

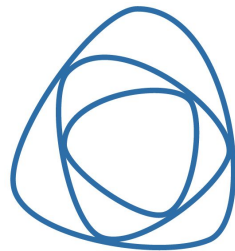
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Community-Based Research and Open Science: Lessons Learned

Nathan Lachowsky (he/him)

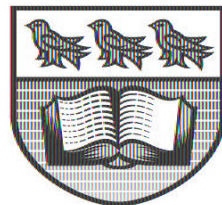
Anu Radha Verma (she/her)

May 24, 2024



cbrc

Community-Based Research Centre



**University
of Victoria**

Land Acknowledgment

CBRC's head office is located in the traditional unceded territories of the Musqueam, Squamish, and Tsleil-Waututh peoples.

CBRC acknowledges the historic and ongoing impacts of colonization on Indigenous peoples in Canada, including countless lives lost, as well as racist systems and institutions that continue to marginalize Indigenous peoples.

CBRC is committed to decolonization and reconciliation as an essential part of equity and inclusion for queer, trans, Two-Spirit, and non-binary people. We acknowledge that we must work continually and meaningfully to create space in which Indigenous peoples can thrive and feel safe.



Getting Grounded

How our lived experiences
inform today's conversation

Learning Objectives

After this webinar, you will be able to



Identify principles for community-based research that relate to 2S/LGBTQQIA+ communities



Describe how open science and community-based research are complementary approaches




Understand the successes and challenges of implementing community-based research with and for 2S/LGBTQQIA+ communities

”

Open science is about making sure not only that scientific knowledge is accessible but also that the production of that knowledge itself is inclusive, equitable and sustainable.

UNESCO Recommendation on Open Science, 2021

A decorative graphic consisting of a large white circle with a smaller yellow circle inside it, partially overlapping a dark grey semi-circle.

Community-based research has the same goals!

CBRC's Research Principles

- **Access**
- Advance Social Justice
- Balance
- Bravery & Love
- **Community Empowerment**
- Centre Lived Experience
- Historically Informed
- Impact-Oriented
- Holistic View of Health
- Intergenerational



CBRC's Principles for our Research Partnerships



**Commitment and
Action to Support Our
Communities**



**Community
Leadership,
Participation, and
Control**



**Financial and
Operational
Transparency**




Participatory Epidemiology

- **Research goal:** risk vs. health, parsimony vs. comprehensive
- **Research question:** motives, sources, parties
- **Population:** attributes and criteria
- **Context:** level of focus
- **Data synthesis:** paradigm, purpose
- **Research management:** proscriptive vs. adaptive, leads, collaboration
- **Dissemination of findings:** format and target



Sex Now Case Study



*Sex Now has been an essential
source of data on the health and
wellbeing of 2S/GBTQ+ people in
Canada since 2002*

Why it began... ...and continues!

“Nothing about us without us!”

-Disability rights activists

Ongoing HIV/AIDS crisis &
government inaction



Our Open Science



- Study population
Evolution over time

- Two-Spirit inclusion
Meaningful change

- Changing questionnaire
Developing and sharing
publicly

- Expansions
Geography and language

- Addressing policy
Creating or responding to
policy windows

- Returning results
Biological samples and data
visualizations

Display Settings

Which variable would you like to see displayed?
Knows about...U=U

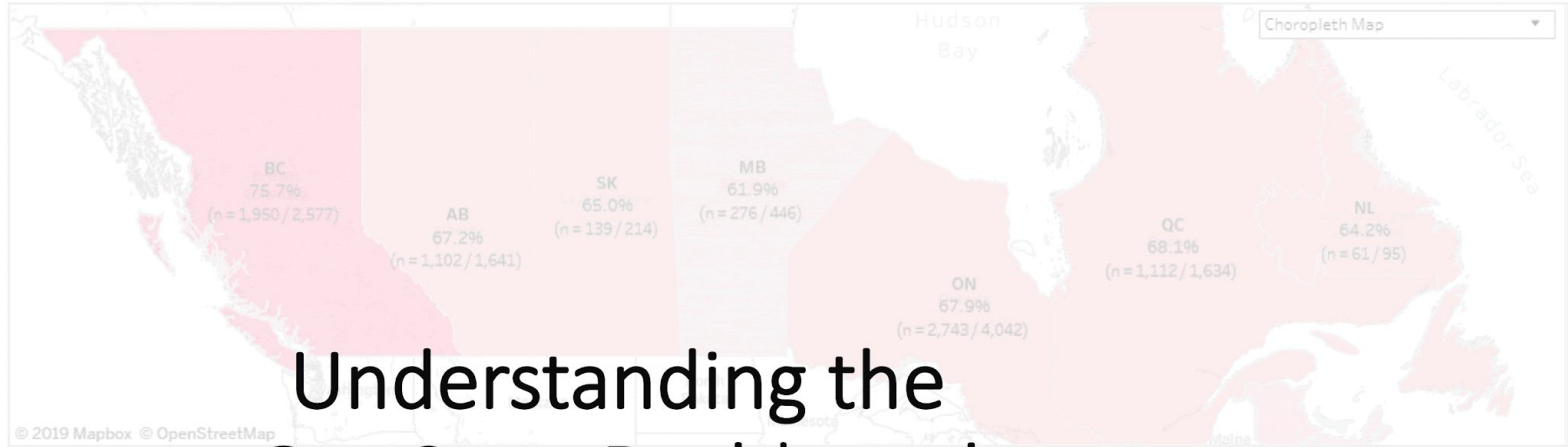
Which variable do you want to group the data by?
(None)

Which subset of participants do you want to see?
(All)

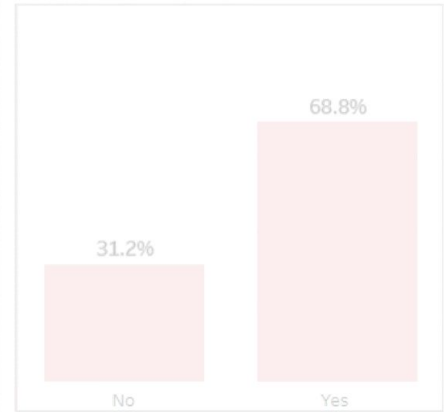
Which province?
(All)

Which years?
 All Years
 Sex Now 2015 (Online)
 Sex Now 2018 (In-person)

What level of geography?
 Province
 Health Region



Understanding the Our Stats Dashboard





Our Health:
Canada-Wide
2SLGBTQIA+
Community Study



Our Health:
Canada-Wide
2SLGBTQIA+
Community Study



Our Health:
Canada-Wide
2SLGBTQIA+
Community Study

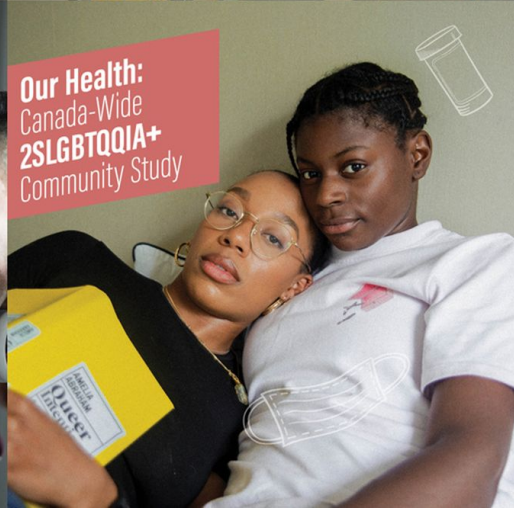
Case Study: Our Health



Our Health:
Canada-Wide
2SLGBTQIA+
Community Study



Our Health:
Canada-Wide
2SLGBTQIA+
Community Study



Our Health:
Canada-Wide
2SLGBTQIA+
Community Study

Open to all 2S/LGBTQQIA+ people

Connecting to CBRC evolving and growing as an organization

Complicating 'surveillance'

Language matters & approach matters

Community Engagement

Survey design, visual imagery, and more



The Four Healthiest, suggest their participants have comparable cost of general support field DEI programs to conducting these:

- 1. REACT WITH EMPLOYEE SUPPORT INSTEAD OF DETRAINING**
Organizations which do not have a solid DEI workforce are more likely to have a higher cost of doing business. DEI training without other organizational support is often not enough. "Our workplace had an issue where somebody made inappropriate comments in a meeting, and that had a ripple effect throughout the organization," says Pickett.
- 2. ALLOCATE ENOUGH RESOURCES TO DEI INITIATIVES**
"Often, the human resources who do these initiatives," says Khan. "So, when they don't get the human resources commitment, they wonder whether the program is worth investing in." That the number one issue in the

INTERNAL EMPLOYEE SUPPORTS
For many companies, participating in DEI programs and seeking out field-level employees are the ultimate goal of support for the LGBTQ+ community. Unfortunately, such internal support can be greatly enhanced by providing internal support programs.

Take the case of a health care provider in Florida. "We use this program of support from the company who provides all these messages saying, 'We support the LGBTQ+ community and we're here for you,'" says Pickett. Meanwhile, they ensure that it is

We want to hear from you! Take part in the Our Health Study.

Visit OH4Health.org or scan the QR code to access the study.

We want to understand what life is like for 250,000+ people across Canada and want to hear from you. How's your mental and physical health? Your spiritual wellness? Your romantic and/or sex life (if applicable)? How are you managing your chronic health condition? How has the COVID-19 pandemic affected

cbr.ca

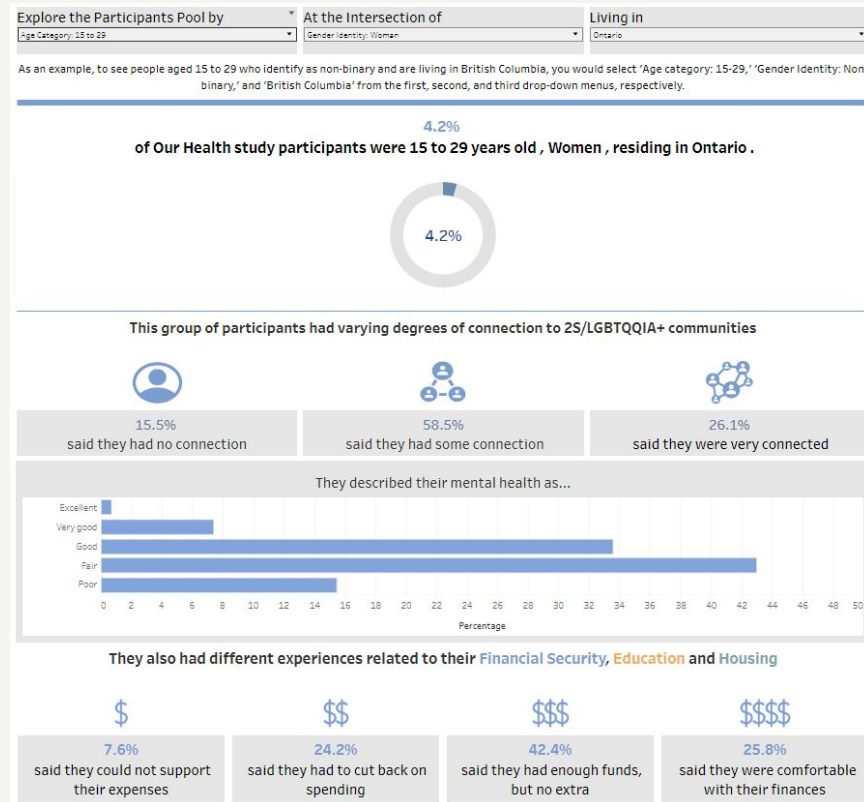
Trying new ways to reach community members



Data Democratization

Dashboard:

- in English & French
- For use on computer, phone, tablet
- Compatible with screen readers





Case Study

Investigaytors



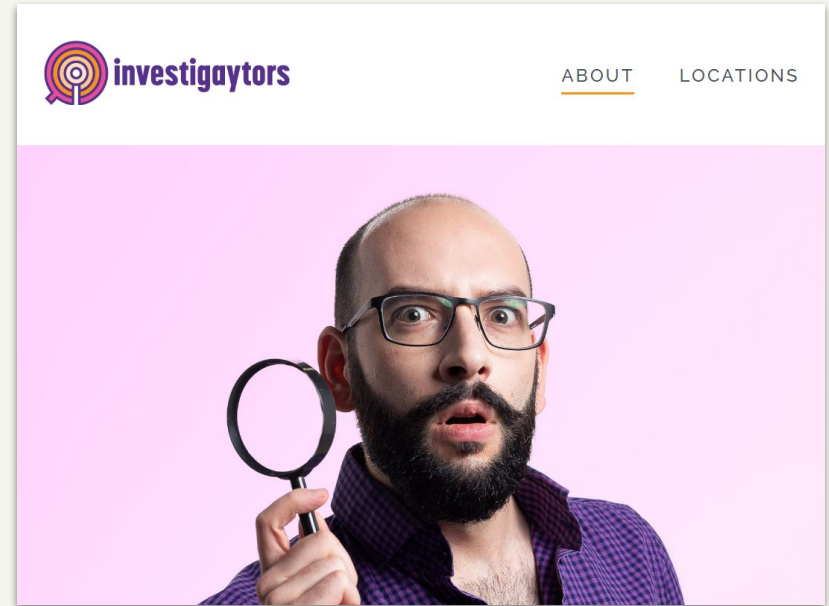
Investigaytors

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Participatory
Community-based
Capacity building

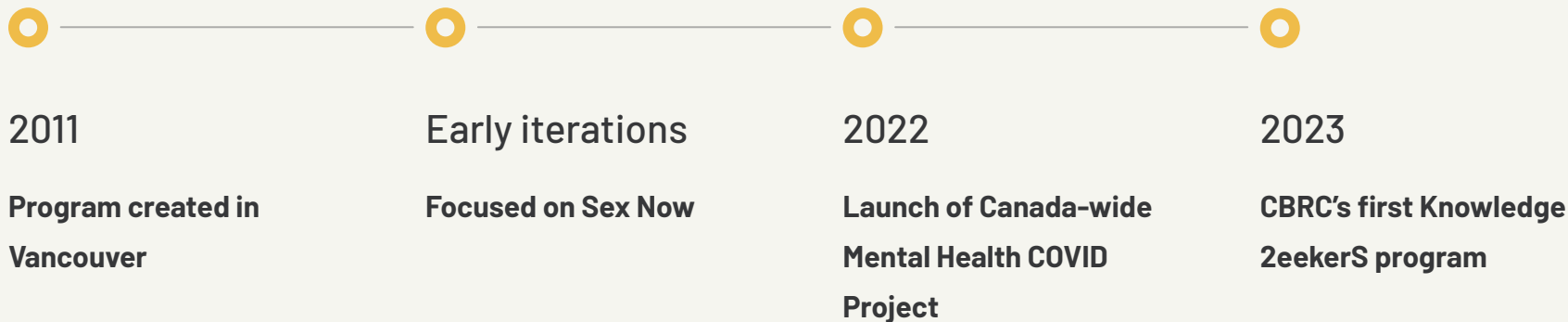
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2S/LGBTQQIA+
Hands-on
Health research



Screenshot of the Investigaytors website

Evolution



Investigaytors: Mental Health for Community

How has the COVID-19 pandemic affected the mental health of gay men?
A snapshot of the research conducted by the HIM Investigaytors group.



New research

Literature review, data analysis of Sex Now/Our Health surveys

Mobilizing knowledge

Primers, policy briefs, public website

Building capacity

Asynchronous learning modules, webinars





A few key takeaways...

A few questions...

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Thank you!

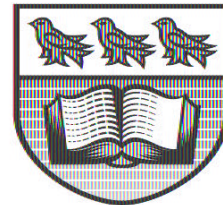
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