



British Columbia's
Office of the Human Rights
Commissioner

Disaggregated demographic data collection in British Columbia: The grandmother perspective



September 2020

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British Columbia's
**Office of the Human Rights
Commissioner**



September 2020

The Honourable Darryl Plecas
Speaker of the Legislative Assembly
Parliament Buildings
Victoria, B.C. V8V 1X4

Dear Mr. Speaker,

It is my pleasure to present the Human Rights Commissioner's Special Report, *Disaggregated demographic data collection in British Columbia: The grandmother perspective*.

The report is presented pursuant to section 47.24(1) of the Human Rights Code.

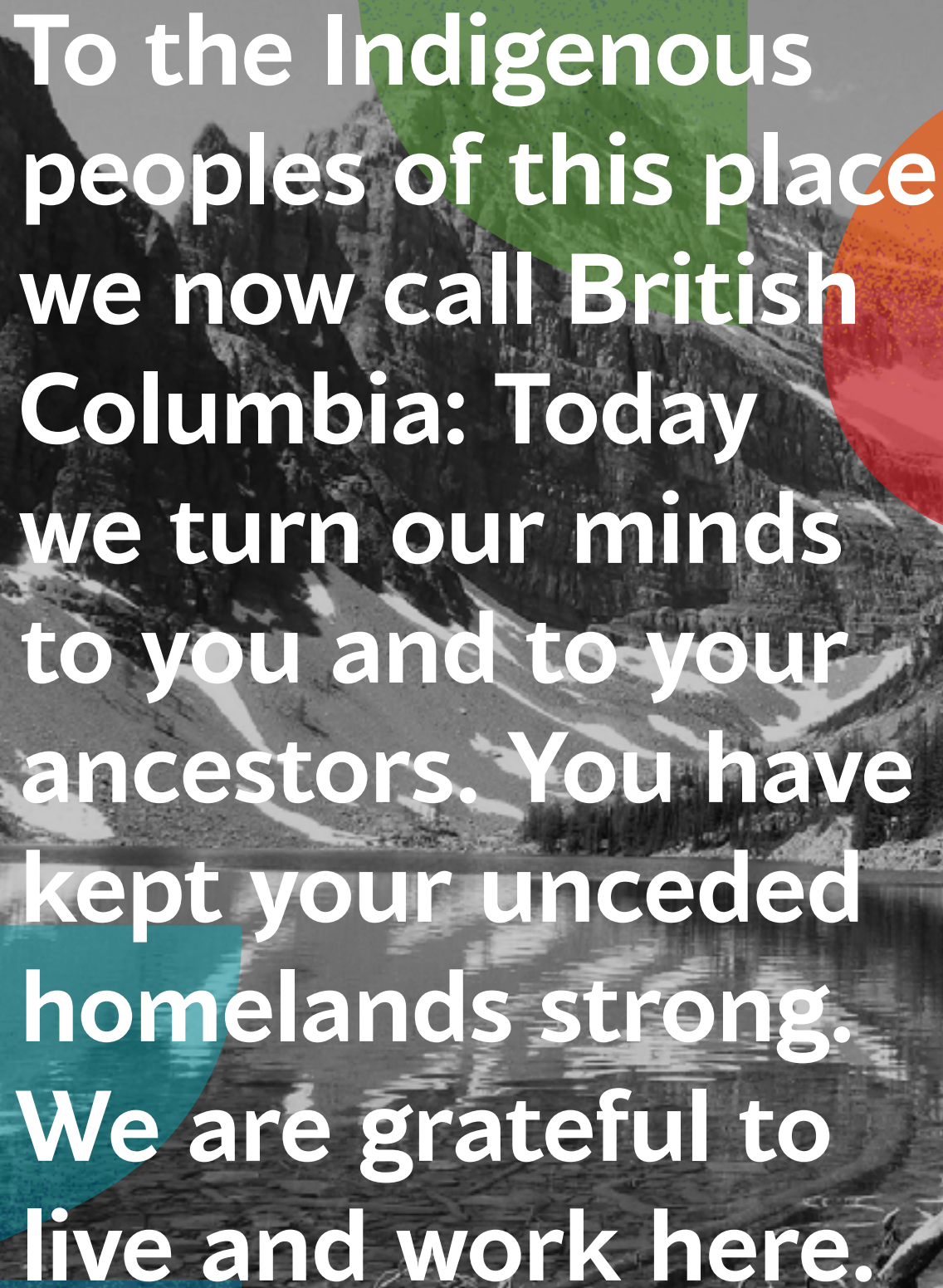
Sincerely,

A handwritten signature in black ink, appearing to read "Kasari Govender".

Kasari Govender
Human Rights Commissioner

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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.

Message from BC's Human Rights Commissioner

On June 5, 2020, I joined Human Rights Commissions from across the country in calling on all jurisdictions in Canada to start collecting race-based and other disaggregated data in relation to COVID-19. We joined a chorus of community voices calling for the collection of this data in order to address systemic discrimination—both in this moment of crisis during the COVID-19 pandemic and more generally. On June 16, 2020, Premier John Horgan invited me and Information and Privacy Commissioner Michael McEvoy to provide recommendations on how to collect, store, use and disclose disaggregated data in a way that furthers the aim of substantive social equality without reinforcing marginalization.

This report both answers and echoes the calls to collect disaggregated data to advance human rights. It emerges from decades of activism—particularly from communities of colour—calling for the data needed to develop policy that effectively addresses systemic inequalities. In other words, it calls—we call—for data that reflects the lived experiences of many, allowing their stories to be amplified and heard clearly by those in power.

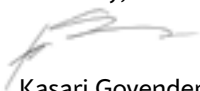
I am grateful for the contributions of those who shared their thoughts, expertise, experiences and fears with us as we developed this report. I am aware that this type of consultation, while vital, does not come without cost: that is, the emotional toll on members of marginalized communities who shared their trauma so that law, policy and institutional practices can be bettered.

I am grateful to Commissioner McEvoy and his team for their comments on the report's information access and privacy protection sections. Finally, I am grateful for the assistance of my team in preparing this report in short order. In particular, primary researcher and Executive Director of Research and Policy, Trish Garner, PhD, and supporting researcher and Manager of Research, Karen-Marie Elah Perry, PhD.

To policy makers who may be reading this report: like one of our key informants and community allies, Gwen Phillips, we urge you to adopt “the grandmother perspective” in the collection of disaggregated data. Rather than monitoring the lives of our citizens, collecting and using disaggregated data is about caring for our communities by informing law, policy and institutional practice that is in service of—and developed in collaboration with—those who are systemically discriminated against.

We cannot act on what we do not know. This is a call for knowledge. We cannot make change without first building the foundations of respectful relationship. This is a call to work alongside community in meaningful partnership. This is the time for commitments to address systemic racism and oppression across British Columbia and to move from words to real change. This is a call to action.

Sincerely,



Kasari Govender
BC Human Rights Commissioner



Kasari Govender
Human Rights Commissioner



British Columbia's
**Office of the Human Rights
Commissioner**

Executive summary

Some 56 per cent of Black Canadians report layoffs or reduced working hours during COVID-19.¹

Only 25 per cent of Indigenous communities in B.C. have basic internet access.²

More than 40 per cent of homeless youth are LGBTQ2S+.³

Powerful statements are made possible by disaggregated data.

By making systemic inequalities in our society visible, data can lead to positive change. The same data, used or collected poorly, can reinforce stigmatization of communities, leading to individual and community harm.

Disaggregated data is data that provides sub-categories of information, for example by ethnic group, gender, occupation or educational status. These are sometimes called **demographic categories**. People tend to provide this form of data through surveys that ask them to identify themselves in relation to these categories, or others. This information is then usually anonymized or de-identified — stripped of personal information like name or date of birth — and used in statistical analysis. Unlike **aggregated data**, which **groups information together**, disaggregated data can reveal inequalities and relationships between categories.⁴

On June 16, 2020, Premier John Horgan invited BC's Human Rights Commissioner and Information and Privacy Commissioner to inform the development of a policy initiative for the collection of race-based, Indigenous and other disaggregated data to address systemic racism. We accepted the invitation and have undertaken a research project over the last two months that included community consultation, an extensive literature review and policy analysis.

This report offers a framework for disaggregated data collection that is grounded in “the grandmother perspective” offered by Gwen Phillips of the Ktunaxa Nation, who is a BC First Nations Data Governance Initiative Champion. Fundamentally, this approach is centred on the **importance of relationship**:

“First Nations governments are not wanting to operate with the Big Brother mentality that we’ve all been groomed into believing in relation to what data does to us — it’s more like we want to come from the grandmother perspective. **We need to know because we care.**”

1. African-Canadian Civic Engagement Council and Innovative Research Group, 2020.

2. Union of BC Indian Chiefs, 2020.

3. True Colours United, 2020. LGBTQ2S+ refers to Lesbian, Gay, Bisexual, Transgender, Queer, Two-Spirit and other gender and sexual minorities.

4 Right to Education, 2017.

We apply a framework that defines the important difference between tools, process and purpose.⁵ **Disaggregated data is merely a tool (to be utilized depending on the context and aim) and it must be accompanied by a process that supports the purpose of reducing systemic racism and oppression and achieving equity.**

Without a well-defined and articulated process and purpose, there is more risk of disaggregated data doing harm. Multiple voices emphasize that collecting data on social determinants of inequalities without structural change can perpetuate inequity.^{6,7,8} After considering the benefits and risks of disaggregated data in this report, we describe the cornerstones of process and purpose in order to achieve the benefits and mitigate against the risks.

Without this approach, there is a danger of focusing on the wrong thing. As Gwen Phillips says, “we are not measuring race, we are measuring racism. Racism is a systems failure; that must be made clear when talking about race-based data.”

In sum, the framework is as follows:



PURPOSE

The elimination of systemic racism and oppression and the cultivation and maintenance of equity



PROCESS

Respectful relationship grounded in community governance



TOOL

Disaggregated demographic data (if appropriate to achieve purpose)

The process of respectful relationship, where marginalized communities are meaningfully involved throughout the stages of collection, storage, use and distribution of disaggregated data, is critical, and principles and recommendations for government in building respectful relationship (defined as relevant, responsible, reciprocal and reflexive⁹) form the bulk of this report. This is a shift from control to care, aligned with the grandmother perspective.

There are also concrete, practical aims to centring positive community relationships: response rates to demographic surveys increase when respondents’ communities are engaged in the design and development of disaggregated data collection. At the outcome stage, this also allows for quicker adoption of solutions by impacted communities, whereas paternalistic models tend to have difficulties promoting uptake of their programming.

Further, multiple participants in our community consultations emphasize that **relationship change precipitates systems change**. We need to do research differently in order to make a difference.

5 Meeting with Kwame McKenzie, August 10, 2020.

6. Smith, 1999.

7. Boilevin et al., 2019.

8. Black Public Health Collective, 2020.

9. Thira, Sharon. “July 28th, Note on Theory in Progress, Re-Thinking the Four Rs,” 2020.

Recommendations

The Anti-Discrimination Data Act

We recommend the development of legislation that is focused on building respectful relationships with marginalized communities to ensure that community needs and voices are meaningfully included in data collection, use and disclosure processes. As experts in their own lives, community members are the ones best equipped to identify priorities and risks in potential data collection projects.

When collecting, using and disclosing disaggregated data, it is important to adequately consider and address both individual harm and community harm. The current legislative framework in B.C. is structured to mitigate individual harm through the protection of individual privacy, but does not adequately consider or protect communities from harms associated with the collection, use and disclosure of disaggregated data, and makes only limited references to “public interest.”¹⁰ Our recommendations address this gap by calling for meaningful consideration of community harm and for the creation of an obligation to conduct responsible, equity-supporting research in collaboration with communities. We also call for protections against individual harm to be updated in response to modern challenges to personal privacy.

We recommend that the government draft the **Anti-Discrimination Data Act (ADDA)**, which would legislate the collection, use and disclosure of demographic data for social change. We also recommend that the government develop the ADDA in consultation with BC’s Office of the Human Rights Commissioner and the Office of the Information and Privacy Commissioner for British Columbia.

The purpose of the ADDA would be to support the BC Human Rights Code, which was established for structural change, including “to identify and eliminate persistent patterns of inequality associated with discrimination prohibited by this Code.”¹¹ In addition, the ADDA must also serve the purposes of the Poverty Reduction Strategy Act¹² and the Declaration on the Rights of Indigenous Peoples Act (DRIPA).¹³ Social condition (or poverty) and Indigeneity are not currently protected within the BC Human Rights Code but demographic data in relation to these areas is important for identifying and eliminating “persistent patterns of inequality associated with discrimination.”¹⁴

The ADDA would also support the B.C. government’s adoption of Gender-Based Analysis Plus (GBA+), which is an analytical tool applied across government to assess differential impacts of policies, programs and initiatives on diverse groups of women, men and gender-diverse people with considerations of intersectional socio-demographic factors such as race, ethnicity, income, age and disability.¹⁵

The ADDA builds on B.C.’s existing Data Innovation Program (DIP). The Program’s approach to protecting the disclosure of demographic data across public bodies offers a strong framework that should be reflected in legislation and in practice. DIP is a good model for the analysis of data on equity-related subjects, particularly those that engage potentially sensitive information, such as sexuality, gender, race,

10. See for example FIPPA, ss 25 and 35(1)(b).

11. Human Rights Code, s. 3(d).

12. Poverty Reduction Strategy Act, S.B.C. 2018, c. 40.13.

14. Declaration on the Rights of Indigenous Peoples Act, S.B.C. 2019.

15. Government of British Columbia.

substance use or homelessness. This is because it treats de-identified data (no personal identifiers such as name and address) with the same level of confidentiality as personal information. Today's technology landscape increases the risk of re-identification of de-identified data — in other words, there is a real possibility of data being connected back to the person. DIP's approach is in line with the trend in privacy legislation to move toward the protection of de-identified data as well as personal information. The program applies the internationally recognized Five Safes model as its privacy and security framework — Safe: People, Projects, Data, Settings, Outputs.

The ADDA would set out a framework for the collection, use and disclosure of disaggregated demographic data and should include provisions that outline:

- **Privacy protections in line with principles of B.C.'s Data Innovation Program** including the FiveSafes model, the protection of de-identified data and personal identifiable data and the completion of privacy impact assessments with full consideration of potential individual and community harms.
- **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.
- **The establishment of a Community Governance Board to make collaborative decisions with government**,¹⁶ whose membership shall include members of systemically oppressed¹⁷ communities for which data — such as race-based, Indigenous, gender and disability data — will be collected. This approach supports the intersectionality of our identities and lives. This Board will be engaged in development of a data governance model, including agreements on sharing information.
- **A Community Data Secretariat** to provide backbone support to this Board, including additional individual supports where necessary for meaningful participation to address financial, logistical and technological barriers.
- **The establishment of data standards as defined by the Community Governance Board and broad engagement with communities** (see below for details).
- **The extension of 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 this legislation.

The introduction of this the ADDA should be accompanied by the **implementation of a comprehensive training and education program**. This will include training for public sector staff administering and analyzing demographic data surveys and a broad public education campaign to increase awareness of the benefits of disaggregated data collection and the enhanced privacy protections associated with these data initiatives.

Data standards

As referenced above, the proposed ADDA includes a mandate to develop data standards to provide guidelines for the collection of data. We also recommend a framework for these data standards, which includes an equity impact assessment process that a data project should comply with in order to be

16. Based on the model defined within the E-GAP framework: Bailey et al., 2020.

17. Mandating government engagement on the right of the IAP2 spectrum: Collaborate.

approved. This framework includes three components: defining the **purpose** of the project, setting up a respectful **process** and defining the scope and limitations of the **tool** (data collection, use and disclosure) with community. The project-specific responses to the assessment tool must then be embedded in an Information Sharing Agreement to provide an adequate and appropriate accountability mechanism for the project in relationship with community.

Immediate targeted opportunities

There is a responsibility to act when missing data can result in a loss of human life.¹⁸ Numbers matter. Ongoing silences in data have harmed the most systemically oppressed communities. While participants emphasized the importance of slowing down and building respectful relationships, they also emphasized that too much focus on research can stall actions that can save lives when communities have already identified clear and present dangers and solutions.

While government is establishing the legislative framework to support community data governance for equity-seeking projects, we recommend that the government immediately start collecting disaggregated demographic data in these areas: health care, mental health, policing, corrections, poverty reduction, education, gender-based violence and children and family development.

Next steps

We have learned an enormous amount from community experts through this project. While disaggregated demographic data has significant power to reveal systemic inequalities and lead to positive policy, there are also significant dangers in relation to individual and community harm. To achieve these benefits and avoid the dangers, the Anti-Discrimination Data Act and the associated data standards must embed “the grandmother perspective” of data governance as caring not controlling through the provision of practical, concrete methods of data collection, use and disclosure.

Coming full circle, in gratitude for the generous gifts of time and knowledge from communities, we hope this report gives back to communities by providing the framework for a new governance model to ensure the collection, use and disclosure of disaggregated demographic data benefits communities.

We appreciate the opportunity to provide these recommendations to the Legislative Assembly. We look forward to working together to ensure the human rights of British Columbians are protected now and for the future.

“While disaggregated data has significant power to reveal systemic inequalities and lead to positive policy, there are also significant dangers of individual and community harm. To achieve the benefits and avoid the dangers, B.C. must embed ‘the grandmother perspective’ of data governance: caring, not controlling.”

18. See Caught in the Middle, a report from the Representative for Children and Youth which describes the circumstances surrounding the death of a young person. The collection of data on ethnicity could have helped in this situation and is one of the recommendations: https://rcybc.ca/wp-content/uploads/2019/12/rcy-caught-in-the-middle_nov2019-webversion.pdf



Introduction

*“First Nations governments are not wanting to operate with the big brother mentality that we’ve all been groomed into believing in relation to what data does to us—it’s more like we want to come from the grandmother perspective. **We need to know because we care.**”*

This report offers a framework for disaggregated data collection that is grounded in “the grandmother perspective” offered by Gwen Phillips of the Ktunaxa Nation, who is a BC First Nations Data Governance Initiative Champion. Fundamentally, this approach is centred on the **importance of relationship**: a reimagining of the community relationships within which data collection occurs and a primacy given to those relationships as both process and product as governments and organizations move toward data collection to address systemic inequities.

Given the short timeline of this project at the invitation of the Premier, we acknowledge that we were only able to start the process of building relationship but were unable to embed this throughout the research project.

Despite this shortcoming, we offer these reflections on the benefits and risks of disaggregated data collection, use and disclosure with the aim to honour community and advance the conversation about social justice in B.C. While we provide a human rights lens to this issue, the themes outlined here have been highlighted many times by community leaders for many decades and we seek to amplify those voices. We raise our hands to the work that has come before us and we acknowledge the weight of that work on those with most at stake in this conversation: Indigenous peoples and communities, racialized people, women, people with disabilities, queer and trans people, those in poverty and other systemically oppressed groups.

In fall of 2019, the Government of BC introduced the Declaration on the Rights of Indigenous Peoples Act, which has as its purpose: “to affirm the application of the Declaration [United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)] to the laws of British Columbia; to contribute to the implementation of the Declaration; to support the affirmation of, and develop relationships with, Indigenous governing bodies.”¹⁹

Article 19 of UNDRIP outlines that: “States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them.”²⁰ As such, there is a responsibility for government to work directly with Indigenous peoples through their own governance systems on the issue of disaggregated data.

19. Declaration on the Rights of Indigenous Peoples Act, SBC 2019, c.44.

20. United Nations, 2007.

While the nation-to-nation relationship that grounds engagement with Indigenous communities is unique, the principles of respectful relationship outlined in this report extend beyond Indigenous communities to other racialized and marginalized communities.

We live in a society that continues to be structured by racism, colonization and other forms of intersecting systemic oppression. Legislation, government policy, institutional and individual practice, as well as the cultures we live in, perpetuate these power structures and the impact is inequitable access to resources, power and opportunities for systemically oppressed groups. For instance:

- 56 per cent of Black Canadians report layoffs or reduced working hours during COVID-19²¹
- Only 25 per cent of Indigenous communities in BC have basic internet access²²
- 40 per cent of homeless youth are LGBTQ2S+²³

These powerful statements are made possible by disaggregated data. By making systemic inequalities in our society visible, data can lead to positive change. The same data, used or collected poorly, can reinforce stigmatization of communities, leading to individual and community harm.



21. African-Canadian Civic Engagement Council and Innovative Research Group, 2020.
22. Union of BC Indian Chiefs, 2020.
23. True Colors United, 2020.



Background

Who we are: BC's Human Rights Commissioner

The role of BC's Human Rights Commissioner was established in 2019 by the Legislative Assembly of British Columbia. The province had been without a Commissioner since 2002. This has left a gap in understanding and awareness of human rights in B.C. The creation of the Commissioner role signals a renewed provincial commitment to human rights and presents an important opportunity to address inequality and injustice in our communities.

BC's Office of the Human Rights Commissioner (BCOHRC) envisions a province free from inequality, discrimination and injustice where we uphold human rights for all and fulfil our responsibilities to one another. We strive to address the root causes of these issues by shifting laws, policies, practices and cultures and do this work through education, research, advocacy, inquiry and monitoring.

Why we are doing this work

British Columbia is a diverse province

With a current population of approximately 5.1 million, a high rate of international immigration, hundreds of unique First Nations communities and a variety of urban and rural regions, B.C. is one of Canada's most diverse provinces:^{24,25}

- According to the latest Census data (2016), almost one in three British Columbians reported that they were a "visible minority"²⁶ (30.3 per cent), up slightly from 2011 (27.3 per cent).²⁷ Amongst this group, Chinese (11.2 per cent), South Asian (eight per cent) and Filipino (3.2 per cent) are the largest racial categories,²⁸ with China, India and the Philippines being the main countries of birth of immigrants, along with the United Kingdom.²⁹ Black people make up one per cent of the population of B.C.³⁰ From Swahili to Yiddish and Nisga'a, there are also a wide range of languages spoken in the province.³¹
- Half of all same-sex couples in Canada reside in either Toronto, Montréal, Vancouver or Ottawa–Gatineau.³² Within B.C., Vancouver in particular is known for its large and diverse LGBTQ2S+ communities.³³

24. Government of British Columbia, 2020a.

25. Statistics Canada, 2016.

26. This reflects the language used in the Census, which is now an outdated descriptor.

27. Government of British Columbia, 2017.

28. Statistics Canada, 2016.

29. Government of British Columbia, 2017.

30. Statistics Canada, 2016.

31. Ibid.

32. Ibid.

33. City of Vancouver, 2020.

- The province’s disability communities are also diverse, including people who are deaf, are blind, have mobility issues, live with pain or have mental health issues.³⁴ Young people are more likely than older people to report learning or mental health related disabilities and most Canadians reporting a disability have more than one type of disability.³⁵
- While the 2016 Census records approximately 90,000 more women than men living in BC,³⁶ the 2020 Census will fill an existing data gap in providing non-binary options, expanding categories for capturing gender diversity in the province.³⁷
- B.C. has the second highest poverty rate in Canada³⁸ and there are significant discrepancies in wealth and income across the province. Recent immigrant children, Indigenous children and racialized children experience disproportionate rates of poverty.³⁹

It is disaggregated demographic data that shows us this diversity and has the potential to make systemic inequalities between and within these diverse categories visible. Many British Columbians belong to multiple, overlapping communities so it is important to capture the intersections of diverse demographic categories.

At the same time, we must be careful not to use these population figures as indicators of the scale of the issues facing these communities. While the Black population in B.C. is one per cent of the total, experiences of systemic racism are clearly significant for Black people. As Dr. June Francis, Director of the Institute for Diaspora Research and Engagement at SFU, and Chair of the Hogan’s Alley Society, explains:

So, we count, we find categories, we tick boxes, and we try and figure out how many people belong where. ... When you do that, one of the implications you have is that the value or the immensity of the problem is somehow related to the number of people. So, if you have a group that has been completely disenfranchised ... how have they been disadvantaged? What has been the impact on them? Then this quantitative data may actually act to obscure and harm because suddenly we get told, “there aren’t enough of you.” The Black community faces that: “Well, there aren’t enough of us because of you, right? You screened us out of your border. You did all kinds of ways to exclude us, and our history is one of erasure. So, you don’t even know anything about us.” So, I’m just bringing that up. Because I know in many places, we see this way in Indigenous numbers as well, where the debt of what the society owes cannot be measured by their numbers, because actually you did a lot to reduce those numbers.

34. Statistics Canada, 2020a.
 35. Statistics Canada, 2018b.
 36. Statistics Canada, 2016.
 37. Statistics Canada, 2020b.
 38. Statistics Canada, 2018.
 39. First Call BC, 2019.

Disaggregated data can advance human rights

Indigenous and community-based organizations,⁴⁰ Indigenous, federal⁴¹ and provincial governments⁴² and health authorities⁴³ in British Columbia are increasingly examining social determinants of inequalities and the merits of more robust disaggregated demographic information as a tool to address inequalities. While researchers in the United States have collected complex demographic information on systemically oppressed populations for over a decade in a variety of areas, including education,⁴⁴ health care⁴⁵ and the penal system,⁴⁶ Canada has been slow to adopt advanced demographic data collection techniques.

Disaggregated data is data that provides sub-categories of information, for example by ethnic group, gender, occupation or educational status. These are sometimes called **demographic categories**. People tend to provide this form of data through surveys that ask them to identify themselves in relation to these categories, or others. Unlike **aggregated data**, which **groups** information together, disaggregated data can reveal inequalities and relationships between categories.

The collection of disaggregated data is a human rights issue and can be used as a powerful tool in advancing human rights. In their report, “Count Me In! Collecting Human Rights-Based Data,” the Ontario Human Rights Commission addresses the misconception that many people may have in thinking that collecting and analyzing data that identifies people by race, sex, disability, and other protected grounds is discriminatory and not allowed.⁴⁷ BCOHRC highlights that collecting data for a human rights purpose “is permitted, and is in accordance with Canada’s human rights legislative framework, including the Code, the Canadian Human Rights Act, the federal Employment Equity Act, and section 15(2) of the Charter of Rights and Freedoms.”⁴⁸ Further, “data collection can play a useful and often essential role in creating strong human rights and human resources strategies for organizations in the public, private and non-profit sectors.”⁴⁹

On June 5, 2020, BC’s Human Rights Commissioner joined representatives from 10 other Commissions across Canada in a joint letter coordinated by the Canadian Association of Statutory Human Rights Agencies (CASHRA) to the federal government (and also BC’s Minister of Health and Provincial Health Officer) calling for a national strategy for the collection of disaggregated health data.⁵⁰ This letter echoed multiple stakeholders, academic and community leaders, and international human rights bodies decrying the absence of this form of comprehensive data in Canada in relation to COVID-19 as the disproportionate impacts of the pandemic on those most marginalized in our communities became clear.

40. Union of BC Indian Chiefs and the BC Civil Liberties Association, 2018.

41. Government of Canada, 2020a.

42. BC Premier’s Office, 2020.

43. Vancouver Coastal Health, 2013.

44. Brey et al., 2019.

45. Cantor and Thorpe, 2018.

46. The Sentencing Project, 2018.

47. Ontario Human Rights Commission, 2010.

48. Ibid.

49. Ibid.

50. Boullard, 2020.

On June 16, 2020, the Premier invited BC's Human Rights Commissioner and the Information and Privacy Commissioner to inform the development of a policy initiative for the collection of race-based, Indigenous and other disaggregated data to address systemic racism.

In particular, the Premier requested advice on:

- Issues arising from race and ethnicity-based data collection and dissemination of disaggregated data that protects individual privacy
- Examples of standards for data collection or management that can be applicable in a British Columbian context
- Gaps and shortcomings in currently available data sets
- The need for an intersectional lens that examines race and ethnicity as well as class, gender, geography, immigration status and the challenges of first-generation immigrations and other data points
- Methodologies for gathering and reporting statistics in a credible and permanent manner
- Transparency policies to ensure disaggregated data is available for scholars, academics, public policy analysts, non-profit and community organizations
- How such a system could be implemented to support the development of a national standard on collection and best practices for procedures
- How race and ethnicity-based data collection can be applicable across multiple ministries, including differential impacts and outcomes of government policy on housing, education, policing, poverty reduction and health care⁵¹



51. BC Premier's Office, 2020.

Our aim is to provide foundational principles that the BC government should hold when they undertake disaggregated data collection to address systemic racism and other forms of oppression, targeted recommendations to embed these principles in a legislative framework and immediate recommendations to move forward on specific data projects.

Overview of project

What we are doing: Offering foundational principles and targeted recommendations

The B.C. government often collects data on Indigenous people in health, education, justice and other sectors, in accordance with the Government Standard for Aboriginal Administrative Data for the defined purposes of “culturally appropriate, effective and efficient policy, program and service development; performance management and measurement; and socio-economic research, analysis and reporting.”⁵² However, the collection of other disaggregated data is far more uncommon and there are no associated data standards. The B.C. Data Catalogue, which is a repository of datasets owned or used by the B.C. government, includes 31 sources in relation to Indigeneity and only 16 for ethnicity.⁵³ As an example, the Ministry of Children and Family Development collects data on children in care in relation to Indigeneity but not consistently in relation to race, ethnicity, sexual orientation, gender identity or other categories.⁵⁴ It is in this context of limited and inconsistent disaggregated data collection that BCOHRC takes up the Premier’s request in providing recommendations.

Scope and limitations

Given the original timeline of the Premier’s request to receive recommendations by September 2020, we are not providing a comprehensive response to all the issues described in the Premier’s letter, which covers multiple categories across ministries and across jurisdictions. Our aim is to provide foundational principles that the B.C. government should hold when they undertake disaggregated data collection to address systemic racism and other forms of oppression, targeted recommendations to embed these principles in a legislative framework and immediate recommendations to move forward on specific data projects.

In support of these recommendations, we:

- Consider the risks and benefits of data collection and dissemination of disaggregated data in relation to race, ethnicity, Indigeneity, class, gender, geography, immigration status and other data points
- Provide and build on examples of community-led standards for the collection, use and disclosure of disaggregated data that could be used in a B.C. context
- Embed intersectionality as a necessary approach in all elements of data projects: collection, use and disclosure
- Provide methodologies that are grounded in community ownership for gathering and reporting statistics, in the context of existing privacy legislation

52. Ministry of Aboriginal Relations and Reconciliation Intergovernmental and Community Relations, 2007.

53. Government of British Columbia, 2020b.

54. The Representative of Children and Youth has made this recommendation in relation to the collection of data on ethnicity: https://rcybc.ca/wp-content/uploads/2019/12/rcy-caught-in-the-middle_nov2019-webversion.pdf

- Consider transparency through the lens of community-controlled access to disaggregated data about themselves
- Consider the risks and benefits of standardization across ministries and jurisdictions for a provincial and national standard respectively

Throughout, we are primarily focused on quantitative data so, for shorthand in this report, we will use the term “data” to mean “quantitative data.” We emphasize this because the reduction and erasure of other forms of data can propagate a colonial approach to research through the prioritization of numbers over stories, voices and other rich sources. It is a significant problem when calls for justice by systemically oppressed communities are ignored until numbers are available. That said, numbers — in the form of quantitative data — can be an important tool for leveraging social change, and the aim of this report is to advise the government on how to use such a tool in service of human rights rather than as a roadblock or weapon. A primary method to ensure this is to include other sources, such as qualitative data like storytelling, in order to provide an appropriate, intersectional, in-depth analysis that does not contribute to further harm. Data, without context, is meaningless. It is the combination of stories and numbers that create the clearer picture needed to properly address the key issues facing marginalized communities.

Our framework

Dr. Kwame McKenzie, physician and full professor in the Department of Psychiatry at the University of Toronto, emphasizes the important difference between tools, process and purpose.⁵⁵ Disaggregated data is merely a tool (to be utilized depending on the context and aim), and it must be accompanied by a process that supports the purpose of reducing systemic racism and oppression and achieving equity.

The collection of socio-demographic and race-based data is not an end in itself. It is one of many tools that may be used to promote health equity. The data needs to be appropriately analyzed as part of a clearly articulated plan for the development and implementation of equity focused interventions if it is to help reduce disparities.⁵⁶

Without a well-defined and articulated process and purpose, there is more risk of disaggregated data doing harm. Multiple voices emphasize that collecting data on social determinants of inequalities without structural change can perpetuate inequity.^{57,58,59} After considering the benefits and risks of disaggregated data in this report, we describe the foundational principles of process and purpose in order to achieve the benefits and mitigate against the risks. Disaggregated data as a tool should not be used without these foundations, and these principles of process and purpose must be applied at every stage of a disaggregated data initiative: collection, storage, use and disclosure.

55. Meeting with Kwame McKenzie, August 10, 2020.

56. Bailey et al., 2020.

57. Smith, 1999.

58. Boilevin et al., 2019.

59. Black Public Health Collective, 2020.

Without this approach, there is a danger of focusing on the wrong thing. As Gwen Phillips says, “we are not measuring race, we are measuring racism. Racism is a systems failure, that must be made clear when talking about race-based data.”

Our framework is as follows:



PURPOSE

The elimination of systemic racism and oppression and the cultivation and maintenance of equity



PROCESS

Respectful relationship grounded in community governance



TOOL

Disaggregated demographic data (if appropriate to achieve purpose)

In relation to purpose, it is critical, as Llana James, PhD candidate at the Faculty of Medicine’s Rehabilitation Sciences Institute, University of Toronto, emphasizes, “that any and all disaggregated data collection and any onward usage of said data must be tracked and restricted to collection and usage only for the specific and express purposes of proactively and retroactively ending and removing systemic anti-Black racism, anti-Indigenous racism and other forms of racism and intersectional oppression.”⁶⁰

The process of respectful relationship, where marginalized communities are meaningfully involved throughout the stages of collection, storage, use and distribution of disaggregated data, is also significant, and principles and recommendations for government in building respectful relationship form the bulk of this report. Gwen Phillips describes it as a fundamental shift from a paternalistic “Big Brother” model to “the grandmother perspective,” a shift from control to care. As well as all the significant reasons for this approach outlined in detail below, there are also concrete, practical aims: response rates to demographic surveys increase through community engagement in the design and development of disaggregated data collection and, at the outcome stage, it also allows for quicker adoption of solutions by impacted communities as uptake of programming is an issue in paternalistic models.

Further, multiple participants in our community consultations emphasize that **relationship change precipitates systems change**. We need to do research differently in order to make a difference.

60. Meeting with Llana James, August 12, 2020.

How we are doing this work: Our methodology

Human rights-based approach

The work of BCOHRC is grounded in a human rights-based approach. A human rights-based approach seeks to centre the voices of those most marginalized and to make inequality visible in order to redistribute unjust distributions of power, resources and opportunities. Our approach to research is to go to community first as experts in their own lives and fields of practice.

Given the short timeline (Sept. 1 in the Premier's original letter), we were unable to conduct a comprehensive community engagement process. We strongly advise government to do so and we provide recommendations for ensuring this is undertaken with a human rights-based and decolonizing approach.

Over July and August, BCOHRC held two community dialogue sessions and multiple one-on-one consultations on the issue of disaggregated data in B.C. with community and academic leaders from diverse Black, Indigenous and People of Colour (BIPOC),⁶¹ LGBTQ2S+⁶² and disability communities. A two-hour Indigenous data collection consultation was conducted on July 28 with 10 participants and a two-hour session, open to diverse BIPOC, LGBTQ2S+ and disability communities, was held on July 27 with 14 participants. Further one-on-one consultations were held with other experts and local leaders. In addition, the research team had the opportunity to meet with the provincial government's Multicultural Advisory Council as the council has identified disaggregated data collection as a priority for government.

These consultations were supported by a literature review and case study analysis to highlight best practices and pitfalls, as well as a policy analysis of the current context in B.C. and other examples of legislative implementation. All of our work was grounded in the theoretical framework of critical race, disability and queer theory in which demographic categories, such as race, disability and sexual orientation, are recognized as social constructions not biological facts (more on this later).

Decolonizing approach

Decolonization is central to the work of human rights in our society, and consequently to the work of BCOHRC. Decolonization is the framework through which we are working toward undoing the oppression and subjugation of Indigenous peoples and unlearning colonial ways of thinking and being. The first of these aims is focused on systemic barriers facing Indigenous peoples and communities, while the second is an intentional adoption of a decolonizing approach to all our work as a theoretical and practical framework that creates new ways of thinking and being, just as feminist theory and critical race, queer and disability theory has.

61. Black, Indigenous and/or People of Colour.

62. Lesbian, Gay, Bisexual, Transgender, Queer, Two-Spirited and other gender and sexual minorities .

In relation to the first aim, we held an Indigenous-specific engagement because we recognize the intersections between the issue of disaggregated data and the self-determination of Indigenous peoples and the expertise Indigenous leaders have to offer on the principle of data sovereignty. In support of sovereignty and self-determination of Indigenous peoples and communities, the B.C. government must continue these conversations with Indigenous peoples on data governance. Indigenous people can and have self-determined how they wish to govern data whether within Indigenous organizations, nations or other bodies, for example, the First Nations Health Authority, the First Nations Education Steering Committee and Metis Nation BC. Government must meaningfully engage with First Nations, Metis and Inuit peoples in this work and, given the numbers of Indigenous people living off-reserve, government must engage meaningfully with Indigenous institutions in urban communities.

In relation to the second aim described above, in striving to apply a decolonizing approach to this project, this was primarily enacted through a recognition of all the constituent elements of our whole selves in working through the issue of disaggregated data: **mind, body, emotion and spirit.**

Mainstream scientific knowledge is predicated on the idea of a disembodied, objective researcher. This is both false and harmful, and acknowledging one's social location as a researcher is now recognized as central to challenging unintentional biases. To this end, Trish Garner, as the Principal Investigator on this project, explains: "I know all too well what is at stake in this project. Many times, I have experienced the sadness and fear of facing a demographic survey that erases my body and identity as a non-binary, transgender person. Seeing only an M or F on that piece of paper undermines who I am every single time. I am excluded by those two letters as are so many other diverse folks; our experience is rarely counted so action on our behalf is rarely taken. None of my identity documentation reflects who I am so I live with this continual disconnection. The cumulative effects of this erasure have a long-term impact on my health and wellness."

The issue of disaggregated data comes with a fraught history that still impacts our present day. Data collection on different communities has harmed, and continues to harm, those communities. For example, the Department of Indian and Northern Affairs Canada collected demographic information on Indigenous households to support the establishment and operation of residential schools.⁶³ In undertaking this project, we acknowledge the grief, fear and anger that marginalized people and communities hold and empathize that talking about data collection can be re-traumatizing. This trauma has been passed from generation to generation and takes time to heal.

We must not forget or shy away from this trauma; we must face it. In moving forward with disaggregated data collection, we must hold in our bodies, hearts, spirits and minds. This tool can increase trauma if handled poorly but it has the potential to provide pathways to healing if done well, provided achieving equity remains the structural aim. We experienced the gift of hope from many participants: this is our attempt to articulate principles of disaggregated demographic data to nurture that hope.

63. Government of Canada, 2020.

Decolonization is the framework through which we are working toward undoing the oppression and subjugation of Indigenous peoples and unlearning colonial ways of thinking and being.

The tool: Benefits and risks of disaggregated data

Benefits: The case for disaggregated data collection

Disaggregated data has the potential to make visible inequalities visible, which can lead to structural change. When policy, practice and law are predicated on statistics, silences and omissions in data can cost human lives. Some community members emphasized that statistics can be the “tipping point” for provincial government decision-makers to take action.

Revealing inequalities for systemic change

Disaggregated data can be important because it reveals patterns obscured by aggregate data and can reveal inequalities and differences between sub-groups that aggregated data cannot.⁶⁴ In contrast, so-called “colour blind” data can hide disproportionate and negative impacts on racialized and other groups. Simply put, we cannot address what we cannot see. In B.C., calls for change commonly draw from research documenting structural inequalities using disaggregated demographic data.⁶⁵

There are many examples of how disaggregated data has changed policy to address systemic inequality. In 2013, the City of Ottawa developed a study of police traffic stops that showed that Black and Middle eastern drivers were stopped at disproportionately higher rates. After the results were released, the police service created a multi-year action plan to address the problem.^{66,67} We also know that Indigenous people are overrepresented in jails in Canada through disaggregated data collection,⁶⁸ which allows policy to be developed to address this problem. An example of this is the mandating of Gladue reporting, which is a tool used in the justice system to address systemic inequality through sentencing in criminal proceedings.⁶⁹ Again, if we can’t see the problem, we can’t address it.

There are also many examples of how the failure to collect disaggregated data perpetuated systemic inequality. An important missed opportunity for the potential of disaggregated data collection to reveal inequities and improve programs and services occurred in the U.S. in December 2019 when New York Governor Andrew Cuomo vetoed Bill A677.⁷⁰ The Bill would have required boards, commissions and state agencies to collect detailed disaggregated data on “specific Asian, Pacific Islander and Native Hawaiian ethnicities,”⁷¹ rather than group people together into monolithic categories. Community-based groups such as the Coalition for Asian American Children and Families (CAAC) advocated for the Bill for almost a decade under the “Invisible No More Campaign,” highlighting that, if communities are not identified, they become invisible and cannot be properly served by State agencies.

64. Teranishi et al., 2013.

65. Go et al., 2020.

66. Griffith, 2020.

67. Foster et al, 2016.

68. Statistics Canada, 2018c.

69. Legal Services Society, n.d.

70. New York State Senate, 2019.

71. Yam, 2019.

Case study: First Nations and disaggregated health data in B.C.

Significant differences in socioeconomic standards, including health outcomes, persist between First Nations in B.C. and other British Columbians. To address these differential experiences and outcomes, in 2005, B.C. First Nations leadership and the provincial and federal governments entered into a new relationship to improve the quality of life of First Nations through the Transformative Change Accord: First Nations Health Plan.⁷²

Among its provisions, the Accord committed all parties to advance First Nations data governance and decision-making, in alignment with the OCAP® principles of First Nations Ownership, Control, Access and Possession, to improve the quality and availability of First Nations data and to create new data sets to enable First Nations in B.C. to monitor the health of First Nations and the success of programs and services provided to First Nations communities.⁷³

Significant work on disaggregated health data continues to be undertaken and championed through the First Nations Health Authority (FNHA), a First Nations-led institution created in 2013 that is governed by, and works on behalf of, all B.C. First Nations and their communities. Through the FNHA's health data and information initiatives, including the creation of the First Nations Client File, disaggregated data has quantitatively shown the differential experiences and outcomes of First Nations people in B.C. in areas such as:

- Access and experiences related to physician, hospital, residential care and home and community care services, through a data linkage with the Ministry of Health's Health Systems Matrix data⁷⁴
- Occurrences and survival rates related to various cancers, through a data linkage with the BC Cancer registry⁷⁵
- Opioid-related events, including deaths and overdoses, through a data linkage with the BC Coroners Service, Drug and Poison Information Centre, and BC Emergency Health Services/Ambulance Service⁷⁶
- COVID-19 transmission rates, through a data linkage with testing databases held by the BC Centre for Disease Control⁷⁷

These examples highlight the importance of disaggregated data in improving policies, programs and perspectives. Challenges persist, however, including ensuring that disaggregated data on Indigeneity is collected in culturally safe and humble ways, plus systematically ensuring that all First Nations data is held and led by First Nations communities and institutions so they can self-determine how data is interpreted and used to inform decisions regarding their own health and wellness.⁷⁸ In addition, individual First Nations communities and Nations have expressed their desire for more community-based health data stewardship, access and capacity.⁷⁹ More work needs to be done in this area.

72. British Columbia Assembly of First Nations, First Nations Summit, Union of British Columbia Indian Chiefs and Government of British Columbia, 2006.

73. Ibid.

74. First Nations Health Authority, 2018.

75. First Nations Health Authority and BC Cancer, 2018.

76. First Nations Health Authority, 2017.

77. First Nations Health Authority, 2020a.

78. First Nations Health Authority, 2020b.

79. Robinson et al., 2020.

For example, the CAAC emphasizes there are “1.1 million Asian Pacific Americans living in New York City” and “40+ Asian Pacific American” communities,⁸⁰ yet government agencies either do not mention this diversity or group people into the generic categories of “Asian, Other or even White.”

Good data leads to good policy

B.C. lags in advanced demographic data collection. Other jurisdictions have established disaggregated data collection over many years, particularly in the United States and this data is being used to enhance policy and practice in various sectors.

Examples of how organizations in the US have used disaggregated data to pursue equity in the delivery and assessment of services, programs and policies

Organization	Examples
<p>Los Angeles County</p>	<p>The county has used disaggregated data on COVID-19, including: age, “race/ethnicity” and socio-economic status indicators to expand culturally competent COVID-19 testing, treatment and prevention strategies in the “African American, Latino and Native Hawaiian and Other Pacific Islanders populations,” as well as in low income areas. For example, disaggregated data has been collected regarding the number of patients hospitalized, test requests via the LA Online Testing Portal, test referrals and deaths.⁸¹</p>
<p>Voices of Youth in Chicago Education</p>	<p>VYCE utilized disaggregated data from Chicago Public Schools, the Chicago Police Department, the US Department of Education Office of Civil Rights Data, and the Illinois State Board of Education to document disparities in expulsions, suspensions and the widespread criminalization of “students of color.” This information was used to successfully advocate for a landmark school discipline reform bill with implications for education institutions across jurisdictions.⁸²</p>

⁸⁰. Coalition for Asian American Children and Families, 2015.
⁸¹. County of Los Angeles Public Health, 2020.
⁸². National Equity Atlas, 2020.

Organization	Examples
<p>Diverse Elders Coalition, New York</p>	<p>DEC advocates for the availability of more nuanced disaggregated data (advocating for sub-group representations within common categories like “Asian” or “LGBT”) in demographic data collection for seniors. It also and utilizes disaggregated data to work to improve health care for Elders, in public policy advocacy generally and in public education campaigns. For example, DEC has used disaggregated data to highlight the disproportionate lack of health insurance for systemically oppressed populations of seniors in America while advocating for the Affordable Care Act.⁸³</p>
<p>National Association for College Admission Counseling</p>	<p>NACAC advocates for and utilizes disaggregated data to help develop support for diverse student populations as they enter college programs. For example, the organization has highlighted the importance of collecting disaggregated data on diverse “Asian/Asian American” students in order to: create appropriate translated materials for families and admission outreach (there are over 2,000 languages spoken in Asia), inform student services on their incoming population in order to provide better service, design “culturally competent” educational environments and examine how diverse Asian student populations are excluded in curriculum narratives.⁸⁴</p>

There are also examples in Canada and B.C., yet far fewer. In the City of Toronto, results and outcomes of major social strategies are reported on in a disaggregated way, such as Toronto’s Newcomer Strategy, the Toronto Youth Equity Strategy, the Toronto Strong Neighbourhoods Strategy 2020 and Community Investment Funding Programs. Disaggregated data is used to assess the quality of, access to and outcomes for City programs and policies: to support a gender lens on budgeting and policy decisions,⁸⁵ for example.

83. Diverse Elders Coalition, 2020.

84. Hua and Lim, 2018.

85. Executive Director, Social Development, Finance and Administration and Director, Equity, Diversity and Human Rights of the City of Toronto, 2018.

In B.C., the Homelessness Services Association, Urban Matters and the BC Non-Profit Housing Association have utilized disaggregated data collected during homeless counts throughout the province to help better address the needs of individuals experiencing homelessness. For example, their work highlights age, Indigeneity, sexuality, immigration or refugee status and disability, among other demographics, allowing for targeted programs in shelters and more robust anti-poverty strategies.⁸⁶

Case study

A recent example highlights the benefit of community-based disaggregated data collection, analysis and disclosure. On May 22, 2020, the Vancouver Police Department (VPD) raised the alarm about the rise in anti-Asian hate incidents during COVID-19.⁸⁷ The VPD had 29 investigations open for anti-Asian crimes compared to four in the same time period the previous year. In recognition that hate crimes are often under-reported by community members,⁸⁸ Project 1907, a grassroots group of Asian women, launched the Racism Incident Reporting Centre, a “community-based reporting tool to track incidents of racism.”⁸⁹ Over 600 incidents have been reported through the tool across Canada, demonstrating the extent to which existing reporting mechanisms do not meet the needs of community members. In addition, Project 1907’s analysis revealed that women are disproportionately impacted, accounting for nearly 70 per cent of reported incidents in B.C.⁹⁰ It will require further analysis to determine if this is due to over-representation of women experiencing hate incidents or reporting them, but this data initiative highlights the strength of community-based disaggregated demographic data collection initiatives in making reporting accessible and making an important issue visible. This information demonstrates the limitations of VPD reporting mechanisms and underscores the need to further support community-led data collection and analysis initiatives.

While advocates have been calling for the collection of disaggregated data for decades, these calls have been renewed during COVID-19. Dr. Kwame McKenzie characterizes the Canadian government’s lack of data on COVID-19 and race-based demographics as neglectful,⁹¹ emphasizing that, “discrimination is not necessarily about what you do. It’s often about what you don’t do.” Other Canadian jurisdictions are moving forward with race-based data collection in relation to COVID-19. A recent study in Toronto found Black people and People of Colour account for 83 per cent of reported COVID-19 cases.⁹² The data highlights the disproportionate impact of the virus on communities facing the systemic inequalities which contribute to poor health outcomes. Inadequate data leads to inadequate policy. Throughout the course of community dialogue sessions, participants emphasized the need for more robust demographic information on COVID-19 in the province, including in relation to the long-term impacts of the virus on communities. Dr. Greta Bauer with the Department of Epidemiology and Biostatistics at Western University in Ontario emphasizes:

My fear is that there is not enough concern for the long-term effects of people post-COVID — even people who supposedly had mild cases — and what that means for the health over

86. BC Housing, 2019.

87. Vancouver Police Department, 2020.

88. Vancouver Police Department, 2020.

89. Project 1907, 2020.

90. Ibid.

91. Cheung, 2020.

92. Cheung, 2020.

the life course. And that if we have inequalities now in who's affected by COVID-19, even if they survive, that that's going to really exacerbate health inequalities going forward over time.

Heather McCain, Executive Director of Creating Accessible Neighbourhoods BC and a disability advocate, speaker, educator and activist, emphasizes:

There's a keen awareness in the disability community, and a lot of conversation about the fact that COVID-19 goes beyond those that are dying and the recovery... as many people who have recovered are still dealing with short term or long-term disabilities. And it is vital that this is captured and addressed.

Within B.C., race-based and other demographic data has only been collected in relation to COVID-19 through the voluntary "BC COVID-19 SPEAK: Your story, our future" population health survey launched in May 2020 through the BC Centre for Disease Control. One in 10 British Columbians completed the survey and the results showed that White⁹³ people "had less difficulty making ends meet," were less likely to have reduced employment because of COVID-19 and "had less food insecurity."⁹⁴ Individuals with lower incomes suffered more negative health and economic consequences than higher income individuals.⁹⁵ In the explanation accompanying the survey, the potential impact on policy, program and practice is emphasized:

We ask about socio-demographic questions (like education, income and ethnicity) to firstly ensure all segments of our population are properly represented based on available census data, and secondly, in recognition that many experiences of health and well-being are highly influenced by our backgrounds and circumstances. This information ensures planning is relevant and responsive to the needs of our diverse population.

One of the advantages of this survey is that it is separate from health care access for COVID-19 so it shows which groups have had difficulty accessing health care. However, disaggregated data is also needed in relation to COVID-19 health data such as infection and death rates in order to be fully relevant. Without such data on COVID-19, diverse community leaders in the province emphasize they are left with little information to inform next steps in the fight against the virus.

93. Defined in this survey using the outdated descriptor: Caucasian

94. Province of British Columbia, 2020.

95. Ibid.

Disaggregated data supports our human rights legal frameworks

The collection of disaggregated data in service of systemic equality supports our human rights legal frameworks.

At the provincial level, we are protected from discrimination by the BC Human Rights Code⁹⁶ which protects multiple grounds, such as race, sex and disability, within the defined areas of employment, housing, services that are usually available to the public and union membership. An important way to know if these provincial human rights protections are being met is by tracking data on protected grounds within these areas, which could reveal incidents or patterns of discrimination.

As an example, following a Freedom of Information request, the Union of BC Indian Chiefs (UBCIC) and BC Civil Liberties Association (BCCLA) discovered that between 2008 and 2017 Black people were subject to over four per cent of street checks undertaken by the Vancouver Police Department despite representing less than one per cent of the population, while Indigenous people were subject to over 16 per cent of street checks despite representing just over two per cent of the population.⁹⁷ These statistics are made possible because of disaggregated data collection by race and Indigeneity and have been used by UBCIC and BCCLA to advocate for policing reforms to ensure human rights protections.

At the national level, one of the fundamental principles in the Canadian Charter of Rights and Freedoms is equality: “the right to the equal protection and equal benefit of the law without discrimination.”⁹⁸ This has been defined in law as substantive equality or equity, which means instead of the same treatment for all, different provisions must be made available depending on different needs or barriers in order to provide the same outcome or opportunity. An important way to know if the principle of equity is being met is by looking at how policies, services and programs are impacting different groups of people, which is exactly what disaggregated data tells us.

At the international level, Canada, and by implication all provinces and territories within it, has committed to seven core human rights conventions, including the International Covenant on Economic, Social and Cultural Rights,⁹⁹ which covers basic universal human rights such as the right to housing, food, health care and education. Domestic protections often lag behind these obligations enshrined in international law. Disaggregated data has the potential to show us who is most impacted by these gaps which supports advocates to prevent these violations through the implementation of meaningful protections within B.C.

96. Government of BC, 1996 [2020]b

97. Union of BC Indian Chiefs and the BC Civil Liberties Association, 2018.

98. Government of Canada, 1982 [2017].

99. United Nations, 1966 [2020].

As the letter from the Canadian Association of Statutory Human Rights Agencies (CASHRA) to government highlights: “The systematic collection and intersectional analysis of disaggregated health data that includes race and Indigeneity are essential to identifying inequalities and advancing human rights in Canada...[T]he right to health is closely related to and dependent upon the realization of other human rights, and the collection and publication of disaggregated data will point to key areas where concerted effort is needed to close existing health care and other human rights gaps.”¹⁰⁰

Many United Nations reports include recommendations for Canada (and jurisdictions within it) to implement disaggregated data collection, including the Committee on the Elimination of Racial Discrimination. The committee wrote in its most recent Concluding Observations (2017): “Systematically collect disaggregated data in all relevant ministries and departments to improve monitoring and evaluation of the implementation and impact of policies to eliminate racial discrimination and inequality.”¹⁰¹ Further, Article 31(2) of the UN Convention on the Rights of People with Disabilities mandates disaggregated data collection as appropriate to further the rights of people with disabilities.¹⁰²

Risks: What could go wrong with disaggregated data

Increasing stigma and systemic oppression

In moving forward with disaggregated data collection, we must face the fact that this data has been used in support of colonization and systemic racism and oppression. Both historically and today, structurally oppressed communities have had to deal with the consequences of research used as a tool for control and surveillance, leading to further stigma and marginalization. For example:

- Between the 1950s and 1990s the Canadian Government exposed and removed LGBTQ2S+ members in the public service, keeping extensive records on individuals and ‘suspect’ activities.¹⁰³
- Japanese British Columbians were documented, tracked and forcibly relocated to internment camps in the interior of the province during the Second World War.¹⁰⁴
- Toronto’s Black Public Health Collective warns that race-based data collection on COVID-19 has at times resulted in “greater police presence in ‘COVID hotspots’ and pathologizing Black communities as ‘sick,’ reinforcing ‘harmful narratives.’”¹⁰⁵

100. Boullard, 2020.

101. United Nations Committee on the Elimination of Racial Discrimination, 2017.

102. United Nations, 2016.

103. Levy, 2018.

104. Price, 2020.

105. Black Public Health Collective, 2020.

Case study: Italy’s “Nomad Emergency Decree”

In May of 2008, Italy declared a state of emergency through the “Nomad Emergency Decree.” The Decree allowed the government to target Romani camps in Campania, Lazio and Lombardia and resulted in an associated census, fingerprinting and the collection of “photometric and other personal information in databases.” The Open Society Justice Initiative, a legal advocacy organization, explains:

An emergency decree in 2008 led to a census of all Romani in Italy, the creation of ethnic databases held by police officers, forced evictions and resettlements, and the creation of new segregated camps. Although the 2008 emergency decree was declared illegal, its legacy continues in the form of segregated housing in Romani-only camps, forced evictions, and a Romani census database that is maintained in some cities.¹⁰⁶

In Italy the “Emergency Decree” was an attempt to bypass usual legal frameworks and privacy protections. Furthermore, the European Committee of Social Rights emphasizes the “Italian government justified the necessity to collect this data with the need to improve health conditions” while providing no indication that measures were taken to improve health and well-being and actively harming communities through segregated and harmful measures.¹⁰⁷

Within this context, there can be a lack of trust of researchers and government agencies collecting information. The fear, grief and anger expressed to us in community consultations are based in this history and continued practices. While communities agree on the purpose of structural change, it is important to acknowledge that there is no consensus among communities that disaggregated data is the tool to achieve that purpose given this history. Thus, while many are hopeful, some groups continue to advocate against data collection.¹⁰⁸

Big Data and the risks to privacy

Within the context of 21st Century computing, disaggregated data is decontextualized, used for algorithms and predictive modeling, commodified and repurposed for domestic and foreign corporations and governments, with insufficient consideration for the negative impacts on human rights, Treaties, social cohesion and Canadian democracy.¹⁰⁹

106. Open Society Justice Initiative, 2020.

107. The Human Rights Centre Clinic, 2013.

108. Black Public Health Collective, 2020.

109. Meeting with Llana James, PhD candidate at the Faculty of Medicine’s Rehabilitation Sciences Institute, University of Toronto, August 12, 2020.

Algorithms and predictive modeling: Computer algorithms take information and make statistical computations in order to predict outcomes.¹¹⁰ Disaggregated data has, for example, been used in marketing, health care and policing algorithms to predict the likelihood of ‘high risk’ criminal behavior, anticipate consumer choices and predict health and well-being. There are dangers in terms of stigmatization, inadequate privacy checks and a lack of regulation in an emergent field of data practices.¹¹¹

There are gaps in the legal and regulatory frameworks governing digital trends that have negative effects on constitutionally protected peoples and groups. These gaps must be prioritized and proactively addressed in relation to the perceived benefits and significant challenges disaggregated data collection pose, in particular, for protecting the privacy and human rights of British Columbians in the era of artificial intelligence (AI).¹¹² As we saw from the Cambridge Analytica scandal in the U.S in 2018, large tech corporations are already using our data to undermine social institutions and democracies.¹¹³ The B.C. government must address the broader technological context and implement strong data laws and regulations before collecting disaggregated data.

The case study of Edmonton’s Police Tech Accelerator provides an example of the risks of moving forward without establishing adequate legal frameworks. On Feb. 11, 2020 the Edmonton Police Department launched their Community Solutions Accelerator.¹¹⁴ This was a partnership driven by venture capitalist Ashif Mawji (Chair of the Edmonton Police Foundation)¹¹⁵ to provide funding to technological entrepreneurs to develop solutions to issues like addiction, homelessness and crime, drawing from data made available from policing, child welfare, social services and the health care system.¹¹⁶ Edmonton Police Service Chief Dale McFee and Mawji indicate that the Community Solutions Accelerator will allow businesses to create predictive modeling software and other digital tools that can then be sold to other cities.¹¹⁷ The Community Solutions Accelerator has secured corporate support for the project from the Telus Corp, the University of Alberta, ATB Financial and Motorola Solutions Canada.¹¹⁸ Critics point out that systemically oppressed communities will be disproportionately impacted by the associated surveillance and interventions in the software, resulting in more (not less) stigma, and that the project does not include a consent process for personal information used for the project.¹¹⁹

The lack of participant consent and corporate freedoms taken with Canadians’ data in the case study of Edmonton’s Community Solutions Accelerator should cause concern. It will be critical to craft legislation to support disaggregated data collection that accounts for technological advancements in predictive modeling in policing, health care and marketing. The European Commission cautions that associated technologies entail, “a number of potential risks, such as opaque decision-making, gender-based or other kinds of discrimination, intrusion in our private lives or being used for criminal purposes.”¹²⁰

110. Geisser, 1993.

111. Eubanks, 2017.

112. Meeting with Llana James, PhD candidate at the Faculty of Medicine’s Rehabilitation Sciences Institute, University of Toronto, August 12, 2020.

113. The Guardian, 2018.

114. Junker, 2020.

115. LinkedIn, 2020.

116. Munn, 2020.

117. Ibid.

118. Cryderman, 2020.

119. Munn, 2020.

120. European Commission, 2020.

Participants in our consultations emphasized that provincial and federal law need to better account for abuses of ‘big data’ within the context of corporate control of citizens’ information. Scholars also stress that predictive modeling for social service agencies, policing and health care come with considerable risks to systemically oppressed communities and ultimately can undermine self-determination and community agency, result in increased surveillance and the misdirection or withholding of social and health services and resources.¹²¹

The United Nations Committee on the Elimination of Racial Discrimination raises concerns about the increasing use of “artificial intelligence, automated decision making, predictive data analysis and the use of algorithms:”

A number of factors ingrain bias into artificial intelligence systems, increasing their discriminatory potential. These include the way in which artificial intelligence systems are designed, decisions as to the origin and scope of the datasets on which these systems are trained, societal and cultural biases that developers may build into those datasets, the artificial intelligence models themselves and the way in which the outputs of the artificial intelligence model are implemented in practice... Some social groups that have been historically discriminated against— such as women, people of African descent, indigenous peoples, Roma, Jews and others — are unequally and disproportionately reflected in the results of the algorithms. Clearly, algorithms reproduce the inequalities of the real world.¹²²

When the tool is not in service of the purpose

A research tool must always be selected for its effectiveness in achieving the research purpose. Ontario’s Anti-Racism Act is an interesting case in which to consider relationships between purpose and tool. The Ontario Government passed the Anti-Racism Act in June 2017.¹²³ It requires government to:

- Create, maintain and consult on a provincial anti-racism strategy
- Establish a framework for an anti-racism impact assessment
- Establish and consult on data standards

In the Act, disaggregated data collection is a central feature of monitoring and responding to systemic racism. In conjunction with the Government of Ontario’s “Data Standards for the Identification and Monitoring of Systemic Racism,”¹²⁴ the Act sets the rules for “the collection, retention, use and disclosure of race-related personal information by Public Sector Organizations.”¹²⁵ This framework provides oversight for “the analysis of personal information and the publication of de-identified data and analysis” for the purpose of “eliminating systemic racism and advancing racial equity.”¹²⁶ The Government of Ontario was also required to consult with the Ontario Human Rights Commission and the Office of the Information and Privacy Commissioner in the development of the data standards and any future amendments.

121. Eubanks, 2017.

122. United Nations Committee on the Elimination of Racial Discrimination, 2019.

123. Anti-Racism Act, 2017.

124. Government of Ontario, 2019a.

125. Anti-Racism Act, 2017.

126. Anti-Racism Act, 2017.

There are strong features of Ontario’s Anti-Racism Act, including the:

- establishment of an Anti-Racism Directorate
- focus on achieving structural change
- acknowledgement of the need to have dedicated strategies for Black and Indigenous racism
- recognition of the context of systemic racism and colonization
- grounding in critical race theory to highlight the social construction of categories
- importance of intersectionality

However, community members emphasized some limitations. These include the fact that the Act applies to public sector organizations within education, justice and child welfare but does not fully apply to health care and has a specific exclusion for health information custodians. This is seen as a huge gap in the effectiveness of the Act to achieve its purpose.

The other primary criticism is that in practice, the Act has legislated data collection, not equity, despite its aims. This can be seen in the targets and indicators contained within the anti-racism strategy, which consist of increases in data collection and response rates but no targets that correspond to eliminating systemic racism and achieving equity.¹²⁷ Data collection has become the end rather than the means. There are also no accountability mechanisms established through the Act or within the anti-racism strategy—it was suggested the relevant Human Rights Commission could hold responsibility for this role.



127. Government of Ontario, 2019b.

When the process undermines the purpose

In addition to the significant danger of disaggregated data leading to further stigma and discrimination, over-researching social inequalities with little follow-up action has also harmed communities in the province. In these cases, research is not grounded in respectful relationship. Following several bad experiences with researchers, residents in the Downtown Eastside of Vancouver drafted “A Manifesto for Ethical Research in the Downtown Eastside,”¹²⁸ noting common pitfalls in research such as:

- Undermining community initiatives “by ‘finding’ they don’t fulfill certain, outsider-created expectations (when they meet important community needs)”¹²⁹
- Triggering trauma in participants
- Devastating people when researchers never return to share their results
- The misrepresentation of communities and individuals with no chance to respond to study findings
- Using research as an “excuse for not taking action” and “delaying action by ‘studying’ the issue instead”¹³⁰
- Sapping resources from communities and tying up “highly capable community members in exhausting bureaucracy and prejudice so they have less to give in more meaningful community contexts”¹³¹
- Conducting research that has no relevance to community members



128. Boilevin et al.,2019.

129. Ibid.

130. Boilevin et al.,2019.

131. Ibid.



The purpose: Addressing systemic inequality

Structural context: Racism, colonization and oppression

Dr. Milan Singh, a member of the government’s Multicultural Advisory Committee (MAC), stressed that right now, “data collection is happening within the current system of structural racism.”¹³² While disaggregated data collection has the potential to change that system, it cannot do that alone. Other tools must be considered and applied simultaneously to address the historical and present-day impacts of structural racism, colonization and oppression. In support of this, Dr. Ismaël Traore, another MAC participant, “cautioned against a focus on representation and inclusion and highlighted the need for using a racial equity lens to inform decisions about the distribution of material goods and services, and to create accountability measures.”¹³³

Ontario’s Data Standards for the Identification and Monitoring of Systemic Racism describe the historical and current context. We recommend embedding this context in the proposed legislation and/or data standards discussed later in the report. The data standards state:

Throughout Canada’s history including prior to Confederation, colonial practices, including the oppression of Indigenous peoples and the enslavement of people of African descent, have entrenched public attitudes, beliefs and practices that continue to negatively impact Indigenous, Black, and racialized individuals and communities in social, economic and political life. The exclusion and devaluing of different groups is also evident in Canada’s history of discriminatory immigration and citizenship policies, including restricted admission for Jewish people at the height of the Holocaust, the Head Tax on Chinese immigrants and the internment of Japanese Canadians during World War II, among many other examples.

The legacy of this history impacts Indigenous, Black, and racialized groups by perpetuating the advantages and institutional power of the historically dominant group (White individuals with higher socio-economic status). The negative consequences of this legacy are compounded over time and transmitted intergenerationally. Systemic racism continues to result in racially inequitable outcomes across public sectors such as education, child welfare and justice. Racist ideas and practices persist in a variety of forms, including anti-Black racism, anti-Indigenous racism, Islamophobia and antisemitism.¹³⁴

132. Meeting with Multicultural Advisory Committee, BC Government, July 17, 2020.

133. Ibid.

134. Government of Ontario, 2019a.

B.C.'s data standards should include similar history and present-day context in relation to the multiple, intersecting systems of oppression for which data will be collected, such as sexism, ableism, heterosexism and classism.

Structural change: Shifting focus from individual failure to systems failure

As Dr. Danièle Behn Smith, Deputy Provincial Health Officer – Indigenous Health, describes:

We need to use disaggregated data to help us illuminate structural determinants of health and health inequities. Disaggregated data should not be used to reinforce stereotypes or othering, but rather used as a tool to assess Western mainstream systems, and their progress towards social inclusion and cultural safety. We need to be explicit about what we're measuring with disaggregated data. We're not measuring inherent deficiencies in different groups: we're measuring the negative impacts of longstanding structural racism and social exclusion on the health of Indigenous and racialized peoples. Disaggregated data can help us move forward in a good way when we use the findings as an indicator of how well Western mainstream systems are meeting the needs of Indigenous peoples and other racialized groups.

A critical challenge with disaggregated data is that it can reinforce deficit narratives—where these narratives are already present, researchers may use data to support them. This, in turn, stigmatizes and individualizes the issue. Shifting the focus from individual failure to systems failure is one way to resist stigma. Applying a strengths-based approach within this shift also counters these challenges by highlighting stories of community resilience rather than individual victimhood.

Deficit narratives represent “people or groups in terms of deficiency—absence, lack or failure.”¹³⁵
Deficit narratives can be damaging and locate responsibility for social problems in individuals or communities without acknowledging larger socio-economic structures and inequalities.¹³⁶

Deficit narratives are also used to undermine community ownership. As Heather Walkus, Chair of the BC Coalition of People who use Guide Dogs, explains, “we're also talking about that whole worldview of less than, different than, not engaged in. And somehow less able to decide for ourselves what information we need to know so we can support our own community.”

Disaggregated data can be an important tool in countering deficit narratives, if used appropriately. Thus, when disaggregated data is selected, we recommend highlighting the purpose in association with the tool at all times, such as disaggregated data for racial equity. This maintains the focus on structural change, in shifting from individual failure to systems failure. Collecting data on social determinants of inequalities without structural change can be another form of violence.

135. Fogarty et al., 2018.

136. Ibid.

Social construction of categories

One of the primary dangers of disaggregated data collection is that it has the potential to reinforce the notion that the defined categories are biological (perpetuating scientific racism and sexism) rather than making them visible as social, political and historical constructions.¹³⁷ The development, design and implementation of any disaggregated data collection must not only be rooted in its role as a tool for addressing systemic inequality, it must also 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, highlighting the issues as systemic rather than individual.

The social construction of race is emphasized in Ontario's Data Standards for the Identification and Monitoring of Systemic Racism:

For the purposes of identifying and monitoring systemic racism barriers and disadvantages, it is important to recognize race as a social construct. Ideas about race are often ascribed to or imposed on people, and individuals and groups can be racialized by others in ways that affect their experiences and how they are treated. Race as a social category is distinct from but may overlap with how people identify themselves, which can be much more varied and complex.¹³⁸

Thus, race is a socially constructed category tied to histories of colonization, social values, politics and culture.¹³⁹ Biologically, there is more genetic variation within so-called 'racial groups' than between them.¹⁴⁰ In other words, race can be understood as a process of racialization: groups of people are racialized over time according to shifting political, economic, social and national values.¹⁴¹ For instance, whiteness as a racial category in North America did not historically include Italians and Eastern Europeans but now generally does. Ontario's Anti-Racism Strategic Plan defines racialization as:

Racialization refers to "the process by which societies construct races as real, different and unequal in ways that matter to economic, political and social life" (Commission on Systemic Racism in the Ontario Criminal Justice System, 1995). Racial categories are not based on science or biology but on differences that society has chosen to emphasize, with significant consequences for people's lives. People can be racialized not only based on skin colour but also other perceived characteristics such as their culture, language, customs, ancestry, country or place of origin or religion as is the case with Islamophobia and antisemitism.¹⁴²

137. Rogers and Bowman, 2005.

138. Government of Ontario, 2019a.

139. Yu, 2018.

140. Goodman, 2008.

141. Bonilla-Silva, 2015.

142. Government of Ontario, 2020.

Below we provide an explanation of social construction in relation to some other common categories included in disaggregated data collection.

Disability/Ability: In demographic surveys, disability is often situated as an individual attribute, sometimes broken down into “physical” or “mental” disabilities or explored through questions about “activities of daily living” like bathing or transferring out of bed. Ableism, however, structures ideas about typical and atypical bodies — this impacts social, institutional, cultural, political and interpersonal practices and values and the inclusion of persons with disabilities in daily life.¹⁴³ Disability activists point out that how we structure our built environment, employment, education, social policy, income assistance and other institutions plays a key role in experiences of disability and oppression.^{144,145,146} For example, stairs are the norm because our environment is built for people who are mobile without the aid of wheels. The increased use of ramps on curbs illustrates how changes to our built environment to account for diverse bodies can become the new norm. In shifting the focus from the biological to the social, from bodies to barriers, a research initiative could use disaggregated data collection to survey health care access rather than health needs.

Sex/Gender: Demographic surveys commonly situate sex and gender as binaries with two options: “male” or “female” and “man” or “woman,” respectively. Sex is related to biological factors while gender is a sense of self-identity. Ideas about sex and gender have changed over time and have always varied across cultures. Many people experience sex and gender in different ways¹⁴⁷ and people who defy expectations about gender can experience “gender policing” and social and institutional pressures to conform.¹⁴⁸ In recognition of this context, where previously the Canadian Census only included binary sex categories, the 2021 Canadian Census will provide for non-binary gender options in addition to sex at birth.¹⁴⁹ The Treasury Board Secretariat’s report, “Modernizing the Government of Canada’s Sex and Gender Information Practices” (2018), states collection of gender information should be the default, “while the collection of information on sex (biological sex) should be an exception for specific reasons or needs.”¹⁵⁰

Poverty/Class: Poverty is often documented in demographic surveys as an individual attribute reflected by household income, census district, homelessness or other common indicators. However, poverty is not an individual attribute — it results from the convergence of multiple systems of oppression and social conditions. Social policy defines who is poor in a system of marginalization where value is associated with productivity in the labour market. Classism provides the structures, attitudes and behaviours that feed discrimination against those of a lower social class, including myths such as “pulling yourself up by your bootstraps.” While demographic data will necessarily rely on indicators listed above (such as income), it’s important to recognize the systemic underpinnings of poverty in the analysis of data.¹⁵¹

143. Fine, 2019.

144. Ibid.

145. Piepzna-Samarasinha, 2018.

146. Disability Visibility Project, 2020.

147. Balestrery, 2012.

148. Guerra, 2010.

149. Statistics Canada, 2020.

150. Treasury Board of Canada Secretariat, 2018.

151. Swanson, 2001.

Intersectionality matters

Researchers argue it is not enough to provide for sub-categories of populations (i.e. socio-economic status, disability, indigeneity, ethnic background, gender, etc.) within disaggregated data breakdowns. Instead, data collection and analysis must account for the ways in which aspects of one's identity intersect and relate.¹⁵² Activists, academics and health care practitioners involved in consultations all emphasized intersectionality from across diverse communities. Intersectionality must be built into both survey questions and the analysis of data: to avoid reductionistic approaches to people's experiences, their identities and social inequalities, and to provide for more accurate information to draw from in policy, practice and law. For example, understanding the crisis of missing and murdered Indigenous women and girls would be impossible without intersectionality. An analysis without this data is not an adequate reflection of real life or the root causes of inequality.

Intersectionality is a concept first developed by lawyer, activist and scholar Kimberlé Crenshaw in relationship to Black women and the law in the United States.¹⁵³ Crenshaw noticed that the legal system failed Black women because it did not acknowledge, or address, systemic inequalities linked to the intersections of racism and sexism. Since that time the concept has been more broadly adopted in health care, education, and other areas. Olena Hankivsky, a professor at Simon Fraser University's School of Public Policy, notes, "according to an intersectionality perspective, inequities are never the result of single, distinct factors. Rather, they are the outcome of intersections of different social locations, power relations and experiences."¹⁵⁴

Intersectionality is another important way of challenging deficit narratives, which are generally applied to a single category. For example, the collection of race-based data in relation to COVID-19 in the United States showed that Black people are experiencing the infection at higher rates than non-Black people. Without an intersectional data collection and analysis that connects race and socio-economic factors, the results of this incomplete research fail to reveal that the over-representation of Black people living in poverty and crowded, substandard housing, as well as the higher likelihood of them being in higher risk employment, are likely some of the root causes of increased rates of COVID-19 among this population. It isn't that Black people are inherently more likely to get sick: the problem is one that society has created and that good policy could undo.

152. Christoffersen, 2017.
153. Crenshaw, 1991.
154. Hankivsky, 2014.

In other words, intersectionality is “the best chance for an effective diagnosis and ultimately an effective prescription.”¹⁵⁵ Intersectionality is also critical for making the social construction of categories visible because the societal structures at play become more evident when one considers the intersections of multiple categories. Ontario’s Data Standards for the Identification and Monitoring of Systemic Racism underscores the necessity of using intersectionality to address systemic racism:

Additional types of personal information may be necessary to understand the nuances of systemic racial barriers. This means recognizing the ways in which people’s experiences of racism or privilege, including within any one racialized group, may vary depending on the individual’s or group’s additional overlapping or intersecting social identities.

For example, a race-based intersectional analysis could explore whether systemic racial barriers are different for men and women, or for different age groups. Indigenous, Black and racialized individuals may experience unique and distinct systemic barriers shaped by multiple and overlapping identities and social locations such as disabilities, low income, language barriers, etc. The use and analyses of additional personal information can help identify other factors that impact group outcomes.¹⁵⁶

There is a common misperception that intersectional research is too complicated to conduct. However, equality researcher Ashlee Christoffersen points out, “in practice, conducting intersectional research is not necessarily complicated, provided that you formulate adequate research questions, choose your methods carefully and interpret your results from an intersectional perspective.”¹⁵⁷ In addition to quantitative research, some researchers also apply qualitative methods, coupling specific case studies and narrative research with larger statistical samples to better highlight unique intersections of identity.¹⁵⁸ An intersectional approach requires working with impacted community to determine the most relevant intersecting categories for collection and analysis, such as race and socio-economic status in the example above.

Focus on purpose not tools: U.S. anti-racism examples

There are recent examples of municipalities in the U.S. addressing systemic anti-Black racism through reparation motions where the focus is on economic justice. Following a resolution committed to addressing structural racism and achieving racial equity¹⁵⁹ and a subsequent public consultation process, the City of Evanston, Illinois, passed a resolution in November 2019 to establish city funding devoted to local reparations for housing assistance and economic development for Black people.¹⁶⁰

155. Hancock, 2007 quoted in Hankivsky, 2014.

156. Government of Ontario, 2019a.

157. Christoffersen, 2017.

158. Briggs and Mantini-Briggs, 2003.

159. City of Evanston, 2019a.

160. City of Evanston, 2019b.

Specifically, the City has committed to diverting cannabis tax revenue to this fund. Following Evanston, the City of Asheville, North Carolina passed a reparations resolution in July 2020 that commits to “address the creation of generational wealth and to boost economic mobility and opportunity in the black community.”¹⁶¹ Here, reparations are defined as the “making of amends for a wrong one has done, by paying money to or otherwise helping those who have been wronged.”¹⁶² In particular, the resolution specifies that:

Resulting budgetary and programmatic priorities may include, but not be limited to increasing minority homeownership and access to other affordable housing, increasing minority business ownership and career opportunities, strategies to grow equity and generational wealth, closing the gaps in health care, education, employment and pay, neighborhood safety and fairness within criminal justice.¹⁶³

While disaggregated data collection will be necessary to show these gaps and to measure improvement in closing them, data collection is not mentioned in these motions. Instead, the motions focus on the goal of structural change through economic justice.



161. City of Asheville, 2020.

162. David, 2020.

163. City of Asheville, 2020.



The process: Respectful relationship

Government must take a decolonizing and human rights-based approach to disaggregated data initiatives. At the heart of both of these approaches is **respectful relationship**, where marginalized communities are meaningfully involved throughout the stages of collection, storage, use (including analysis and interpretation) and distribution of disaggregated data. Working in relationship is not the traditional government engagement approach of townhall consultations or online surveys where government continues to hold all the power and merely takes advice from others without fundamental change.

Many of the community and academic leaders we spoke to highlight the need for **data sovereignty as the foundation of respectful relationship**. Data sovereignty provides for community-led decision making and centres community-based needs, experiences and knowledge. Data sovereignty is an effective way to mitigate against the risks of further stigmatization. While data sovereignty is a principle that has been substantially developed by Indigenous communities in relation to their data, we are learning from this principle and applying it to all communities for which data will be collected. There is an opportunity here to develop and adopt new frameworks and principles to support meaningful community engagement, as well as transformative justice.¹⁶⁴

Transformative justice offers a relational approach to justice, acknowledging complex social systems, conditions and unequal relationships that structure not just society, but the very tools designed to address social problems.¹⁶⁵ It is an approach that emphasizes process over output.

¹⁶⁴. June Francis in community consultation, July 27, 2020.

¹⁶⁵. Kim, 2018.

In relation to this project, we define respectful relationship as relevance, responsibility, reciprocity and reflexivity:^{166,167}

Relevance

In engaging with communities on data collection, the relevant benefits and risks of data collection according to those communities must be heard and attended to: data must be used in ways that communities want and need, which includes a strengths-based approach with appropriate indicators. Through recognizing knowledge and skills communities bring and the history and ongoing inequity experienced by many, it's more likely we will reap the benefits and mitigate the risks of disaggregated data.

Responsibility and Reciprocity

Structural change must accompany data collection, including through the shift to data stewardship and sovereignty. Thus, systemically oppressed communities are not merely engaged in consultation, but supported by a larger social change through which these communities “gain access to power, authority, and an opportunity to exercise control over the affairs of everyday life.”¹⁶⁸ Governments have a responsibility to systemically oppressed communities and those communities have a reciprocal responsibility to convey their strategic recommendations on the basis of this redistribution of power.¹⁶⁹

Reflexivity

Data collection, analysis and use must include a deep and continual examination of individual, social and institutional biases to ensure that the overall aim of equity is being met. Research practices are not value neutral, nor are the products of research projects. True collaboration requires a process of re-evaluation of assumptions, biases and cultural differences of researchers and communities, which needs to be built in through constant bias-checking mechanisms in any long-term data collection process. Reflexivity in this context also requires that researchers and policy makers continually revisit whether the data collections remains in service of the ultimate goals: that is, is it necessary and useful in addressing systemic inequality.

Without a balance between relevance, reciprocity, responsibility and reflexivity as interconnected principles in building respectful relationships, approaches to disaggregated data collection are likely to reproduce systemic inequalities and social harms. As a process, a relational approach to disaggregated data moves beyond a deficit narrative to achieve structural change because it is focused on the strengths and needs of the community. It is impossible to generalize across, between and within marginalized communities in the province; however, if one thing is clear from community consultations, it is that research values need to change and that relationships must take precedence in approaches to disaggregated data.

As participants in our consultations emphasized, **relationship change leads to systems change**. On the flipside, without building relationship, attempts to change existing systems of oppression are less likely to succeed. This was clear in the response to B.C.'s Missing Women Commission of Inquiry led by Wally Oppal when the commission released the final report in December 2012, which was met by anger and recrimination as many families did not feel heard during the inquiry.¹⁷⁰

166. Kirkness and Barnhardt, 2001.

167. Thira, 2020.

168. Kirkness and Barnhardt, 2001.

169. Cultural Safety Attribute Working Group, 2019.

170. MacQueen, 2012.

In developing this approach to research, there is an opportunity to begin to transform the very social structures and institutional practices that have historically contributed to systemic inequalities in B.C. Transformative justice as an ethical imperative reflects the responsibility to commit to “fostering justice and equity in and through”¹⁷¹ data collection, analysis and use. As participants underscored, justice for systemically oppressed communities does not simply arise in documenting inequalities through disaggregated data and taking urgent action based on what the data shows (although this is important), but also in reimagining and rebuilding how research is done in order to address ongoing social harm that has taken place through standard research practices in the province.

Relevance

Problems with social categories used in surveys

Researchers often impose their own categorial imperatives in data collection, with little regard for how community members themselves may identify.¹⁷² Thus, for many participants, naming came up as a theme, particularly when people did not see their lived experience or identity reflected in binary options, identity boxes or outdated notions of race, racialization and Indigeneity. Common naming issues raised include:

- Pan-Indigenous demographic frameworks that do not account for the broad spectrum of Indigenous community diversity in the province
- Transgender and gender non-confirming people skipping surveys because language is “disrespectful around their being, it has Othered them,” sometimes literally with tick box options for gender labeled “Other”¹⁷³
- Failure to recognize diversity within the cross-disability community
- The inclusion of “Two-Spirit” in broader LGBTQ2S+ demographic frameworks has resulted in non-Indigenous people identifying as Indigenous

In response, anti-oppressive researchers have changed demographic surveys in various ways to provide for more inclusivity, including the addition of space to self-identify and/or providing lists with multiple options to allow for multiple participant socio-cultural backgrounds. Other options are not only more inclusive, but also allow for more demographically accurate information.

While participants have explicit warnings about limitations and needs in defining social categories for research, others emphasize the importance of understanding that swapping one social category for

171. Souto-Manning and Winn, 2019.

172. Smith, 1999.

173. Trans Focus, 2019.

another isn't a one-size fits all solution to ongoing problems in disaggregated data collection; rather, the broader foundations of research must be challenged for systemic inequalities to be addressed, including a deeper examination of questions like:

- Who comes up with the categories?
- Who collects the data?
- Who owns or exercises rights over the data?
- Who uses the data and for what purpose?

Henry Yu, a professor in the University of British Columbia's History Department emphasizes, "that is actually the matter at hand. If it's the same people, collecting the same way, but just using different categories, that's no more a decolonized approach than the one we have...in fact...that's actually one of the problems: the idea that if we just change the categories then it'll all be okay."

This underlies the importance of grounding disaggregated data collection in the principle of respectful relationship, which would mitigate the risk of using inaccurate social categories. For example, in Manitoba, the provincial government began collecting data on racial and ethnic identifiers in relation to COVID-19 in May 2020. One important concern was that Black as a racial identifier does not always reflect the multiple ways in which community identify and, as a consequence, could erase positionality. In structuring categories in ways that are meaningful to communities, that reflect the ways that they perceive themselves, the data collection model now includes "Black and African Descent." Through the engagement of a data collection group with racialized and Indigenous experts, including the Executive Director of Manitoba Human Rights Commission, discussions continue on appropriate racial categories and other relevant issues.



Asking the wrong questions

As one participant of our consultations emphasized, data tells stories. Without community-based involvement, the wrong questions may get asked, which translates into the wrong stories being told.

Dr. June Francis, explains:

We need data that can truly do some of the things we want to do. So it's not just collecting this data. We're trying to get at a problem. And the question is, how can data get us there? And so some of it is to be truly transformative and to go back to things that have been brought up over and over. How do we get people's experience to be understood? How do we get everybody to understand that those questions on those questionnaires came out of a deeply racist past? ...I remember being on a Statistics Canada consultation and I was trying to explain to them that belonging, which is why they ask the question, how do you feel connected to your neighborhood? Benign question, they think? Right?... No, who is your neighborhood? And all of that — for Black communities, it's their cultural community. And they've — in fact, they're scared of their neighborhood. Now, let me just say that nobody set up interrogations of belonging? What does it mean for Indigenous populations to belong? And those are important constructs, right? Those are the things we really want to know. Because we know those determine health. Right? We know that. So, I'm just saying that there's so much in these questionnaires that are deeply rooted in a history of asking the wrong questions based on an assumption about why middle-class or white rich people and their notions of connectedness and what's important and all of this. So I think we cannot go forward if we don't deeply go back to very important fundamental transformative research.

Dr. Rod McCormick of the Kanienuk Nation and Professor and Research Chair at Thompson Rivers University's Faculty of Education and Social Work also emphasizes:

The indicators or measurements that are used in that they're often not culturally relevant to us.¹⁷⁴ And I say that recently I was in a video conference with colleagues from Australia. It was a Canadian Australian research committee and the Australians were congratulating Canada on, "wow, your rates of COVID-19 on reserves are so low. What's your success story?" and I'm kind of rolling my eyes and one of the Canadians say that we just block people from entering the reserves. And I said, "well, you know the data that's being collected is not particularly relevant because if you were to look at mental health, we aren't doing well at all." So the very fact of self-isolating and blocking access to and from the communities is having a devastating effect on our mental health. And I think FNHA [First Nations Health Authority] did do one report, I was happy to see, just showing how the overdoses have doubled during COVID-19... Much of what's important to non-Indigenous people is based on sort of a reductionist worldview. And I hate to generalize here, but it's not a relational worldview that as Indigenous peoples, so many of us sort of follow. And so, I guess it's just a caution that you know, worldview permeates all aspects of this, different types of data that's collected.

174. The First Nations Health Authority (FNHA) has done work on developing culturally appropriate indicators, e.g., section 3.2 of this report provides examples of the health and wellness measurements through the Population Health and Wellness Agenda jointly developed by the Provincial Health Office and FNHA: <https://www.fnha.ca/Documents/FNHA-BC-Tripartite-Agreement-Case-Study-Data-and-Information-Governance.pdf>

When it comes to disaggregated data collection there are many reasons to prioritize data sovereignty and respectful relationship—better, more relevant, research questions are just one example. Better questions are also more likely to strike at the root of inequalities and program and service measures, making research more applicable and placing solutions within reach.

Responsibility and reciprocity

In grounding disaggregated data in respectful relationship, community governance in the collection, storage, use and disclosure of data is a priority.

Indigenous communities are leading the way on defining and advocating for this. Participants in our consultations described ongoing efforts to take community-led approaches to research: to change how research is conducted so that it takes community-specific Indigenous perspectives into account, plays to the strengths of the communities involved, and adapts its measures and practices to meet community needs. In fact, “as Friesen and colleagues (2017) point out, much of the recent energy and innovation in the ethics of protecting marginalized communities from exploitive research emerged first in the resistance of Indigenous communities to colonial research practices.”¹⁷⁵

The British Columbia Tripartite Framework Agreement on First Nation Health Governance¹⁷⁶ between the Government of Canada, the Government of B.C., and First Nations in B.C. is a good example of an agreement grounded in principles of First Nations governance and respectful relationship. The impact of this framework, which now governs the First Nations Health Authority, was described by a participant in the 2019 evaluation of the agreement:

What I think makes this work isn't the fact that we're transforming health services, it's the fact that we're doing that to a health governance structure where First Nations governance matters. Because you could throw any subject matter in there and it still would be the importance of the governance that makes a difference to how that works—the whole notion of nothing for us, without us... I describe it as the largest self-determination decision ever made in this country by First Nations.¹⁷⁷

In relationship to each other, the signing parties have agreed to act in accordance with Reciprocal Accountability, defined as working in collaboration with each other and upholding their respective obligations.¹⁷⁸ This is very similar to the principles of Responsibility and Reciprocity we have outlined.

175. Boilevin et al., 2019.

176. British Columbia Tripartite Framework Agreement on First Nation Health Governance, 2011

177. First Nations Health Authority et al, 2019.

178. British Columbia Tripartite Framework Agreement on First Nation Health Governance, 2011, ss. 2.2(1).

Gwen Phillips describes data governance as the heart of “the grandmother perspective” needed for disaggregated data:

I think we need to consider flipping the whole thing and asking who has the data and why? What is the ownership component of it? This is critical — are we collecting data to get rid of problems that Indigenous people have, or are we collecting data to measure the strength of Indigenous people, families, communities and Nations? Indigenous people live all over the place, but we belong to Nations; our cultural identity is key to our well-being and how that identity is portrayed through deficit-based data or strengths-based data leads to a picture being formed in the minds of Canadians and in the minds of Indigenous people. And the personal data that relates to First Nations citizens is everywhere and treated differently by different agencies. Data needs to come from all sorts of places, but the Nations are the ones who need to actually be controlling it; measuring what matters. The Nations must be recognized as governments and as the owners and custodians of population data that relates to their citizens; to their identity as a distinct society — a Nation of people with a unique language and attachment to the land.

It is useful to consider a model of public participation developed by the International Association of Public Participation (IAP2),^{179,180} to understand what communities are asking for in changing the parameters of engagement. The IAP2 spectrum of public participation ranges from informing to consulting to involving to collaborating to empowering. In general government work, *informing* is the standard approach: providing the public with information on government priorities and aims. In developing legislation and policy, government sometimes undertakes *consultation* in order to “obtain public feedback on analysis, alternatives and/or decision.” However, there is no commitment to incorporating this feedback into final decisions. It is rare that government moves further up the engagement spectrum, although the development of BC’s Declaration on the Rights of Indigenous Peoples was a positive and historic example of collaboration between the provincial government and Indigenous leadership.

179. International Association for Public Participation.

180. The B.C. Ministry of Health and the First Nations Health Authority have provided a reconsideration of the IAP2 engagement framework from the perspective of First Nations participation. In particular, this update embeds community participation goals, and reciprocity and responsibility at every stage from both the organization and the community. Indigenous Engagement and Cultural Safety Guidebook: A Resource for Primary Care Networks, Appendix B, https://www.pcnbc.ca/media/pcn/PCN_Guidebook-Indigenous_Engagement_and_Cultural_Safety_v1.0.pdf, Sept. 2019.

Public participation spectrum

GOAL				
INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
To provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/ or solutions	To obtain public feedback on analysis, alternatives and/ or decision	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution	To place final decision-making in the hands of the public

PROMISE				
INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
We will keep you informed	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible	We will implement what you decide

In relation to disaggregated data, communities are advocating for government to fundamentally change their approach to engagement. Government must engage with communities at the far end of the spectrum to meaningfully collaborate or empower. As Gwen Phillips has articulated, it is a shift from a paternalistic ‘Big Brother’ relationship of control to “the grandmother perspective” of care, so communities can decide how to engage with their data on their own terms. As examples, OCAP® is a template for data sovereignty and E-GAP is a model for Empowerment (leading to data sovereignty in the long term), both described below.

Given the impact of racism, colonization, misogyny, ableism, classism and other systems of oppression which have resulted in systemic inequality of power, resources and opportunities, government must prioritize funding and capacity building in order for communities to be able to participate meaningfully. Funding could provide for technological infrastructure for data storage,

research training for communities in quantitative and qualitative analysis or ongoing investment in public participation to support community governance frameworks with meaningful decision-making powers.

When done well, this process of collaboration or empowerment enhances the potential of research as a tool for social transformation as described in “A Manifesto for Ethical Research in the Downtown Eastside.” In addition to creating positive outcomes to address inequity, this process provides for positive change benefitting the community including:

- Educating and empowering the community, “especially if the questions being answered come from community members themselves”¹⁸¹
- Helping to challenge stigma
- Helping to “complexify the issues” for example, “help people understand the wider story behind complicated social issues such as substance use”¹⁸²
- Helping “to create evidence to support important community resources”¹⁸³
- Creating “meaningful sources of income for people” and helping them to “learn new skills”¹⁸⁴



181. Boilevin et al.,2019.

182. Ibid.

183. Ibid.

184. Ibid.

OCAP® (Ownership, Control, Access, Possession)

In 2010, the First Nations Information Governance Centre became an independent entity struck to safeguard Indigenous communities' ownership, control, access and possession (OCAP®) of research data.¹⁸⁵ OCAP® principles were created within the context of a national First Nations health survey developed nearly two decades ago.¹⁸⁶ The First Nations Information Governance Centre emphasizes that OCAP® principles are specific to First Nations Peoples and they do “not apply to non-First Nations information or research.” The principles are:

Ownership: The notion of ownership refers to the relationship of a First Nations community to its cultural knowledge, data and information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. Ownership is distinct from stewardship. The stewardship or custodianship of data or information by an institution that is accountable to the group is a mechanism through which ownership may be maintained.

Control: The aspirations and inherent rights of First Nations to maintain and regain control of all aspects of their lives and institutions extend to information and data. The principle of control asserts that First Nations people, their communities and representative bodies must control all aspects of information management, from collection of data to the use, disclosure and ultimate destruction of data.

Access: First Nations must have access to information and data about themselves and their communities, regardless of where it is held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding who can access their collective information.

Possession: While ownership identifies the relationship between a people and their data, possession reflects the state of stewardship of data. First Nation possession puts data within First Nation jurisdiction and therefore, within First Nation control. Possession is the mechanism to assert and protect ownership and control. First Nations generally exercise little or no control over data that is in the possession of others, particularly other governments.¹⁸⁷

185. First Nations Information Governance Centre, 2020.

186. Ibid.

187. First Nations Information Governance Centre, 2014.

OCAP[®] was developed in response to colonization and the role of research in “reproducing colonial relations.”¹⁸⁸ While it offers lessons in building alternative frameworks to support community-driven data, First Nations, Inuit and Métis communities are constitutionally sovereign with “inherent rights to self-determination” and therefore distinct from other systemically oppressed communities.¹⁸⁹ Furthermore, the OCAP[®] framework is not a pan-Indigenous approach; rather, it is uniquely enacted within diverse local Indigenous community contexts, traditions and governance systems. It is a model for data sovereignty only within these contexts.

However, OCAP[®] does serve as a model for reimagining and rebuilding how research is done in order to address ongoing social harm that has taken place through standard research practices. In a public statement on race-based data and COVID-19, Toronto’s Black Public Health Collective emphasizes Black ownership of research products and processes and the value of OCAP[®] as a model.¹⁹⁰

Our own communities are much better suited and trusted to collect data for the purposes of ending health disparities. We should consider learning from Indigenous communities who have recognized principles in place of Ownership, Control, Access, and Possession (OCAP[®]), which stress Indigenous self determination in research processes.



188. Espey, 2002.

189. First Nations Information Governance Centre, 2014.

190. Black Public Health Collective, 2020.

E-GAP (Engagement, Governance, Access, Protection)

E-GAP is a “data governance and accountability framework for the collection and use of socio-demographic data in health care” in development by the Black Health Equity Working Group in Toronto.¹⁹¹ While the document emphasizes the longer-term strategy is that Black communities would become data owners and stewards in order to achieve data sovereignty, the E-GAP framework provides for true partnerships in the meantime and provides a path toward data sovereignty. Within the framework, the processes and strategies defined in response to community concerns and potential for harms are emphasized as “non-negotiable.”

Engagement: “Province-wide community engagement process that involves broad consultation with community members, leaders and organizations. Meaningful engagement must focus on development of infrastructure that allows communities to collect, store, manage and analyze their own data.”

Governance: “Development of infrastructure that allows communities to collect, store, manage and analyze their own data. The Community Governance Table would be on the front line of building transparent accountability. As the data stewards, the Ministry of Health and Public Health Units are considered accountable to Black communities. Consultation with the Community Governance Table should be done prior to the release of all reports to ensure that reporting does not further stigmatize marginalized communities.”

Access: Capacity building “in communities to use their data. In addition there need to be transparent pathways for access to data. There will be a need to actively facilitate access to and the use of data by communities. E-GAP framework also requires a process that permits or denies access by external researchers or organizations based on an approval criteria.”

Protection: “One of the major ways that communities can be protected is through the ownership of their data. Data sovereignty for Black communities is a way of facilitating protection. The province should begin working with Black communities to establish timelines and milestones for an independent data management system that supports community ownership of data. It should also develop systems to help communities monitor and influence the use of existing data resources. The Community Governance Table should have a focus on developing the specific protections that need to be in place to protect communities from the misuse of data in lieu of full data ownership.”

¹⁹¹. See Bailey et al., 2020. Drawing on OCAP, the E-GAP principles in development by the Black Public Health Working Group in Ontario are an emerging practice on meaningful engagement and data governance with Black communities.

Case study: The Assembly of Manitoba Chiefs and the COVID-19 Data Sharing Agreement

This is another example of collaboration between a provincial government and Indigenous leadership formalised through a data sharing agreement. During the H1N1 pandemic, First Nations communities in Manitoba were hit hard by the virus and this has informed the swift response of the Assembly of Manitoba Chiefs to the challenges COVID-19 has posed. In a first of its kind response, the Assembly of Manitoba Chief's Health Information Research Governance Committee, the Province of Manitoba and the First Nations Health and Social Secretariat of Manitoba have developed a data sharing plan rooted in OCAP® principles.¹⁹² As part of the agreement, the Province of Manitoba has requested “patients testing positive for COVID-19 to voluntarily self-identify if they are First Nations, Métis or Inuit.”¹⁹³ While the data will be shared with First Nations leadership in the province to help stop the spread of COVID-19, out of respect for First Nations' data sovereignty, it will not be shared with the public without consent.

Garrison Settee, Grand Chief of Manitoba Keewatinowi Okimakanak, points to the critical role First Nations leadership must play in health care decisions, given unequal access to health care services and rural and remote community locations.¹⁹⁴ Dr. Marcia Anderson, a Cree-Anishinaabe doctor and Vice Dean for Indigenous health at the University of Manitoba, indicates First Nations leadership will “make visible the racism that exists in health care and in other settings” and will “make sure we intervene” and “measure our interventions and improve.”¹⁹⁵

Others have expressed frustration with the exclusivity of the agreement.^{196,197} The Manitoba Métis Federation and urban Indigenous non-profit organizations have critiqued the agreement because it did not include provisions for their involvement in the data sharing plan.¹⁹⁸ In Winnipeg, for example, non-profit organizations provide a range of services, programs and supports for urban Indigenous populations. The province is now investigating similar agreements with Inuit and Métis leadership.¹⁹⁹

As demonstrated in the case study, there are challenges in identifying community leadership to steward data as communities are not homogenous and perspectives can be incredibly diverse. Moving into these tensions, not away from them, will better equip the provincial government to establish realistic guidelines for disaggregated data collection. Taking the time to establish the appropriate community leaders or governance table is critical.

192. Geary, 2020.

193. Ibid.

194. Ibid.

195. Andrew-Gee, 2020.

196. Skye, 2020.

197. Sanders, 2020.

198. Geary, 2020.

199. Geary, 2020.

Reflexivity

Evaluation

Reflexivity is the process of continually questioning assumptions and activities in order to ensure that the defined purpose is being met. Strong evaluation processes must be applied to projects that are integrating disaggregated data collection in order to ensure the process of building and maintaining respectful relationship and the purpose of structural change continue to be the focus and that targets within these areas are being met. Defined outcomes must be identified as meaningful by communities themselves as with all stages of the project. Evaluation must not only be built in at the end of projects but continually throughout the lifetime of projects as process is foundational to success.

Standardization

Reflexivity must be applied to key considerations of any research initiative and here we outline how that process could apply to the question of standardization. The issue of standardization in disaggregated data collection—put simply, asking the same questions with the same categories across provincial sectors for a provincial standard and across jurisdictions for a national standard—is complex. While many researchers and community participants recognize the value of comparability of data, the risks of standardization are high, in particular, as it may undermine the principle of respectful relationship grounded in community ownership.

The United Nations Economic and Social Affairs highlight this issue in relation to “Data Collection and Disaggregation for Indigenous Peoples,” emphasizing that “standard forms of questions used do not always accurately reflect the situation of Indigenous peoples—for example, Indigenous family and social patterns are sometimes very different from the profile of the rest of the population.”²⁰⁰ The UN recommends: “In all relevant data collection exercises, questions on Indigenous identity with full respect for the principle of self-identification have to be included. It is important to develop multiple criteria with local indigenous peoples’ active and effective participation to accurately capture identity and socio-economic conditions.”

The solution from Ontario’s Data Standards for the Identification and Monitoring Systemic Racism is:

The question and response values may deviate from the below [model] at the request of Indigenous communities, or if data sharing agreements are in place between PSOs [public sector organizations] and Indigenous communities or organizations. However, responses have to map to “First Nations,” “Métis,” and “Inuit” for the purpose of analyses and reporting under the ARA [Anti-Racism Act].

200. United Nations Department of Economic and Social Affairs, Indigenous Peoples, 2020.

Dr. Kwame McKenzie supports this approach in describing a “minimum data set that is standard and nationally agreed upon but allows expansion for local reasons and retains the ability to collapse into larger categories. This produces partnerships in provinces, cities and communities in the co-creation of data sets.” The result would be an accordion approach to national data collection: where some categories are standardized and more granular, regional or community specific categories can be expanded as necessary and as developed in relationship with communities.

However, some community members and academics express concerns with this approach. As an example of the risks, when the United States’ National Center for Health Statistics (NCHS) calculated birth and death rates for 2000 and 2001, it reduced 31 distinct “race categories” used in the 2000 American census to five race categories, assigning “multiple-race persons to single race categories.”²⁰¹ This reformulation of statistics erased critical elements of American experiences.

In the B.C. context, First Nation, Inuit and Métis communities are incredibly diverse. Demographic studies that do not account for differences between, and within, First Nations, Inuit and Métis communities can perpetuate colonial norms. For example, there are over 200 distinct First Nations across BC, more than 30 distinct languages and approximately 60 dialects spoken in the province.²⁰² Reducing this diversity to three monolithic categories has the potential to undermine Indigenous self-determination.

Finding localized solutions—achieved through work with Indigenous and other communities and determined through community governance processes—is a priority that should not be set aside due to the need for standardization. While we recognize that it is necessary to have enough standardization across regions to influence the development of good provincial and federal policy and law, it is possible to strike a fair balance between cross-country consistency and regional specificity. The Community Governance Board should be key contributors in determining how to strike such a balance.

Balancing immediate action and long-term community engagement

There is a persistent tension between over consultation and a lack of meaningful consultation on disaggregated data. Many participants in our dialogue sessions expressed fatigue over the sheer number of consultations they had participated in. Dr. Malinda Smith, Vice-Provost (Equity, Diversity and Inclusion) at the University of Calgary emphasizes, “I think most racialized and Indigenous communities will tell you that we’ve been over-studied and reported on. Now what we want is to get something done for a change.”

Participants caution the government to engage in meaningful consultations (which take time), while not using it as an excuse to preclude actions that can save lives, for example, within the context of COVID-19 responses, policing reforms, or enhancing the health and safety of youth in government care.

201. Ingram, et al., 2003.
202. Indigenous Canada, 2020.

The sudden renewed interest in disaggregated collection as it relates to policy, practice and law in BC presents distinct opportunities and challenges — a key recommendation from our dialogue sessions is to **slow down consultations so that they are meaningful** while making necessary changes to save lives (see immediate recommendations below). Participants caution not to reproduce work that has already been done. Dr. Malinda S. Smith states:

I really don't want us to be repeating the very careful, expensive work that's been done already by leading research institutions, by Canadian researchers, by Women and Gender Equality, by Statistics Canada's Immigration and Ethnocultural Statistics team, by the Canada Research Chairs Program, among others... I think we need to use this time not to review the literature yet again, not to repeat what they've already done, but to draw on this research to say what is necessary to recommend to the government in B.C.



“I think most racialized and Indigenous communities will tell you that we’ve been over-studied and reported on. Now what we want is to get something done for a change.”

Legislative reform in support of this purpose and process

Current context

Protection of individual privacy by FIPPA

Within B.C., the Freedom of Information and Protection of Privacy Act (FIPPA)²⁰³ and the Personal Information Protection Act (PIPA)²⁰⁴ govern the collection, use and disclosure of personal information in relation to public bodies²⁰⁵ (including health authorities) and organizations (such as medical clinics). Our recommendations focus on public bodies, making FIPPA the relevant legislation. Before providing recommendations, we will outline how the collection, use and disclosure provisions of FIPPA relate to disaggregated data.

FIPPA applies to disaggregated data in different ways depending on whether the data is “personal information,” meaning that it may reasonably lead to the identification of an individual either alone or in conjunction with other available data.²⁰⁶ Developing disaggregated data usually begins with the collection of information from identifiable individuals, that is then anonymized for statistical purposes, meaning that FIPPA’s provisions on the collection of personal information²⁰⁷ apply to the collection of information that may be the source of disaggregated data.

The circumstances under which public bodies may collect personal information under FIPPA are broad. These include circumstances in which the information relates directly to or is necessary for a program or activity of a public body, or its planning or evaluation, the information is collected for a prescribed purpose by the regulations, or other circumstances expressly authorized by another Act. Consent is only discussed in the context of information collection for a “prescribed purpose.” This relates to narrow information collection purposes outlined in the regulations²⁰⁸ (for example, a public body updating an individual’s contact information or name).

Public bodies’ use of data is regulated by Part 3 of FIPPA, which relates only to personal information. This means that public bodies’ use of disaggregated data is only regulated by FIPPA to the extent that it is “personal information.” If the information in the disaggregated data is de-identified, it is therefore not regulated by FIPPA.

203. Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996, c. 165.

204. Personal Information Protection Act, S.B.C. 2003, c. 63.

205. “Public body” is defined in FIPPA, Schedule 1.

206. *Vancouver (City) (Re)*, 2019 BCIPC 15 at para 16 citing *Kelowna (City) (Re)*, 2018 BCIPC 14 at para 32.

207. FIPPA, s 26.

208. *Freedom of Information and Protection of Privacy Regulation*, BC Reg 155/2012, s 9.

This leaves public bodies' use of much, if not most, disaggregated data, unregulated, giving rise to the risks identified in this report.

FIPPA regulates the disclosure of information held by public bodies in accordance with two core pillars: promoting access to information and protecting privacy. These two interests are balanced against each other through a scheme that provides a general right of access to information held by public bodies subject to a number of exceptions, including harm to personal privacy.²⁰⁹ The exception for information that would unreasonably invade a third party's privacy applies to personal information only. Therefore, disaggregated data that is not identifiable will only be subject to the remaining disclosure exceptions, which are more limited. These include: harm to individual or public safety, harm to business interests and harm to intergovernmental relations. Much disaggregated data held by public bodies is therefore likely to be available upon request, provided it does not constitute personal information or trigger another exception.²¹⁰

The Statistics Act

The Statistics Act authorizes the collection of information by the Director of Statistics for research and statistical purposes. The Statistics Act contains a general provision against discrimination stating that the Director must not use the Director's powers to prejudice any person.²¹¹ The Statistics Act prohibits the disclosure of information collected pursuant to the Statistics Act in a manner that allows identification of the information with an individual, notwithstanding the right of access to information set out in FIPPA.²¹² Nothing in the Statistics Act mandates collection of any particular type of information.

Gaps in the current legislative scheme

No positive obligation to conduct equity-enhancing research

Data collection and use plays a crucial role in policy development, and numerous acts commit B.C. to advancing social equity through policy and practice.²¹³ However, while FIPPA provides a positive right of access to information for the public, it does not impose a positive obligation to collect data in support of advancing equity objectives. The Statistics Act empowers the Director of Statistics to collect and analyze data on the social and economic conditions of people in British Columbia,²¹⁴ but aside from the prohibition on discrimination, it does not reference public interest or human rights concerns. Legislation to mandate the collection of intersectional disaggregated data relating to human rights issues would lay the groundwork for the data-informed policy needed to effectively address these issues.

209. FIPPA, s 22(1).

210. See FIPPA ss 12 to 22.1.

211. *Statistics Act*, R.S.B.C. 1996, c. 439, s. 6.

212. *Ibid*, s 9.

213. For example, the *BC Human Rights Code*, *Declaration on the Rights of Indigenous Peoples Act*, and the *Poverty Reduction Strategy Act*.

214. *Statistics Act*, s 5(1).

The existing scheme does not provide any standards for the appropriate identity categories for use in data collection. This may limit the potential for intersectional analyses of data. Developing a data collection scheme that reflects the diversity of identities and experiences present in communities, particularly those that have been historically marginalized, will support the objectives of current equity-seeking legislation and bring an equity lens to data collection under all acts.

This objective would seem to be best served by enacting new legislation, the **Anti-Discrimination Data Act**, rather than amending FIPPA. The purpose of mandating the collection of this information is separate and apart from FIPPA's purposes of protecting personal privacy and providing access to information, and the Information and Privacy Commissioner of British Columbia specializes in privacy and access concerns, not equity concerns. A new act with its own principles and purpose would be a more effective vehicle for achieving equity outcomes than trying to do so through the amendment of FIPPA. However, portions of FIPPA may be amended to support purposes and operation of the new act.

Growing risk of re-identification

Within today's global technological context, the protection of individual privacy is challenged by the

Rapid technological developments and globalization have brought new challenges for the protection of personal data. The scale of the collection and sharing of personal data has increased significantly. Technology allows both private companies and public authorities to make use of personal data on an unprecedented scale in order to pursue their activities. Natural persons increasingly make personal information available publicly and globally. Technology has transformed both the economy and social life and should further facilitate the free flow of personal data within the Union and the transfer to third countries and international organisations, while ensuring a high level of the protection of personal data.²¹⁵

Population Data BC also recognizes the need for legislation, regulation, policy, and practice to catch up in B.C. to provide the higher level of protection needed:

The power of data lies in their use to make discoveries that can affect and benefit the public. This power is even greater when data of different types and from different sources are combined or linked together. Linking data, however, also can introduce risks, such as the potential to identify certain sub-populations or communities. The increase in both the opportunity offered by data use but also potential threat of that use creates uncertainty for data access, and uncertainty often leads to long, slow processes. Current practices surrounding the use and the sharing of data were established prior to the explosion of both data and analytic capabilities.²¹⁶

With this high risk of re-identification of de-identified data or the data being connected back to the person, the trend in privacy legislation is moving toward the protection of de-identified data as well as personal information.

215. European Union, 2016.

216. Population Data BC, 2020.

Concern about avoiding re-identification is reflected in FIPPA²¹⁷ and other legislation involving the collection of data, such as the Statistics Act.²¹⁸ However, there has been more innovation in modernizing privacy protection through program and policy development than through legislative changes. B.C.'s Data Innovation Program (DIP) is an excellent example.

The DIP uses de-identified information in the service of population-level analysis to improve government services and programs, and “treats the data as confidential, sensitive and subject to the Freedom of Information and Protection of Privacy Act (FOIPPA).”²¹⁹ The DIP is run by the Ministry of Citizens’ Services under the guidance of a board of deputy ministers from across the B.C. government. The program applies the internationally recognized Five Safes model as its privacy and security framework — “Safe: People, Projects, Data, Settings, Outputs.” The Office of the Information and Privacy Commissioner was involved in the development of this approach and supports the protection of de-identified data at the same level as personal information.²²⁰

The DIP’s approach to protecting the disclosure of demographic data across public bodies offers a strong framework that should be reflected in legislation and in practice. The DIP may serve as either a model or a vehicle for the analysis of data on equity-related subjects, particularly those that engage potentially sensitive information such as sexuality, gender, race, substance use or homelessness.

Limited role of consent in the collection process

Literature in the field of community-partnered research highlights the significance of ensuring consent to participate in a research project is as free and informed as possible. This means the potential participant must be informed of the purpose for which the information is being collected, and must be assured that their access to programs or services will not be affected by their choice to participate.²²¹ While this standard is challenging to realize in the context of data collection by public bodies, the role of consent could be expanded with respect to the collection of information that is gathered for the purpose of evaluating whether equity goals are being achieved. This may be done through the amendment of FIPPA or in provisions under the new Act.

Because the data to be used for equity research purposes is associated with an individual at the time it is collected, FIPPA provisions relating to collection of this information will apply. FIPPA currently authorizes the collection of data, without consent, if it is necessary for the operation or evaluation of a program. This could support the collection of equity data without consent for equity research purposes. However, amendments to FIPPA or the new Act could provide that where information on certain topics is collected for research equity purposes but is not otherwise necessary for the administration or evaluation of a government program, the individual must be offered an opportunity to refuse collection and to provide informed consent.

217. FIPPA, ss 22 and 35(1)(b).

218. Section 9(1)(b) states that a person “must not disclose or knowingly cause to be disclosed, by any means, information obtained under this Act in a manner that it is possible from the disclosure to relate the particulars obtained from an individual return to an identifiable individual person, business or organization.”

219. Government of British Columbia, 2020c.

220. Office of the Information and Privacy Commissioner of British Columbia, 2017.

221. Community consultations, July 2020.

Limited reflection of community harm in the use and disclosure of equity data

Currently, community harm in the collection, use, and disclosure of equity related data is not directly considered or protected against by legislation. As discussed throughout this report, protecting communities against harm stemming from data collection, use and disclosure remains a pressing objective. The Data Innovation Program recognizes this and emphasizes in Safe Projects that “B.C. will ensure that data projects have a public benefit and pose no harm to individuals or communities.”²²² These considerations must be informed by the voices of impacted communities and protected in legislation.

The use and disclosure of disaggregated data can occur in two ways. First, the government may utilize the data it has created to perform analyses and publish reports, and this would be mandated by the new proposed Act. The provisions in FIPPA relating to use and disclosure of personal information may not apply to the data once it is disaggregated if it is de-identified. As a result, standards should be provided for in the new legislation to regulate this use. The DIP’s required Privacy Impact Assessment may serve as a model for developing an equity impact assessment to be required for projects involving the collection, use and disclosure of demographic information. The content of the equity impact assessment could draw on the objectives in equity-seeking legislation (for example, the BC Human Rights Code, Declaration on the Rights of Indigenous Peoples Act, and the Poverty Reduction Strategy Act), and the welfare impact components of research ethics standards, such as the “Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2).”²²³ It could also mandate community approval through the Community Governance Board.

The second way that disaggregated data collected by public bodies may be used and disclosed is through a request by a member of the public for the disclosure of such data for their own use. FIPPA provides a right of access to records within the custody and control of a public body, subject to certain defined exceptions. None of the exceptions relate to harm that may result to systemically oppressed communities if the data is misused. Indeed, FIPPA’s disclosure requirements normally operate without regard to the use that the individual requester intends to make of the information, since disclosure under FIPPA is “disclosure to the world.” The broader harms of failing to adopt a “nothing about us without us” approach in building responses to issues affecting marginalized communities are therefore not captured.

One exception where subsequent use is relevant is s. 35 of FIPPA, which relates to agreements whereby researchers are provided access to personal information if certain requirements are met. FIPPA or the new legislation could be amended to provide that information that is derived from a collection made for equity research purposes can only be disclosed under an agreement that meets specified criteria, including the approval of the Community Governance Board, mirroring the standards put on government use of data.

222. Government of British Columbia, 2020c.

223. Government of Canada, 2018.

To avoid the risks of re-identification, these agreements must include provisions that a statistical element can only be disclosed if, in relation to the size of community, it is above a certain threshold to ensure that it does not reveal personal information about an individual or small group. This issue has been acknowledged through experiences with the opioid overdose data, “raising the important issues around sharing data with communities for the First Nations Health Authority (FNHA), helping to identify some of the tensions that exist between the FNHA’s obligation to consult with communities and provide them with their data, and the risks to individual and community privacy when working with data that is highly sensitive and often involves such small numbers that the potential for identification is increased.”²²⁴



224. First Nations Health Authority, 2020b.



Moving forward: Recommendations

To begin this transformative work, we provide recommendations for:

- **Legislative changes** grounded in the foundational principles of “the grandmother perspective” to guide government’s engagement in equity-advancing initiatives involving the use, collection and disclosure of race-based, Indigenous and other disaggregated demographic data. These changes will protect against community harm that may result from the use, collection and disclosure of disaggregated data during the research process, and embed responsibility and reciprocity by ensuring meaningful community governance and capacity building in disaggregated data initiatives
- **Data standards** to ensure these principles are applied in practice to provide relevance to communities by addressing the strengths and challenges of the collection, use and disclosure of disaggregated data collection and reflexivity by continually evaluating research assumptions, questions and activities
- **Immediate targeted recommendations** for data projects²²⁵

While our recommendations only apply to public bodies, they could be adapted for the private sector. The private sector could benefit from legislative changes targeting the collection, use and disclosure of disaggregated data to ensure enhanced protection of individual and community privacy given the issues discussed throughout this report.

The Anti-Discrimination Data Act

We recommend the development of legislation that is focused on building respectful relationships with marginalized communities to ensure that community needs and voices are meaningfully included in the data collection, use and disclosure process. As experts in their own lives, community members are the ones best equipped to identify priorities and risks in potential data collection projects.

225. In totality, this reflects the United Nations model of data revolution, which is grounded in: principles and standards; technology, innovation, and analysis; capacity and resources; and, leadership and governance: <https://www.undatarevolution.org/wp-content/uploads/2014/11/A-World-That-Counts.pdf>

When collecting, using and disclosing disaggregated data, it is important to adequately consider and address both individual harm and community harm. The current legislative framework in B.C. is structured to mitigate individual harm through the protection of individual privacy, but does not adequately consider or protect communities from harm associated with the collection, use and disclosure of disaggregated data, aside from limited references to “public interest.”²²⁶ Our recommendations address this gap by calling for meaningful consideration of community harm, and for the creation of a positive obligation to conduct responsible, equity-supporting research in collaboration with community. We also call for the protections against individual harm to be updated in response to modern challenges to personal privacy.

We recommend that the government draft the **Anti-Discrimination Data Act (ADDA)**, which would legislate the collection, use and disclosure of demographic data for social change. We also recommend that the government develop the ADDA in consultation with the Office of the Human Rights Commissioner and the Office of the Information and Privacy Commissioner.

The purpose of the ADDA would be defined in support of the BC Human Rights Code, which was established for structural change, including “to identify and eliminate persistent patterns of inequality associated with discrimination prohibited by this Code.”²²⁷ In addition, the ADDA must also serve the purposes of the Poverty Reduction Strategy Act²²⁸ and the Declaration on the Rights of Indigenous Peoples Act (DRIPA).²²⁹ Social condition (or poverty) and Indigeneity are not currently protected within the BC Human Rights Code, however demographic data in relation to these areas is important for identifying and eliminating “persistent patterns of inequality associated with discrimination.”

The proposed ADDA can serve as a step toward aligning laws that govern B.C. with UNDRIP, as required by DRIPA.²³⁰ DRIPA, which came into effect November 2019, is historic piece of legislation that supports the foundational principles outlined here regarding Indigenous peoples. It also lays some important groundwork for community governance and data sovereignty. One of the primary purposes of DRIPA is “to support the affirmation of, and develop relationships with, Indigenous governing bodies.” All activities mandated in DRIPA require “consultation and cooperation with the Indigenous peoples in British Columbia.”²³¹ Together with UNDRIP, these purposes have implications for data which engages Indigenous peoples.

While research and data collection are not directly addressed in UNDRIP, rights to research by and for Indigenous peoples flow from the right to self-determination and the pursuit of economic, social, and cultural development set out in Article 3. In addition, Indigenous peoples’ right to develop strategies supporting their right to development is set out in Article 23. Gathering data is a core component of policy-building, so supporting the development of Indigenous-led community research is necessary to fulfil these rights.

226. See for example FIPPA, ss. 25 and 35(1)(b).

227. Human Rights Code, s. 3(d).

228. Poverty Reduction Strategy Act, S.B.C. 2018, c. 40

229. Declaration on the Rights of Indigenous Peoples Act, S.B.C. 2019.

230. DRIPA, s. 3.

231. DRIPA, s. 2.

Indigenous peoples have the right to financial and technical state support in fulfilling the rights outlined in UNDRIP,²³² and states must take measures, including legislative measures, to achieve the Declaration's ends.²³³ Legislation, such as the proposed ADDA, can support the right to Indigenous self-determination through supporting data sovereignty.

The ADDA would also support the B.C. government's adoption of Gender-Based Analysis Plus (GBA+), which is an analytical tool applied across government to assess differential impacts of policies, programs and initiatives on diverse groups of women, men and gender-diverse people with considerations of intersectional socio-demographic factors, such as race, ethnicity, income, age and disability.²³⁴

The ADDA would set out a framework for the collection, use and disclosure of disaggregated demographic data and should include provisions that outline:

- **Privacy protections in line with principles of B.C.'s Data Innovation Program**, including: The Five Safes model, the protection of de-identified data and personal identifiable data, and privacy impact assessments completed with full consideration of individual and community harm.
- **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.
- **The establishment of a community governance board²³⁵ to make collaborative decisions with government,²³⁶** whose membership shall include members of systemically oppressed communities for which data will be collected, for example, race-based, Indigenous, gender and disability data. This approach supports the intersectionality of our identities and lives. This Board will be engaged in the development of a data governance model, including agreements about sharing information.
 - The decision-making process of this governance committee should be deliberation, not consensus. This means protections in relation to the collection, use and disclosure of demographic data are agreed upon in dialogue together, rather than people's pre-conceived ideas being agreed upon. The process of dialogue will be important in such a diverse committee and based in the model of collaboration not consult or inform.
 - Ongoing public deliberations,²³⁷ at least annually, designed and hosted by the Community Governance Board to provide check-in points for their data governance decisions.
 - A **Community Data Secretariat** to provide backbone support to this Board, including additional individual supports where necessary for meaningful participation to address financial, logistical and technological barriers.

232. UNDRIP, article 39.

233. UNDRIP, article 38.

234. Government of British Columbia.

235. Based on the model defined within the E-GAP framework: Bailey et al., 2020.

236. Mandating government engagement on the right of the IAP2 spectrum: Collaborate.

237. "A public deliberation is a method of public engagement that allows for an in-depth conversation that can result in direct policy recommendations. Although it is similar to a focus group, a deliberation is different in that it is more structured (e.g., specific discussion questions are pre-chosen) and lengthier" https://www.popdata.bc.ca/bc_data_deliberation

- **The establishment of data standards as decided by the Community Governance Board and broad engagement with communities.** These standards will be developed in collaboration the Office of the Human Rights Commissioner and the Office of the Information and Privacy Commissioner. These will supersede the existing Government Standard for Aboriginal Administrative Data (2007),²³⁸ which currently provides guidelines for the collection of Indigenous data. Data standards must follow the model outlined below to ensure the primacy of a relational process and social change purpose.
- **The extension of 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 this legislation.

The introduction of the ADDA to mandate appropriate privacy protections to mitigate individual and community harm should be accompanied by **the implementation of a comprehensive training and education program**. This will include providing training for public sector staff administering and analyzing demographic data surveys, a broad public education campaign to increase awareness about the benefits of disaggregated data collection, as well as the enhanced privacy protections associated with these data initiatives.

The ADDA may include provisions that apply to dovetail with FIPPA in order to achieve its objectives. Alternatively, or in addition, FIPPA may be subject to consequential amendments in order to create an interlocking scheme with the ADDA in relation to the collection, use, and disclosure of defined categories of equity-engaged data.

238. Ministry of Aboriginal Relations and Reconciliation Intergovernmental and Community Relations, 2007.

Data standards

As referenced above, the proposed ADDA includes a mandate to develop data standards to provide guidelines for the collection of data. We recommend a framework for these data standards, which includes an equity impact assessment process that a data project should comply with in order to be approved. This framework includes three components: defining the **purpose** of the project, setting up a respectful **process** and defining the scope and limitations of the **tool** (data collection, use and disclosure) with the community.

Proposed data standards framework



Purpose — Equity (apply Safe Projects²³⁹ principles from Five Safes model of Data Innovation Program):

- Define the purpose of the project in relation to a specific equity goal:
 - Ensure the focus is on systems failure not individual failure.
 - Align the defined purpose through the collection, use and disclosure of disaggregated data.
 - Describe why disaggregated data is needed to achieve the purpose and tie the tool to the purpose at all times. For example, disaggregated data for anti-racism in education.
 - Define targets and indicators specific to the purpose of the project that focus on structural changes that will result from the project.
 - Develop appropriate and adequate accountability mechanisms in relation to these targets.
- Embed the social construction of demographic categories throughout the initiative to avoid pathologizing groups:
 - Define this critical framework in relation to the project and where this contextual language will be included in project materials.
 - Where possible, hire researchers with critical race, queer and disability theory expertise to coordinate the collection, use and disclosure of disaggregated demographic data.
 - Define how this lens informs the research questions and data analysis.
- In order to achieve the purpose of the project, describe the level of standardization, if any, that is necessary across sector or geography.

239. Government of British Columbia, 2020c: "Data projects must be in the public interest." <https://www2.gov.bc.ca/gov/content/data/about-data-management/data-innovation-program/privacy-security>.



Process — Respectful relationship grounded in community data governance:

- For each project, identify communities impacted by the systemic issue that the project aims to address, in order to build a process grounded in respectful relationship
- Establish a small working group²⁴⁰ with these communities and empower members with decision-making authority (within scope and limitations of project and within the confines of law):
 - What practical supports will the project team offer for meaningful participation: financial, logistical, technological or otherwise?
 - How will the project team reach those most marginalized in relation to the issue? Will the outreach be accessible for diverse people?
 - If necessary, at the advice of the working group, conduct broad deliberations with impacted communities.
- Ensure evaluation is built in continually throughout the lifetime of the project as process is key to success — evaluate process, the system within which data collection is occurring and outcomes in relation to defined purpose of the project.
- Provide definitions for standard categories so that they may be broken into subcategories to reflect communities' data needs.



Tool — Data collection, use and disclosure applied with community:

- Validate purpose as appropriate and effective with community.
- Define research questions that are relevant to community and apply a strengths-based approach.
- Is disaggregated demographic data the most effective and appropriate tool to meet the purpose of the project in relationship with community?
- What other data collection sources (such as qualitative) need to be defined and implemented in order to provide a useful analysis that does not contribute to further harm?
- How will the project team build in protections for individual and community harm through all elements of the project — collection, use and disclosure of disaggregated demographic data?
- Engage community in defining what intersections are most relevant in collection, analysis and disclosure of the data.

240. The Community Governance Board operates as the data steward through assessment of data collection, use and disclosure requests but a community-based working group for each project is required to ensure the appropriate considerations are embedded in a specific project, for example, the collection of LGBTQ2S+ data in education requires a working group including LGBTQ2S+ students, teachers and educators to determine the relevant questions and considerations.

- Collection:
 - Determine specific questions in relation to demographic categories that are appropriate for these communities within the context of the project. For example, inclusion of “Black and African descent” in race-based data collection.
 - Define when demographic questions will be asked within context of project to reduce potential harm and increase response rates. For instance, consider administering survey at point of discharge from hospital when people are healed rather than admittance.
 - Apply informed consent protocol to collection of data: ensure the equity- seeking purpose is clearly defined, state participation in any government program or benefit is not dependent on such information being provided, clarify that information, even in disaggregated form, would only be used to promote equity seeking objectives.
- Use (apply Safe Data, Safe Settings and Safe People²⁴¹ principles):
 - De-identify data (remove personal identifiers such as name, address, etc.)
 - Store the data to ensure it can be cross-referenced to draw out significant intersections, such as race-based and socio-economic data analyzed together.
 - Define boundaries on potential use by other bodies that may request access to data in the future to be applied by the Community Governance Board when considering these requests.
 - Define boundaries on potential data-linking, which may be applied to strengthen data analysis with other relevant data sets but needs to be considered to ensure risks of individual and community harm are mitigated.
- Disclosure (apply Safe Output²⁴² principles):
 - With the small working group described above:
 - Define protections for individual privacy including the statistical threshold below which the risks of re-identification are high.
 - To mitigate community harm, use data to tell the stories that community want to tell.
 - Build in a pre-publication review through the Community Governance Board that we have recommended the government establish.

Once these steps are completed and approved by the Community Governance Board, the project-specific responses to this assessment tool should be embedded in an agreement between the Board and relevant parties (either through a research agreement or information sharing agreement depending on the specific nature of the project) in order to provide an adequate and appropriate accountability mechanism for the project in relationship with community.²⁴³

241. Government of British Columbia, 2020c: Data is de-identified but is protected as sensitive and confidential and subject to the Freedom of Information and Protection of Privacy Act; data can only be accessed in a secure setting; only authorized people can access the data: <https://www2.gov.bc.ca/gov/content/data/about-data-management/data-innovation-program/privacy-security>

242. Government of British Columbia, 2020c: Additional protection of privacy in research outputs

243. Using established model of data protection applied through Population Data BC.

Immediate targeted opportunities

There is a responsibility to act when missing data can result in a loss of human life.²⁴⁴ Numbers matter. Ongoing silences in data have harmed the most systemically oppressed communities. While participants emphasized the importance of slowing down and building respectful relationships, they also emphasized that too much focus on research can stall actions that can save lives when communities have already identified clear and present dangers and solutions.

While government is establishing the legislative framework to support community data governance for equity-seeking projects, we recommend that the government immediately start collecting disaggregated demographic data in these specific areas outlined below, which are drawn from existing community advocacy where the mechanism and type of data collection can be clearly defined.

We also recommend government consider establishing an interim community governance board to guide these initiatives, particularly the disclosure of statistical results, which may inadvertently cause community harm. However, in the absence of the community governance board and broader community engagement, government is still required to go through the pilot assessment tool offered above to the extent possible. In relation to considerations of demographic questions, government should refer to existing guidance.²⁴⁵



244. For example, see: Ministry of Aboriginal Relations and Reconciliation Intergovernmental and Community Relations, 2007; Canadian Institute for Health Information, 2020; and Statistics Canada, 2020.

245. See Caught in the Middle, a report from the Representative for Children and Youth which describes the circumstances surrounding the death of a young person. The collection of data on ethnicity could have helped in this situation and is one of the recommendations: https://rcybc.ca/wp-content/uploads/2019/12/rcy-caught-in-the-middle_nov2019-webversion.pdf

Health care

- We recommend the Ministry of Health direct health authorities across B.C.:
 - to collect race-based, Indigenous and other disaggregated demographic data in relation to COVID-19 to reveal and address systemic inequalities in social determinants of health and access to health care.
 - Data could include the number of medical visits, treatments in community or acute settings, admissions to, time spent in, and health outcomes from hospital stays, including data to determine discharge needs, unique public health needs, test requests and referrals, and data to track medical errors, misdiagnosis, deaths and allegations of discrimination in the provision of care and these indicators could be used to target culturally competent testing, treatment, and prevention strategies in racialized populations, as well as in low income areas. In the long term, the data could support targeted policy and practice to improve social determinants of health, such as poverty, housing, education, etc.
 - to collect disaggregated demographic data, particularly race-based, Indigenous and non-binary gender data for adults and children/youth (including children in government care), in relation to mental health detentions, including:
 - Number of involuntary admissions under s. 22 of the Mental Health Act²⁴⁶
 - Admission as an involuntary patient via police (s. 28); jail (s. 29(1)(a)); youth detention (s. 29(1)(b)); corrections (s. 29(1)(a)); and from another province (s. 42)
 - Length of involuntary detention periods including renewals (s. 22–24)
 - Number of people on extended leave (s. 37)

Policing

- We recommend the Ministry of Public Safety and Solicitor General draft a provincial policing standard requiring all police forces in B.C. to collect and analyze race-based data across the full spectrum of police services,²⁴⁷ including both victims and offenders of gender-based violence on arrest and cleared by charge rates. As far as possible we recommend disaggregated data collection of victims as well as accused persons and offenders.

246. Mental Health Act, R.S.B.C. 1996, c. 288.

247. Ontario Human Rights Commission, 2010b.

Corrections

- We recommend the Ministry of Public Safety and Solicitor General direct BC Corrections to collect race-based, Indigenous and other disaggregated demographic data, including data on inmates' histories of substance use and addiction, in correctional facilities in relation to:
 - Use of force, including total uses of force, Emergency Response Team interventions, people who have had more than one use of force against them, pepper spray deployments
 - Segregation placements
 - Separate confinement placements

Poverty reduction/Housing

- We recommend the Ministry of Social Development and Poverty Reduction and the Ministry of Housing collect disaggregated demographic data of users of the following programs:
 - Income and Disability Assistance
 - Rental Assistance Program
 - Temporary COVID-19 supplements
- In relation to targeted populations defined within the Poverty Reduction Strategy Act: children, youth, women and persons of all genders, Indigenous peoples, persons living with disabilities, persons living in rural and remote communities, immigrants and refugees, LGBTQ2S+ persons, seniors, persons and families working and earning low incomes, persons living with or fleeing abuse, persons living with mental illness or addiction, persons of colour.

Education

- We recommend the Ministry of Education expand the collection of disaggregated demographic data (currently Indigeneity, sex and disability) to include race, gender identity and expression, and other relevant categories in the annual Student Learning Survey to address systemic oppression within education and provide additional supports for marginalized students.

Children and family development

- We recommend the Ministry of Children and Family Development record the self-identified ethnicity,²⁴⁸ sexual orientation and gender identity of children in their care in the ministry's case management system and direct staff to speak with children in care about their desired supports and connections in relation to these identities.

248. See Representative for Children and Youth, 2019. RCY included this recommendation in this report and directed that it be completed by June 2020, but this disaggregated data collection has still not been implemented

Conclusion

We have learned an enormous amount from community experts through this project. While disaggregated demographic data has significant power to reveal systemic inequalities and lead to positive policy, there are also significant dangers in relation to individual and community harm. To achieve these benefits and avoid the dangers, the Anti-Discrimination Data Act and the associated data standards embed “the grandmother perspective” of data governance as caring not controlling through the provision of practical, concrete methods of data collection, use and disclosure.

Coming full circle, in gratitude for the generous gifts of time and knowledge from communities, we hope this report gives back to communities by providing the framework for a new governance model to ensure the collection, use and disclosure of disaggregated demographic data benefits communities. In any demographic data initiative, we must define an equity-seeking purpose and establish a process of respectful relationship before determining if and how to conduct data collection. The principles of relationship are relevance, responsibility, reciprocity and reflexivity—all elements must be held by all parties to ensure success in both process and outcome. In fact, relationship change precipitates systems change.

We appreciate the opportunity to provide these recommendations to the Legislative Assembly. We look forward to working together to ensure the human rights of British Columbians are protected now and for the future.

Human rights glossary

Visit our online Human Rights Glossary at: bchumanrights.ca/glossary

A

Ableism

An ideology and system of oppression in society that holds that some bodies are more valuable than others, which limits the potential of people with disabilities. People with disabilities are assumed to be less worthy of respect and consideration, less able to contribute and take part and of less value than other people. Ableism can be conscious or unconscious and is embedded in institutions, systems and the broader culture of a society.

Anti-oppressive

An active and consistent process of change to eliminate individual, institutional and systemic racism (and other systemic forces of oppression) as well as the oppression and injustice they cause.²⁴⁹

B

Biases

A predisposition, prejudice or generalization about a group of persons based on personal characteristics or stereotypes.

Binary/binaries

Binary means relating to, composed of or involving two things. An example in gender identity is the sex/gender binary, a system of viewing sex and gender as consisting solely of two categories: male and female or man and woman.

C

Classism

Discrimination or prejudice based on social or economic class. Classism, in which one group has power and privilege over another group based on income or access to resources, is a form of systemic oppression.

Community governance framework

A community governance framework is one that encompasses data sovereignty, governance and stewardship principles.

Constitutionally protected peoples

Recognition that Indigenous peoples have an inherent, constitutionally protected right to self-government, which means a right to manage their own affairs.

Critical race, disability and queer theory

Critical race, disability and queer theory analyze race, disability and sexuality, sex and gender, respectively, as cultural, historical, relative, social and political constructions.

D

Data governance

Data governance refers to who holds decision making powers about the use, collection, dissemination and storage of data.

²⁴⁹. Ontario Human Rights Commission, 2013.

Data sovereignty

Data sovereignty can be understood as the right of a nation, group of people or individual to exert control over the governance of data collection, application and ownership.

Data stewardship

Data stewardship can be understood as data management, including such issues as the “acquisition, storage, aggregation and deidentification and procedures for data release and use.”

Decolonization

The ongoing process of recognizing and removing colonial powers.

De-identified information

De-identified information refers to data that has been ‘cleaned’ of details that would allow someone’s identity to be known. In qualitative and quantitative research, it can encompass both direct information (like someone’s name or date of birth) and contextual information that might make it easy to figure out someone’s identity (like someone’s job). De-identified information, then, is information that has been stripped of all “direct identifiers” — that is, all information that can be used to identify the people from whom information was derived.²⁵⁰

E

Equity

Equity is the condition that would be achieved if one’s identity no longer predicted, in a statistical sense, how one fares. Equity work includes work to address root causes of inequities, not just their manifestation. This includes elimination of policies, practices, attitudes and cultural messages that reinforce differential outcomes or fail to eliminate them.²⁵¹

250. Laffel, 2010.

251. Racial Equity Tools, 2019.

Equity-enhancing research

Equity-enhancing research refers to applied research that contributes to alleviating social inequalities by surfacing the root causes of inequalities in areas such as healthcare, education and the law. It takes a direct and intentional approach — a distinct process of recognizing differences within groups of individuals and using this recognition to achieve equality in all aspects of a person’s life — to make society more just.

G

Gender policing

Gender policing is the act of imposing or enforcing normative gender expressions on an individual who is perceived as not adequately performing these via their appearance or behavior, the sex that was assigned to them at birth.

Gladue reports

A Gladue report is a pre-sentencing report that makes recommendations to a judge about what an appropriate sentence might be for an Indigenous person convicted of a crime. Gladue reports can be prepared for anyone who self-identifies as Indigenous. Gladue reports consider the unique systemic or background factors that may have played a part in the Indigenous person being charged with a criminal offence. The Criminal Code makes it mandatory for judges to consider these factors in sentencing an Indigenous person regardless of whether a Gladue report has been prepared.

H

Heterosexism

Heterosexism is the assumption that heterosexuality is superior, preferable and the only right, normal or moral expression of sexuality. It can be the reason for less overt forms of discrimination against LGBTQ2S+ people, in which the person or organization responsible may not intend or recognize their bias.²⁵²

I

Indigeneity and Indigenous

Indigeneity is tied to land and place. The term 'Indigenous' recognizes this connection of being from and belonging to the land (for example, one could state, "I am indigenous to North America" or "I am indigenous to this body of water").²⁵³

Information sharing agreement

Information sharing agreements provide the terms of reference for data sharing between multiple organizations or people; may be legally binding; highlight specific responsibilities, including data control, access, use and storage; and can support a "wide variety of data sharing policies" at the institutional level.

Intersectionality

Intersectionality is a concept first developed by lawyer, activist and scholar Kimberlé Crenshaw in relationship to Black women and the law in the United States.²⁵⁴ Crenshaw noticed that the legal system failed Black women because it did not acknowledge, or address, systemic inequalities linked to the intersections of racism and sexism. Since that time the concept has been more

broadly adopted in health care, education, and other areas. Olena Hankivsky, a professor at Simon Fraser University's School of Public Policy, notes, "according to an intersectionality perspective, inequities are never the result of single, distinct factors. Rather, they are the outcome of intersections of different social locations, power relations and experiences."²⁵⁵

L

LGBTQ2S+

Short for Lesbian, Gay, Bisexual, Transgender, Queer, Two-Spirit and many other people on the wide, diverse spectrum of human gender and sexuality.²⁵⁶

M

Marginalized

Marginalized populations are groups and communities that experience discrimination and exclusion (social, political and economic) because of unequal power relationships in economic, political, social and cultural dimensions.²⁵⁷

Misogyny

The term "misogyny" is derived from the Ancient Greek word "mīsoḡuniā," which means hatred towards women. It includes hatred of femininity. Misogyny has taken shape in multiple forms such as toxic masculinity, male privilege, patriarchy, gender discrimination, sexual harassment, belittling of women and gender-diverse people, gender-based violence and sexual objectification.²⁵⁸

252. Ontario Human Rights Commission, 2013.

253. Brant-Birioukov, 2017.

254. Crenshaw, 1991.

255. Hankivsky, 2014.

256. Ontario Human Rights Commission, 2013.

257. National Collaborating Centre for Determinants of Health, 2015.

258. Srivastava et al., 2017.

N

Norms

Norms are behaviors or ways of being that are considered normal, expected or accepted standards within a setting or group.

O

Over-researching

Over-researching subjects systemically oppressed communities to multiple research projects with little say in terms of the who, what, where, when, why and how of research. This has affected many oppressed communities in B.C. Because research can be a way of intentionally or unintentionally exerting social control, there is a tendency for people in power to over-research systemically oppressed groups, to tokenize experiences of oppression as a novel or interesting social issue and to reproduce previous research with little accountability to the communities they study. “Outsider” researchers have sometimes inadvertently harmed communities when their research has created more difficulties for communities than solutions to the problems they face.

P

Pan-Indigenous

A pan-Indigenous approach is a philosophical and political approach that promotes unity — and, to some extent, reduction in cultural diversity — among different Indigenous communities, regardless of distinctions between Nations and cultural differences.

Pathologization

Pathologization is the process of approaching a health or behavioural condition arising from political, socioeconomic, oppressive and power-based disadvantage as if it were a medical or psychological condition.

Positionality

Positionality is the social and political context shaping your identity in terms of your race, class, gender, sexuality and ability status. Positionality also describes how this identity influences — and potentially biases — your understanding of and outlook on the world.

Positive obligation

A positive obligation means a person or organization is required to do something. A positive obligation is different from a negative obligation, which requires the person or organization not to do something.

Positive right

A positive right means the right to something, usually from the government. For example, the rights to be provided with housing or income by the government are positive rights.

R

Racialization

Racialization is the process by which societies construct races as real, different and unequal in ways that affect economic, political and social life.

Redistributive politics and economics

A redistributive political or economic policy is one in which costs are borne by a relatively small number of groups or individuals while benefits are expected to be enjoyed by a different group in society.

Reparation motions

A reparation motion is the formal procedure of asking a government body to consider taking action to repair the ongoing wealth and opportunity gaps caused by historic racism and discrimination against a particular group.

S

Self-determination

Self-determination is the fundamental right of all people to freely decide their own political status and to freely pursue their own cultural, economic, and social development.²⁵⁹

Sexism

Sexism is an ideology and system of oppression in society that holds that one sex or gender is more valuable, more worthy of respect and consideration and more able to contribute and participate than people of other sexes or genders. Sexism can be conscious or unconscious and is embedded in institutions, systems and the broader culture of a society.

Social construction

Social construction is the understanding that categories often taken to be natural and biological such as race, sex and gender are cultural, historical, relative, social, and political constructions.

Social determinants of health

The social determinants of health are the conditions in which people are born, grow, live, work and age. These conditions are shaped by the distribution of money, power and resources at global, national and local levels. Social determinants of health are often responsible for health inequities—unfair and avoidable differences in health status within and between countries.²⁶⁰

Socio-demographic

Socio-demographic qualities are those characterized by a combination of sociological and demographic characteristics including age, sex, education, migration background and ethnicity, religious affiliation, marital status, household, employment and income, among other things.

Sovereignty

Sovereignty is the right of a nation or group of people to exert control over governance of all aspects of their lives, including legal, political, economic, social and cultural factors.

Stigmatization

Stigmatization has been described as “a dynamic process of devaluation that significantly discredits an individual in the eyes of others.”²⁶¹

The qualities to which stigma adheres can be quite arbitrary—for example, skin colour, manner of speaking, sexual preference, frequency of sexual activity or whether one lives with HIV/AIDS. Within particular cultural settings, certain attributes are seized on and defined by others as discreditable or unworthy. Stigma is constructed and reinforced in language.

259. WebFinance Inc., n.d.

260. World Health Organization, n.d.

261. Goffman, 1963.

Strength-based approach

Strengths-based (or asset-based) approaches focus on strengths—including personal strengths and social and community networks—rather than on deficits.

Structural

Structural means relating to or affecting the structure of something. In sociology, society is seen as a structure with interrelated parts designed to meet the social needs of the individuals in that society.

Structural change

Structural change occurs when there is a transformation in the interaction or arrangement of parts in a system, in networks of social relationships or in groupings such as caste, kinship, family and occupational groups. Structural change addresses the root causes of social issues through these transformations.

Structural context

Structural context, in sociology, refers to the distinct stable arrangement of institutions whereby human beings in a society interact and live together.

T

Treaties

Treaties, as described by the Government of Canada, are “agreements made between the Government of Canada, Indigenous groups and, often, provinces and territories, which define ongoing rights and obligations on all sides.”²⁶²

262. Government of Canada, n.d.



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