



UBC Health Disaggregated Data Dialogue Series

Using data to advance human rights:

A UBC dialogue about the collection and use of disaggregated data

UBC Health and its partners are committed to being part of ongoing conversations about the collection and use of disaggregated data. UBC Health exists to enable stronger interdisciplinary collaborations in education and research; collectively, we inform and influence systems of policy and practice to advance equity and the health of people in British Columbia. We convene, facilitate, and enable work in priority health-related areas that demand a collaborative approach. Data is one such priority.

Disaggregated Data Dialogue Series

This dialogue series reflects UBC Health's commitment to being part of conversations related to disaggregated data. By convening researchers and other colleagues from the Vancouver and Okanagan campuses as well as community members, we are part of the process of understanding how to achieve transparency about the stigma, discrimination and suffering of specific and identifiable groups. We will support the sharing of compelling messages of strength and resilience, enabling them to be amplified and heard clearly by those in power.

PART I: The grandmother perspective report

On January 14, 2021, we hosted a webinar to spark conversation between UBC and BC's Office of the Human Rights Commissioner on the collection of disaggregated data to advance human rights. During this session, over 140 participants heard the BC Human Rights Commissioner Kasari Govender, Trish Garner, Executive Director Research & Policy, and Gwen Phillips, BC First Nations Data Governance Initiative Champion and citizen of the Ktunaxa Nation speak about the [*Disaggregated demographic data collection in British Columbia: The grandmother perspective*](#) report. After the presentation, there was time for questions and discussion about the content and recommendations of the report. This webinar was the start of an ongoing conversation about how this report informs the responsibilities of researchers and UBC as an institution.

Disaggregated demographic data collection in British Columbia: The grandmother perspective

The BC's Office of the Human Rights Commissioner report is the foundation for this dialogue series. 2020 put a spotlight on data—particularly, detailed demographic data. The past year showed us how not having such information can limit our understanding of the causes of suffering and the concentration of that suffering within distinct groups. In September 2020, BC's Office of the Human Rights Commissioner published the *Disaggregated demographic data collection in British Columbia: The grandmother perspective* report. The report calls for the collection of data needed to develop policy that effectively addresses systemic inequalities—data that reflects the lived experiences of many, allowing their stories to be amplified and heard clearly by those in power. The report also includes recommendations for the collection and use of disaggregated demographic and race-based data to reveal and address systemic racism and inequities in our province and enable populations and communities to have meaningful control over data use. However, we acknowledge that the very same data that bring light to hidden truths can also be used to further entrench discrimination. Data, used or collected poorly, can reinforce stigmatization of communities, leading to individual and community harm. As an academic institution engaged in research, UBC has a responsibility to ensure that does not happen.



PART II: The responsibilities of researchers and UBC as an institution

On February 24, 2021, over 50 researchers and other colleagues from both campuses as well as community members convened for a focused discussion about the responsibilities of researchers and UBC as an institution around the collection and use of disaggregated data. The objective of this session was to continue and focus the conversations started during the January webinar and to:

- Identify the types of focused discussions that will facilitate thinking around how the Commissioner’s report informs the responsibilities of researchers at UBC and UBC as an institution.
- Facilitate a conversation between UBC and community, reflecting what individual researchers can do, and how to integrate community voice.
- Make explicit commitments for further discussions and actions.

The Ongoing Conversations

Participants who came together for Part II of the *UBC Health Disaggregated Data Dialogue Series* generously shared their ideas about what conversations we, as UBC and with community, need to be having around the issue of disaggregated data. There were five themes that emerged from these conversations:

Understanding the purpose of data collection

- How can we facilitate a foundational, broad understanding at UBC about what disaggregated data means?
- How do we ensure clarity on motive and purpose, including when data are intended to be “collected once and used many times”?
- Who, or what groups, are the focus of this discussion?
- What defines value for those who share their data?
- What do we owe to the people whose information we hold?
- Who is able to provide guidance? (research ethics boards, others?)

Data collection

- What is valid and/or credible information?
- What kind of data “should” we be collecting?
- Can/should research ethics boards evaluate research purpose, process, and tools with the lens of community-level harms? Is another entity required (e.g., community research ethics board)?
- How do we address the complexity of intersectionality—people don’t fit into boxes and identities are not fixed (e.g. multi-race background, difference between ethnicity and race)?
- How do we create a paradigm shift—re-thinking the entire idea of data “ownership”?

Data use and interpretation

- Who defines acceptable use?
- What resources are needed to support appropriate use?
- How do we handle/enforce/structure accountability?
- How do we support secondary use of disaggregated data? Are there additional considerations for data that are already collected but might not be in line with the recommendations in the report?
- How do we appropriately bring together “facts” and “narrative”?
- How do we consider the data source and the way that influences how we make interpretations?



Engagement

- How do we do this with communities?
- What do models of engagement look like practically?
- Who needs to be at the table, e.g. research ethics boards, data stewards, private sector, communities?
- How do we accommodate multiple perspectives?
- How do we talk about specific groups without further marginalizing?
- How do we ensure project timelines include relationship building and capacity building?
- How do we address the fact that it takes courage to stand up and stand out when you've had negative experiences?
- Can we develop tools for appropriate and meaningful community engagement?

Education

- What do training and education for students, staff, and researchers around the collection of disaggregated data look like?
- How do we introduce students to data-related ethics, algorithms etc.?
- How do we integrate training about community engagement and involvement?
- How do we support everyone to confront their own biases?
- How do we think about our role in educating the broader public around the use of data in research and related ethical principles?
- Can we develop common language, definitions, and standards?

Participants who came together for Part II also shared their ideas about the groups that need to be convened for focused discussions. These groups include, but are not limited to:

- Researchers
- Educators
- Students
- Practitioners
- Communities, members of the public
- Ethics offices
- Data custodians
- Corporate/private sector partners
- University admissions
- Appointment, promotion, and tenure committees

As we convene these groups, we will need to consider different ways for people to contribute to the conversation, ensure that we do not create barriers to joining the conversation, and provide resources to bring people together.

Next Steps

As a next step, UBC Health will be reaching out to participants and asking for volunteers to help plan the next set of conversations. These conversations could be formed around the themes identified in this report and should include the perspectives of the various groups noted above. Planning conversations will be organized for April 2021, with subsequent discussions to follow.