

POPLAR NETWORK LUNCH 'N' LEARN WEBINARS EDIIA IN RESEARCH

Part 4: Using Data to Advance EDIIA



Alliance for Healthier Communities Advancing Health Equity in Ontario

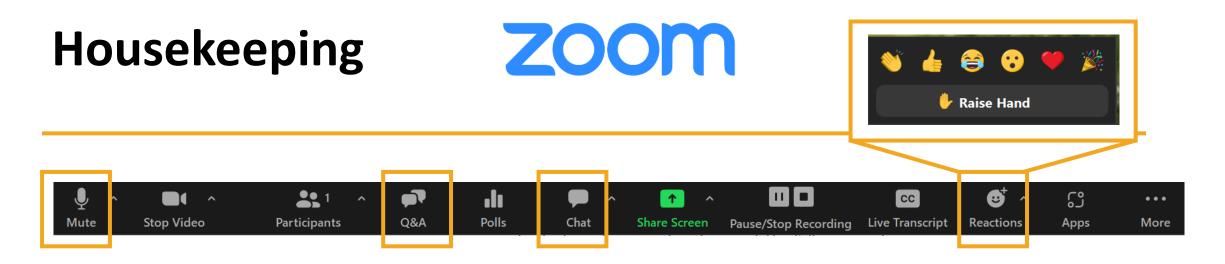


Welcome & Introduction

- Housekeeping
- Land Acknowledgement
- Speaker Introduction
- Building Capacity for using Data to Advance EDIIA in Practice
- Q&A / Discussion







- Microphones are muted by default.
- You may enter questions through the Q&A panel at any time.
- Please use the "chat" function for technical assistance.
- During the Q&A period, you may use the "raise hand" function (under "reactions"), and we'll unmute you when we call on you.





Acknowledgement of Traditional Indigenous Territories

We recognize that the work of the Alliance for Healthier Communities, our members, and the POPLAR Network takes place across what is now called Ontario, on traditional territories of Indigenous people. They have lived here since time immemorial and have deep connections to these lands. We further acknowledge that Ontario is covered by 46 treaties, agreements and land purchases, as well as unceded territories. We are grateful for the opportunity to live, meet and work on this territory.

Ontario continues to be home to vibrant, diverse Indigenous communities who have distinct and specific histories, needs, and assets as well as constitutionally protected and treaty rights. We honour this diversity and respect the knowledge, leadership and governance frameworks within Indigenous communities. In recognition of this, we commit to building allyship relationships with First Nation, Inuit and Métis peoples in order to enhance our knowledge and appreciation of the many histories and voices within Ontario. We also commit to sharing and upholding our responsibilities to all who now live on these lands, the land itself, and the resources that make our lives possible.





Introduction

Dr. Andrew Pinto (he/him)

Founder and director, Upstream Lab Family Physician, St. Michael's Hospital Associate Professor, University of Toronto







Equity, Diversity, Indigeneity, Inclusion, Accessibility (EDIIA) and Data

POPLAR EDIIA Webinar Series

October 19, 2022

Andrew Pinto MD CCFP FRCPC MSc

Upstream Lab, MAP/Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute, Unity Health Toronto Department of Family and Community Medicine, Fac. of Medicine, University of Toronto Department of Family and Community Medicine, St. Michael's Hospital Dalla Lana School of Public, University of Toronto





Routledge Studies in Indigenous Peoples and Policy

INDIGENOUS DATA SOVEREIGNTY AND POLICY

Edited by Maggie Walter, Tahu Kukutai, Stephanie Russo Carroll and Desi Rodriguez-Lonebear



Disclosures

Relationships with commercial interests:

Research Support: None from for-profit/commercial entities.

Canadian Institutes for Health Research; Ontario government, including the Ministry of Health and Long-Term Care; TD Financial Literacy Grant Fund, administered by Prosper Canada; PSI Foundation; Legal Aid Ontario; Maytree Foundation; Atkinson Foundation; Metcalf Foundation; Healthier Cities and Communities Hub, DLSPH, University of Toronto; Toronto Central LHIN; St. Michael's Hospital Foundation; Gambling Research Exchange Ontario; Institute for Global Health Equity and Innovation, DLSPH, University of Toronto; Ontario SPOR Support Unit; Newfoundland Health Accord (Memorial University)

Speakers Bureau/Honoraria: None from for-profit/commercial entities.

I have received honoraria for presentations at Queen's University (2010), University of Saskatchewan (2012), Mount Sinai Hospital (2012), Toronto Reference Library (2016), Law Society of Ontario (2016), Japan Network of Health Promoting Hospitals & Health Services (2018), Ghent University, Belgium (2020), Joint Centre for Bioethics, University of Toronto (2019, 2021), North American Primary Care Research Group (2021), Ryerson University (2021).

Salary support: None from for-profit/commercial entities.

Department of Family and Community Medicine, St. Michael's Hospital; Department of Family and Community Medicine, Faculty of Medicine, University of Toronto; Li Ka Shing Knowledge Institute, St. Michael's Hospital. Recipient of the 2019 PSI Graham Farquharson Knowledge Translation Fellowship. Recipient of a CIHR Applied Public Health Chair in Upstream Prevention.

Consulting Fees: None.

Other: I serve as an unpaid scientific advisor to a start-up company, Mutuo Health Solutions.



Outline

- 1. Upstream Lab & our journey
- 2. Lessons from COVID-19
- 3. Can EDIIA be transformative?



1. Upstream Lab & our journey







Home About - Impact Research Publications Resources - News & Events Contact - Q

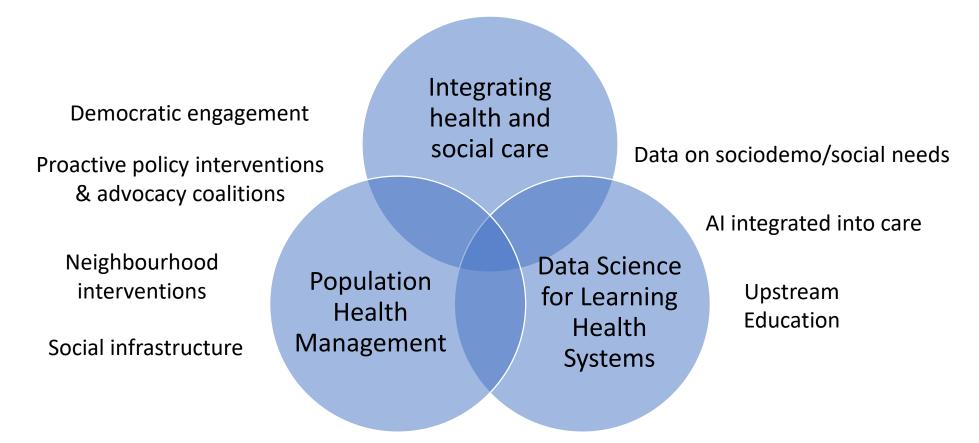




upstreamlab.org

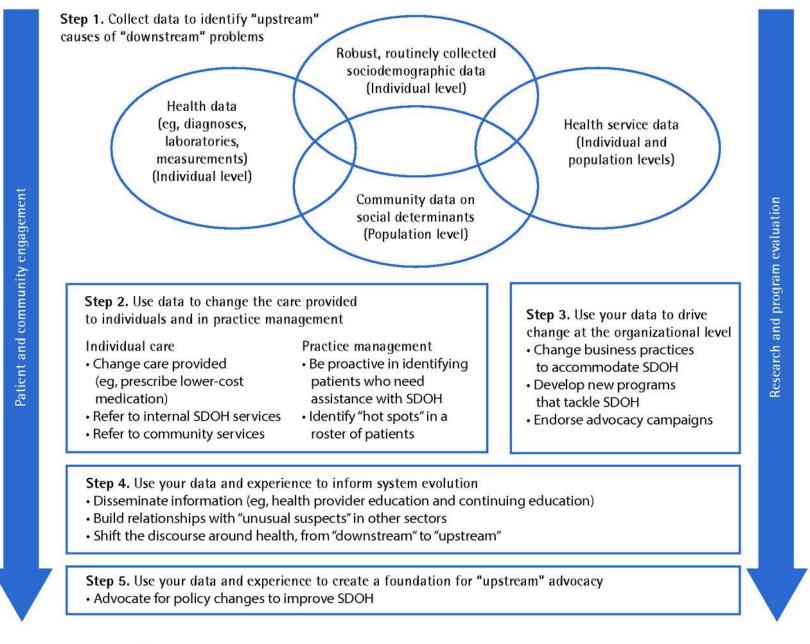


Addressing social needs of individuals

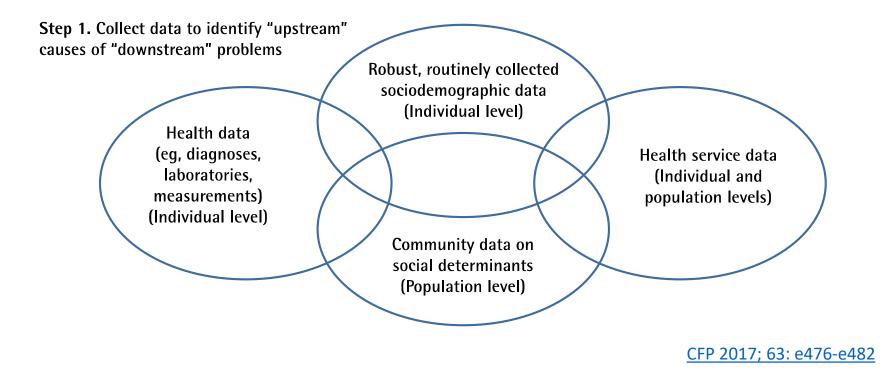


Shifting health organizations to population thinking and community accountability





Patient Reported and Inferred Social Measures (PRISMs)





Data collection at SMHAFHT (2013 -)



http://torontohealthequity.ca/

8 mandatory questions

- 1. Language (speaking to health 1. Language (reading care provider)
- 2. Born in Canada
- 3. Racial or ethnic group
- Illness or disability 4.
- 5. Gender
- Sexual orientation 6.
- 7. Family income
- 8. No. income supports

3 optional questions

- healthcare info)
- **Religious or** 2. spiritual affiliation
- 3. Housing

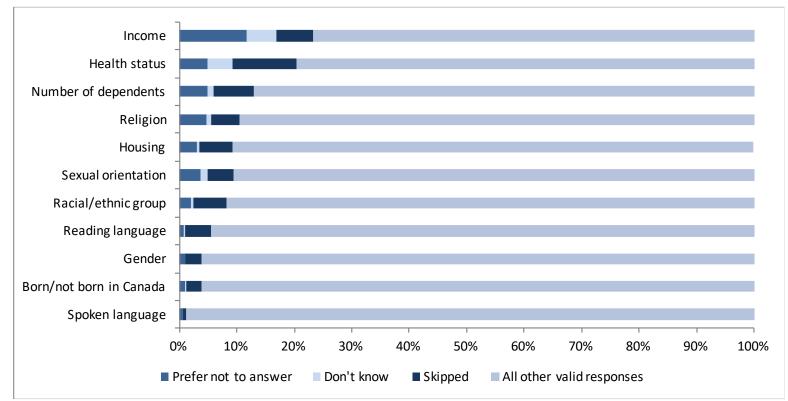


Response rate

Building a Foundation to Reduce Health Inequities: Routine Collection of Sociodemographic Data in Primary Care

Andrew D. Pinto, MD, CCFP, MSc, Gabriela Glattstein-Young, MD, MPH, Anthony Mohamed, MES, Gary Bloch, MD, CCFP, Fok-Han Leung, MD, CCFP, and Richard H. Glazier, MD, CCFP, MPH

JABFM 2016; 29 (3): 348-355.





Data to identify inequities

Open Access	BMJ Quality Improvement Programme
Submitted from Quality	Measuring and improving cervical, breast, and colorectal cancer screening rates in a multi-site urban practice in Toronto, Canada

Joshua Feldman, Sam Davie, Tara Kiran

BioMed Central	
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BMC Family Practice



RESEARCH ARTICLE OPEN ACCESS OPEN PEER REVIEW

Using self-reported data on the social determinants of health in primary care to identify cancer screening disparities: opportunities and challenges AK. Lofters © Q. A. Schuler, M. Slater, N. Parsaud, A.D. Pinto, E. Kucharski, S. Davie, R. Nisenbaum and T. Kiran

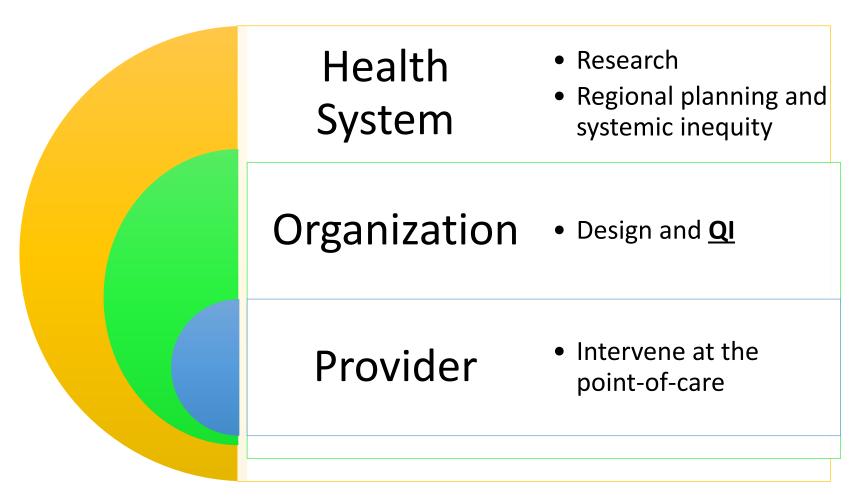
BMC Family Practice BMC series – open, inclusive and trusted 2017 18:31 DOI: 10.1186/s12875-017-0599-z

© The Author(s). 2017 Received: 6 September 2016 Accepted: 9 February 2017 Published: 28 February 2017

Percentage of patients up-to-date with cancer screening stratified by low income cutoff 100 90 80 70 60 50 40 30 20 10 0 Below Low Income Cutoff Colorectal Cervical Breast



How can we use this data?



Based on research co-led by Dr. Tara Kiran, with many patient partners and collaborators



<u>Screening for Poverty And Related social determinants and intervening to</u> improve <u>K</u>nowledge of and links to resources (SPARK)



https://upstreamlab.org/project/spark/

lavtree









Ministry of Research, Innovation and Science

Primary Healthcare Research Unit





FACULTY OF MEDICINE





CFP 2019, 65 (8) e363-e369;





Implementing data collection in health settings

Key requirements:

- 1. Committed leadership and staff
- 2. Indigenous data governance and sovereignty
- 3. Community engagement e.g. EGAP framework
- 4. Transparency
- 5. Commitment to taking action (not just data collection!)
- 6. Continuous data quality
- 7. Staff training & quality assurance
- 8. Appropriate communication to patients
- 9. Complaint process around discrimination

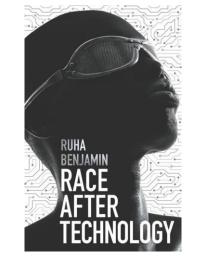
10. Data security and privacy

Note: These key issues have been raised by <u>many</u> before me!





https://www.publicaffairsbooks.com/titles/shoshanazubeff/the-age-of-surveillance-capitalism/9781610395694/



https://www.ruhabenjamin.com/race-after-technology

Concerns about the misuse of data, algorithmic bias & surveillance

How to Stop Silicon Valley from Building a Dew Global Underclass **GHOST** Mary L. Gray and Siddharth Suri

https://ghostwork.info/

ARTIFICIAL UNINTELLIGENCE How Computers Misunderstand the World

6 6

https://mitpress.mit.edu/books/artificialunintelligence

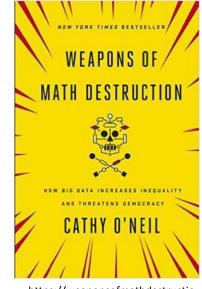


AUTOMATING INEQUALITY

HOW HIGH-TECH TOOLS PROFILE, POLICE, AND PUNISH THE POOR



https://us.macmillan.com/books/9781250074317



https://weaponsofmathdestructio nbook.com/

Sociodemo data to identify systemic racism

Dr. Onye Nnorom, Dr. Kate Mulligan, Dr. Marcia Anderson



https://www.youtube.com/watch?v=7KepfKI1bS8







EGAP Framework

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



A vision of community data governance from the Black Health Equity Working Group

https://blackhealthequity.ca/

- Engagement: genuine, ongoing, accessible, transparent consultation with community members, recognized leaders and organizations
- Governance: community decision-making about collection, analysis/interpretation, use, management
- Access: right to access data and determine who else can access community data trust
- Protection: safeguarding data, including the use of de-identified and anonymized data



2. Lessons from social data collection during the COVID-19 pandemic



RESEARCH ARTICLE

Social determinants of COVID-19 incidence and outcomes: A rapid review

Tara L. Upshaw^{1,2°}, Chloe Brown^{1,3°}, Robert Smith^{1,4,5}, Melissa Perri^{1,6}, Carolyn Ziegler⁷, Andrew D. Pinto^{1,4,5,6,8}*

 Upstream Lab, MAP Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, Canada, 2 Translational Research Program, Faculty of Medicine, University of Toronto, Toronto, Canada, 3 Undergraduate Medical Education, Faculty of Medicine, University of Toronto, Toronto, Canada, 4 Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, Toronto, Canada, 5 Department of Family and Community Medicine, Faculty of Medicine, University of Toronto, Toronto, Canada, 6 Dalla Lana School of Public Health, University of Toronto, Toronto, Canada,
Health Sciences Library, Unity Health Toronto, Toronto, Canada, 8 Department of Family and Community Medicine, St. Michael's Hospital, Toronto, Canada

https://journals.plos.org/plosone/article/authors?id=10.1371/journal.pone.0248336



Ontario's lack of diversity data for COVID-19 is an embarrassment

TRENDING

Second-in-comr Forces steps dov

leave after golf

7 Ten strongly pro

3 Large but unren condo sells \$170
4 Families face off vaccination stat more social sur

that investors m

Torstar buyers s as VerticalScope

ADAM KASSAM SPECIAL TO THE GLOBE AND MAIL PUBLISHED APRIL 15, 2020
PUBLISHED APRIL 15, 2020 This article was published more than 1 year ago. Some information in it may no longer be current.
= 49 comments the share ${\mathrm{A}}$ \mathbf{A} + text size \square bookmark

https://www.theglobeandmail.com/opinion/article-ontarioslack-of-diversity-data-for-covid-19-is-an-embarrassment/ Ignorance of history and contemporary data:

"regardless of race, ethnic or other backgrounds, they're all equally important to us." - Dr. David Williams





Collecting data on race during the COVID-19 pandemic to identify inequities

April 14, 2020

Andrew D. Pinto MD MSc Ayu Hapsari MSc

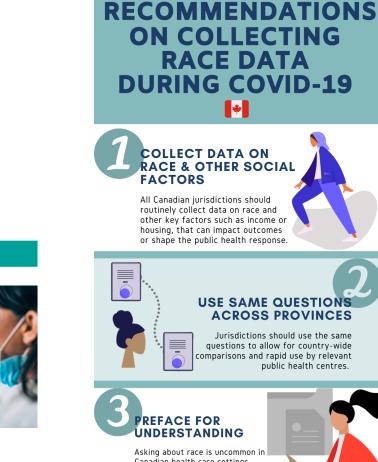
CIHI Update | May 2020

Race-Based Data Collection and Health Reporting

Summarv

There is heightened awareness of and interest in collecting information to better understand the spread of COVID-19 and the impact of the pandemic, particularly within racialized communities.

The lack of data on race in Canada makes it difficult to monitor racial health inequalities. To help harmonize and facilitate collection of high-quality data, the Canadian Institute for Health Information (CIHI) is proposing an interim race data collection standard based on work that has been ongoing for a number of years, including engagement with researchers, clinicians, organizations representing racialized communities, and federal, provincial and territorial governments. It is intended for use by any jurisdiction or organization that decides to collect this type of data.



Canadian health care settings. Explaining why questions are asked about race can help patients understand the context and avoid reinforcing false ideas about race.

THE UPSTREAM LAB



BE TRANSPAREN

public health centres.

Commit to transparency and engagement with local leaders on questions used, proper question administration, and to help create community-based interventions to reduce inequities.

INFOGRAPHIC BY: BREAGH & BRIANNA CHENG SOURCE: ANDREW PINTO, AYU HAPSARI, UPSTREAM LAB https://upstreamlab.org @upstreamlab Created April 17, 2020



Stigma, discrimination & lack of intersectional thinking

CONTRIBUTORS OPINION

South Asians play a part in COVID-19 transmission and we need to acknowledge it

By Zain Chagla Contributors Sumon Chakrabarti Tajinder Kaura Sun., Nov. 15, 2020 () 5 min. read

https://www.thestar.com/opinion/contributors/2020/11/15/south-asians-play-apart-in-covid-19-transmission-and-we-need-to-acknowledge-it.html

Why Brampton has become a hot spot for COVID-19

JAREN KERR

Globe and Mail. Nov 13, 2020

PUBLISHED 2 DAYS AGO

https://www.theglobeandmail.com/canada/article-why-brampton-hasbecome-a-hot-spot-for-covid-19/



Stigma, discrimination & lack of intersectional thinking

Dryden: Racist responses to COVID-19 continue to place all of us at greater risk

Posted by Dr. OmiSoore Dryden on September 3, 2020 in News



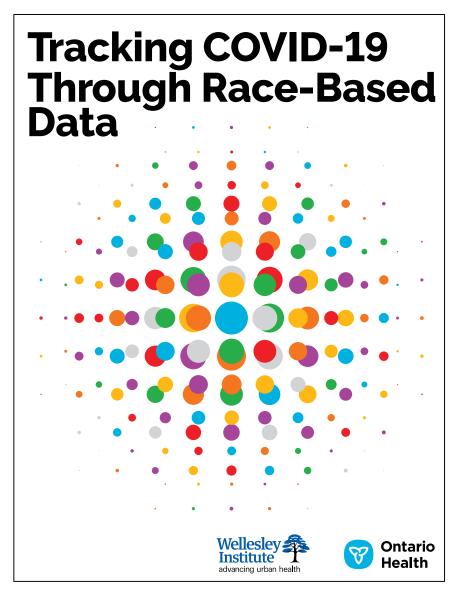
"In January 2020, I tweeted a caution about how <u>outbreaks</u> become a vehicle for perpetuating racism and racist stereotypes. And unfortunately, we have seen numerous examples of exactly this."

Dr. OmiSoore Dryden is the James R. Johnston Chair in Black Canadian Studies

*This op-ed was originally posted by the Chronicle Herald on September 2, 2020

https://medicine.dal.ca/news/2020/09/03/dryden racist responses to covid 19 continue to place all of us at greater risk.html





https://www.ontariohealth.ca/about-us/our-programs/provincial-equity-indigenous-health/equityinclusion-diversity-anti-racism/report-tracking-covid-19-through-race-based-data







https://www.thestar.com/news/gta/2021/05/08/light-at-the-end-ofthe-tunnel-toronto-set-to-reach-covid-19-vaccine-milestone-with-50of-adults-having-had-first-jab.html



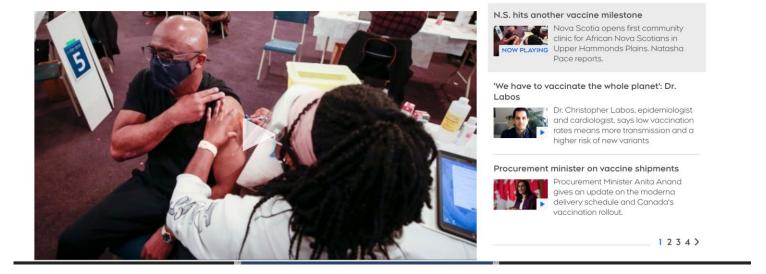
City of Toronto awards \$5.5 million in COVID-19 Vaccine Engagement Teams Grants to local agencies for vaccine outreach in vulnerable communities



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'Good public health policy': The success of vaccine clinics for Black, racialized Canadians



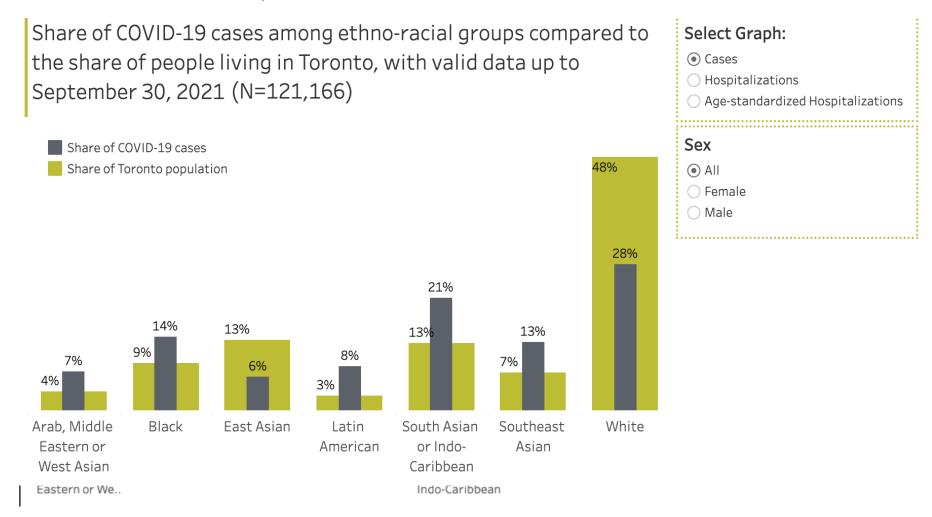


"It's not just equitable, it's actually good public health policy," Hamilton critical care physician Dr. Abubaker Khalifa told CTVNews.ca in a phone interview, citing the city's own census and race-based COVID-19 data as the driving factor.

https://www.ctvnews.ca/health/coronavirus/good-public-health-policy-the-success-of-vaccine-clinics-for-black-racialized-canadians-1.5416822



August 2020 September 2021



https://www.toronto.ca/home/covid-19/covid-19-latest-city-of-toronto-news/covid-19-status-of-cases-in-toronto/ https://www.toronto.ca/home/covid-19/covid-19-pandemic-data/covid-19-ethno-racial-group-income-infection-data/



3. Can EDIIA be transformative?



How can EDIIA initiatives be transformative for health research?

Pinto AD. Healthcare Papers 2022; 20(3): 53-60 https://www.longwoods.com/content/26843/healthcarepapers/can-a-focus-on-equitydiversity-and-inclusion-transform-health-service-research-



1) We must take an honest and clear history of the role of research in upholding injustice. After acknowledgement and apologies, we must commit to justice and reparations.



Current push for EDIIA: A response to mass movements







https://www.youthco.org/blm_act

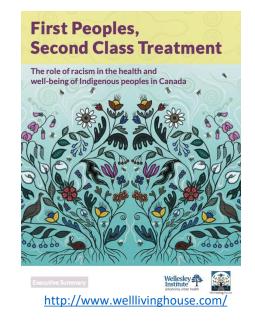
Mural by Kenny Altidor. Via: https://www.smithsonianmag.com/smithsonian-institution/remembering-george-floydand-movement-he-sparked-one-year-later-180977817/



Current push for EDIIA: A response to mass movements



https://idlenomore.ca/





2) We must stop EDIIA as performative. No statements without actions, timelines, and changes in the distribution of resources and power.



3) Data collection alone **must** never be the end goal of EDIIA. If data collection occurs, we must be transparent so the numbers can be put in the hands of individuals and communities working for change.



4) We must ground our efforts in praxis, as part of movements to create change. EDIIA continues to be a response, in many ways, to maintain the status quo.





"We were talking about what the different hospitals are doing to address health equity ... someone at another institution said, 'Yeah we're addressing health equity also. We did the Health Equity Survey.' Uh, period. Like that was the approach to health equity...that file is closed."(provider)

https://upstreamlab.org/project/spark/





"Collecting race-based data is a policy decision, but it does not guarantee that good policy decisions will follow from the data that is collected. ... We must be clear, then, that collecting data is not an end in itself: further work is needed to make something happen, and that work is political work."

Prof. Rinaldo Walcott, TVO. Feb 23, 2021

https://www.tvo.org/article/race-based-covid-19-data-needs-to-lead-to-political-action



Conclusion

EDIIA initiatives must lead us to see and judge what we do with **new eyes**.

We must honestly think about who sets priorities, who benefits, what is the collective impact, and is it **emancipatory**.



Questions?





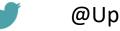
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@AndrewDPinto



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- @UpstreamLabToronto
- in Upstream Lab

Scan the QR code to subscribe to our newsletter:



Questions/Discussion

Please type questions into the Q&A panel and we will moderate them.

If you prefer, you may raise your hand and we'll call on you to ask your question aloud.



Thank you!

For follow-up questions:

LHS@AllianceON.org

info@poplarnetwork.ca

