-identified manner to minimize any breaches in patient confidentiality.

Impact and Dissemination

This study seeks to identify barriers to accessing LDKT in ACB communities in the GTA, Ontario. The objectives of the study are to explore participants' perspectives on and experiences with the healthcare system, CKD and kidney failure, and kidney replacement therapies, particularly LDKT. We want to gain a deeper understanding of the perspectives and experiences of ACB community members, including those with and without lived experience of CKD and kidney care. Ultimately, we wish to generate knowledge and collaborate with ACB community partners to co-develop culturally safe and responsive educational materials and clinical pathways to help raise awareness about CKD and kidney replacement therapies (especially LDKT), and to improve equitable access to the best kidney care for ACB individuals with kidney failure. The final dissemination plan will be determined by study co-investigators and patient and community partners, and will likely include various formats and locations, such as patient and community forums, national and international meetings, peer-reviewed journals, and conference presentations. Study participants will receive reports generated by the study if they wish and where possible.

Study status

The study is ongoing. Participants of the "Barriers" study (UHN REB #15-9775) participated in in-person focus groups in 2018 and 2019. From 2020 onwards, adult members of the ACB community, ACB individuals with lived experience of CKD, and nephrology professionals are being recruited for in-person and virtual focus groups and interviews. Additional participant candidates are being identified on an ongoing basis by clinical teams at participating hospitals. Recruitment through both hospital-based methods as well as through community partnerships continues for additional focus groups and interviews. Data collection and analysis are ongoing and community partner check-ins are planned for 2023. Additional interviews and focus groups will be completed by December 31, 2023 as a target end date for study recruitment.

Acknowledgments

Funding

This work was supported by Health Canada Health Policy Contribution Program (1920-HQ-000109); 2020 Canadian Society of Transplantation-Astellas T3 Competition; Mount Sinai Hospital-University Health Network Academic Medical Organization Innovation Funding. The funders had no role in study design, data collection, analysis, reporting, or the decision to submit for publication.

Author contributions

JG, LJM, IM, and PN participated in conceiving this study. The conduct of the study will be led by BE, LJM, IM, PN. Study recruitment, data collection, and data analysis will be undertaken by LA, GA, RA, SB, BE, LJM, IM, PN, PO, and ER. All authors (LA, GA, RA, SB, PB, BE, JG, CEJ, LJM, IM, PN, PO, and ER) will participate in regular team meetings to support this research project.

All authors provided input into the protocol, critical feedback on the manuscript, and approved the final manuscript.

We would like to thank all of the community partners who have shaped the design of this study.

Competing interests statement

Conflict of Interest: The authors have indicated they have no potential conflicts of interest to disclose.

Financial Disclosure: The authors have indicated they have no financial relationships relevant to this article to disclose.

References

1. de Groot, I.B., et al., *Difference in quality of life, fatigue and societal participation between living and deceased donor kidney transplant recipients.* Clin Transplant, 2013. **27**(4): p. E415-23.
2. *Alberta annual kidney care report: prevalence of severe kidney disease and use of dialysis and transplantation across Alberta from 2004–2013. .* Alberta Annual Kidney Care Report Kidney - Strategic Clinical Network, 2015.
3. Pinson, C.W., et al., *Health-related quality of life after different types of solid organ transplantation.* Ann Surg, 2000. **232**(4): p. 597-607.
4. Ortiz, F., et al., *Health-related quality of life after kidney transplantation: who benefits the most?* Transpl Int, 2014. **27**(11): p. 1143-51.
5. Neipp, M., et al., *Quality of life in adult transplant recipients more than 15 years after kidney transplantation.* Transplantation, 2006. **81**(12): p. 1640-4.
6. Evans, R.W., et al., *The quality of life of patients with end-stage renal disease.* N Engl J Med, 1985. **312**(9): p. 553-9.
7. Molnar, M.Z., M. Novak, and I. Mucsi, *Sleep disorders and quality of life in renal transplant recipients.* Int Urol Nephrol, 2009. **41**(2): p. 373-82.
8. Information., C.I.f.H., *Annual Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2009 to 2018.* 2019: Ottawa.
9. Mucsi, I., et al., *Ethnic Background Is a Potential Barrier to Living Donor Kidney Transplantation in Canada: A Single-Center Retrospective Cohort Study.* Transplantation, 2017. **101**(4): p. e142-e151.
10. Yeates, K.E., et al., *Access to renal transplantation for minority patients with ESRD in Canada.* Am J Kidney Dis, 2004. **44**(6): p. 1083-9.
11. Bansal, A., et al. *Ethnocultural barriers to pre-emptive kidney transplantation: a single centre retrospective cohort study*. in American Journal of Transplantation. 2017. Wiley 111 River St, Hoboken 07030-5774, NJ USA.
12. Yeates, K., et al., *Similar outcomes among black and white renal allograft recipients.* J Am Soc Nephrol, 2009. **20**(1): p. 172-9.
13. El-Dassouki, N., et al., *Barriers to Accessing Kidney Transplantation Among Populations Marginalized by Race and Ethnicity in Canada: A Scoping Review Part 2-East Asian, South Asian, and African, Caribbean, and Black Canadians.* Can J Kidney Health Dis, 2021. **8**: p. 2054358121996834.
14. *Diversity of the Black population in Canada: An overview*. 2019; Available from: https://www150.statcan.gc.ca/n1/pub/89-657-x/89-657-x2019002-eng.htm.
15. Fante-Coleman, T., et al., *'Getting shut down and shut out': Exploring ACB patient perceptions on healthcare access at the physician-patient level in Canada.* Int J Qual Stud Health Well-being, 2022. **17**(1): p. 2075531.
16. *Social determinants and inequities in health for Black Canadians: A Snapshot*. 2020; Available from: https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health/social-determinants-inequities-black-canadians-snapshot.html.

17. *Read the landmark Toronto police report on race and officer use of force*. 2022; Available from: https://www.thestar.com/news/gta/2022/06/15/read-the-landmark-toronto-police-report-on-race-and-officer-use-of-force.html.
18. *COVID 19: Ethno-Racial Identity & Income*. Available from: https://www.toronto.ca/home/covid-19/covid-19-pandemic-data/covid-19-ethno-racial-group-income-infection-data/.
19. Yancy, C.W., *COVID-19 and African Americans.* JAMA, 2020. **323**(19): p. 1891-1892.
20. Dyer, O., *Covid-19: Black people and other minorities are hardest hit in US.* Bmj, 2020. **369**: p. m1483.
21. de Lusignan, S., et al., *Risk factors for SARS-CoV-2 among patients in the Oxford Royal College of General Practitioners Research and Surveillance Centre primary care network: a cross-sectional study.* The Lancet Infectious Diseases, 2020. **20**(9): p. 1034-1042.
22. Poteat, T., et al., *Understanding COVID-19 risks and vulnerabilities among black communities in America: the lethal force of syndemics.* Ann Epidemiol, 2020. **47**: p. 1-3.
23. Gagné, T. and G. Veenstra, *Inequalities in Hypertension and Diabetes in Canada: Intersections between Racial Identity, Gender, and Income.* Ethn Dis, 2017. **27**(4): p. 371-378.
24. Chae, D.H., et al., *Racial discrimination, mood disorders, and cardiovascular disease among black americans.* Ann Epidemiol, 2012. **22**(2): p. 104-11.
25. Navaneethan, S. and S. Singh. *Barriers to access to renal trasnplantation among African Americans in the US-A systematic review*. in Americam Journal of Kidney Diseases. 2006. WB Saunders Co-Elsevier Inc 1600 John F. Kennedy Blvd Ste 1800 ….
26. Hall, G.L. and M. Heath, *Poor Medication Adherence in African Americans Is a Matter of Trust.* J Racial Ethn Health Disparities, 2021. **8**(4): p. 927-942.
27. Transplant, N.B.a., *Annual report on ethnicity differences 2021-2022*. 2022, National Health Service. p. 1-57.
28. Wong, K., et al., *Investigating Ethnic Disparity in Living-Donor Kidney Transplantation in the UK: Patient-Identified Reasons for Non-Donation among Family Members.* Journal of Clinical Medicine, 2020. **9**(11): p. 3751.
29. *Consultation to explore people's views on organ and tissue donation: discussions with indigenous peoples.* . Canadian Council for Donation and Transplantation, 2005.
30. Available from: https://blackhealthalliance.ca/.
31. Wallerstein, N.B. and B. Duran, *Using community-based participatory research to address health disparities.* Health Promot Pract, 2006. **7**(3): p. 312-23.
32. Barbara A. Israel, E.E., Amy J. Schulz, and Edith A. Parker, *Introduction to Methods in Community-Based Participatory Research for Health*. 2005: Jossey-Bass.
33. Ford, C.L. and C.O. Airhihenbuwa, *Commentary: Just What is Critical Race Theory and What's it Doing in a Progressive Field like Public Health?* Ethn Dis, 2018. **28**(Suppl 1): p. 223-230.

34. Douglas, D., et al., *Black Health Education Collaborative: the important role of Critical Race Theory in disrupting anti-Black racism in medical practice and education.* CMAJ, 2022. **194**(41): p. E1422-E1424.
35. Molina, K.M. and D. James, *Discrimination, internalized racism, and depression: A comparative study of African American and Afro-Caribbean adults in the US.* Group Process Intergroup Relat, 2016. **19**(4): p. 439-461.
36. Donovan, R.A., et al., *Impact of racial macro-and microaggressions in Black women's lives: A preliminary analysis.* Journal of Black Psychology, 2013. **39**: p. 185-196.
37. Choi, S., et al., *Is ethnic identity a buffer? Exploring the relations between racial microaggressions and depressive symptoms among Asian-American individuals.* Journal of Ethnic & Cultural Diversity in Social Work: Innovation in Theory, Research & Practice, 2017. **26**: p. 18-29.
38. Nadal, K.L., et al., *Racial microaggressions and Asian Americans: An exploratory study on within-group differences and mental health.* Asian American Journal of Psychology, 2015. **6**: p. 136-144.
39. Ford, C.L. and C.O. Airhihenbuwa, *The public health critical race methodology: Praxis for antiracism research.* Social Science & Medicine, 2010. **71**(8): p. 1390-1398.
40. https://blackhealthalliance.ca/home/antiblack-racism/.
41. Dryden, O. and O. Nnorom, *Time to dismantle systemic anti-Black racism in medicine in Canada.* CMAJ, 2021. **193**(2): p. E55-E57.
42. Ashburn-Nardo, L., K. Thomas, and A.J. Robinson, *Broadening the conversation: why black lives matter.* Equality, Diversity and Inclusion: An International Journal, 2017. **36**(8): p. 698-706.
43. http://2020.rapportccdp.ca/chief-commissioners-message.html.
44. Braun, V., et al., *Thematic Analysis*, in *Handbook of Research Methods in Health Social Sciences*. 2018. p. 1-18.
45. Campbell, K., et al., *Reflexive Thematic Analysis for Applied Qualitative Health Research.* The Qualitative Report, 2021.
46. Braun, V. and V. Clarke, *To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales.* Qualitative Research in Sport, Exercise and Health, 2021. **13**(2): p. 201-216.
47. Malterud, K., V.D. Siersma, and A.D. Guassora, *Sample Size in Qualitative Interview Studies: Guided by Information Power.* Qual Health Res, 2016. **26**(13): p. 1753-1760.
48. Olmos-Vega, F.M., et al., *A practical guide to reflexivity in qualitative research: AMEE Guide No. 149.* Med Teach, 2022: p. 1-11.

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.

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Psycho-Social and Ethno-Cultural Barriers to Living Donor Kidney Transplant: Focus Groups in the Community.

Investigator/Study Doctor: Dr. Istvan Mucsi

Contact Information:

Principle Investigator: Dr. Mucsi: (xxx) xxx-xxxx
Co-Investigators:
Dr. S. Joseph Kim
Dr. Jeffrey Zaltzman

Study Coordinator: Heather Ford: (xxx) xxx-xxxx

Introduction:

You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study's risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background/Purpose:

Ethnicity is of the factors that will affect whether patients seek a LDKT (Living Donor Kidney Transplant). South Asian, East Asian and African Canadians are half less likely than their Caucasian counterparts to receive a living donor kidney transplantation. You have already taken part in the first part of our study where you were asked to answer questionnaires. This consent form is for the second part of the study. You have been asked to participate in this part of the study because you have indicated that you would be interested in participating in a focus group. Factors related to ethnicity can be a barrier to LDKT and we are interested in exploring barriers that affect all ethnic groups.

Information gained from this study will help us to better address the needs of patients with kidney disease, especially those patients from a minority ethnic background. It will also help us to improve the education that will be better at answering all the questions and concerns and deal with the health-related needs of patients similar to yourself. We will also share the findings of this study with other kidney doctors and public health organizations so that they can also better serve their patients.

There will be a total of 20 focus groups, 90 to 120 minutes long, each including 6-8 participants for a total of 160 participants. You will be asked to take part in just one focus group.

Study Visits and Procedures:

For the second part of the study, you will be asked to participate in a **facilitated group discussion,** or focus group, to discuss social and cultural factors which influence access to healthcare and LDKT. We are also interested in learning about your knowledge and understanding of living donor transplants. A moderator (an individual who will lead the discussion), co-moderator (an individual who will assist the moderator and help to translate where necessary) and one researcher (who will take notes) will be present for each group. The moderator will make sure that everyone gets to express their views. For those participants with limited English, focus groups will be available in their native language (Cantonese, Mandarin, Urdu, Hindi, Punjabi, Tamil, Arabic, Bangla). Also, should you be uncomfortable with a focus group, we also offer one-on-one interviews. For some focus groups or interviews, members of community organizations, such as the Black Health Alliance and the Council of Agencies Serving South Asians will assist in co-moderating the focus group.

Note that since you will be asked to share your feelings and opinions openly in the presence of others, you will need to be mindful of each other's opinions and maintain confidentiality. Also you do not need to answer any questions that make you feel uncomfortable during the course of the focus group discussion.

Each focus group will be audio recorded. Only researchers will have access to the audiotapes. Once the tapes have been transcribed, the tapes will be destroyed.

For African, Caribbean, and Black community focus groups organized through the Black Health Alliance, de-identified focus group transcripts will be shared with the Black Health Alliance. This will allow us to analyze and interpret the data in collaboration with the community, so that the concerns of community members around access to LDKT can be addressed in a culturally competent way.

Risks:

There are no risks in taking part in this part of the study. Should you feel uncomfortable or distressed while in the group discussion, you will be able to address your concern immediately with the moderator. Additionally, the treating team in the nephrology department will be available for support on a one-on-one basis if required, and community supports will be identified to connect with for support if needed.

Benefits:

You may not get any direct benefits from being in this study. Information learned from this study may help us to better understand how cultural beliefs may prevent patients learning about and getting a living donor kidney transplant (LDKT). With this information, we can improve our transplant education program to include any psychological issues that may prevent people pursuing a living donor transplant. In particular with these focus groups, we also want to be able to understand and reduce the barriers that exist within some cultural groups in getting a transplant.

Alternatives to Being in the Study:

You simply may decide not to be involved in this study. Your study doctor will talk with you about these options available to you, if you wish.

Confidentiality:

Personal Health Information

If you agree to join this study, the study doctor and his/her study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could be used to identify you and includes your:

- name,
- date of birth (month and year),
- telephone number (so that we can contact you)
- Other demographic information

The information that is collected for the study will be kept in a locked and secure area by the study doctor for 10 years. Only the study team or the people or groups listed below will be allowed to look at your records.

Representatives of the University Health Network Research Ethics Board may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

Study Information that Does Not Identify You

Data from this study will be entered into a computerized database through a secured website. Only study staff with a password will be allowed to enter data. All study data are identified by code, not by your name. A list linking your study number with your name will be kept by the study doctor in a secure place, separate from your study file. Efforts will be made to keep your personal information private. However, we cannot guarantee complete confidentiality. You will be identified by a code, and personal information from your records will not be released without your written permission. All information will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be identified in any publications or presentations that may come from this study.

Transcribed audiotapes will be kept with the researchers (in a secure a locked cabinet) for the duration of the study. Once the transcriptions have been analyzed and verified, the audiotapes will then be destroyed.

Voluntary Participation:

Your participation in this study is voluntary. You may withdraw from the study at any time. If you decide to withdraw, your care will not be affected in any way. We will give you any new information that is learned during the study that might affect your decision to stay in the study. If you decide to withdraw from the study, the information about you that was collected before you leave the study will still be used in order to answer the research question. No new information will be collected unless this is required to fulfill safety reporting obligations.

Costs and Reimbursement:

You will be given a one-time $30 in honorarium to compensate for travel-related expenses to the focus group session.

Rights as a Participant:

By signing this form you do not give up any of your legal rights against the investigators or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Conflict of Interest:

Researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study. You should not feel pressured to join this study.

Questions about the Study:

If you have any questions, concerns or would like to speak to the study team for any reason, please call:

Dr. Istvan Mucsi at (xxx) xxx-xxxx, or
Heather Ford at (xxx) xxx-xxxx.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board

(UHN REB) or the Research Ethics office number at (xxx) xxx-xxxx. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given a signed copy of this consent form.

Consent:

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

Print Study Participant's Name	Signature	Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent	Signature	Date

Was the participant assisted during the consent process? ☐ **YES** ☐ **NO**
If **YES**, please check the relevant box and complete the signature space below:

☐ The person signing below acted as an interpreter for the participant during the consent process and attests that the study as set out in this form was accurately interpreted and has had any questions answered.

Print Name of Interpreter	Signature	Date

Relationship to Participant	Language

e Entered: _____________ Study ID: __________

Demographics Questionnaire for Focus Groups

Study Title: Psychosocial and ethnocultural barriers to living donor kidney transplantation

Investigator/Study Doctor: Dr. Istvan Mucsi

Contact Information:

Principal Investigator:	Dr. Istvan Mucsi	(xxx) xxx-xxxx
Study Coordinator:	Heather Ford	(xxx) xxx-xxxx
	Lydia-Joi Marshall	(xxx) xxx-xxxx

What is your sex:
☐ Male ☐ Female ☐ Other ☐ Prefer not to answer

What is your birthdate: Month_______ Year_______ ☐ Prefer not to answer

What are the first three digits of your postal code? ___ ___ ___ ☐ Prefer not to answer

In what country were you born?
- ☐ Canada
- ☐ Other (please specify): _________________
- ☐ Prefer not to answer

Are you on dialysis?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Is someone you know on dialysis?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Are you undergoing evaluation for kidney transplant, or have you received a kidney transplant?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Has someone you know undergone evaluation for kidney transplant or received a kidney transplant ?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Are you now or have you ever been a landed immigrant, refugee or been on a work/minister permit in Canada?
☐ Yes ☐No ☐ Don't know ☐ Prefer not to answer

If yes, in what year did you first arrive in Canada to live? ____________
☐ Don't know ☐ Prefer not to answer

What is the highest degree or level of school you have completed? If currently enrolled, please list the

e Entered: _____________ Study ID: __________

highest degree received to date:

- ☐ No schooling completed
- ☐ Nursery school to 8th grade
- ☐ Some high school, no diploma
- ☐ High school graduate, diploma or the equivalent (e.g. GED)
- ☐ Some college credit, no degree
- ☐ Trade/technical/vocational training
- ☐ Diploma or certificate from community college (e.g. RN, RPN)
- ☐ Bachelor's degree (BA, BSc, LL.B, B.Ed)
- ☐ Master's degree (MA, MSc, Med)
- ☐ Professional degree (MD, DDS, DVD)
- ☐ Doctorate (PhD, DSc, DHSc)
- ☐ Other (please specify): ___________
- ☐ Don't know
- ☐ Prefer not to answer

Which of the following best describes where your income comes from? (Select all that apply)

- ☐ Full-time employment
- ☐ Part-time employment
- ☐ Self-employed
- ☐ Unemployed and looking for work
- ☐ Unemployed and not looking for work
- ☐ Unemployed, unspecified as to whether seeking work or not
- ☐ A homemaker
- ☐ Retired
- ☐ Student
- ☐ Unable to work
- ☐ Unknown
- ☐ Welfare
- ☐ Disability
- ☐ Other (e.g., homeless)
- ☐ Prefer not to answer

Do you identify as a first, second, or third generation Canadian?

- ☐ First generation (I was born outside of Canada)
- ☐ Second generation (I was born in Canada, and at least one of my parents was born outside of Canada)
- ☐ Third generation or more (I was born in Canada, and both of my parents were born in Canada)
- ☐ Not applicable
- ☐ Don't known
- ☐ Prefer not to answer

What language or dialect do you speak <u>most often</u> at home? <u>Choose only one.</u>

- ☐ Amharic
- ☐ Arabic
- ☐ ASL
- ☐ Bengali
- ☐ Chinese (Cantonese)
- ☐ Chinese (Mandarin)
- ☐ Czech
- ☐ Dari
- ☐ English
- ☐ Farsi
- ☐ French
- ☐ Greek
- ☐ Hindi
- ☐ Hungarian
- ☐ Italian
- ☐ Karen
- ☐ Korean
- ☐ Nepali
- ☐ Polish
- ☐ Portugese
- ☐ Punjabi
- ☐ Russian
- ☐ Serbian
- ☐ Slovak
- ☐ Somali
- ☐ Spanish
- ☐ Tagalog
- ☐ Tamil
- ☐ Tigrinya
- ☐ Turkish
- ☐ Twi
- ☐ Ukrainian
- ☐ Urdu
- ☐ Vietnamese
- ☐ Prefer not to answer
- ☐ Don't know
- ☐ Other: (please specify) ____________

Which of the following categories best describes your ethnicity?

e Entered: _____________ Study ID: __________

North American Indigenous
- ☐ First Nations
- ☐ Inuit
- ☐ Metis
- ☐ Other (please specify): _________

Black or African
- ☐ North American Black/African (e.g. Canadian, American)
- ☐ Central or West African (e.g. Ghanaian, Nigerian, Senegalese)
- ☐ North African (e.g. Algerian, Moroccan, Sudanese)
- ☐ Southern or East African (e.g. Somali, Ugandan, Ethiopian)
- ☐ Other (please specify): _________

Asian
- ☐ West Central Asian or Middle Eastern (e.g. Afghan, Jordanian, Yemeni)
- ☐ South Asian (e.g. Bangladeshi, Pakistani, Punjabi)
- ☐ East or Southeast Asian (e.g. Chinese, Korean, Filipino, Indonesian)
- ☐ Other (please specify): _________

White or European
- ☐ White - North American (e.g. Canadian, American)
- ☐ Northern European (e.g. British, Danish, Swedish)
- ☐ Southern European (e.g. Greek, Italian, Portuguese)
- ☐ Eastern European (e.g. Hungarian, Ukrainian, Russian)
- ☐ Western European (e.g. Dutch, French, German)
- ☐ Other (please specify): _________

Other
- ☐ Latin, Central, or South American (e.g. Brazilian, Chilean, Mexican)
- ☐ Caribbean (e.g. Haitian, Jamaican, Carib)
- ☐ Oceanian (e.g. Australian, New Zealander, Pacific Islander)
- ☐ Other (please specify): _________

What is your religious or spiritual affiliation?

- ☐ I do not have a religious or spiritual affiliation
- ☐ Islam
- ☐ Hinduism
- ☐ Christianity
- ☐ Judaism
- ☐ Sikhism
- ☐ Buddhism
- ☐ Confucianism
- ☐ Native Spirituality
- ☐ Taoism
- ☐ Jainism
- ☐ Spiritual
- ☐ Atheism
- ☐ Prefer not to answer
- ☐ Do not know
- ☐ Other(s) – Please Specify: __________

Qualitative Arm- Focus Group/Interview Guide

Introduction:

Welcome everyone! I want to take this opportunity to thank you all for participating in our focus group today. My name is (_____________) and I am the facilitator and beside me, we have our co-facilitator (_________________) who will also be helping me today in our group discussion.

The goal of our focus group today is to understand what you think about kidney disease, kidney failure, kidney transplant, and organ donation. We would also like to know about any barriers or challenges you may have experienced when trying to access information or care related to your kidney health, or your health in general, and any suggestions you may have to overcome these barriers and challenges. We are interested in all of your experiences, opinions, beliefs, thoughts, and feelings about these issues and there are no right or wrong answers. So, please feel free to speak openly and honestly. It is my job to guide our discussion today. I will make sure everyone who wants to speak has a chance to do so. I will also make sure that we stay on track in terms of our topic and our timing. But, hopefully, you will do most of the talking and (_________) and I will mostly listen.

Our focus group will run for approximately 1½ - 2 hours. If you do need to step out during the group discussion, please feel free to do so.

Ground Rules:

I would like to set some ground rules to ensure that everyone in the group feels comfortable and safe during our discussion. Is that ok with everyone?

[If yes, have everyone proceed to create ground rules]

Sample Group Rules:

- One person speaks at a time (i.e., Taking turns before speaking)
- Respecting each other's opinions (i.e., members will show respect in a non-judgmental way)
- Privacy/confidentiality (i.e., what is said in the group, stays in the group. Each member will respect each other's personal information and will not reveal that information outside of the group)

[Clarify ground rules or uncertainty with participants when needed]

- As you already know, we will be recording today's discussion. Our conversation will be audio recorded and then transcribed, so that we do not lose any of the information that is discussed and it will be easier for the research team to analyze.

Please be assured that your personal information will be kept private within our research team. Is everyone comfortable with this?

[If yes, proceed forward and if no, answer additional questions participants might have]

Turn on Audio Recorder.

Participant Introduction:

1.) Let's start by going around the room to introduce ourselves. Will each person please tell us:

   a. Your preferred name
   b. Tell us briefly your connection, if any, to kidney disease, organ donation, and kidney transplant, and/or, why you chose to participate in today's discussion

Focus Group Questions

Ethnocultural Identity

1. Which ethnocultural group(s) do you identify with and what does this mean to you?
   a. What does this look like in your everyday life? (e.g. language, food, traditions, approaches to health and healing)

2. In what ways do you think your ethnocultural identity as [participant answer] influences your experience with the health/kidney care system?
   a. Do you feel that you experience the healthcare system differently than others? If so, why do you think that is?
   b. How have these experiences shaped how you interact with the health care system?

3. What types of healing & treatment practices are important to you?
   a. Do you use any healing practices that are different than the treatments typically provided by the Canadian healthcare system?
   b. Are there any factors that you consider that make you lean on one approach over the other?
      i. Probe around access, finances, quality of experience, results.

4. Are you aware of any thoughts, feelings, or concerns in your community around kidney disease, kidney transplant, and organ donation?

Next questions will need to be modified for community members vs. patients on dialysis, recipients, donors, family members/caregivers. For example, for participants with lived experience of CKD, participants can answer questions based on their actual vs. a hypothetical experience.

General Knowledge & Awareness

1. What do you know about the kidneys and their function?
    a. How would a person know if their kidneys were not working properly?
    b. What do you think causes kidney disease?
    c. What is kidney failure?
    d. How serious are kidney disease and kidney failure?

2. If someone has kidney failure what are their treatment options?
    a. Do you think that one option is better than another? Why or why not?

3. What do you know about kidney transplant as a treatment option?
    a. If someone needed a kidney transplant, where could they get a kidney?
    b. What is the difference between a deceased and living donor transplant?
    c. What do you see as the advantages or disadvantages to the different types of kidney transplant?
        i. Probe around risks and benefits of each.

4. What do you know about organ donation?
    a. Probe around living vs. deceased organ donation.

5. How did you come to learn this information? Do you feel that you know enough about these topics?
    a. *If patient or caregiver:* What did you know about these topics before diagnosis? What do you wish you had known about these topics prior to diagnosis?

Family and Support

1. If you had kidney failure and were considering your treatment options, who would you talk to? Who would you rely on for support (emotional, practical)?
    a. What about if you had a different health problem? What about another type of problem, such as financial?

2. If you had kidney failure and required a transplant, would you accept a kidney? Why or why not?
    a. Would you accept a kidney from a living donor? If yes, who would you accept a kidney from?

    b. Would you accept a kidney from a deceased donor? Why or why not?

3. If you or someone in your family/community had kidney disease or kidney failure, what effects could this have on your/their relationships in the family/community?
    a. What about if they needed a transplant?

5. If you or someone in your family/community wanted to be a living kidney donor, what effects could this have on your/their relationships in the family/community?

6. How can relationships with family/friends change in the context of organ donation/kidney transplant?

7. Do you or would you feel comfortable discussing kidney disease, kidney transplant, and organ donation with family and friends?
    a. Would you have fears, concerns about what they think?
    b. Are there any circumstances which would make you feel uncomfortable having a discussion about kidney disease with your family and friends?
    c. What would help make discussing these topics easier?

Information Needs

1. Where do you go to find health information or to learn more about your health-related concerns?
    a. Have you encountered any difficulties when seeking information or resources related to your health?
    b. What about your friends or family?

2. *If patient or caregiver:* Have you (or your family and friends) encountered any difficulties when seeking information or resources related to kidney disease, kidney transplant, and organ donation?
    a. What information or support did you receive related to your treatment options?
    b. What types of resources were helpful to you? What resources were not helpful? What else would you need?
    c. Do you think you know enough about these topics? Is there any more or different information that you desire? If so, what kind of information are you looking for?
    d. Are there particular resources or supports regarding kidney disease and its treatment that you would recommend to others?

Religion and Cultural Values

1. How do you think your culture influences how you or your family, friends, community members think about kidney disease and transplant?

2. What about religion and spirituality? How does that shape how you or your family, friends, community members think about these topics?
    a. Is it acceptable to donate your organs while alive? After death?
    b. Is it ok to accept an organ from another?

3. Do you or would you feel comfortable discussing kidney disease, kidney transplant, and organ donation with community members or religious leaders?
    a. Would you have fears, concerns about what they think?
    b. Are there any circumstances which would make you feel uncomfortable having a discussion about kidney disease with these individuals?
    c. What would help make discussing these topics easier?

4. If you had kidney failure, what factors do you think might impact your decision regarding your treatment options?
    a. Would you consider both dialysis and transplant? Living donor kidney transplant? Why or why not?

5. What are some of your values and beliefs (if any) that would impact your decision to have a living donor kidney transplant? To donate a kidney either before or after your death?

Immigration & Society

1. How do you think immigrating to Canada impacts the way people receive support related to kidney disease or transplant?

2. What issues do you think immigrants to Canada face if they have major health concerns?
    a. Probe: What about those wishing to pursue LDKT or be living donors?

3. Have you or your family members faced any barriers to accessing health/kidney care in Canada?

4. Are there similarities and differences in the way kidney transplant awareness is delivered here and in other places where you have lived?

Trust

1. Would you say that you trust the Canadian health care system? Do you trust your doctor/healthcare team? Why or why not?
    a. Probe around experiences, attitudes, outcomes, follow through, access to alternatives.

2. Can you remember a situation where you or someone you know did not fully trust the healthcare team looking after them?

3. Have you had any negative experiences in healthcare in Canada where you felt you were being discriminated against (because of your age, sex, gender, race, ethnicity, religion, language skill etc.)?

4. When speaking with your health care provider/team, do you feel respected? Why or why not?

5. How does your health care provider/team integrate your values (e.g. religious/cultural) and beliefs when discussing matters related to major health issues, such as kidney transplant?

6. If you needed treatment for a serious health condition, such as kidney failure, would you want to have it done in Canada or elsewhere (e.g. your country of origin, another country)?

7. Would you feel more comfortable receiving treatment if your health care provider was from the same ethnocultural background as you? Why or why not?

Closing Questions

1. How can we create a better system of care for people with kidney disease from ACB communities?

2. How can we better support ACB community members wishing to be living donors?

3. Is there anything that we have missed today that you think is important for us to know? Do you have anything else at all to add to the discussion?

Conclusion:

On behalf of the research team we would like to take this opportunity to thank you all for participating in our focus group today. You have shared some very interesting and important information. We hope that today's discussion has been enjoyable for you and if you think of anything else that you would like us to know, please do not hesitate to contact us anytime. Thank you!

Individual Interview Script for Healthcare Professionals

As you already know, we will be recording today's interview. Our conversation will be audio recorded and then transcribed, so that we do not lose any of the information that is discussed and it will be easier for the research team to analyze. Please be assured that your personal information will be kept private within our research team. Are you comfortable with this?

[If yes, proceed forward and if no, address any concerns or questions that participants might have.]

Turn on Audio Recorder.

Ethnocultural Identity

1. Which ethnocultural group(s) do you identify with and what does this mean to you?
    a. What does this look like in your everyday life? (e.g. language, food, traditions, approaches to health and healing)

2. In what ways do you think your ethnocultural identity as [participant answer] influences your experience with the kidney care system or the healthcare system in general?
    a. What is your role in the kidney care system?
    b. Do you feel that you experience the healthcare system differently than others? If so, why do you think that is?
    c. How have these experiences shaped how you interact with the system?

3. What types of healing & treatment practices are important to you? How about for your patients?
    a. Do you or your patients use any healing practices that are different than the treatments typically provided by the Canadian healthcare system? If so, can you tell me a little bit more about that?

General Knowledge & Awareness

1. What do you think most of your patients know and understand about the kidneys, kidney disease, and kidney failure before and/or after they are diagnosed?

2. What do you think most of your patients know and understand about their treatment options before and/or after they are diagnosed?
    a. Probe regarding the perceived advantages and disadvantages, risks and benefits of dialysis, DDKT and LDKT
    b. What factors do you think impact your patients' decisions regarding their treatment options?

3. How do most of your patients access this information? Do you think that they are satisfied with the information they have on these topics?

4. Sometimes patients and families tell us that people from ACB communities are less likely to explore or pursue transplant or donate their organs while alive or after their death. What do you think about this? Have you observed any differences in your ACB and non-ACB patients?

5. Are you aware of any thoughts, feelings, or beliefs around organ donation or transplantation in ACB communities?

6. In your opinion what might be the main barriers to organ donation and transplantation in ACB communities?

Family and Support

1. Who do your ACB patients talk to when they are considering their treatment options?

2. Who do they rely on for support (e.g. emotional, practical)?

3. If one of your ACB patients required a kidney transplant, would they discuss this with their family, friends, community?
    a. Would they ask and/or accept a kidney from a living donor? If so, who might they accept a kidney from?
    b. Would they accept a kidney from a deceased donor?
    c. What factors do you think would play into these decisions?

4. How can relationships with family/friends change in the context of kidney disease, organ donation, kidney transplant?

5. Do you think your ACB patients have open conversations about their health, especially as it relates to their kidney disease, with their family, friends, and communities?
    a. If not, what might help make these conversations easier for your patients?

Information Needs

1. Where do your ACB patients go to find out information about their health, especially related to kidney disease and treatment options?
    a. Probe around who, where, and in what form the information comes from.
    b. Probe around any difficulties patients experience in accessing information.

2. What has been your experience providing information and resources to your ACB patients?

3. Do you think your approach is the same or different from your colleagues?

4. Are there particular resources or supports regarding kidney disease and its treatment that you would recommend?

5. Do you observe any differences between your ACB and non-ACB patients in this regard?

6. What do you think about the idea of tailoring information and support to ACB communities?
    a. Probe around what this would look like in their view.

Religion and Cultural Values

1. How do you think culture and religion influence your ACB patients' beliefs and behaviours regarding kidney disease and its treatment?

2. How do you, as a healthcare provider, integrate your patients' values (e.g. religious/cultural) and beliefs when discussing matters related to major health issues, such as kidney transplant?
    a. Do you face any challenges in this area and, if so, how do you handle them?

Immigration and Society

1. How do you think immigrating to Canada impacts the way people receive information or support related to kidney disease or transplant?

2. What issues do you think immigrants to Canada face if they have major health concerns?
    a. Probe: What about those wishing to pursue LDKT or be living donors?

3. Have any of your ACB patients that have immigrated faced any barriers to accessing health/kidney care in Canada?
    a. How do the barriers that your ACB patients have faced differ from your patents that have immigrated from other countries?

4. Are there similarities and differences in the way kidney transplant awareness is delivered here and in other places that you know of?

Trust

1. Would you say that your ACB patients trust the Canadian health care system? Why or why not?

2. Can you remember a situation where one of your ACB patients did not fully trust a member of their healthcare team?

3. Do you think your ACB patients would more comfortable receiving treatment if their healthcare provider was from the same ethnocultural group as them? Why or why not?

4. Have you yourself had any negative experiences in healthcare in Canada where you felt you were being discriminated against (because of your age, sex, gender, race, ethnicity, religion, language skill etc.)?

<u>Closing Questions</u>

1. How can we create a better system of care for people with kidney disease from ACB communities?

2. How can we better support healthcare providers from ACB communities working in the Canadian healthcare system?

3. Is there anything that we have missed today that you think is important for us to know?

Conclusion:

On behalf of the research team I would like to take this opportunity to thank you for participating in this interview. You have shared some very interesting and important information. I hope that today's conversation has been enjoyable for you and if you think of anything else that you would like us to know, please do not hesitate to contact us anytime. Thank you!

BMJ Open

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

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2023-073176.R1
Article Type:	Protocol
Date Submitted by the Author:	07-Jul-2023
Complete List of Authors:	Edwards, Beth; University Health Network; University of Toronto Marshall, Lydia-Joi; Black Health Alliance Ahmadzadeh, Ghazaleh; University Health Network; University of Toronto Ahmed, Ranie; University Health Network; University of Toronto Angarso, Lydia; University Health Network; University of Toronto Balaji, Shilpa; University Health Network; University of Toronto Okoh, Princess; University Health Network; University of Toronto Rogers, Emma; University Health Network; University of Toronto Neves, Paula; University Health Network Boakye, Priscilla; Toronto Metropolitan University Gill, Jagbir; The University of British Columbia James, Carl Everton; York University Mucsi, Istvan; University Health Network; University of Toronto
Primary Subject Heading:	Renal medicine
Secondary Subject Heading:	Qualitative research
Keywords:	Health Equity, Adult nephrology < NEPHROLOGY, End stage renal failure < NEPHROLOGY, Renal transplantation < NEPHROLOGY, Chronic renal failure < NEPHROLOGY

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

Authors: Beth Edwards[1*], Lydia-Joi Marshall[2*], Ghazaleh Ahmadzadeh[1], Ranie Ahmed[1], Lydia Angarso[1], Shilpa Balaji[1], Princess Okoh[1], Emma Rogers[1], Paula Neves[3], Priscilla Boakye[4], Jag Gill[5], Carl Everton James[6], Istvan Mucsi[1]

[1] Multi-Organ Transplant Program and Division of Nephrology, University Health Network, University of Toronto, Toronto, Ontario, Canada
[2]Black Health Alliance, Toronto, Ontario, Canada
[3]Centre for Living Organ Donation, University Health Network, Toronto, Ontario, Canada
[4]Daphne Cockwell School of Nursing, Toronto Metropolitan University, Toronto, Ontario, Canada
[5]Division of Nephrology, Department of Medicine, University of British Columbia, Vancouver, British Columbia, Canada
[6]Jean Augustine Chair in Education, Community & Diaspora, Faculty of Education, York University, Toronto, Ontario, Canada

* Co-first authors, contributed equally

Author for correspondence: Dr. Istvan Mucsi
Academic Degree(s): MD, PhD, FRCPC, FASN
Affiliations: Multi-Organ Transplant Program and Division of Nephrology Department
University Health Network
Address: 585 University Avenue, MARS Building, Floor 9 Room 9062
Toronto, Ontario, M5G 2N2, Canada
Phone: 416-340-4084
Fax: 647-689-3070
E-mail: Istvan.mucsi@utoronto.ca

Abstract (word count = 295/300)

Introduction

Living donor (LD) kidney transplant (KT) is the best treatment option for many patients with kidney failure as it improves quality of life and survival compared to dialysis and deceased donor KT. Unfortunately, LDKT is underused, especially among groups marginalized by race and ethnicity. African, Caribbean, and Black (ACB) patients are 60-70% less likely to receive LDKT in Canada compared to White patients. Research from the United States and the United Kingdom suggests that mistrust, cultural and generational norms, access, and affordability may contribute to inequities. To date, no Canadian studies have explored the beliefs and behaviours related to LDKT in ACB communities. Research approaches that utilize a critical, community-based approach can help illuminate broader structural factors that may shape individual beliefs and behaviours.

In this qualitative study, we will investigate barriers to accessing LDKT in ACB communities in the Greater Toronto Area (GTA), to enhance our understanding of the perspectives and experiences of ACB community members, both with and without lived experience of chronic kidney disease (CKD).

Methods and analysis

Hospital and community-based recruitment strategies will be used to recruit participants for focus groups and individual interviews. Participants will include self-identified ACB individuals with and without experiences of CKD and nephrology professionals. Collaboration with ACB community partners will facilitate a community-based research approach. Data will be analyzed using reflexive thematic analysis and critical race theory. Findings will be revised based on feedback from ACB community partners.

Ethics and dissemination

This study has been approved by the University Health Network Research Ethics Board UHN REB file #15-9775. Study findings will contribute to the co-development of culturally safe and responsive educational materials to raise awareness about CKD and its treatments and to improve equitable access to high quality kidney care, including LDKT, for ACB patients.

Strengths and Limitations

Insert 5 bullet points only relating specifically to the methods.

- Community-based approach to study design fosters relationships between academic and community partners.
- Theoretically-informed data analysis goes beyond documentation of health inequities.
- Reflexive data analysis examines biases and challenges assumptions of the research team.
- Inclusion of diverse participant perspectives, e.g. gender, age, representation from diverse ACB communities (but not all), patients, healthcare professionals, and community members without lived experience of kidney disease.
- Community partners were not involved in the initial phases of study design.

Introduction (word count = 4234/4000)

From a medical perspective, living donor kidney transplant (LDKT) is considered the best treatment for many patients with kidney failure who require kidney replacement therapies (dialysis or kidney transplant [KT]). [1] LDKT is associated with better quality of life, graft survival, and life expectancy compared to dialysis [1-7]. LDKT is also associated with shorter wait times compared to deceased donor KT (DDKT). [1] Importantly, along with medical considerations, major treatment decisions (such as LDKT) can also include financial, social, emotional, and cultural considerations. [8] LDKT is underused internationally and in Canada, [9] especially among groups marginalized by race and ethnicity. [10, 11] Specifically, African, Caribbean, and Black (ACB) patients are 60-70% less likely to receive LDKT in Canada compared to White patients. [11-13]

ACB communities represent 4.6% of the population of Canada and include generations of Canadians, recent immigrants from Africa and the Caribbean, individuals of Afro-Indigenous origin, and diasporic ACB communities who identify with various ethnic and geographic regions. [14, 15] While these are diverse communities based on countries of origin, immigration status, religion, and culture, they are all likely to face systemic anti-Black racism both within and outside the healthcare system. [16]

Racism and discrimination against ACB individuals remain deeply entrenched and normalized in Canadian institutions, policies, and practices. [17] For example, a landmark police report revealed that ACB individuals in Toronto are overrepresented among victims of police use of force. [18] The COVID-19 pandemic further unveiled systemic anti-Black racism and long-standing inequities faced by ACB communities in

Toronto. [19-23] ACB Canadians experience higher incidence of diabetes and hypertension compared to the general population. [24, 25] This may be related, in part, to the stress associated with discrimination and anti-Black racism which in turn can contribute to higher rates of chronic kidney disease (CKD) in this population. [24, 25]

In the United States (US) and the United Kingdom (UK) studies have shown that mistrust in physicians and the healthcare system, cultural and generational norms, access, and affordability substantially limit accessing KT and LDKT among ACB patients. [26] [27] [28] [29] Although these studies provide valuable insights, we cannot directly extrapolate these findings to Canada because there are fundamental differences in the social, environmental, and healthcare systems between Canada, the US, and the UK.

However, despite the repeatedly documented inequities in access to KT and LDKT, no academic research studies have been conducted in Canada to explore and understand the factors that influence beliefs and behaviours around KT and LDKT in ACB communities. For example, respect for death-related rituals and rites, and concern about the religious permissibility of KT are likely to create hesitation among Muslim Canadians who comprise an increasing proportion of ACB communities. In addition, individuals may prefer to obtain donation directly from members of their community because of their experiences with racism, oppression, and mistrust of the healthcare system. [30] Moreover, individuals may feel alienated from the healthcare system due to its dominantly Eurocentric approaches that privilege biomedical care with little consideration for socio-environmental conditions influencing health outcomes. Such topics are best explored using qualitative research methods.

A better understanding of the perspectives and experiences of ACB patients and families, healthcare professionals (HCPs), and community members will facilitate the tailoring of information and clinical pathways to the needs of ACB patients.

Aims

The purpose of our study is to identify barriers to accessing LDKT in ACB communities in the Greater Toronto Area (GTA), Ontario. The objectives of the study are to explore study participants' perspectives on and experiences with the health and kidney care system, CKD, kidney failure and its treatments, particularly LDKT, to deepen our understanding of the perspectives and experiences of ACB community members -- both with and without lived experience with kidney disease. Ultimately, we wish to generate knowledge to inform the co-development (with ACB community partners) of culturally safe and responsive educational materials to raise awareness about CKD, kidney failure and its treatments, and to ensure equitable access to the best kidney care for ACB patients.

Methods and Analysis

Study Design

We will conduct an exploratory, qualitative study including focus groups and individual interviews with self-identified ACB individuals both with and without lived experience of CKD.

Setting and context

ACB individuals with lived experience of CKD who previously participated in quantitative research conducted by our team, and who have indicated their interest in participating in focus groups or interviews will be invited to participate in this qualitative study. We previously conducted a cross-sectional study to assess psychosocial and ethnocultural barriers to accessing LDKT among patients with CKD. All ACB patients referred for pre-KT assessment from various renal programs across the GTA, as well as potential KT candidates treated with maintenance dialysis from renal programs at the Toronto General Hospital, St. Michael's Hospital, Humber River Hospital, or Scarborough General Hospital were eligible to participate in the study. Of these, any individuals who indicated interest in participating in focus groups or interviews will be contacted by a member of the qualitative research team and invited to participate in the current study. Collaboration with our community partner, Black Health Alliance (https://blackhealthalliance.ca/), a community-led registered charity that works to improve the health and well-being of ACB communities, will facilitate recruitment of individuals with no connection to CKD. [31]

Sample and recruitment

We have chosen to speak with individuals from three mutually exclusive groups of participants, whom we anticipate may have unique perspectives on CKD, kidney failure, and kidney replacement therapies such as LDKT: individuals with lived experience with CKD, general community members with no known lived experience of CKD, and nephrology professionals with no known lived experience of CKD (e.g.

physicians, nurse practitioners, nurses). All three groups likely have experiences with racialization, and their relationship with CKD and kidney care is likely to help shape their perspectives. Purposive and snowball sampling will be used to recruit study participants.

Study recruitment has been impacted by the COVID-19 pandemic and its effects on in-person data collection, the disproportionate burden on ACB communities, and the increased workload of HCPs. The pandemic has had a detrimental impact on the ability to recruit study participants and conduct in-person focus groups. Additionally, the increased burden on ACB communities and HCPs as a direct result of the pandemic resulted in further recruitment challenges. As a result, we ceased in-person data collection soon after the pandemic started and will conduct virtual data collection via telephone and MS Teams when we can safely resume doing so which will be in line with recommendations of participating hospitals and community partners.

Individuals with lived experience with CKD

Individuals who self-identify as members of ACB communities with lived experience with CKD (e.g. individuals with kidney failure before or on dialysis, waitlisted for KT, KT recipients, family members of patients with kidney failure, living kidney donors, and individuals undergoing living donor evaluation) will be invited to participate in focus groups and/or individual interviews. We aim to hold 5-6 focus groups with 6-8 participants per group.

ACB community members with no lived CKD experience

We will also invite self-identified ACB community members with no known lived experience of kidney disease to participate in the study. We aim to hold 5-6 groups with

6-8 participants per group. The rationale for speaking with this group is that anyone may be considered a potential living donor; therefore it is important to understand their perspectives and experiences regarding CKD, kidney transplant, and organ donation.

Healthcare professionals (HCPs)

Finally, we will interview 8 -10 nephrology professionals who self-identify as ACB community members. We have chosen to interview HCPs individually since it can be challenging to coordinate focus groups with this particular participant group. The rationale for speaking with this group is to understand their unique perspective as ACB community members and HCPs with intimate knowledge of the kidney care pathway. The inclusion criteria for all three participant groups are as follows: self-identified members of ACB communities, ≥18 years of age, able to speak and understand English. The exclusion criteria are as follows: unwilling or unable to provide informed consent and, in the case of the second group (individuals with lived experience of CKD), dementia or significant mental delay/challenge as identified by the individual's healthcare team.

Study recruitment will occur via hospital-based methods, such as the posting and distribution of flyers and in-clinic study recruitment efforts. The research team will also collaborate with community partners and a community engagement specialist (LJM) with close ties to ACB communities, who will utilize established connections to extend personal invitations to participate in the study. Study recruitment will benefit from the established and trusted relationships that both our community partners and community engagement specialist have with diverse ACB communities.

Potential study participants will be approached by a member of their healthcare team (in the case of the first participant group) or a community host known to the community engagement specialist (e.g. community leader, social influencer) in the case of the second participant group. The community host will be a trusted individual who will act as a liaison between the community engagement specialist and the study participants. The host will help to plan, organize, and schedule the groups, answer questions, and assist with practical matters at the time of the focus group. For the third participant group, potential participants will be identified by study co-investigators and contacted by a research team member. Once potential study participants have agreed to learn more about the study, they will be connected to a qualitative team member who will provide further details, answer questions, and address any concerns about the study.

Information regarding the study and invitations to participate will be distributed in person, as well as via existing communication channels of our community partners, such as: direct person-to-person contact through phone, in-person communication, and online messaging platforms such as e-mail, Facebook Messenger, and WhatsApp; informational sessions with interested groups who request the opportunity to hold a focus group during regularly scheduled meetings; and connecting to new community groups and partners to inform them of the opportunity to participate in the study. In an attempt to maximize the diversity of the sample, we will connect with various ethnic groups within ACB communities, including: Jamaican; Haitian; Somalian; Nigerian; Ethiopian; Ghanaian; Caribbean; and Sudanese. Consideration will also be given to ensure representation across age, immigration status, religion, gender, and geographic region in the GTA.

Theoretical Framework

This study was not initially designed in collaboration with ACB community partners; however, as a result of discussions with the community engagement specialist and other collaborators, the study evolved from a more traditional institution-driven approach to one that is informed by the principles of community-based participatory research (CBPR) to guide data collection, data analysis, and dissemination of study findings. [32] [33] CBPR is a research paradigm which integrates education and social action to improve health and reduce health disparities. [32] CBPR focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment with the aim of incorporating community theories, participation, and practices into the research efforts. [33]

Critical race theory (CRT) [34, 35] will be used during data analysis to understand how the experience of "race," and by extension, racialization influence the perspectives and experiences of study participants regarding accessing or considering healthcare and specifically, kidney care and LDKT. The term "racialization" emphasizes the complex historical, social, and political processes that result in unequal power distribution between groups. The term "racialized" refers to individuals in groups that are socially and politically constructed as distinct from the "reference" group or the one holding the majority of the economic, social, and political power.

Racialized individuals face implicit or overt bias, micro- and macroaggression, racism, and discrimination, including during their interactions with the healthcare system. These experiences and interactions are also related to health inequities. [36-39] Critical race research and interventions in the health sector must go beyond merely documenting disparities and instead seek to uncover the causes of health disparities; how racialization shapes disciplinary conventions; and how knowledge is produced within the existing, inequitable frameworks, in order to better understand and to challenge the existing power hierarchies. [40] Accordingly, we will draw upon four tenets of CRT in our data analysis:

Racial Consciousness

The research team will approach the analysis with the knowledge that race and racialization are salient realities that shape the lived experiences of members of ACB communities both within and outside of the healthcare system. This racial consciousness is also informed by an understanding of anti-Black racism which is evident in prejudicial attitudes and beliefs, and operationalized in stereotyping and discrimination that are directed at people of African descent and rooted in the unique history and legacy of colonization, enslavement, and racial stratification which continue to impact the experiences of Canadians today, and racialized individuals in particular. [41] [42]

Social, geographical, and temporal location

The research team will bear in mind that Canada's race relations are greatly informed by the existence of a particular type of racism often dismissed because of the country's identity as being "polite", "friendly", and "tolerant." While Canada prides itself on its ethos of multiculturalism, discrimination against ACB individuals remains deeply entrenched and normalized in Canadian institutions, policies, programs and practices. [17] Until relatively recently, public opinion was that racism did not exist in Canada; however, the murder of George Floyd, an unarmed African American man, by a White police officer in the United States in 2020 prompted worldwide protests, the further rise of the Black Lives Matter movement [43], and an increasingly open public discourse about the enduring existence of anti-Black racism in Canada. As Marie-Claude Landry, the Chief Commissioner of the Canadian Human Rights Commission stated, “It is time for all Canadians to acknowledge that anti-Black racism is pervasive in Canada. In fact, the belief that there is little to no racism in Canada is in itself a barrier to addressing it.” [44] Similarly, Prime Minister Justin Trudeau stated in his 2022 Emancipation Day (August 1) communiqué: “Although slavery was abolished nearly 200 years ago, its effects continue to live on today. The legacy of systemic anti-Black racism is still embedded throughout our society, including in our institutions.” [45] Indeed, Canada has a long history of systemic racism including colonialism, the trans-Atlantic slave trade, the Indian Act, Residential Schools, and more.

Power Relations and Processes

The research team will also approach this analysis with an understanding of how race, racism, and racialization are manifested both within and outside of institutional settings, and how individual, institutional, and societal racism are interlinked and operating systemically – generating systemic racism – which in turn produce and reproduce the social structures that mediate the lives of individuals.

Counternarratives as valid data

Lastly, the research team will acknowledge, respect, and accept the experiences of ACB community members that are shared during interviews and focus group sessions – taking them as valid data that serve to disrupt existing institutional perspectives. Elements of CRT will be employed in the analytical process to expose and challenge the mechanisms by which racism produces inequities in access to healthcare in general and to LDKT, specifically. Ultimately, we will seek to centre the multiple and diverse lived experiences of the study participants in order to disrupt ideas that may be commonly taken for granted by the healthcare system regarding the inequitable access to LDKT experienced by ACB communities in the GTA.

Research Team

The research team consists of a diverse group of individuals from different ethnocultural backgrounds (including ACB communities) and varying degrees of educational and professional training and experiences which confer power and privilege in numerous ways. Please see Appendix A for positionality statements from all co-authors. The community engagement specialist and the qualitative lead will conduct all focus groups and interviews with support from community partners and qualitative research team members.

Data Collection

Focus groups and interviews

Informed consent and demographic information (see Appendices B and C) will be obtained from study participants prior to their participation in focus groups and interviews. Participants will be given the opportunity to ask questions and obtain assistance in completing consent forms and demographic questionnaires. In addition to the hospital environment, focus groups and interviews will also be held in community locations. If necessary, virtual (MS Teams) or telephone options will be offered. For in-person focus groups, food incorporating the culture of the participant group will be provided, when possible, to foster a comfortable atmosphere for participants and to support ACB-owned businesses. When necessary, childcare, language translation (for words or short phrases), and accommodation for specific meal observances will be provided. Necessary support and resource materials will be available to participants after focus groups or interviews sessions. Due to the sensitive nature of the research, it is a priority of the research team to create both a psychologically and culturally safe environment for participants. We will also aim to respect community norms around meetings; as such, focus groups will be conducted in conjunction with existing meetings. Study participants will be provided with $30 honoraria as a token of our appreciation.

Focus group/interview discussion guide

Semi-structured focus group/interview guides (see Appendices D and E) were developed by the research team based on clinical experience, literature review, and discussion with community partners. Focus groups were originally focused on perspectives of kidney disease, treatment options for kidney failure, and experiences of kidney care. Revisions to the focus group guide resulted in the addition of an introductory discussion about ethno-racial identity, health, and the Canadian healthcare system. This is particularly important for the general community focus groups, since the majority of these participants will have no direct connection to kidney disease or transplant. The focus group moderators will then guide the discussion into topics related to kidney disease, kidney transplant and LDKT, and organ donation. Moderators will ask open-ended questions designed to explore the participants' views on the topics of interest and stimulate discussion and group interaction among participants.

As is common in qualitative research, not all questions will be asked the same way, in the same order during each focus group or individual interview, and participants will be encouraged to take the discussion in different directions if desired. Moderators and interviewers will be responsible for maintaining the flow and focus of the conversations, while enabling study participants, as experts in their own lives and experiences, to speak about topics they deem relevant and important.

Focus group moderator/interviewer training

To prepare for focus group moderation, the primary focus group moderator (the community engagement specialist) and additional co-moderators (representatives from community partner organizations and research students) have been provided with focus group training by the qualitative research lead (BE). The community engagement specialist and community partners have also provided the qualitative research team with information and resources on conducting culturally responsive research with ACB communities. For example, although it is common for a focus group moderator to interrupt a study participant who is dominating the conversation in order to give all participants the opportunity to speak, might not occur in all cases, since interrupting a participant, particularly a community elder, may be viewed as rude and could erode trust between the research team and the focus group participants.

Focus group co-moderators will be responsible for note-taking, asking follow-up questions, and assisting with language translation if necessary. Regular debriefing regarding data collection will occur between the qualitative team and the community engagement specialist throughout the duration of the study. All focus groups and interviews will be audio recorded, transcribed verbatim, verified, and de-identified for data analysis. Hard copy data will be stored in locked filing cabinets at the University Health Network (UHN) and electronic data will be stored on secure UHN servers. Data management and analysis will be facilitated by the use of NVivo 12 software (QSR

International) designed to assist with the storage, organization, and analysis of qualitative data.

Data Analysis

Data will be analyzed using reflexive thematic analysis (RTA) [46] [47] which will result in the development of themes that are reflective of the data as a whole. The goal of this approach is to move from a detailed, descriptive level of analysis to a broader, more thematic level. Data analysis will begin in conjunction with data collection and will be informed by the tenets of CRT. Data collection will cease when the research team determines that the study sample holds enough information power, meaning the volume and quality of the data are sufficient to address the research objectives. [48, 49] The reflexive aspect of RTA is particularly relevant due to the diversity of our team and effects of our varying social positions on data interpretation. [50] We wholeheartedly view this as a strength, rather than something to be mitigated, and will actively engage in reflexivity exercises throughout the analysis to account for how our individual subjectivities influence study findings. [50]

We will also be fortunate to have continuous input from our community engagement specialist and community partners throughout the duration of the study, which will include both formal team presentations as well as informal discussions during analytical sessions and other meetings. The research team has participated in anti-racism and anti-oppressive training. Finally, we will regularly engage in discussions regarding power relations, as they arise in research partnerships between community organizations and academic institutions such as universities and hospitals.

RTA is also deemed a suitable choice of analytic method due to its strong grounding in qualitative philosophies, as well as its alignment with applied qualitative health research. The process of RTA consists of six phases: (1) familiarization, (2) generation of initial deductive and inductive codes, (3) construction of themes, (4) review of potential themes, (5) naming and defining themes, and (6) production of the final report. [46] [47] In order to identify patient and institutional level barriers, including the impact of various forms of racism on those considering kidney transplant and LDKT, we will generate a coding framework which includes both deductive and inductive codes, in that some of our codes will be pre-determined based on the literature and our theoretical framework; and others will be generated directly from the data. This coding framework will be revised as our analysis progresses and final codes will be applied to all of the data.

Emerging ideas will be discussed in diverse, expanding circles, i.e. research seminars, community town halls. We will actively seek feedback as our analysis progresses to ensure the rigour and trustworthiness of the study and its findings.

Patient and public involvement

Both patient and community partners have been involved in the study design and will be involved in how the study is conducted as described above. We will adhere to the principles of community-based research principles to facilitate a collaborative and equitable partnership that fosters co-learning and capacity-building among all partners -- with the goal of generating knowledge that will benefit everyone involved. Patient and community partners will be asked to review and disseminate study findings. Importantly, we will seek advice from patient and community partners on how and where to disseminate study findings beyond the traditional academic routes such as conferences and publications.

Ethics

Ethical approval for this study was obtained from the University Health Network Research Ethics Board (UHN REB #15-9775) and from the ethics boards of participating hospitals (#2016-011-M; #16-249; #NEP-18-016). All study procedures will be conducted in accordance with the standards of the UHN REB and the 1964 Helsinki declaration and its later amendments. No study procedure will begin until the study participant has provided informed consent and participants can leave the study at any time and for any reason without any consequences. Data will be stored in a de-identified manner to minimize any breaches in patient confidentiality.

Impact and Dissemination

This study seeks to identify barriers to accessing LDKT in ACB communities in the GTA, Ontario. The objectives of the study are to explore participants' perspectives on and experiences with the healthcare system, CKD and kidney failure, and kidney replacement therapies, particularly LDKT. We want to gain a deeper understanding of the perspectives and experiences of ACB community members, including those with and without lived experience of CKD and kidney care. Ultimately, we wish to generate knowledge and collaborate with ACB community partners to co-develop culturally safe and responsive educational materials and clinical pathways to help raise awareness about CKD and kidney replacement therapies (especially LDKT), and to improve equitable access to the best kidney care for ACB individuals with kidney failure. The final dissemination plan will be determined by study co-investigators and patient and community partners, and will likely include various formats and locations, such as patient and community forums, national and international meetings, peer-reviewed journals, and conference presentations. Study participants will receive reports generated by the study if they wish and where possible.

Study status

The study is ongoing. Participants of the “Barriers” study (UHN REB #15-9775) participated in in-person focus groups in 2018 and 2019. From 2020 onwards, adult members of the ACB community, ACB individuals with lived experience of CKD, and nephrology professionals are being recruited for in-person and virtual focus group and individual interviews. Additional potential participants are being identified on an ongoing basis by clinical teams at participating hospitals. Recruitment through both hospital-based methods as well as community partnerships will continue for additional focus group and interview participants. Data collection and analysis are ongoing and community partner check-ins are planned for 2023. Additional interviews and focus groups will be completed by December 31, 2023 which is set as a target end date for study recruitment.

Acknowledgments

Funding

Health Canada Health Policy Contribution Program (1920-HQ-000109)

2020 Canadian Society of Transplantation-Astellas T3 Competition

Mount Sinai Hospital-University Health Network Academic Medical Organization Innovation Funding

Author contributions

JG, LJM, IM, and PN participated in conceiving this study. The study will be led by BE, LJM, IM, PN. Study recruitment, data collection, and data analysis will be undertaken by LA, GA, RA, SB, BE, LJM, IM, PN, PO, and ER. All authors (LA, GA, RA, SB, PB, BE, JG, CEJ, LJM, IM, PN, PO, and ER) will participate in regular team meetings to support this research project.

All authors provided input into the protocol, critical feedback on the manuscript, and approved the final manuscript.

We would like to thank all of the community partners who have shaped the design of this study.

Competing interests statement

Conflict of Interest: The authors have indicated they have no potential conflicts of interest to disclose.

Financial Disclosure: The authors have indicated they have no financial relationships relevant to this article to disclose.

References

1. de Groot, I.B., et al., *Difference in quality of life, fatigue and societal participation between living and deceased donor kidney transplant recipients.* Clin Transplant, 2013. **27**(4): p. E415-23.
2. *Alberta annual kidney care report: prevalence of severe kidney disease and use of dialysis and transplantation across Alberta from 2004–2013. .* Alberta Annual Kidney Care Report Kidney - Strategic Clinical Network, 2015.
3. Pinson, C.W., et al., *Health-related quality of life after different types of solid organ transplantation.* Ann Surg, 2000. **232**(4): p. 597-607.
4. Ortiz, F., et al., *Health-related quality of life after kidney transplantation: who benefits the most?* Transpl Int, 2014. **27**(11): p. 1143-51.
5. Neipp, M., et al., *Quality of life in adult transplant recipients more than 15 years after kidney transplantation.* Transplantation, 2006. **81**(12): p. 1640-4.
6. Evans, R.W., et al., *The quality of life of patients with end-stage renal disease.* N Engl J Med, 1985. **312**(9): p. 553-9.
7. Molnar, M.Z., M. Novak, and I. Mucsi, *Sleep disorders and quality of life in renal transplant recipients.* Int Urol Nephrol, 2009. **41**(2): p. 373-82.
8. Arriola, K.R.J., et al., *Living donor transplant education for African American patients with end-stage renal disease.* Progress in Transplantation, 2014. **24**(4): p. 362-370.
9. Information., C.I.f.H., *Annual Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2009 to 2018.* 2019: Ottawa.
10. Mucsi, I., et al., *Ethnic Background Is a Potential Barrier to Living Donor Kidney Transplantation in Canada: A Single-Center Retrospective Cohort Study.* Transplantation, 2017. **101**(4): p. e142-e151.
11. Yeates, K.E., et al., *Access to renal transplantation for minority patients with ESRD in Canada.* Am J Kidney Dis, 2004. **44**(6): p. 1083-9.
12. Bansal, A., et al. *Ethnocultural barriers to pre-emptive kidney transplantation: a single centre retrospective cohort study*. in *AMERICAN JOURNAL OF TRANSPLANTATION*. 2017. WILEY 111 RIVER ST, HOBOKEN 07030-5774, NJ USA.
13. Yeates, K., et al., *Similar outcomes among black and white renal allograft recipients.* J Am Soc Nephrol, 2009. **20**(1): p. 172-9.
14. El-Dassouki, N., et al., *Barriers to Accessing Kidney Transplantation Among Populations Marginalized by Race and Ethnicity in Canada: A Scoping Review Part 2-East Asian, South Asian, and African, Caribbean, and Black Canadians.* Can J Kidney Health Dis, 2021. **8**: p. 20543581211996834.
15. *Diversity of the Black population in Canada: An overview*. 2019; Available from: https://www150.statcan.gc.ca/n1/pub/89-657-x/89-657-x2019002-eng.htm.
16. Fante-Coleman, T., et al., *'Getting shut down and shut out': Exploring ACB patient perceptions on healthcare access at the physician-patient level in Canada.* Int J Qual Stud Health Well-being, 2022. **17**(1): p. 2075531.

17. *Social determinants and inequities in health for Black Canadians: A Snapshot*. 2020; Available from: https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health/social-determinants-inequities-black-canadians-snapshot.html.
18. *Read the landmark Toronto police report on race and officer use of force*. 2022; Available from: https://www.thestar.com/news/gta/2022/06/15/read-the-landmark-toronto-police-report-on-race-and-officer-use-of-force.html.
19. *COVID 19: Ethno-Racial Identity & Income*. Available from: https://www.toronto.ca/home/covid-19/covid-19-pandemic-data/covid-19-ethno-racial-group-income-infection-data/.
20. Yancy, C.W., *COVID-19 and African Americans.* JAMA, 2020. **323**(19): p. 1891-1892.
21. Dyer, O., *Covid-19: Black people and other minorities are hardest hit in US.* Bmj, 2020. **369**: p. m1483.
22. de Lusignan, S., et al., *Risk factors for SARS-CoV-2 among patients in the Oxford Royal College of General Practitioners Research and Surveillance Centre primary care network: a cross-sectional study.* The Lancet Infectious Diseases, 2020. **20**(9): p. 1034-1042.
23. Poteat, T., et al., *Understanding COVID-19 risks and vulnerabilities among black communities in America: the lethal force of syndemics.* Ann Epidemiol, 2020. **47**: p. 1-3.
24. Gagné, T. and G. Veenstra, *Inequalities in Hypertension and Diabetes in Canada: Intersections between Racial Identity, Gender, and Income.* Ethn Dis, 2017. **27**(4): p. 371-378.
25. Chae, D.H., et al., *Racial discrimination, mood disorders, and cardiovascular disease among black americans.* Ann Epidemiol, 2012. **22**(2): p. 104-11.
26. Navaneethan, S. and S. Singh. *Barriers to access to renal trasnplantation among African Americans in the US-A systematic review*. in *AMERICAN JOURNAL OF KIDNEY DISEASES*. 2006. WB SAUNDERS CO-ELSEVIER INC 1600 JOHN F KENNEDY BOULEVARD, STE 1800 ….
27. Hall, G.L. and M. Heath, *Poor Medication Adherence in African Americans Is a Matter of Trust.* J Racial Ethn Health Disparities, 2021. **8**(4): p. 927-942.
28. Transplant, N.B.a., *Annual report on ethnicity differences 2021-2022*. 2022, National Health Service. p. 1-57.
29. Wong, K., et al., *Investigating Ethnic Disparity in Living-Donor Kidney Transplantation in the UK: Patient-Identified Reasons for Non-Donation among Family Members.* Journal of Clinical Medicine, 2020. **9**(11): p. 3751.
30. *Consultation to explore people's views on organ and tissue donation: discussions with indigenous peoples.* . Canadian Council for Donation and Transplantation, 2005.
31. ; Available from: https://blackhealthalliance.ca/.
32. Wallerstein, N.B. and B. Duran, *Using community-based participatory research to address health disparities.* Health Promot Pract, 2006. **7**(3): p. 312-23.
33. Barbara A. Israel, E.E., Amy J. Schulz, and Edith A. Parker, *Introduction to Methods in Community-Based Participatory Research for Health*. 2005: Jossey-Bass.

34. Ford, C.L. and C.O. Airhihenbuwa, *Commentary: Just What is Critical Race Theory and What's it Doing in a Progressive Field like Public Health?* Ethn Dis, 2018. **28**(Suppl 1): p. 223-230.

35. Douglas, D., et al., *Black Health Education Collaborative: the important role of Critical Race Theory in disrupting anti-Black racism in medical practice and education.* CMAJ, 2022. **194**(41): p. E1422-E1424.

36. Molina, K.M. and D. James, *Discrimination, internalized racism, and depression: A comparative study of African American and Afro-Caribbean adults in the US.* Group Process Intergroup Relat, 2016. **19**(4): p. 439-461.

37. Donovan, R.A., et al., *Impact of racial macro-and microaggressions in Black women's lives: A preliminary analysis.* Journal of Black Psychology, 2013. **39**: p. 185-196.

38. Choi, S., et al., *Is ethnic identity a buffer? Exploring the relations between racial microaggressions and depressive symptoms among Asian-American individuals.* Journal of Ethnic & Cultural Diversity in Social Work: Innovation in Theory, Research & Practice, 2017. **26**: p. 18-29.

39. Nadal, K.L., et al., *Racial microaggressions and Asian Americans: An exploratory study on within-group differences and mental health.* Asian American Journal of Psychology, 2015. **6**: p. 136-144.

40. Ford, C.L. and C.O. Airhihenbuwa, *The public health critical race methodology: Praxis for antiracism research.* Social Science & Medicine, 2010. **71**(8): p. 1390-1398.

41. https://blackhealthalliance.ca/home/antiblack-racism/.

42. Dryden, O. and O. Nnorom, *Time to dismantle systemic anti-Black racism in medicine in Canada.* CMAJ, 2021. **193**(2): p. E55-E57.

43. Ashburn-Nardo, L., K. Thomas, and A.J. Robinson, *Broadening the conversation: why black lives matter.* Equality, Diversity and Inclusion: An International Journal, 2017. **36**(8): p. 698-706.

44. http://2020.rapportccdp.ca/chief-commissioners-message.html.

45. Trudeau, J. *Statement by the Prime Minister on Emancipation day*. 2022; Available from: https://www.pm.gc.ca/en/news/statements/2022/08/01/statement-prime-minister-emancipation-day.

46. Braun, V., et al., *Thematic Analysis*, in *Handbook of Research Methods in Health Social Sciences*. 2018. p. 1-18.

47. Campbell, K., et al., *Reflexive Thematic Analysis for Applied Qualitative Health Research.* The Qualitative Report, 2021.

48. Braun, V. and V. Clarke, *To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales.* Qualitative Research in Sport, Exercise and Health, 2021. **13**(2): p. 201-216.

49. Malterud, K., V.D. Siersma, and A.D. Guassora, *Sample Size in Qualitative Interview Studies: Guided by Information Power.* Qual Health Res, 2016. **26**(13): p. 1753-1760.

50. Olmos-Vega, F.M., et al., *A practical guide to reflexivity in qualitative research: AMEE Guide No. 149.* Med Teach, 2022: p. 1-11.

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.

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Psycho-Social and Ethno-Cultural Barriers to Living Donor Kidney Transplant: Focus Groups in the Community.

Investigator/Study Doctor: **Dr. Istvan Mucsi**

Contact Information:

Principle Investigator: Dr. Mucsi: (xxx) xxx-xxxx
Co-Investigators:
Dr. S. Joseph Kim
Dr. Jeffrey Zaltzman

Study Coordinator: Heather Ford: (xxx) xxx-xxxx

Introduction:

You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study's risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background/Purpose:

Ethnicity is of the factors that will affect whether patients seek a LDKT (Living Donor Kidney Transplant). South Asian, East Asian and African Canadians are half less likely than their Caucasian counterparts to receive a living donor kidney transplantation. You have already taken part in the first part of our study where you were asked to answer questionnaires. This consent form is for the second part of the study. You have been asked to participate in this part of the study because you have indicated that you would be interested in participating in a focus group. Factors related to ethnicity can be a barrier to LDKT and we are interested in exploring barriers that affect all ethnic groups.

Information gained from this study will help us to better address the needs of patients with kidney disease, especially those patients from a minority ethnic background. It will also help us to improve the education that will be better at answering all the questions and concerns and deal with the health-related needs of patients similar to yourself. We will also share the findings of this study with other kidney doctors and public health organizations so that they can also better serve their patients.

There will be a total of 20 focus groups, 90 to 120 minutes long, each including 6-8 participants for a total of 160 participants. You will be asked to take part in just one focus group.

Study Visits and Procedures:

For the second part of the study, you will be asked to participate in a **facilitated group discussion,** or focus group, to discuss social and cultural factors which influence access to healthcare and LDKT. We are also interested in learning about your knowledge and understanding of living donor transplants. A moderator (an individual who will lead the discussion), co-moderator (an individual who will assist the moderator and help to translate where necessary) and one researcher (who will take notes) will be present for each group. The moderator will make sure that everyone gets to express their views. For those participants with limited English, focus groups will be available in their native language (Cantonese, Mandarin, Urdu, Hindi, Punjabi, Tamil, Arabic, Bangla). Also, should you be uncomfortable with a focus group, we also offer one-on-one interviews. For some focus groups or interviews, members of community organizations, such as the Black Health Alliance and the Council of Agencies Serving South Asians will assist in co-moderating the focus group.

Note that since you will be asked to share your feelings and opinions openly in the presence of others, you will need to be mindful of each other's opinions and maintain confidentiality. Also you do not need to answer any questions that make you feel uncomfortable during the course of the focus group discussion.

Each focus group will be audio recorded. Only researchers will have access to the audiotapes. Once the tapes have been transcribed, the tapes will be destroyed.

For African, Caribbean, and Black community focus groups organized through the Black Health Alliance, de-identified focus group transcripts will be shared with the Black Health Alliance. This will allow us to analyze and interpret the data in collaboration with the community, so that the concerns of community members around access to LDKT can be addressed in a culturally competent way.

Risks:

There are no risks in taking part in this part of the study. Should you feel uncomfortable or distressed while in the group discussion, you will be able to address your concern immediately with the moderator. Additionally, the treating team in the nephrology department will be available for support on a one-on-one basis if required, and community supports will be identified to connect with for support if needed.

Benefits:

You may not get any direct benefits from being in this study. Information learned from this study may help us to better understand how cultural beliefs may prevent patients learning about and getting a living donor kidney transplant (LDKT). With this information, we can improve our transplant education program to include any psychological issues that may prevent people pursuing a living donor transplant. In particular with these focus groups, we also want to be able to understand and reduce the barriers that exist within some cultural groups in getting a transplant.

Alternatives to Being in the Study:

You simply may decide not to be involved in this study. Your study doctor will talk with you about these options available to you, if you wish.

Confidentiality:

Personal Health Information

If you agree to join this study, the study doctor and his/her study team will look at your personal health information and collect only the information they need for the study. Personal health information is any information that could be used to identify you and includes your:

- name,
- date of birth (month and year),
- telephone number (so that we can contact you)
- Other demographic information

The information that is collected for the study will be kept in a locked and secure area by the study doctor for 10 years. Only the study team or the people or groups listed below will be allowed to look at your records.

Representatives of the University Health Network Research Ethics Board may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines:

Study Information that Does Not Identify You

Data from this study will be entered into a computerized database through a secured website. Only study staff with a password will be allowed to enter data. All study data are identified by code, not by your name. A list linking your study number with your name will be kept by the study doctor in a secure place, separate from your study file. Efforts will be made to keep your personal information private. However, we cannot guarantee complete confidentiality. You will be identified by a code, and personal information from your records will not be released without your written permission. All information will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be identified in any publications or presentations that may come from this study.

Transcribed audiotapes will be kept with the researchers (in a secure a locked cabinet) for the duration of the study. Once the transcriptions have been analyzed and verified, the audiotapes will then be destroyed.

Voluntary Participation:

Your participation in this study is voluntary. You may withdraw from the study at any time. If you decide to withdraw, your care will not be affected in any way. We will give you any new information that is learned during the study that might affect your decision to stay in the study. If you decide to withdraw from the study, the information about you that was collected before you leave the study will still be used in order to answer the research question. No new information will be collected unless this is required to fulfill safety reporting obligations.

Costs and Reimbursement:

You will be given a one-time $30 in honorarium to compensate for travel-related expenses to the focus group session.

Rights as a Participant:

By signing this form you do not give up any of your legal rights against the investigators or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

Conflict of Interest:

Researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study. You should not feel pressured to join this study.

Questions about the Study:

If you have any questions, concerns or would like to speak to the study team for any reason, please call:

Dr. Istvan Mucsi at (xxx) xxx-xxxx, or
Heather Ford at (xxx) xxx-xxxx.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board

(UHN REB) or the Research Ethics office number at (xxx) xxx-xxxx. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given a signed copy of this consent form.

Consent:

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

Print Study Participant's Name	Signature	Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

Print Name of Person Obtaining Consent	Signature	Date

Was the participant assisted during the consent process? ☐ **YES** ☐ **NO**
If **YES**, please check the relevant box and complete the signature space below:

☐ The person signing below acted as an interpreter for the participant during the consent process and attests that the study as set out in this form was accurately interpreted and has had any questions answered.

Print Name of Interpreter	Signature	Date
Relationship to Participant	Language	

Date Entered: _____________ Study ID: __________

Demographics Questionnaire for Focus Groups

Study Title: Psychosocial and ethnocultural barriers to living donor kidney transplantation

Investigator/Study Doctor: Dr. Istvan Mucsi

Contact Information:

Principal Investigator:	Dr. Istvan Mucsi	(xxx) xxx-xxxx
Study Coordinator:	Heather Ford	(xxx) xxx-xxxx
	Lydia-Joi Marshall	(xxx) xxx-xxxx

What is your sex:
☐ Male ☐ Female ☐ Other ☐ Prefer not to answer

What is your birthdate: Month_______ Year_______ ☐ Prefer not to answer

What are the first three digits of your postal code? ___ ___ ___ ☐ Prefer not to answer

In what country were you born?
- ☐ Canada
- ☐ Other (please specify): _________________
- ☐ Prefer not to answer

Are you on dialysis?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Is someone you know on dialysis?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Are you undergoing evaluation for kidney transplant, or have you received a kidney transplant?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Has someone you know undergone evaluation for kidney transplant or received a kidney transplant ?
☐ Yes ☐ No ☐ Don't know ☐ Prefer not to answer

Are you now or have you ever been a landed immigrant, refugee or been on a work/minister permit in Canada?
☐ Yes ☐No ☐ Don't know ☐ Prefer not to answer

If yes, in what year did you first arrive in Canada to live? ____________
☐ Don't know ☐ Prefer not to answer

What is the highest degree or level of school you have completed? If currently enrolled, please list the

highest degree received to date:

- ☐ No schooling completed
- ☐ Nursery school to 8th grade
- ☐ Some high school, no diploma
- ☐ High school graduate, diploma or the equivalent (e.g. GED)
- ☐ Some college credit, no degree
- ☐ Trade/technical/vocational training
- ☐ Diploma or certificate from community college (e.g. RN, RPN)
- ☐ Bachelor's degree (BA, BSc, LL.B, B.Ed)
- ☐ Master's degree (MA, MSc, Med)
- ☐ Professional degree (MD, DDS, DVD)
- ☐ Doctorate (PhD, DSc, DHSc)
- ☐ Other (please specify): ___________
- ☐ Don't know
- ☐ Prefer not to answer

Which of the following best describes where your income comes from? (Select all that apply)

- ☐ Full-time employment
- ☐ Part-time employment
- ☐ Self-employed
- ☐ Unemployed and looking for work
- ☐ Unemployed and not looking for work
- ☐ Unemployed, unspecified as to whether seeking work or not
- ☐ A homemaker
- ☐ Retired
- ☐ Student
- ☐ Unable to work
- ☐ Unknown
- ☐ Welfare
- ☐ Disability
- ☐ Other (e.g., homeless)
- ☐ Prefer not to answer

Do you identify as a first, second, or third generation Canadian?

- ☐ First generation (I was born outside of Canada)
- ☐ Second generation (I was born in Canada, and at least one of my parents was born outside of Canada)
- ☐ Third generation or more (I was born in Canada, and both of my parents were born in Canada)
- ☐ Not applicable
- ☐ Don't known
- ☐ Prefer not to answer

What language or dialect do you speak <u>most often</u> at home? <u>Choose only one.</u>

- ☐ Amharic
- ☐ Arabic
- ☐ ASL
- ☐ Bengali
- ☐ Chinese (Cantonese)
- ☐ Chinese (Mandarin)
- ☐ Czech
- ☐ Dari
- ☐ English
- ☐ Farsi
- ☐ French
- ☐ Greek
- ☐ Hindi
- ☐ Hungarian
- ☐ Italian
- ☐ Karen
- ☐ Korean
- ☐ Nepali
- ☐ Polish
- ☐ Portugese
- ☐ Punjabi
- ☐ Russian
- ☐ Serbian
- ☐ Slovak
- ☐ Somali
- ☐ Spanish
- ☐ Tagalog
- ☐ Tamil
- ☐ Tigrinya
- ☐ Turkish
- ☐ Twi
- ☐ Ukrainian
- ☐ Urdu
- ☐ Vietnamese
- ☐ Prefer not to answer
- ☐ Don't know
- ☐ Other: (please specify) ____________

Which of the following categories best describes your ethnicity?

Date Entered: _____________ Study ID: __________

North American Indigenous
- ☐ First Nations
- ☐ Inuit
- ☐ Metis
- ☐ Other (please specify): _________

Black or African
- ☐ North American Black/African (e.g. Canadian, American)
- ☐ Central or West African (e.g. Ghanaian, Nigerian, Senegalese)
- ☐ North African (e.g. Algerian, Moroccan, Sudanese)
- ☐ Southern or East African (e.g. Somali, Ugandan, Ethiopian)
- ☐ Other (please specify): _________

Asian
- ☐ West Central Asian or Middle Eastern (e.g. Afghan, Jordanian, Yemeni)
- ☐ South Asian (e.g. Bangladeshi, Pakistani, Punjabi)
- ☐ East or Southeast Asian (e.g. Chinese, Korean, Filipino, Indonesian)
- ☐ Other (please specify): _________

White or European
- ☐ White - North American (e.g. Canadian, American)
- ☐ Northern European (e.g. British, Danish, Swedish)
- ☐ Southern European (e.g. Greek, Italian, Portuguese)
- ☐ Eastern European (e.g. Hungarian, Ukrainian, Russian)
- ☐ Western European (e.g. Dutch, French, German)
- ☐ Other (please specify): _________

Other
- ☐ Latin, Central, or South American (e.g. Brazilian, Chilean, Mexican)
- ☐ Caribbean (e.g. Haitian, Jamaican, Carib)
- ☐ Oceanian (e.g. Australian, New Zealander, Pacific Islander)
- ☐ Other (please specify): _________

What is your religious or spiritual affiliation?

- ☐ I do not have a religious or spiritual affiliation
- ☐ Islam
- ☐ Hinduism
- ☐ Christianity
- ☐ Judaism
- ☐ Sikhism
- ☐ Buddhism
- ☐ Confucianism
- ☐ Native Spirituality
- ☐ Taoism
- ☐ Jainism
- ☐ Spiritual
- ☐ Atheism
- ☐ Prefer not to answer
- ☐ Do not know
- ☐ Other(s) – Please Specify: __________

Qualitative Arm- Focus Group/Interview Guide

Introduction:

Welcome everyone! I want to take this opportunity to thank you all for participating in our focus group today. My name is (_____________) and I am the facilitator and beside me, we have our co-facilitator (_________________) who will also be helping me today in our group discussion.

The goal of our focus group today is to understand what you think about kidney disease, kidney failure, kidney transplant, and organ donation. We would also like to know about any barriers or challenges you may have experienced when trying to access information or care related to your kidney health, or your health in general, and any suggestions you may have to overcome these barriers and challenges. We are interested in all of your experiences, opinions, beliefs, thoughts, and feelings about these issues and there are no right or wrong answers. So, please feel free to speak openly and honestly. It is my job to guide our discussion today. I will make sure everyone who wants to speak has a chance to do so. I will also make sure that we stay on track in terms of our topic and our timing. But, hopefully, you will do most of the talking and (_________) and I will mostly listen.

Our focus group will run for approximately 1½ - 2 hours. If you do need to step out during the group discussion, please feel free to do so.

Ground Rules:

I would like to set some ground rules to ensure that everyone in the group feels comfortable and safe during our discussion. Is that ok with everyone?

[If yes, have everyone proceed to create ground rules]

Sample Group Rules:

- One person speaks at a time (i.e., Taking turns before speaking)
- Respecting each other's opinions (i.e., members will show respect in a non-judgmental way)
- Privacy/confidentiality (i.e., what is said in the group, stays in the group. Each member will respect each other's personal information and will not reveal that information outside of the group)

[Clarify ground rules or uncertainty with participants when needed]

- As you already know, we will be recording today's discussion. Our conversation will be audio recorded and then transcribed, so that we do not lose any of the information that is discussed and it will be easier for the research team to analyze.

Please be assured that your personal information will be kept private within our research team. Is everyone comfortable with this?

[If yes, proceed forward and if no, answer additional questions participants might have]

Turn on Audio Recorder.

Participant Introduction:

1.) Let's start by going around the room to introduce ourselves. Will each person please tell us:

   a. Your preferred name
   b. Tell us briefly your connection, if any, to kidney disease, organ donation, and kidney transplant, and/or, why you chose to participate in today's discussion

Focus Group Questions

Ethnocultural Identity

1. Which ethnocultural group(s) do you identify with and what does this mean to you?
   a. What does this look like in your everyday life? (e.g. language, food, traditions, approaches to health and healing)

2. In what ways do you think your ethnocultural identity as [participant answer] influences your experience with the health/kidney care system?
   a. Do you feel that you experience the healthcare system differently than others? If so, why do you think that is?
   b. How have these experiences shaped how you interact with the health care system?

3. What types of healing & treatment practices are important to you?
   a. Do you use any healing practices that are different than the treatments typically provided by the Canadian healthcare system?
   b. Are there any factors that you consider that make you lean on one approach over the other?
      i. Probe around access, finances, quality of experience, results.

4. Are you aware of any thoughts, feelings, or concerns in your community around kidney disease, kidney transplant, and organ donation?

Next questions will need to be modified for community members vs. patients on dialysis, recipients, donors, family members/caregivers. For example, for participants with lived experience of CKD, participants can answer questions based on their actual vs. a hypothetical experience.

General Knowledge & Awareness

1. What do you know about the kidneys and their function?
    a. How would a person know if their kidneys were not working properly?
    b. What do you think causes kidney disease?
    c. What is kidney failure?
    d. How serious are kidney disease and kidney failure?

2. If someone has kidney failure what are their treatment options?
    a. Do you think that one option is better than another? Why or why not?

3. What do you know about kidney transplant as a treatment option?
    a. If someone needed a kidney transplant, where could they get a kidney?
    b. What is the difference between a deceased and living donor transplant?
    c. What do you see as the advantages or disadvantages to the different types of kidney transplant?
        i. Probe around risks and benefits of each.

4. What do you know about organ donation?
    a. Probe around living vs. deceased organ donation.

5. How did you come to learn this information? Do you feel that you know enough about these topics?
    a. *If patient or caregiver:* What did you know about these topics before diagnosis? What do you wish you had known about these topics prior to diagnosis?

Family and Support

1. If you had kidney failure and were considering your treatment options, who would you talk to? Who would you rely on for support (emotional, practical)?
    a. What about if you had a different health problem? What about another type of problem, such as financial?

2. If you had kidney failure and required a transplant, would you accept a kidney? Why or why not?
    a. Would you accept a kidney from a living donor? If yes, who would you accept a kidney from?

    b. Would you accept a kidney from a deceased donor? Why or why not?

3. If you or someone in your family/community had kidney disease or kidney failure, what effects could this have on your/their relationships in the family/community?
    a. What about if they needed a transplant?

5. If you or someone in your family/community wanted to be a living kidney donor, what effects could this have on your/their relationships in the family/community?

6. How can relationships with family/friends change in the context of organ donation/kidney transplant?

7. Do you or would you feel comfortable discussing kidney disease, kidney transplant, and organ donation with family and friends?
    a. Would you have fears, concerns about what they think?
    b. Are there any circumstances which would make you feel uncomfortable having a discussion about kidney disease with your family and friends?
    c. What would help make discussing these topics easier?

Information Needs

1. Where do you go to find health information or to learn more about your health-related concerns?
    a. Have you encountered any difficulties when seeking information or resources related to your health?
    b. What about your friends or family?

2. *If patient or caregiver:* Have you (or your family and friends) encountered any difficulties when seeking information or resources related to kidney disease, kidney transplant, and organ donation?
    a. What information or support did you receive related to your treatment options?
    b. What types of resources were helpful to you? What resources were not helpful? What else would you need?
    c. Do you think you know enough about these topics? Is there any more or different information that you desire? If so, what kind of information are you looking for?
    d. Are there particular resources or supports regarding kidney disease and its treatment that you would recommend to others?

Religion and Cultural Values

1. How do you think your culture influences how you or your family, friends, community members think about kidney disease and transplant?

2. What about religion and spirituality? How does that shape how you or your family, friends, community members think about these topics?
    a. Is it acceptable to donate your organs while alive? After death?
    b. Is it ok to accept an organ from another?

3. Do you or would you feel comfortable discussing kidney disease, kidney transplant, and organ donation with community members or religious leaders?
    a. Would you have fears, concerns about what they think?
    b. Are there any circumstances which would make you feel uncomfortable having a discussion about kidney disease with these individuals?
    c. What would help make discussing these topics easier?

4. If you had kidney failure, what factors do you think might impact your decision regarding your treatment options?
    a. Would you consider both dialysis and transplant? Living donor kidney transplant? Why or why not?

5. What are some of your values and beliefs (if any) that would impact your decision to have a living donor kidney transplant? To donate a kidney either before or after your death?

Immigration & Society

1. How do you think immigrating to Canada impacts the way people receive support related to kidney disease or transplant?

2. What issues do you think immigrants to Canada face if they have major health concerns?
    a. Probe: What about those wishing to pursue LDKT or be living donors?

3. Have you or your family members faced any barriers to accessing health/kidney care in Canada?

4. Are there similarities and differences in the way kidney transplant awareness is delivered here and in other places where you have lived?

Trust

1. Would you say that you trust the Canadian health care system? Do you trust your doctor/healthcare team? Why or why not?
    a. Probe around experiences, attitudes, outcomes, follow through, access to alternatives.

2. Can you remember a situation where you or someone you know did not fully trust the healthcare team looking after them?

3. Have you had any negative experiences in healthcare in Canada where you felt you were being discriminated against (because of your age, sex, gender, race, ethnicity, religion, language skill etc.)?

4. When speaking with your health care provider/team, do you feel respected? Why or why not?

5. How does your health care provider/team integrate your values (e.g. religious/cultural) and beliefs when discussing matters related to major health issues, such as kidney transplant?

6. If you needed treatment for a serious health condition, such as kidney failure, would you want to have it done in Canada or elsewhere (e.g. your country of origin, another country)?

7. Would you feel more comfortable receiving treatment if your health care provider was from the same ethnocultural background as you? Why or why not?

Closing Questions

1. How can we create a better system of care for people with kidney disease from ACB communities?

2. How can we better support ACB community members wishing to be living donors?

3. Is there anything that we have missed today that you think is important for us to know? Do you have anything else at all to add to the discussion?

Conclusion:

On behalf of the research team we would like to take this opportunity to thank you all for participating in our focus group today. You have shared some very interesting and important information. We hope that today's discussion has been enjoyable for you and if you think of anything else that you would like us to know, please do not hesitate to contact us anytime. Thank you!

Individual Interview Script for Healthcare Professionals

As you already know, we will be recording today's interview. Our conversation will be audio recorded and then transcribed, so that we do not lose any of the information that is discussed and it will be easier for the research team to analyze. Please be assured that your personal information will be kept private within our research team. Are you comfortable with this?

[If yes, proceed forward and if no, address any concerns or questions that participants might have.]

Turn on Audio Recorder.

Ethnocultural Identity

1. Which ethnocultural group(s) do you identify with and what does this mean to you?
    a. What does this look like in your everyday life? (e.g. language, food, traditions, approaches to health and healing)

2. In what ways do you think your ethnocultural identity as [participant answer] influences your experience with the kidney care system or the healthcare system in general?
    a. What is your role in the kidney care system?
    b. Do you feel that you experience the healthcare system differently than others? If so, why do you think that is?
    c. How have these experiences shaped how you interact with the system?

3. What types of healing & treatment practices are important to you? How about for your patients?
    a. Do you or your patients use any healing practices that are different than the treatments typically provided by the Canadian healthcare system? If so, can you tell me a little bit more about that?

General Knowledge & Awareness

1. What do you think most of your patients know and understand about the kidneys, kidney disease, and kidney failure before and/or after they are diagnosed?

2. What do you think most of your patients know and understand about their treatment options before and/or after they are diagnosed?
    a. Probe regarding the perceived advantages and disadvantages, risks and benefits of dialysis, DDKT and LDKT
    b. What factors do you think impact your patients' decisions regarding their treatment options?

3. How do most of your patients access this information? Do you think that they are satisfied with the information they have on these topics?

4. Sometimes patients and families tell us that people from ACB communities are less likely to explore or pursue transplant or donate their organs while alive or after their death. What do you think about this? Have you observed any differences in your ACB and non-ACB patients?

5. Are you aware of any thoughts, feelings, or beliefs around organ donation or transplantation in ACB communities?

6. In your opinion what might be the main barriers to organ donation and transplantation in ACB communities?

Family and Support

1. Who do your ACB patients talk to when they are considering their treatment options?

2. Who do they rely on for support (e.g. emotional, practical)?

3. If one of your ACB patients required a kidney transplant, would they discuss this with their family, friends, community?
    a. Would they ask and/or accept a kidney from a living donor? If so, who might they accept a kidney from?
    b. Would they accept a kidney from a deceased donor?
    c. What factors do you think would play into these decisions?

4. How can relationships with family/friends change in the context of kidney disease, organ donation, kidney transplant?

5. Do you think your ACB patients have open conversations about their health, especially as it relates to their kidney disease, with their family, friends, and communities?
    a. If not, what might help make these conversations easier for your patients?

Information Needs

1. Where do your ACB patients go to find out information about their health, especially related to kidney disease and treatment options?
    a. Probe around who, where, and in what form the information comes from.
    b. Probe around any difficulties patients experience in accessing information.

2. What has been your experience providing information and resources to your ACB patients?

3. Do you think your approach is the same or different from your colleagues?

4. Are there particular resources or supports regarding kidney disease and its treatment that you would recommend?

5. Do you observe any differences between your ACB and non-ACB patients in this regard?

6. What do you think about the idea of tailoring information and support to ACB communities?
    a. Probe around what this would look like in their view.

Religion and Cultural Values

1. How do you think culture and religion influence your ACB patients' beliefs and behaviours regarding kidney disease and its treatment?

2. How do you, as a healthcare provider, integrate your patients' values (e.g. religious/cultural) and beliefs when discussing matters related to major health issues, such as kidney transplant?
    a. Do you face any challenges in this area and, if so, how do you handle them?

Immigration and Society

1. How do you think immigrating to Canada impacts the way people receive information or support related to kidney disease or transplant?

2. What issues do you think immigrants to Canada face if they have major health concerns?
    a. Probe: What about those wishing to pursue LDKT or be living donors?

3. Have any of your ACB patients that have immigrated faced any barriers to accessing health/kidney care in Canada?
    a. How do the barriers that your ACB patients have faced differ from your patents that have immigrated from other countries?

4. Are there similarities and differences in the way kidney transplant awareness is delivered here and in other places that you know of?

Trust

1. Would you say that your ACB patients trust the Canadian health care system? Why or why not?

2. Can you remember a situation where one of your ACB patients did not fully trust a member of their healthcare team?

3. Do you think your ACB patients would more comfortable receiving treatment if their healthcare provider was from the same ethnocultural group as them? Why or why not?

4. Have you yourself had any negative experiences in healthcare in Canada where you felt you were being discriminated against (because of your age, sex, gender, race, ethnicity, religion, language skill etc.)?

Closing Questions

1. How can we create a better system of care for people with kidney disease from ACB communities?

2. How can we better support healthcare providers from ACB communities working in the Canadian healthcare system?

3. Is there anything that we have missed today that you think is important for us to know?

Conclusion:

On behalf of the research team I would like to take this opportunity to thank you for participating in this interview. You have shared some very interesting and important information. I hope that today's conversation has been enjoyable for you and if you think of anything else that you would like us to know, please do not hesitate to contact us anytime. Thank you!