British Columbia's
Office of the Human Rights
Commissioner

Disaggregated data:
Summary of recommendations
to prevent harm to communities

Research brief | June 2021

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RESEARCH BRIEF | JUNE 2021

This publication can be found in electronic format on the website of British Columbia's Office of the Human Rights Commissioner: **bchumanrights.ca/datacollection/harm**

British Columbia's
Office of the Human Rights Commissioner

To the Indigenous peoples of this place we now call British Columbia:

Today we turn our minds to you and to your ancestors. You have kept your unceded homelands strong. We are grateful to live and work here.

Disaggregated data: Summary of recommendations to prevent harm to communities

In the fall of 2020, BC's Office of the Human Rights Commissioner (BCOHRC) released a report with recommendations on how to collect, store, use and disclose disaggregated data in a way that furthers the aims of equity and justice without reinforcing marginalization. Disaggregated data is important because when policy, practice and law are based on statistics, silences and omissions in data can cost human lives, human well-being and human rights. On the other hand, collecting data can cause numerous harms if not done well. This is a summary of BCOHRC's recommendations for mitigating those potential harms.

What is disaggregated data?

Disaggregated data is data that provides sub-categories of information, for example by ethnic group, gender, occupation or educational status. Sometimes this is called demographic data. Unlike aggregated data, which groups information together, disaggregated data can reveal inequalities and relationships between categories. By making visible the impacts of systemic racism, sexism and other forms of intersecting oppression, disaggregated data can inform systemic change.

Disaggregated data can cause harm

Disaggregated data is a tool. It can be used to advance equality and justice or to support oppression. Today, marginalized communities continue to live the consequences of data being used as a tool for control and surveillance.

"The grandmother perspective," offered by Gwen Phillips of the Ktunaxa Nation and BC First Nations Data Governance Initiative, offers a blueprint for using disaggregated data to leverage systemic change while minimizing risks to community. This approach centres the importance of a strong relationship between government or other researchers and the affected community. It envisions a shift from data as a tool of control to a tool of care. It is grounded in the concept of data sovereignty, where communities lead decision-making as much as possible and all processes centre community needs, experience and knowledge throughout the stages of data collection, storage, use (including analysis and interpretation) and distribution.

Specific harms and potential mitigation

To put the grandmother perspective into action, BCOHRC has offered several recommendations[1] to government designed to make sure disaggregated data promotes equality and justice.

As an overarching recommendation, we called for the establishment of a Community Governance Board empowered to make collaborative decisions with government on disaggregated data standards, including how data is collected, stored, used and distributed. Membership would include members of systemically oppressed communities for which data — such as race-based, Indigenous, gender and disability data — will be collected. A Community Data Secretariat provided by government would support this Board, including additional individual supports where necessary for meaningful participation to address financial, logistical and technological barriers.
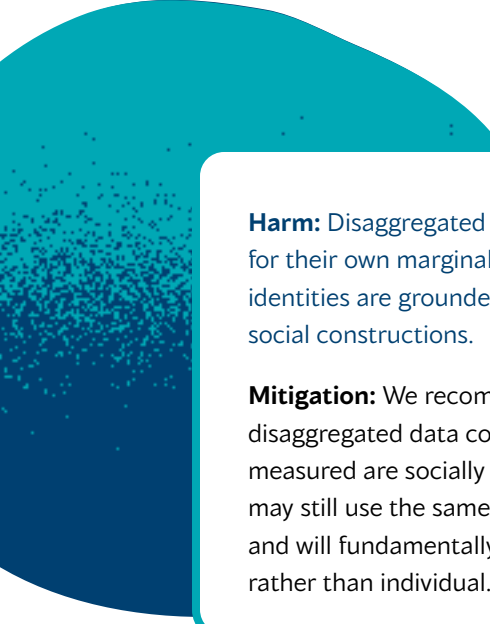
Harm: The collection of data relating to Indigenous peoples has often violated Indigenous sovereignty by ignoring the right of Indigenous communities to own and control their own data.

Mitigation: We recommend the development of a data governance model with Indigenous institutions and governments, based on nation-to-nation relationships, in support of self-determination and sovereignty.

Harm: Disaggregated data can reinforce stigma and systemic oppression against marginalized people and communities.

Mitigation: We recommend that data standards established under new legislation include a requirement to define the purpose of every disaggregated data project in relation to a specific equity goal. This maintains the focus on structural change and shifts the framing from individual failure to systems failure.

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[1] For the full set of recommendations, please refer to the full report, Disaggregated demographic data collection in British Columbia: The grandmother perspective.

Harm: Disaggregated data can reinforce the idea that individuals and groups are to blame for their own marginalization by portraying them as lacking in some way or implying that identities are grounded in innate biological differences rather than making them visible as social constructions.

Mitigation: We recommend that the development, design and implementation of disaggregated data collection be rooted in an understanding that the categories being measured are socially constructed rather than biologically defined. While the data collection may still use the same demographic categories, this lens may change the research questions and will fundamentally change analysis of the data, again highlighting the issues as systemic rather than individual.

Harm: Disaggregated data has been used as a tool of oppression and surveillance over marginalized communities.

Mitigation: We recommend that data standards established under new legislation include a requirement to identify the communities impacted by the systemic issue that each data project aims to address, establish a small working group with these communities, and empower members with decision-making authority. Communities should define the research questions, consider the use of disaggregated data as an appropriate tool and shape the approach to data collection, use and disclosure.

Harm: While disaggregated data is usually de-identified or stripped of personal information, rapid advances in technology have led to a growing risk for the re-identification of data.

Mitigation: We recommend implementing privacy protections in line with the Five Safes model that B.C.'s Data Innovation Program applies and extending the mandate of the Office of the Information and Privacy Commissioner to include the evaluation of complaints or concerns about the collection, use or disclosure of data covered by legislation.

These recommendations should be accompanied by a broad public education campaign and a comprehensive training program for public sector staff administering and analyzing demographic data.

Disaggregated data is a tool that has great potential to leverage systemic change, but its use must be grounded in an equity-based purpose and a process of building respectful relationships embodied in the grandmother perspective. We offer this approach as a way to consider individual and community harms and potential mitigation tactics in our shared commitment to achieve a more equitable and just society.