

Ethically Sound Community Based Research with Black and Racialized Communities

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Land Acknowledgement

- The University of Calgary, located in the heart of Southern Alberta, both acknowledges and pays tribute to the traditional territories of the peoples of Treaty 7, which include the Blackfoot Confederacy (comprised of the Siksika, the Piikani, and the Kainai First Nations), the Tsuut'ina First Nation, and the Stoney Nakoda (including Chiniki, Bearspaw, and Goodstoney First Nations). The City of Calgary is also home to the Métis Nation of Alberta (Districts 5 and 6).
- I am mindful of broken covenants and strive to make this right, with the land and with each other.
- I reaffirm my commitment to supporting Indigenous sovereignty and Indigenous self determination and walking parallel path for the wellbeing of Indigenous people



Land Acknowledgement

- Many of us are located on the traditional lands, referred to as Treaty 6 Territory and the homeland of Metis Region #4. This land is home to many diverse groups of Indigenous peoples including the Cree, Dene, Blackfoot, Saulteaux, Nakota Sioux, Inuit, and Métis. I also acknowledge that the City of Edmonton and all the people here are beneficiaries of Treaty No. 6. which encompasses the traditional territories of numerous western Canadian First Nations as well as the Métis people who have called these lands home since time immemorial.



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Acknowledgement

Participants

Communities

Co-
Investigators

Research
Personnel

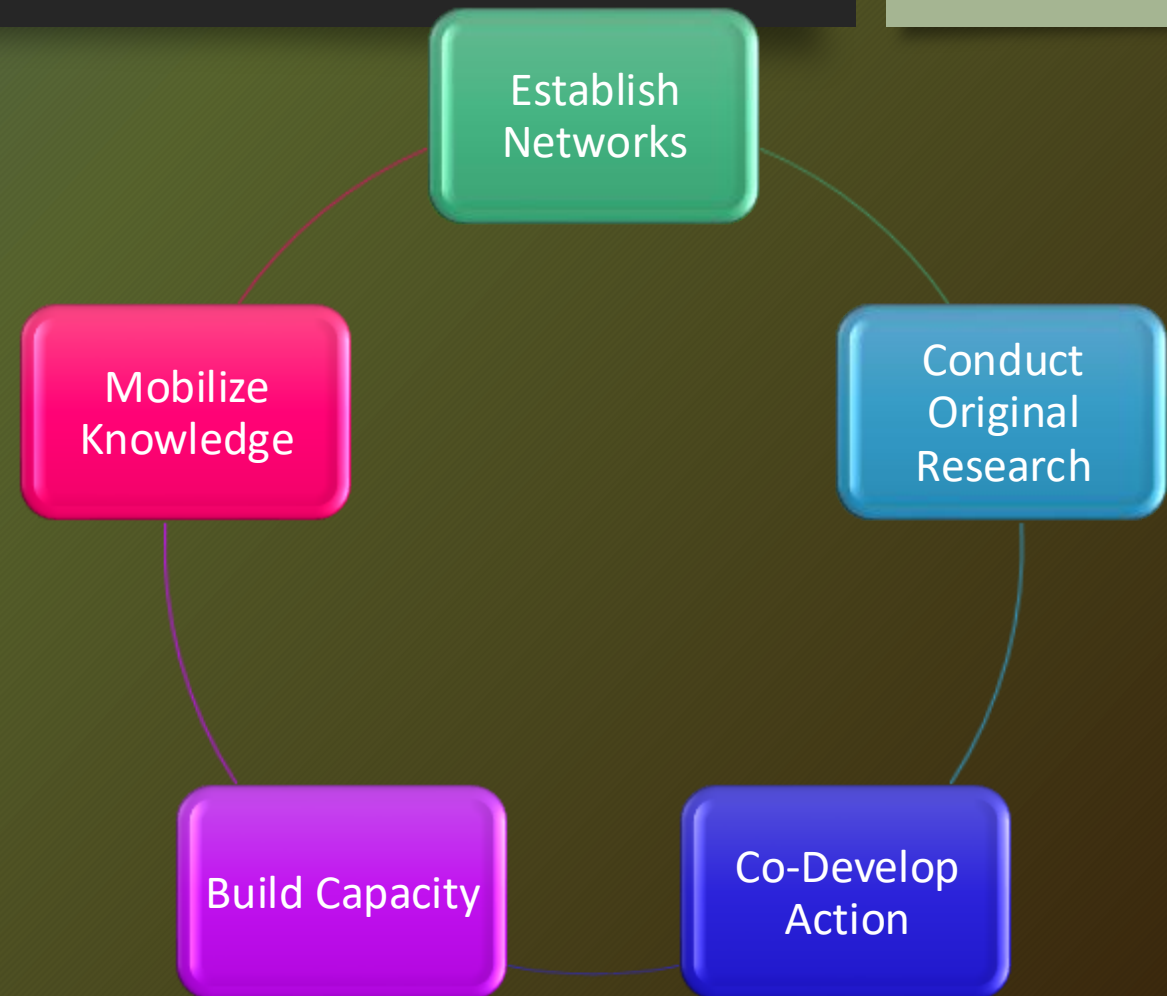
Objectives

- At the end of this presentation, participants will be able to:
 - Describe key features of community based participatory research
 - Identify issues and challenges that may arise in participatory research with Black, immigrant and racialized communities
 - Describe strategies to achieving success in community based participatory research as well as key equity considerations with immigrant, Black and racialized communities
 - Discuss strategies for navigating ethical tensions and dilemmas in community based participatory research including building trust, navigating consent processes, and co-creating research goals with communities historically marginalized in research



Black and Racial Equity (BARE) Research Program

- Canadians faces racialized health inequalities, which have a negative impact on the health of Black and racialized people.
- Racism plays a significant role in contributing to poor health outcomes, leading to a decrease in overall population health.



Community Based Participatory Research

- Community based participatory research is a power-equalizing, collaborative research approach that sees community members as partners in the research process and experts on the issues of concern in their lives (Kemmis, McTaggart, & Nixon, 2014; Minkler & Wallerstein, 2008).
- This methodology is based on principles of shared leadership, collaborative decision-making, and researcher-community trust building with the end aim of creating sustainable, action-oriented research outcomes.
- Local knowledge and perspectives are not only acknowledged but form the basis for research and planning (Cornwall and Jewkes, 1995).
- Practitioners take an explicitly political stance, focusing on empowering disenfranchised and marginalized groups to take action to transform their lives (Cornwall and Jewkes, 1995)



Community Based Participatory Research

(Braun, MacDougall and Smith, 2006)

- Reflects questioning about the nature of knowledge and the extent to which knowledge can represent the interests of the powerful and serve to reinforce their positions in society.
- It affirms that experience can be a basis of knowing and that experiential learning can lead to a legitimate form of knowledge that influences practice
- Attention to power relations
- Reflexive, flexible and iterative

Purpose of Community Based Participatory Research

(Young, 2006)

- To understand and improve the world by changing it
- Co-creation of knowledge that is useful for the community by co-researchers
- Development of a sense of community
- Educate each other by negotiating meaning
- Raise consciousness
- Mobilize to change, generate, or evaluate practices or policies

Epistemic Disobedience, Independent Thought and De-Colonial Freedom

- “Well, you get the idea of the interrelations between the politics of identity and epistemology. You could certainly be a Maori and an anthropologist and by being an anthropologist suppress the fact that you are Maori or Black Caribbean or Aymara (for example). Or you can choose the de-colonial option: engage in knowledge-making to ‘advance’ the Maori cause rather than to ‘advance’ the discipline (e.g. anthropology). Why would someone be interested in advancing the discipline if not for either alienation or self-interest? If you engage in the de-colonial option and put anthropology ‘at your service’ like Smith does, then you engage in shifting the geography of reason - in unveiling and enacting geopolitics and body-politics of knowledge.” (Mignolo, 2009, pp. 13-14).

Epistemic Violence

- *“Epistemic violence, that is, violence exerted against or through knowledge, is probably one of the key elements in any process of domination. It is not only through the construction of exploitative economic links or the control of the politico-military apparatuses that domination is accomplished, but also and, I would argue, most importantly through the construction of epistemic frameworks that legitimise and enshrine those practices of domination.”* Enrique Galván-Álvarez 2010

Unethical Research

- Tuskegee-Syphilis Study
- Henrietta Lacks Cells
- Sims



Canada's Racist Immigration Policy

- Canada's racist immigration policy: Section 38 of the Immigration Act of 1910 states:
 - “The Governor in Council may, by proclamation or order whenever he deems it necessary or expedient, prohibit for a stated period, or permanently, the landing in Canada, or the landing at any specified port of entry in Canada, of immigrants belonging to any race deemed unsuited to the climate or requirements of Canada, or of immigrants of any specified class, occupation or character.”
 - Order-in-Council P.C. 1324 was approved on 12 August 1911 by the Cabinet of Prime Minister Sir Wilfrid Laurier. “the Negro race...is deemed unsuitable to the climate and requirements of Canada.”

Distrust

- So, there is a lot of broken trust between the ACB [African Caribbean Black] communities and the mainstream medical health care because of the medical history between the ACB communities and the system, the health system We could talk about the Tuskegee experiments And similarly, to look at other Black experiences in the health care that we see. (P001, female, 36 yr)
- I know it sounds really hard and it sounds bizarre, but at the core of it I think is anti-Black racism. I think when you are a population that's the most hated population, when you're a population that faces the most disenfranchisement, when you're a population that has, next to the Indigenous, the highest number of people in child — in the number of Black kids in childcare, when you have the highest number of Black men incarcerated, I think it's all that. So Black people just don't trust. (P019, female, 44-54 yr [participant provided an age range])

What contributes to COVID-19 online disinformation among Black Canadians: a qualitative study

Janet Kemei PhD, Dominic A. Alaazi PhD, Adedoyin Olanlesi-Aliu PhD, Modupe Tunde-Byass MD, Ato Sekyi-Otu MD, Habiba Mohamud PhD, Bukola Salami PhD

Abstract

Background: Black Canadians are disproportionately affected by the COVID-19 pandemic, and the literature suggests that online disinformation and misinformation contribute to higher rates of SARS-CoV-2 infection and vaccine hesitancy in Black communities in Canada. Through stakeholder interviews, we sought to describe the nature of COVID-19 online disinformation among Black Canadians and identify the factors contributing to this phenomenon.

Methods: We conducted purposive sampling followed by snowball sampling and completed in-depth qualitative interviews with Black stakeholders with insights into the nature and impact of COVID-19 online disinformation and misinformation in Black communities. We analyzed data using content analysis, drawing on analytical resources from intersectionality theory.

Results: The stakeholders ($n = 30$, 20 purposively sampled and 10 recruited by way of snowball sampling) reported sharing of COVID-19 online disinformation and misinformation in Black Canadian communities, involving social media interaction among family, friends and community members and information shared by prominent Black figures on social media platforms such as WhatsApp and Facebook. Our data analysis shows that poor communication, cultural and religious factors, distrust of health care systems and distrust of governments contributed to COVID-19 disinformation and misinformation in Black communities.

Interpretation: Our findings suggest racism and underlying systemic discrimination against Black Canadians immensely catalyzed the spread of disinformation and misinformation in Black communities across Canada, which exacerbated the health inequities Black people experienced. As such, using collaborative interventions to understand challenges within the community to relay information about COVID-19 and vaccines could address vaccine hesitancy.

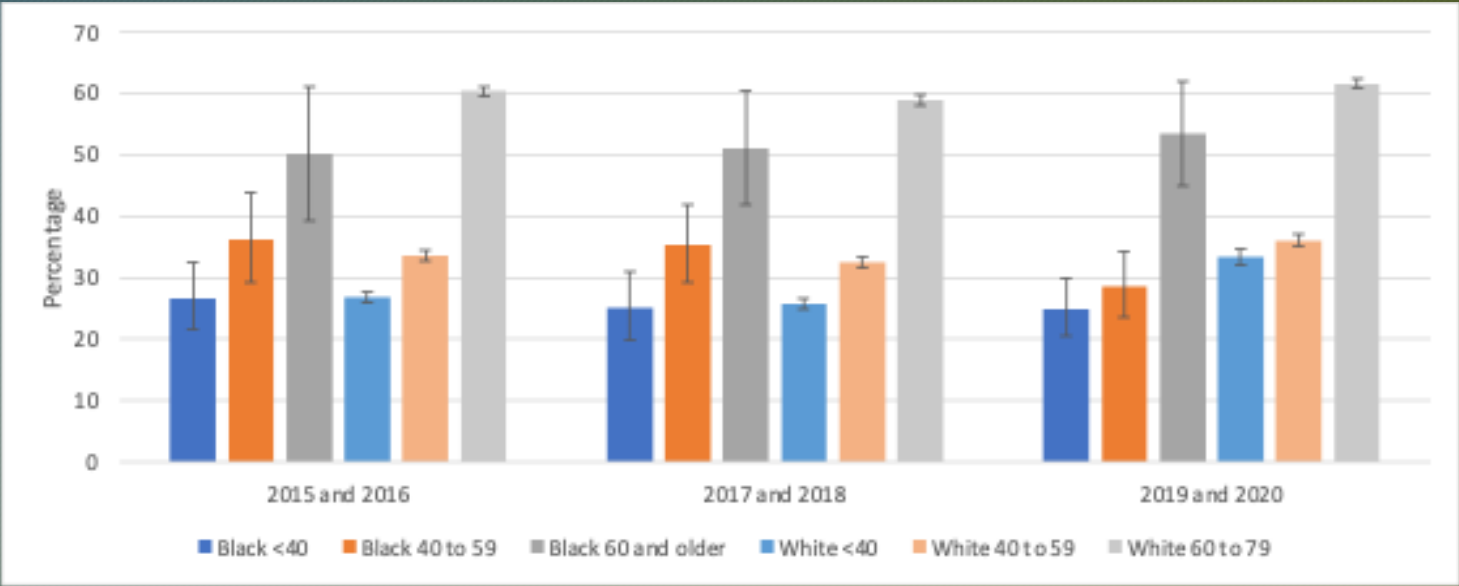
Black Canadians are disproportionately affected by the COVID-19 pandemic.¹ For example, as of September 2020, data tracking of COVID-19 cases in Toronto showed Black people accounted for 24% of positive cases despite constituting only 9.3% of the city's total population.² Black people and other racialized communities in Canada are also more likely to be admitted to hospital with COVID-19 than White and East Asian people.³ Further, evidence shows a universal vaccine hesitancy across countries and subgroups.⁴ Disinformation and misinformation about COVID-19 contributes to health disparities by posing a threat to the acceptance of the SARS-CoV-2 vaccine among Black Canadians.⁵⁻¹⁰

The vulnerability of Black Canadians to COVID-19

Canadian institutions expose Black people to socioeconomic vulnerabilities, which increase the burden of COVID-19 morbidity and death to this population,^{12,13} thus increasing vaccine skepticism and hesitancy. On completing a scoping review of online disinformation among Black people,¹⁴ we wanted to deepen our knowledge and situate the findings from our scoping review within the Canadian context. Despite the negative health behaviours promoted by disinformation, there is a paucity of qualitative studies examining online COVID-19 disinformation in Black communities in Canada. We aimed to describe the nature of online COVID-19 disinformation and misinformation among Black Canadians and identify the factors contributing to this phenomenon.

Flu vaccination in the last 2 years among Black and White adults in Canada

Prevalence of Flu vaccination in Black and White adults by age group



Black adults had lower flu vaccination rates compared to White adults

Characteristic	aPR*	95% CI	95% CI	p value
Cultural/racial background				
White only	Ref.			
Black only	0.92	0.86	0.98	0.013
Age group				
<40	Ref.			
40 to 59	1.03	1.00	1.06	0.023
60 and older	1.49	1.44	1.53	<0.001
Sex at birth				
Male	Ref.			
Female	1.14	1.13	1.16	<0.001

*Adjusted by age, sex at birth, sexual orientation, population center, marital status, education, income, among others.

Report of the United Nations Working Group of Experts on People of African Descent on its mission to Canada

- “Despite Canada’s reputation for promoting multiculturalism and diversity and the positive measures taken to address racial discrimination, the Working Group is deeply concerned about the human rights situation of African Canadians. Canada’s history of enslavement, racial segregation and marginalization has had a deleterious impact on people of African descent, which must be addressed in partnership with communities. Across the country, many people of African descent continue to live in poverty and poor health, have low educational attainment and are overrepresented in the criminal justice system.”

EGAP Principles

ENGAGEMENT, GOVERNANCE,
ACCESS, AND PROTECTION (EGAP)

A Data Governance Framework
for Health Data Collected from
Black Communities in Ontario



EGAP Principles

- Engagement: Genuine, cyclical, accessible consultation with communities regarding data collection management, analysis and use
- Governance: Community decision-making about engagement processes and data collection, management, analysis and use, achieved through the establishment of Community Governance Tables
- Access: The right of communities to access their collective data and to determine who else can access it, along with the capacity building required to enable this right
- Protection: The safeguarding of all individual rights and types of data, including identifiable, de-identified and anonymized data.

Culturally Appropriate Research with Black Communities

- The purpose of this project is to contribute to health equity efforts and an improved understanding of the social determinants of health in Canada by:
 - identifying key issues and challenges preventing the use of culturally relevant approaches for the collection, analysis, and reporting of health data on Black Canadians in the Prairie Provinces of Manitoba, Saskatchewan, and Alberta; and
 - identifying existing culturally responsive best or promising practices/approaches for the collection, analysis, and reporting of health data on Black Canadians in these three provinces.

Culturally Appropriate Research with Black Communities

- Phase 1: Scoping Review: 24 Studies
- Phase 2: Interviews of 12 Researchers

Scoping Review

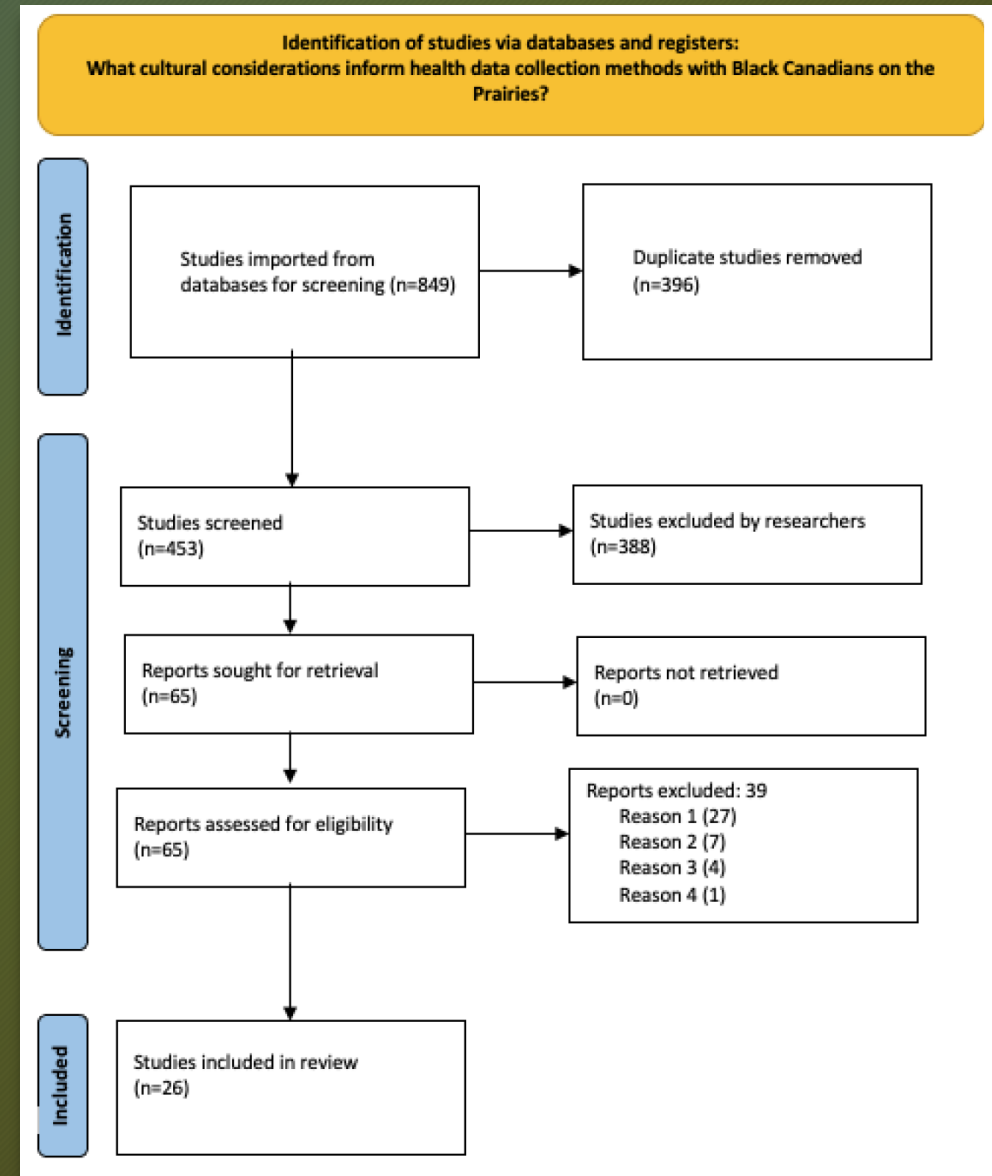


Table 3: Scoping Review Themes and Sub-themes

Themes	Sub-themes
Use of Theory	—
Research Leadership	—
Research Participation, Uptake, and Community Engagement	<ul style="list-style-type: none">• Research Collaboration• Community Members on Research Teams• Outreach into Community Hubs• Research Compensation or Honorariums
Data Collection	<ul style="list-style-type: none">• Gender• Age• Addressing Sensitive Topics and Fears• Challenges with Language and Interpretation/Translation

Key Considerations

- Creating formal partnerships and actively involving Black community members as co-researchers, advisory committee members, research assistants, and translators/interpreters
- Matching female interviewers with female participants and male interviewers with male participants, or all-male or all-female sets in the context of focus groups
- Intentional inclusion of Black Canadian community members as members of research teams as co-researchers, research assistants, and research coordinators
- Recruitment through gatekeepers, community hubs, ethnic organizations, local service agencies, local businesses, community leaders, religious leaders
- Ensuring that research projects involving Black communities are either Black-led or at least have critical Black representation
- Co-designing data collection protocols and methods with Black Canadian community collaborators in research projects involving sensitive topics
- When researching subjects involving taboo or sensitive issues, framing questions that invite participants to share their knowledge of experiences of others within their community can be an additional mechanism for obtaining information.

Trust, Early Engagement, Sustained Engagement

- Don't just jump in, you know, like the fly-by-night scholars. Do you have a relationship with them? Because that will also affect the quality of your data. Our people are suspicious of the mainstream, and rightly so. You're dealing with people who their suspicions. You need to gain their trust and you don't gain it in one week. [P001]
- If research agendas do not understand our realities, then I'm a little bit concerned about somebody who is not Black heading - to what extent can they relate to these inequities from a distance? The second reason why I don't understand is what is the interest? Because a lot of the people we study in the communities. A lot of the participants including - and also organizations within our communities complain that a lot of researchers are fly-by-night. Before they come to us they have already designed their research project. [P001]

Black Community Role in Research

- We can also work with them and work on partner-driven initiatives, such as if they want to run a survey, we can work on something like shared partnership so that we can help them. We can work with them on the survey. We can generate the questions with them. We can develop the survey and run it by them. They have reach of the community, especially the grassroots, which we don't. It's likely that if we work with them, we - we learn from them in terms of how to frame our questions. They learn from us in terms of basic rudiments of doing research. [P001]
- It's important to make sure that you're not going in as the expert, but you're also gaining expertise from individuals from that community. It goes back to the community engagement that you mentioned earlier is having someone from that community be a part of the research team. [P002]

Recruitment

- When I wasn't known and not trusted, I wasn't even given a chance to talk to anybody. They would not show up, they would not talk to me. But I overcame that one in Manitoba, of course, almost like, being taken under the wing of someone who was really a community mobiliser and a community leader. And then getting to know people afterwards. [P_007]
- I think, involving and hiring not only Black students, but Black community members for projects, I've hired both. And that's been successful, because once again, they are, and especially the community members, they're at the grassroots, they're well connected. They know the key people in the community. And so that has worked. [P008]
- I have to make myself more visible in the community. Even though my name is an African name and people know me or identify me as an African woman, I still have to make myself visible to the community. So go to community events, attend community organization events as well. Attend churches that I wasn't necessarily a member of, because I think when people put a face to the name then they were more willing to actually assist with the survey or assist with recruitment or wanted to take part in the study. [P003]

Data Analysis

- I think cultural interpretation sometimes where in some ethnic groups they use parables where they explain stuff that I don't always, can understand. So, I think even having a Black colleague that's, maybe come back to that previous question where you ask, should you be the lead on the project with Black. I think that sensitising for the information, really the cultural understanding of what is shared with you, you cannot do that with my background. You need somebody from, with the same background type of to help you with the interpretation, because you can misinterpret the data very, very, very easily. So, that's why I think you need to have a Black colleague with you or help you with the interpretation. [P012]

Knowledge Mobilization

- It is extremely important that if one is doing research with Black communities, that there is both a professional and moral obligation to make sure that we make opportunities, not have opportunities, that we make opportunities to disseminate that information above and beyond the traditional academic means, such as peer review articles, book chapters, and conference presentations. Because those types of scholarly products are primarily geared to a specific audience. [P008]
- We have to move beyond that in academics and be able to do presentations in those communities and also engage them in workshops. I feel like workshops that are incentivized, that would have lunch, would have food, because we have food as a major part of our culture. So, workshops that have food that have practical applications will be productive after research project has been completed. [P004]

Implications

- Black Canadian inclusion on research teams
- Recruitment through community gatekeepers and through informal and innovative strategies
- Community involvement in data analysis
- Setting the research agenda
- Researchers should: (1) consider intersectional identities when conducting research with Black community members, (2) understand that community acts as a gatekeeper to participant recruitment, (3) frame individual issues as community issues, and (4) consider cultural safety for engagement with participants.
- Innovative knowledge mobilization strategies
- Challenges to research with Black communities: Longstanding mistrust of health researchers, addressing diversity among and within communities, language barriers, ethics requirements, and lack of sustained funding can all impede health research with Black Canadian communities
- Respect and reciprocal relationships
- Recognition of prolonged community engagement in funding models
- Equitable incentives for research participation



Parenting and Mental Health Promotion Practices with African Immigrants

Background

- Doctoral research with live-in caregivers
- Initial research in Edmonton with temporary foreign workers
- Volunteer as a Board member of Africa Center
- Listening to the needs of the community
- Critical Ethnography to Community Based Participatory Research



Advisory Committee



African Community Leaders



Lessons about the community

Naming: Black versus African
Cultural Appropriateness
Timing



Compensation

Methodology



Phase 1: Interviews with 14 African immigrant community leaders

Individual interviews of 45 mins to 2.5 hours
11 were men and 3 were women



Phase 2: Interviews with 32 African immigrant parents

Interviews lasted 45 mins to 2.5 hours
Recruited from: a grocery store (8), a social service provider (8), two community liaisons (7), an immigrant service provider (2), a community leader (4), and the network of the PI (3)
25 were women and 7 were men



Phase 3: Interviews of 12 service providers and policy makers

Success

- Rich data
 - P: ...She had a mental problem. Yeah, she ended up in Royal Alex Hospital....
 - I: How is the kid now?
 - P: The girl now is - she took her to Somalia.
 - I: Oh. Why did she take her to Somalia?
 - P: She said she doesn't like the, you know, the medication ...
 - I: ... So the person that took the child back to Somalia, what treatment is the child getting in Somalia now?
 - P: Somalia, she said she's getting a lot of Quran.
 - I: Quran?
 - P: Yes. And she has a lot of relative. She is - she's not - actually, she is feeling okay, she said. Like she's not 100 percent, but she's not somebody who's going to cause a problem.... It's very difficult.
- Completed project 12 months ahead of schedule
- Added additional component to project --- stakeholder engagement

Impact



Stakeholder
engagement day
with over 150
stakeholders

<https://www.youtube.com/watch?v=ZLsJOfb3Ak4&t=1s>



Community report



Presentation to
the Prime Minister
of Canada

<https://www.youtube.com/watch?v=3bhgVYBSDrw>

Lessons Learned: Recruitment



Multiple community workers



Community engagement



Strategic
locations

Grocery
store
Sport
events

Lessons Learned: Cultural Appropriates

- Literacy
- Prayer Times
- Food
- Gender



Lessons Learned



Ethically Important
Moments



Confidentiality



Stigma and Sensitive
Topics

Lessons Learned: Stakeholder Engagement Day

Community First

Childcare

Parking

Letter or certificate of attendance

Framing and Naming

Mental Health of Black Youth in Alberta

How it Started

- Board member of Africa Center
- Meeting with Youth Leader and Executive Director
- Meeting with YEG ComeUp Group

Key Lessons from Youth



Participatory / Involvement



Intersectionality



Reciprocity

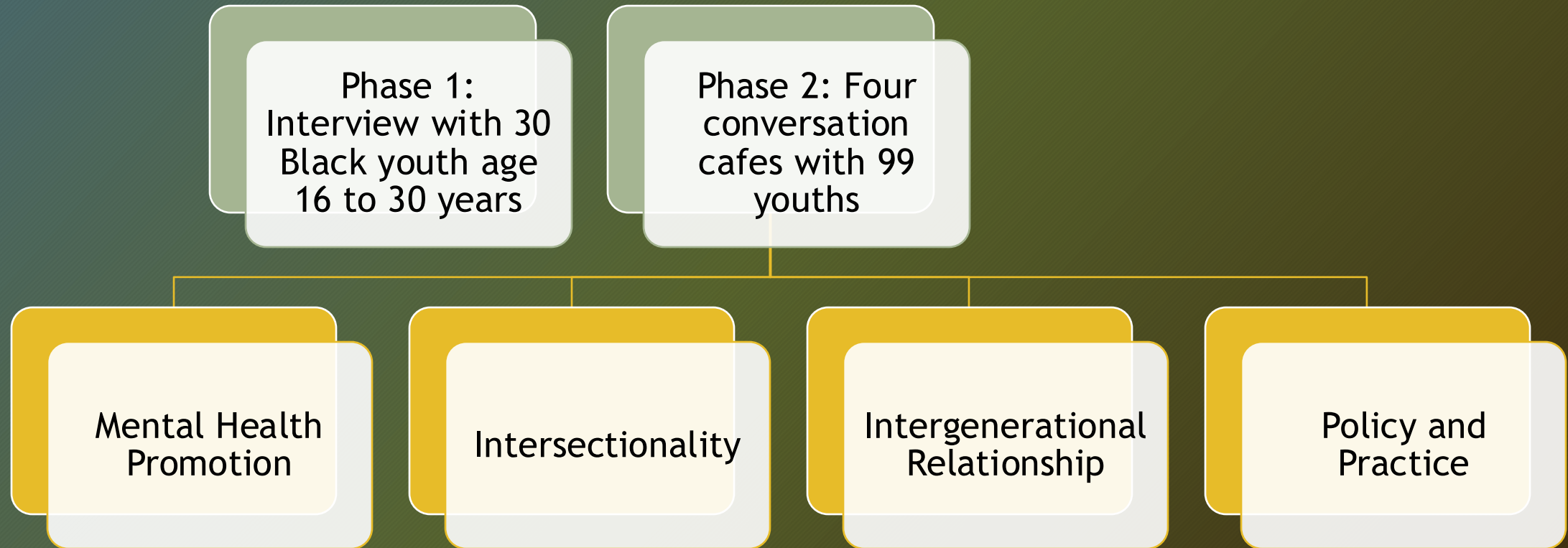


Collective Identity

Research Questions

- What are the mental health needs of African, Black, and Caribbean youths in Alberta?
- What are the barriers to access to and use of mental health services for African, Black, and Caribbean youths in Alberta?
- What are culturally relevant and effective approaches to increasing access to and uptake of mental health supports by African, Black and Caribbean youths in Alberta?
- What potential exists to mobilize African, Black, and Caribbean youths to improve mental health outcomes and/or to build resilience and capitalize on their agency?

Method



Advisory Committee Members



10 advisory committee members



7 research assistants



Equivalent hourly pay for both groups



Frequent meetings

Role of Research Assistants and Advisory Committee Members

- Facilitate participant recruitment
- Interview participants
- Organize and lead conversation cafes
- Develop initial conversation café guide
- Analyze data
- Co-author reports and publications
- Advise on data collection procedures
- Advise on knowledge mobilization and dissemination

Training

- Four hour training on qualitative research and research ethics
- Completion of TCPS 2 research ethics module
- Two trained on use of NVivo
- Close mentorship by two senior doctoral student
- At least one meeting with project lead before each conversation cafe
- Capitalize on strengths

Conversation Café Questions Developed by Youth

- Your parents are a few of many immigrants who have escaped civil war, persecution and other traumatic events. You notice signs of PTSD in one of your parents and whenever you try to hint at it, they are in denial. How would you approach them about this? How would you wish they'd respond?
- You decide that you do not want to attend university, but wish to pursue a different career (art, music, entrepreneurship) how do you think your parents will react? How comfortable are you sharing this with your parents?
- Your child comes home from school and tell you that they wish they had lighter skin. How would you respond to your child and why do you think they might feel this way?
- You approach your parents and try to explain to them that you are depressed. They tell you that you have food, clothes and a house to live in and have no reason to be depressed. How does this make you feel and why do you think they respond this way?
- It has been two years since you and your family immigrated to Canada. Before leaving to attend a cultural event, your child tells you they do not want to go because they do not claim your culture/ethnicity anymore. Where might your child's feelings rise from? How do you respond?
- You are worried that your sibling may be contemplating suicide and when you tell your parents, they tell you that they are probably just experiencing stress and to pray for them. How do you respond to this?

Success

- Recruited more participants
- Rich data
- Capacity building of youth
- Personal fulfilling experience



Challenges

Power relations

Time

Flexibility

Academic vs
community
priorities

Funding
limitations

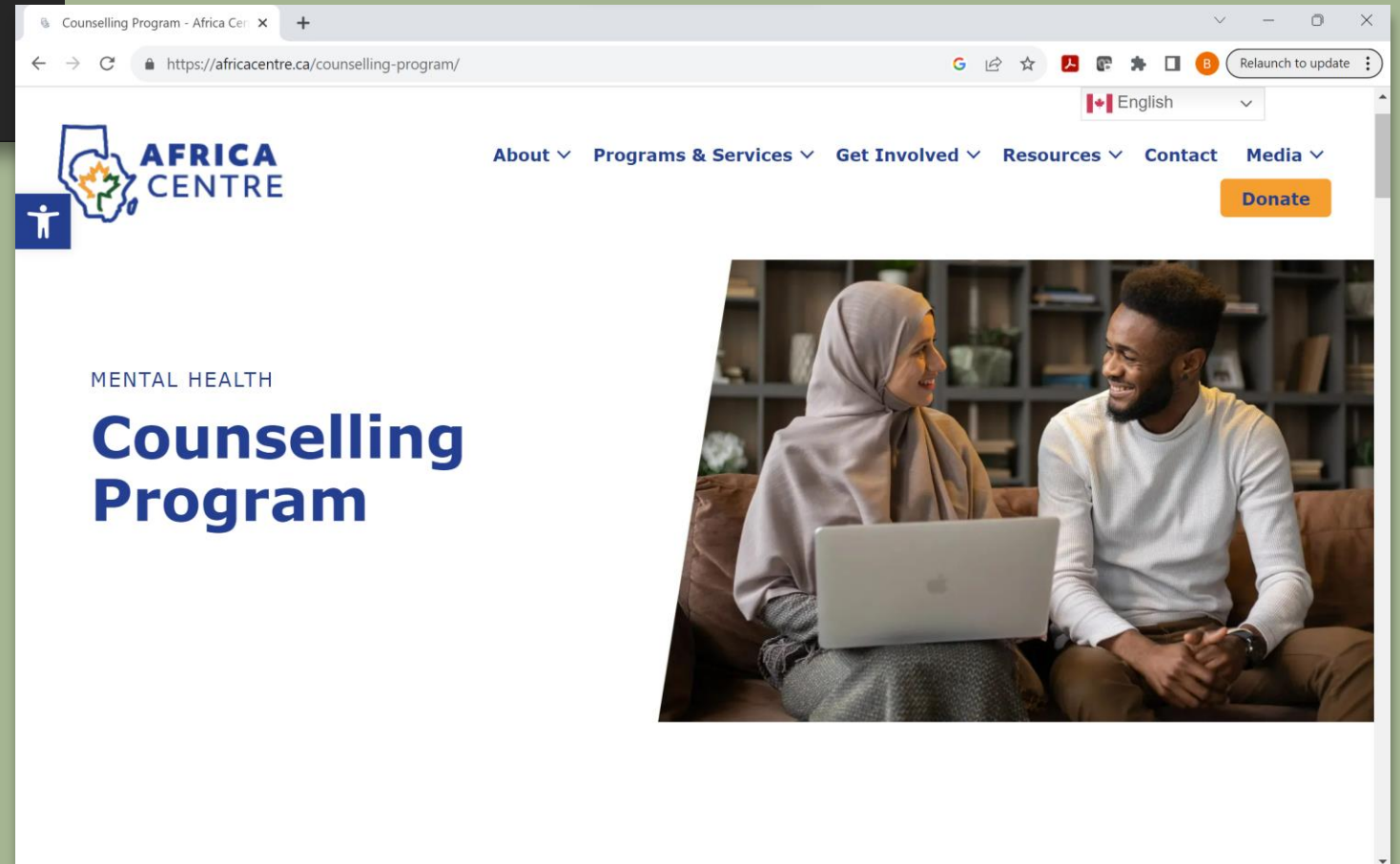
Confidentiality

Which
Intersectionality

Diversifying
sample

Impact

- Rich data
- Capacity building of youth
- Co-authorship and co-presentation with youth
- Youth led dissemination to community
- Creation of a Mental Health Clinic



Lessons: Creating Impact through Community Based Research with Black Communities

- Rethink impact
- Advisory committee
- Engage with community
- Prioritize community needs over academic needs
- Develop reciprocal relationships
- Intentionally build capacity
- Attend to cultural nuances

Thank You