# COVID-19 research within Black communities: Utility of a community advisory group

Chantal Phillips, Renee Bailey, Mariana Abdulnoor, Alicia Polack, Michelle Barton-Forbes, Julia Upton, Annette Bailey, Aaron Campigotto, Alice Litosh, Peter Wong, Andrew Allen, Walter Byrne, Kimberly Thompson, Carl James, Upton Allen



CITF 2023 - The importance of community engagement in research

## **Conflicts of Interest**

#### **Chantal Phillips, MD Candidate 2023**

- Member of the Community Advisory Group (CAG) since August 2020.
- Participant & research assistant (compensated) in the seroMARK study.

# **Background & Aim**

- Racialized communities, including Black community members, were disproportionately affected by COVID-19.<sup>1,2</sup>
- Historical and present-day systemic anti-Black racism result in underrepresentation of Black communities in clinical research.
- This was an anticipated barrier for our <u>seroMARK study</u>, focused on "understanding COVID-19 immunity among Black Canadians," which required participation from Black communities in order to be applicable and effective.
- Implemented a Community Advisory Group (CAG) as a solution.



Goal: list of potential members.



**Establishment** 



**Effectiveness** 



**Empowerment** 



**Equity** 



- Co-developed by Black academics in clinical medicine, social sciences, education, etc.
- Word of mouth through networks to connect with Black and non-Black academics focused on equity and Black leaders (e.g., community health centres, non-profits).
- Engaged un(der)represented individuals (i.e., Black youth).





#### Establishment -

**Goal:** confirmed list of diverse/intersectional members.



#### **Effectiveness**



**Empowerment** 



**Equity** 



- Confirmed membership list.
- Reflect on CAG representation (e.g., race, age, gender, ethnicity, etc.) and gaps.
- Reinforce iterative membership model.





#### **Establishment**



#### **Effectiveness**

Goal: regular meeting attendance & increased Black community research participation.



#### **Empowerment**

- Regular meetings with consistent, diverse representation.
- Monitor and report metrics (i.e., Black research project participant numbers).



**Equity** 







#### **Establishment**



#### **Effectiveness**



#### **Empowerment**

**Goal:** protocol modifications and shifts in project direction due to CAG impact.



#### **Equity**



- Regularly update CAG on research (i.e., subject recruitment, knowledge translation, etc.).
- CAG suggestions should be incorporated where possible.
- CAG should have opportunities to learn/capacity-building.





**Establishment** 



**Effectiveness** 



**Empowerment** 



**Equity** 

Goal: a plan to decrease barriers to participation & to directly benefit communities involved.



- Compliance with Tri-council guidelines on equity.
- Facilitate project participation.
- Leverage resources for health equity (e.g., health promotion related to chronic illness).





**Establishment** 



**Effectiveness** 



**Empowerment** 



**Equity** 



**Evaluation** 

Goal: awareness of strengths and weaknesses, in an iterative way that allows for revision.

- Informal evaluation (i.e., CAG discussions post-outreach events).
- Structured evaluation (on impact and process).

# Impact of CAG on Research

- Enhanced engagement of Black communities.
- Increase in proportion of Black participants in the seroMARK study (i.e., two out of every three participants).
- Opportunities for co-benefits using a collaborative infrastructure to address non-COVID-19-related issues (i.e., health promotion).
- More thorough evaluation of the impact on the team is to be conducted.

## **Lessons Learned**

Process	<ul> <li>Reflect on who is not represented in your community engagement</li> <li>Community engagement = relationship building</li> </ul>
What went well	• Partnerships should be mutually beneficial for research teams and engaged communities
Challenges	• Shifts in capacity over COVID–19 and with time

# Take-aways

Research teams need to understand historical and present-day barriers to recruitment and plan community engagement accordingly.

Community engagement should not be merely extractive; it should be based on **partnerships**.

"Community" is a **monolithic term** for communit*ies* that are very diverse and might still be un(der)represented despite efforts.

### **Author Affiliations**

- 1. Division of Infectious Diseases, Department of Paediatrics, The Hospital for Sick Children, Toronto, ON, Canada.
- 2. Division of Infectious Diseases, Department of Paediatrics, London Health Sciences Centre, London ON, Canada.
- 3. Division of Allergy and Immunology, Department of Paediatrics, The Hospital for Sick Children, Toronto, ON, Canada.
- 4. Ryerson University, Toronto, Ontario.
- 5. Division of Microbiology, Department of Paediatric Laboratory Medicine, The Hospital for Sick Children, Toronto, ON, Canada.
- 6. Department of Pediatrics, The Hospital for Sick Children, Toronto, ON, Canada.
- 7. University of Windsor, Ontario
- 8. York University, Toronto, ON, Canada.

#### References

- 1. McKenzie K, Dube S, Peterson S. Tracking COVID-19 through race-based data. [Internet] Ontario Health; 2014 [updated 2022 Mar 09; cited 2023 Feb 24]. Available from: <a href="https://www.ontariohealth.ca/sites/ontariohealth/files/2021-08/Tracking%20COVID%2019%20Through%20Race%20Based%20Data-EN.pdf">https://www.ontariohealth.ca/sites/ontariohealth/files/2021-08/Tracking%20COVID%2019%20Through%20Race%20Based%20Data-EN.pdf</a>
  2. Statistics Canada. COVID-19 in Canada: A one-year update on social and economic impacts.
- [Internet] Statistics Canada; 2021 [updated 2021 Mar 11; cited 2023 Feb 24]. Available from: <a href="https://www150.statcan.gc.ca/n1/pub/11-631-x/11-631-x2021001-eng.htm">https://www150.statcan.gc.ca/n1/pub/11-631-x/11-631-x2021001-eng.htm</a>
- 3. Huang HH, Coker AD. Examining issues affecting African American participation in research studies. Journal of Black Studies. 2010 Mar;40(4):619–36.

# Thank You

#### **Chantal Phillips, MD Candidate 2023**

University of Toronto chantal.phillips@mail.utoronto.ca

