Community-Based Research and Open Science: Lessons Learned

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cbrc
Community-Based Research Centre

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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

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

Bach et al. 2017

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

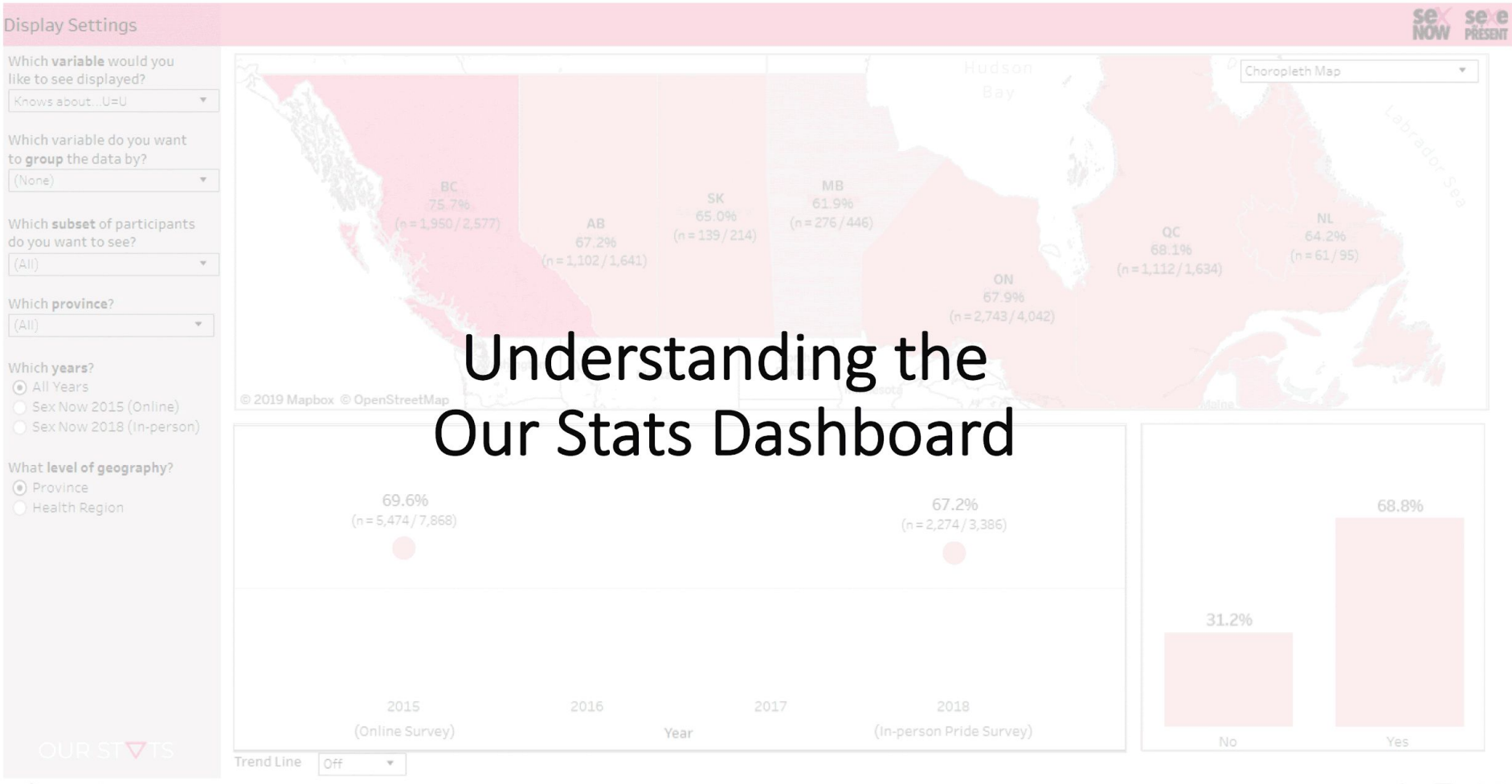
Geography and language

Addressing policy

Creating or responding to policy windows

Returning results

Biological samples and data visualizations



Understanding the Our Stats Dashboard

Our Health:
Canada-Wide
2SLGBTQQIA+
Community Study
Case Study:
Our Health

Open to all 2S/LGBTQQIA+ people

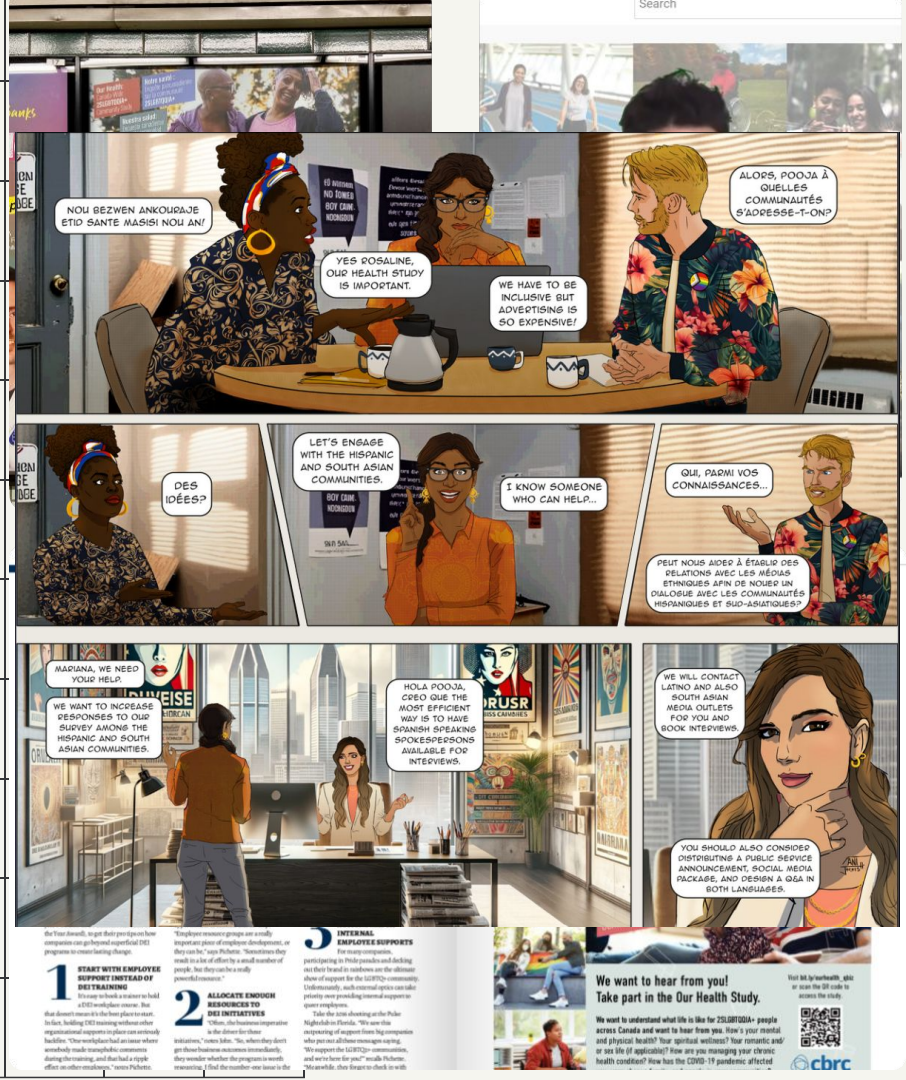
Connecting to CBRC evolving and growing as an organization

Complicating ‘surveillance’

Language matters & approach matters

Community Engagement

Survey design, visual imagery, and more



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

Investi*gay*tors

Investigaytors

1

Participatory

Community-based

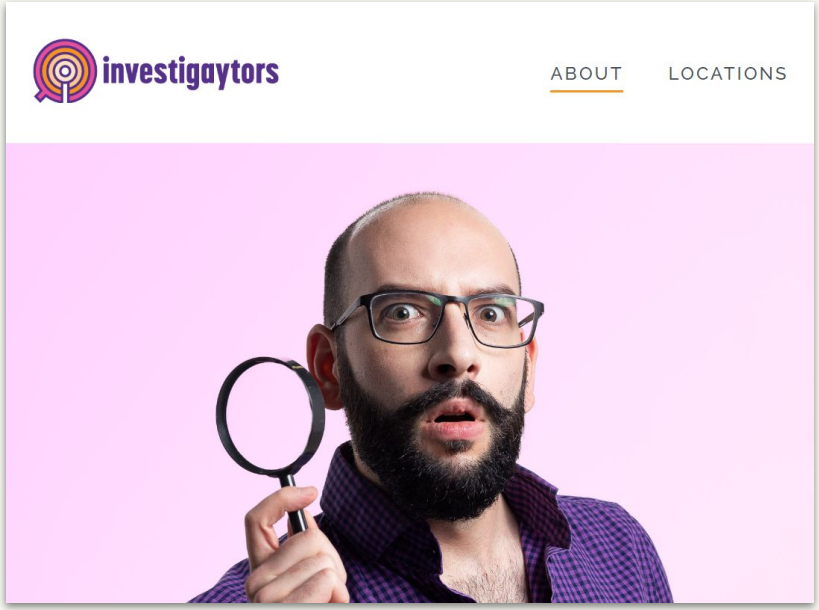
Capacity building

2

2S/LGBTQQIA+

Hands-on

Health research



Screenshot of the Investigaytors website

Evolution

- HIM (Vancouver, BC)
- QTHC (Edmonton, AB)
- VIllage Lab (Winnipeg, MB)
- CRUISELab (Toronto, ON)
- Qollab (Montréal, QC)
- SHaG Lab (Halifax, NS)

2011

Program created in Vancouver

Early iterations

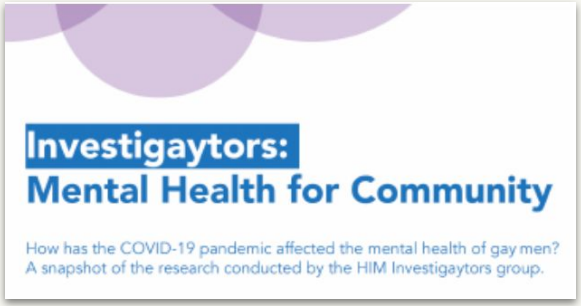
Focused on Sex Now

2022

Launch of Canada-wide Mental Health COVID Project

2023

CBRC's first Knowledge 2eekerS program



New research

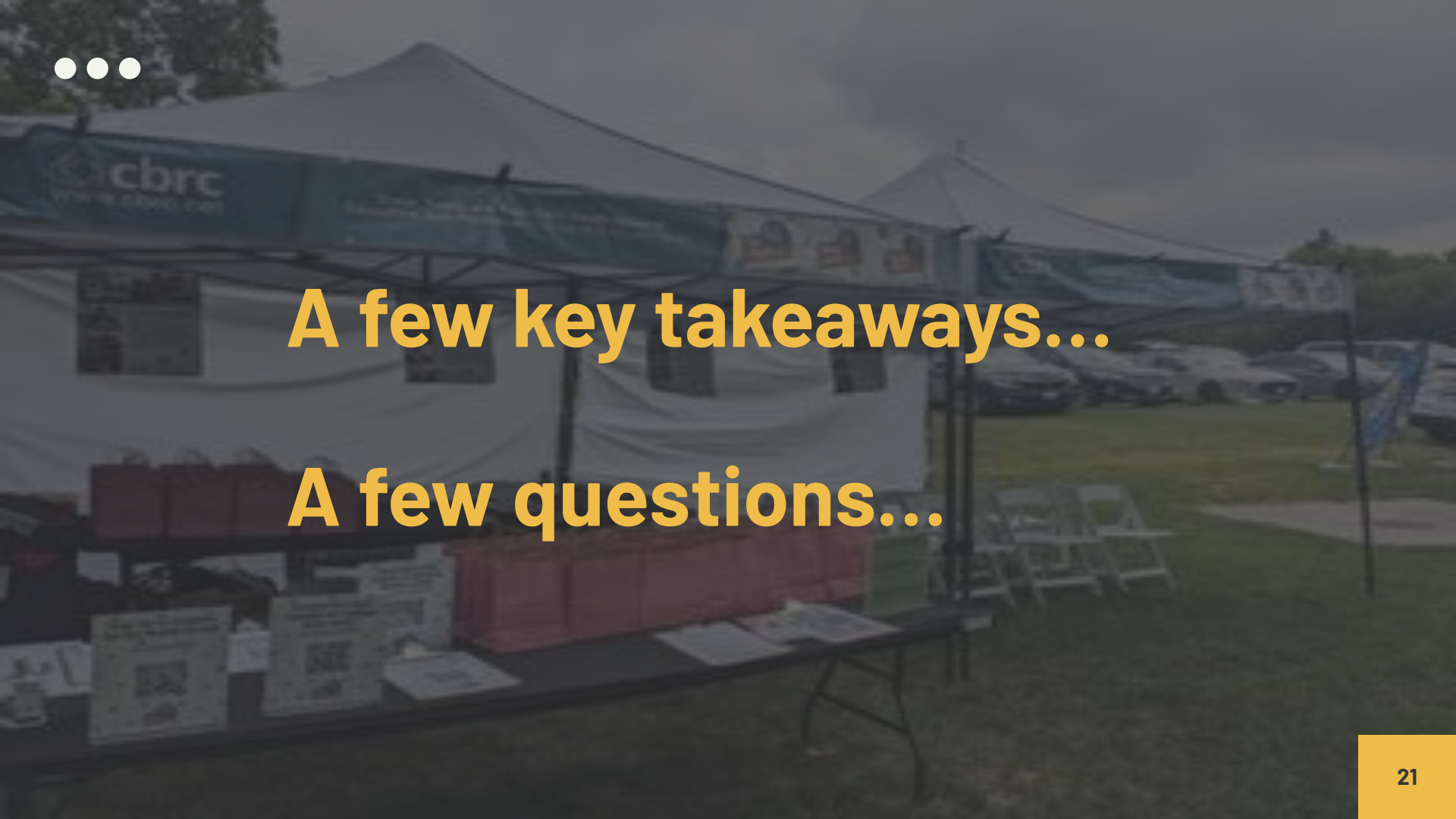
Literature review, data analysis of Sex Now/Our Health surveys

Mobilizing knowledge

Primers, policy briefs, public website

Building capacity

Asynchronous learning modules, webinars



A few key takeaways...

A few questions...

Thank you!

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