Highlights and Key Lessons

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Principle	Ethically Sound Community Based Research with Black and Racialized Communities

Presentation Objectives

Participants were expected to:

- Understand the principles of community-based participatory research (CBPR)
- Identify challenges in conducting research with Black, immigrant, and racialized communities
- Learn strategies for ethical engagement and trust-building
- Explore equity considerations and ethical dilemmas in CBPR

Context and Rationale

- **Health Inequities:** Black and racialized communities in Canada face systemic health disparities, often exacerbated by racism and historical injustices.
- **Mistrust in Research:** Historical unethical research practices (e.g., Tuskegee Study, Henrietta Lacks) have led to deep-rooted mistrust in health systems and researchers.
- **Need for Ethical Engagement:** Ethical, culturally appropriate, and community-led research is essential to address these disparities.

Key Concepts and Frameworks

Community-Based Participatory Research (CBPR)

- A collaborative, power-equalizing approach where community members are co-researchers.
- Emphasizes shared leadership, trust-building, and action-oriented outcomes.
- Recognizes local knowledge as valid and central to research design and implementation.

Epistemic Disobedience & Violence

- Challenges dominant knowledge systems that marginalize non-Western ways of knowing.
- Calls for decolonial approaches that prioritize community needs over academic prestige.

EGAP Principles (Ontario Health Data Governance)

- **Engagement:** Ongoing, accessible consultation
- **Governance:** Community-led decision-making
- **Access:** Community control over data
- **Protection:** Safeguarding all forms of data

Strategies for Ethical and Effective Research

Building Trust

- Avoid "fly-by-night" research; invest in long-term relationships.
- Engage early and sustain involvement throughout the project.
- Include Black researchers and community members in leadership roles.

Culturally Appropriate Practices

- Match interviewers and participants by gender when appropriate.

- Use community hubs, religious leaders, and local businesses for recruitment.
- Frame sensitive questions in ways that respect cultural norms.

Data Collection & Analysis
- Co-design tools with community input.
- Involve community members in interpreting culturally nuanced data.
- Avoid misinterpretation by including culturally competent team members.

Knowledge Mobilization
- Go beyond academic outputs—host community workshops, share findings in accessible formats, and ensure community benefit.
- Incentivize participation with culturally relevant offerings (e.g., food, childcare).

Case Studies and Impact

Mental Health of Black Youth in Alberta
- Youth-led research with over 100 participants.
- Focused on mental health needs, barriers, and culturally relevant supports.
- Outcomes included a youth-led dissemination strategy and the creation of a mental health clinic.

Parenting and Mental Health Promotion with African Immigrants
- Multi-phase project with community leaders, parents, and service providers.
- Emphasized cultural appropriateness, stakeholder engagement, and early success in project delivery.

Key Takeaways for Researchers

1. **Rethink Impact:** Prioritize community-defined success over academic metrics.
2. **Build Reciprocal Relationships:** Mutual learning and respect are foundational.
3. **Center Cultural Nuance:** Attend to language, gender, food, and religious practices.
4. **Ensure Representation:** Black-led or critically inclusive research teams are essential.
5. **Mobilize Knowledge Creatively:** Use community events, storytelling, and accessible formats.