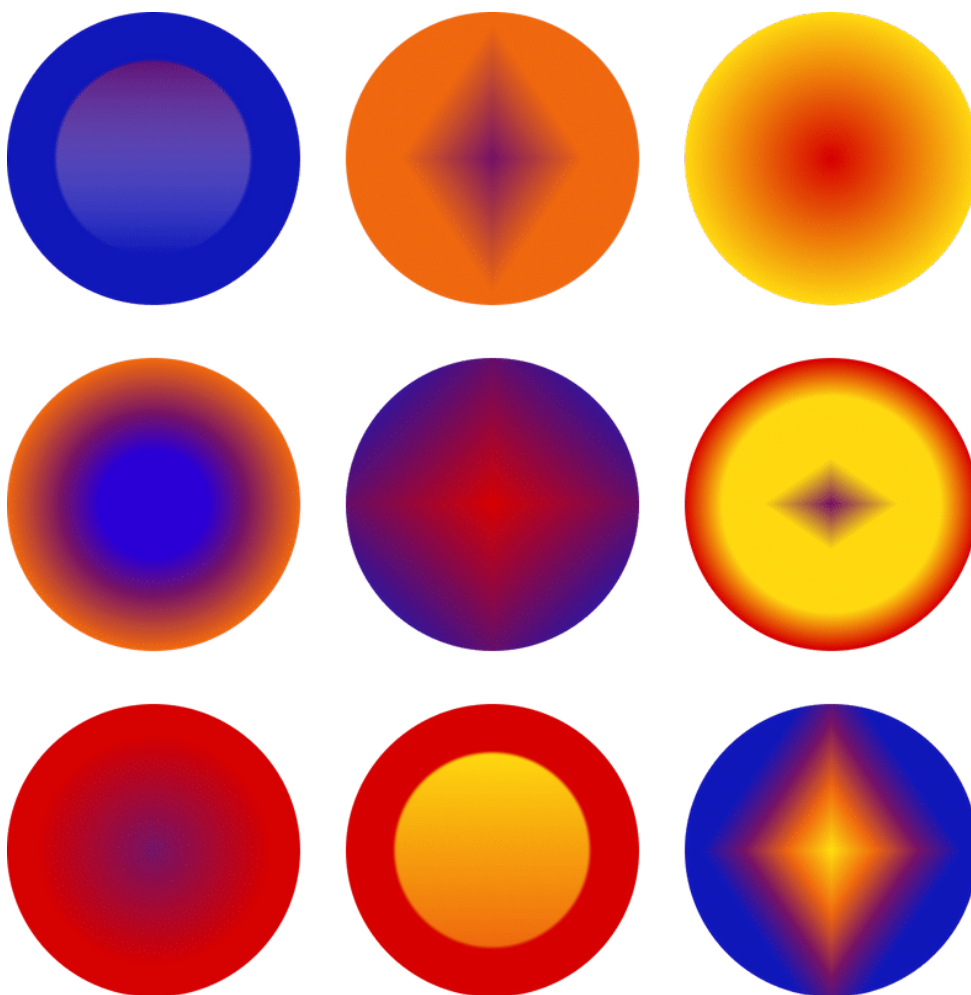


VERSION 3  
MARCH 2022

# COMMUNITY-BASED RESEARCH & DATA JUSTICE RESOURCE GUIDE

UBC ORICE | GENDER+ COLLECTIVE



THE UNIVERSITY OF BRITISH COLUMBIA

Collective for Gender+ in Research  
Office of Regional & International Community Engagement

# ACKNOWLEDGEMENTS

This project was spurred by the COVID-19 pandemic and originated in May 2020 with the numerous calls for more specific data collection along multiple axes of identity. These included calls to collect data that better represented the unique lived experiences of racialized groups, Indigenous communities, people with disabilities and those in the LGBTQI/2S community (1).

These communities face oppressive social structures which traditional data collection methods often disregard. We also acknowledge that we are building upon a lineage of scholarship; it is important to note that data (in)justice is not new, but is an ongoing issue--for example, First Nations in Canada have a well-established protocol to support information governance that was developed to protect First Nations, Métis, and Inuit control over data pertaining to health called OCAP® (2). In response to the exclusion of Black patrons and books from American libraries, "fugitive libraries" emerged to share marginalized Black thoughts and ideas (3). Fairness in visibility and representation is essential to data justice, and while COVID-19 once again drew fresh attention to the need for more specific and refined research questions, the problems identified have been responded to in creative and constructive ways that are foundational to this discourse.

To explore the many follow-up questions arising from the increasing need to collect data and how community organizations might go about this work, the Office for Regional and International Community Engagement's (ORICE) Collective for Gender+ in Research launched a research "engagementship." The Collective works to promote a community for rich dialogue in which gender, race, class, sexuality, ability, and other intersections are considered when engaging in any form of research or data collection process. In addition, we focus on capacity building and providing the tools community organizations need to utilize a Gender+ lens.

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(1) Wyton, "Race Matters in a Pandemic, But We're Not Gathering Basic Data."

(2) The First Nations Principles of OCAP®

(3) Mattern, "Fugitive Libraries."

Through 5 cohorts, building on each others' work, we addressed many questions about data justice, community-based research, and how community organizations might engage with these concepts.

**The primary focus of this guide is to introduce the concept of 'data justice' to community organizations that work with data or are looking to work on data-based projects, for them to bring this alongside as a resource to their existing work in this area. In addition, this guide explores dismantling power structures and privilege through definitions, examples, reflexivity, and critical thinking.**

This guide has been created collaboratively by numerous local and international community organizations and diverse teams of students and recent graduates from the University of British Columbia (UBC). As members of the Gender+ Collective, we recognize that we have had many resources and opportunities to interact and engage with community members and organizations who work in community-based research and data justice. However, because of our limited perspectives and capacities, this guide should not be considered complete nor comprehensive. Several questions will remain unanswered, and we encourage readers to make the necessary space to engage in such discussions with other community organizers.

## LAND ACKNOWLEDGEMENT

This guide began in 2020 and has been collaboratively worked on during the global COVID-19 pandemic. Although all collaborators were located in different places around the world, this guide is based and located on the traditional, stolen, and occupied homelands of the xwməθkwəy̓əm people. As non-Indigenous settlers living and learning on these lands, we recognize our responsibility to centre xwməθkwəy̓əm sovereignty and decolonial practices in all of our work. We recognize the violent and extractive nature of traditional research approaches and their potential to recreate, reinforce, and perpetuate such traumas. Our guide hopes to move away from such research methods, actively rejecting such extractive processes, and instead wishes to cultivate collectivist and decolonial thought grounded in intersectional and accessible community-based learning.

# ABOUT US

The work of the Gender+ Collective comes from the ORICE Team, which includes:

ORICE TEAM / TAMARA BALDWIN, HOLLY BENNA, VLADIMIR CHINDEA, GAYLEAN DAVIES, CHRISTINA FUNG, MAHTAB LAGHAEI, MULALO SADIKE

Five cohorts consisting of undergraduate students, graduate students, and recent graduates worked iteratively with community partners and the ORICE team to research and design this guide.

COHORT 1 / CHELSEA BEAN, MUKTA CHACHRA, RACHEL CHEANG, LIDIA COOEY-HURTADO, KIRA KNIGHT, CRISTINA KIM, ALEXA TRABOULAY

COHORT 2 / ALEXANDRIA AHLUWALIA, KIM CORREA, NASTYA MOZOLEVYCH, JULIA POISSANT

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COHORT 4 / ALEXANDRIA AHLUWALIA, SOLANA CHENG, KIM CORREA, ANNEKE DRESSELHUIS, JACQUELINE SARVINI

COHORT 5 / ANNEKE DRESSELHUIS, BALIE TOMAR, KRISTIN CONRAD KILGALLEN, RACHEL CHAN

A sixth cohort then started the distribution of the guide by facilitating events and crafting support resources. It included:

COHORT 6 / VICTORIA MARISSA BARCLAY, KRISTIN CONRAD KILGALLEN, ANNEKE DRESSELHUIS, SOLAL QUÉRÉ, SOPHIE SARGENT, BALIE TOMAR

Our work would not have been possible if not for the help of the organizations and academic groups that have supported us along the way.

[CITYHIVE](#) / KATHRYN TRNAVSKY

[DATASHIFT](#) / CIVICUS / HANNAH WHEATLEY

[DTES NEIGHBOURHOOD HOUSE](#) / TINTIN YANG

[GROOTS KENYA](#) / ESTHER MWAURA

[KAMBO ENERGY GROUP](#) / YASMIN ABRAHAM

[UBC AMS SASC](#) / JOELLE JEFFERY, ALEX DAUNCEY, VICKY GERLINGS

[UBC LEARNING EXCHANGE](#) / HEATHER HOLROYD, NICK UBELS

[UNIVERSITY OF WINNIPEG](#) / SHAUNA MACKINNON

[THE UNIVERSITY OF BRITISH COLUMBIA](#) / ALEKSANDRA DULIC, CHRISTINE D'ONOFRIO

## ABOUT US

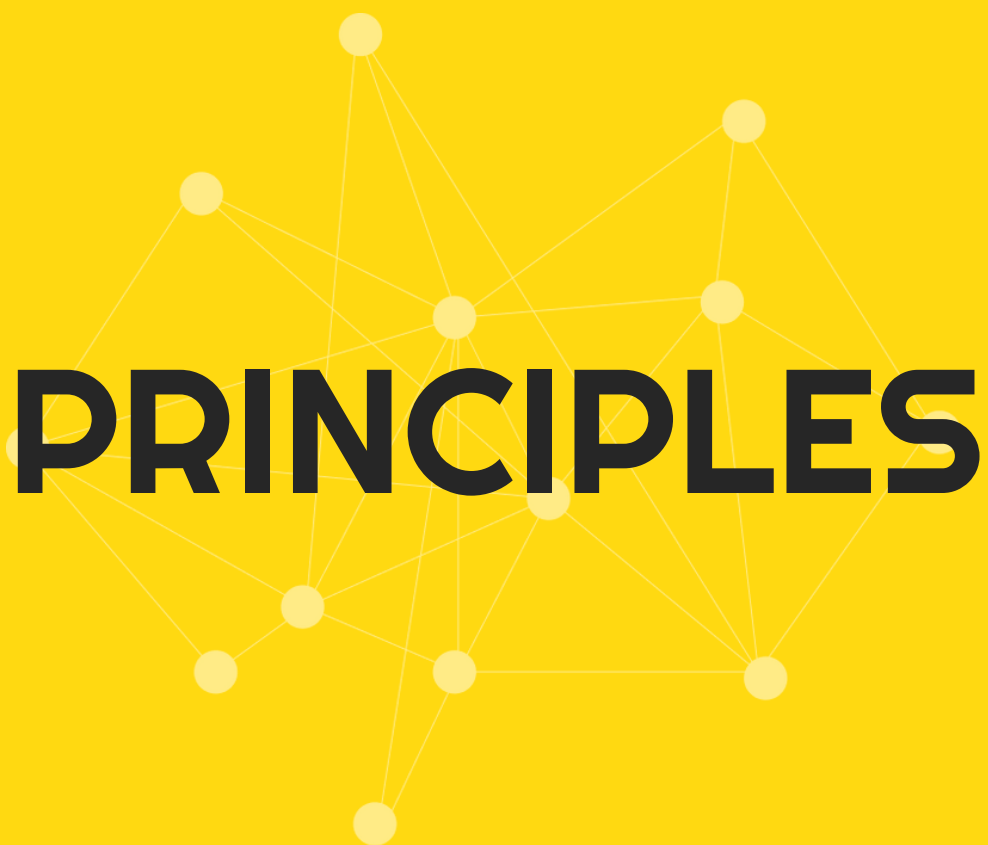
The Collective for Gender+ in Research works to promote a community for rich dialogue in which gender and other intersections, including race, Indigeneity, class, sexuality, and ability (among other intersections of identity), are considered when conducting community-based research. The Collective focuses on capacity building and providing the tools researchers need to utilize a gender+ lens. The Collective is housed within and supported by UBC ORICE.


## ANTI-RACISM AND ETHICS OF ENGAGEMENT

The Collective for Gender+ in Research and ORICE are committed to embedding anti-racism in our daily work and ongoing projects. Students are encouraged and expected to consider how they can take an anti-racist lens to the work they produce around citizen science, data collection and use, and connections between community-based organizations, academics, and government. This might include, but is not limited to, ensuring the incorporation of the ongoing and often unrecognized work of organizations advocating for justice for minorities, particularly during the pandemic; or engaging with the politics of citation by including and citing the work of non-white scholars and other researchers.

# TABLE OF CONTENTS

<b>6</b>	<b>PRINCIPLES</b> Guiding Principles
<b>9</b>	<b>THE HEART OF THE MATTER</b> The Research Question
<b>11</b>	<b>DATA PROCESS</b> Data Process
<b>16</b>	<b>PLANNING</b> Data Process
<b>32</b>	<b>COLLECTING</b> Data Process
<b>35</b>	<b>CLEANING</b> Data Process
<b>40</b>	<b>ANALYZING</b> Data Process
<b>44</b>	<b>SHARING</b> Data Process
<b>48</b>	<b>DEFINITIONS</b> Appendix
<b>49</b>	<b>TRAUMA AND HEALING LENSES</b> Appendix
<b>54</b>	<b>FINAL REMARKS</b> From the ORICE Team
<b>55</b>	<b>REFERENCES</b>
<b>60</b>	<b>OTHER RESOURCES</b>





The five principles below have shaped our work, engagement, and collaboration throughout this project. These have been established through dialogue and exchanges during the development of this guide. All of the questions and information in this guide stem from our principles. When working on a data-based project, considering these principles alongside your community's principles can help make working with data better.

## RECIPROCITY & REFLEXIVITY

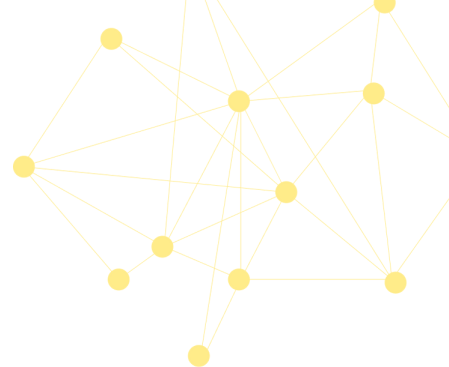
Reciprocity refers to the mutual exchange of privileges, paying close attention to the researcher-participant relationship and considers the benefits that are gained between the two groups. Reflexivity refers to the personal examination of one's own beliefs and judgements and how these may have influenced the research itself. Together, they emphasize the importance of thoughtful and deliberate exchange. We all need to remember that the people from whom we collect data are providing the service that we need and, thus it may be important to assess what we can provide in return. This principle encourages us to consider how to foster relationships between and among each other, the establishment of boundaries, and the provision of services in return for the data we collect and the stories we hear. Every version of the future that comes from this data collection should endeavour to include all involved in a fair and equitable way (4).

## ACCESSIBILITY

Access is fundamental. The ways in which access is provided should not be considered equal, and it is important to ensure equal access to the resources produced from data collection projects. All bodies should be regarded as valid in physical spaces and should be treated accordingly by making spaces accessible to all. In digital spaces, this principle encourages considering the types of barriers that may prevent users from accessing online resources needed to help our user communities.

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(4) Coghlan and Brydon-Miller, *The SAGE Encyclopedia of Action Research*; Corlett and Mavin, "Reflexivity and Researcher Positionality"; D'Arcangelis, "Revelations of a White Settler Woman Scholar-Activist"; Recollet and Robinson, "Interventions Into the Maw of Old World Hunger: Frog Monsters, Kinstellatory Maps, and Radical Relationalities in a Project of Re-Worlding."



## PRIVACY AND ACCOUNTABILITY

Everyone has the right to privacy and the right to be remembered and forgotten on their own terms. Consider situating your organization within this framework and determine your ideal process for collecting data. Aim to protect the community from institutions and systems that could harm, including the government and police forces. Moreover, aim to hold yourself accountable to your community collaborators and release your documents, processes, and data collection methods, where appropriate, in the spirit of transparency and accountability.

## STRUCTURES OF SUPPORT

Any data collection endeavour should consider how it can tend to all parties' mental, physical, and spiritual health. This can be approached by using trauma-informed and healing-centred frameworks. Both frameworks recognize and respect the emotional labour of all participants in the process-- those collecting the data and those giving the data. Decide how care and support can be encouraged in all places and all steps of the data collection.

## ANTI-OPPRESSION

We encourage embedding an anti-oppressive framework into data collection projects, as cultural narratives often reinforce and maintain power imbalances at all levels within the system. It is important to centre the voices and experiences of marginalized populations directly impacted and bear the brunt of systemic inequities and state violence. How these systems of injustices interact with your organization will be unique, but they all exist and should be engaged with. The people from whom we collect data are equals and peers; they have their own agency, and it is important to seek to find our power with them, rather than over them.



# WHO IS THIS GUIDE FOR?

This guide can be used by anyone interested in data and social justice. This guide primarily focuses on introducing concepts of 'data justice' to community organizations that work with data or are looking to work on a data-based project by walking through ways that justice-centred approaches can be woven into each stage of a data project.

# WHAT IS DATA JUSTICE?

Data justice is a movement that comes as a response to the historical (and ongoing) ways of collecting and sharing data that erase, invisibilize, misrepresent, or harm marginalized communities (5, 6). Gathering and using data is inherently political and the 'neutrality of data' is a myth that has allowed for the ongoing marginalization of vulnerable communities. Data justice seeks to prevent (further) harm against marginalized populations by ensuring that the community's interests and participation are at the forefront of each research project.

Data justice can look like many different things, it is above all process-driven and responsive to the community. A data-justice informed project should:

- 1. Represent and make visible the challenges and strengths of the community.**
- 2. Treat data in ways that promote community self-determination, which include considerations of consent and ownership of data.**
- 3. Pro-actively consider potential harm to the community and work to mitigate it.**
- 4. Make critical consideration of the value of invisibility and disengagement for certain communities.**

One way to work towards data justice is through community-based participatory research. Community-based participatory research emphasizes the full and equal participation of all community members, recognizing the need to question who research is for and who conducts it (7). Through an asset-based approach, it recognizes and builds upon the strengths and resources of the community, promoting a mutual learning environment among everyone involved. By actively exploring, incorporating, and adopting local ways of knowing, community-based participatory research seeks to maintain a long-standing commitment to thoughtful and meaningful collaboration to address complex problems and situations.

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(5) "Data Equity Framework."

(6) Daly et al., Good Data; "Decolonizing Digital."

(7) MacKinnon, Practising Community-Based Participatory Research.



# THE DATA PROCESS



Before starting a data-based project, and at all stages throughout the project itself, it is important to plan and try to remain reflective about:

**What is being done?**

**How is something being done?**

**For whom is this for?**

**Why is it being done?**

Community-based data collection projects are unique and community-specific, however, they may follow and organize their steps through what is referred to as the data process. The data process originated from data scientists who refer to the common procedure to plan, collect, process, analyze, and share data (8).

Although this is a commonly used procedure (often called the data pipeline), it is important to acknowledge that data systems and data collection methods have been, and are currently, used to discriminate, dehumanize, and oppress marginalized groups. Thus, it is important to consider and be aware of why a project is being done, who it can impact, and how it is significant. There are biases in all aspects of our world, and it is our responsibility to be aware of these biases to avoid perpetuating them. This is particularly true when working with data.

## DATA

Data refers to information. Data can be collected in a data-based project for analysis or sharing (9). So much of what we do and interact with can be represented in data: the ages of everyone in our community, the daily growth of our favourite tree, the history of the land that we live on-- and so much more.


Data can be categorized under two broad groups: quantitative data (which refers to a collection of numerical data such as age or a rating of a service or program on a scale from 1-5) and qualitative data (which refers to a collection of non-numerical data such as the name of your favourite tree; or a description of why a service is or is not useful for a particular client). Data-based projects often collect both quantitative data and qualitative data.

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(8) "Data Equity Framework."

(9) "Daly et al., Good Data; "Decolonizing Digital."

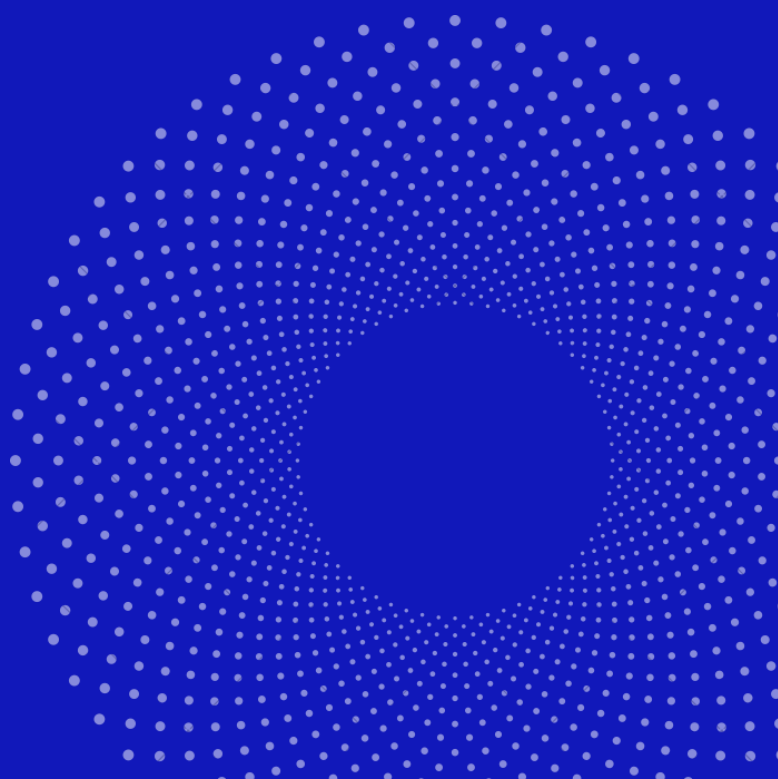




*preparing the ground.  
the labour of anticipation.  
establishing conditions that foster  
the health and success  
of the task at hand.  
cultivating a space of  
receptiveness for what is to come.*

# DATA PROCESS STEP 1: PLANNING TO COLLECT DATA

This is where a project will emerge. It might start with simple questions: Why are these specific community members using this service? What are their stories? It might start with an organizational need: We want to apply for a grant, but the grant-giving agency needs the ages of community members that are using my service and we don't have that information; how do we get it? It might be simple curiosity: The voices of our community deserve to be preserved: how can we do that? Each of these scenarios involves collecting data in some way. Now that you know you want data, it's time to plan how to collect it.



# PLANNING TO COLLECT DATA

To prioritize the lives and experiences of those involved in your data-based project as well as hold everyone involved accountable, we encourage you to consider the following questions:

## DEFINITION, GOALS, AND INVOLVEMENT

- **Have you checked in with the community about the project?**
  - Have you received the consent of the community?
  - Does the community have any existing principles of research and data collection that should be followed?
  - Are you beginning with a research idea that emerges from the community?
- **What are the goals of this project?**
  - How are these goals being measured? Why are these the measurement points?
- **Who will this project be for?**
  - How will their voices be represented in this project?
  - How will they benefit from this project in the short- or long term?
  - Who will be involved in the facilitation of this project?
    - Will they be involved throughout the entire duration of the project? If or when they leave, how will the privacy of those anonymously involved remain private?
    - How will they be held accountable for the collection and processing of data?
- **Who is defining what a successful project looks like?**
  - Why are they the ones who are responsible for defining the measurements of success?
  - How are they collaborating with the broader community to ensure that success is measured similarly among everyone involved?
- **Who has/will have ownership and control over the data?**
  - Can the data be owned and controlled by the community? Why or why not?
  - Is there a plan to eventually give ownership and control over the data back to the community?
  - If the community does not own the data, how will they be consulted on its use or sale after the research project?

# LABOUR AND FUNDING

Emotional labour occurs when a person has to manage difficult emotions during their job, which often takes an emotional toll. It often disproportionately falls on people already marginalized, such as women and Black, Indigenous, and People of Colour (BIPOC) individuals. Emotional labour is also often part of invisible and unpaid labour. For example, Dr. June Francis, Director of the Institute for Diaspora Research and Engagement at Simon Fraser University (SFU), talks about how some people have to bear the burden of recounting their 'lived experiences' over and over again to prove that injustices exist (10).

An example of emotional labour in the context of data collection: Data about someone's life and someone's experiences can bring up memories, challenges, and traumas. For most people, it is hard to talk about and think about their own traumatic experiences. To give their data clearly, participants might need to manage their feelings (emotional labour) and express themselves even when they are experiencing reactions to traumatic memories.

In this case, is it wise to be aware of the possible answers or data being collected and if it could potentially bring up sensitive issues. For example, knowing these issues, knowing resources, or knowing how to lower the emotional labour risk when collecting data should be considered. With this, you will be able to start to outline your overall expectations, which will be beneficial for the overall goals and transparency of the data-based project itself.

- **How can we value emotional labour and other forms of labour equally?**
  - Are we planning to pay the people involved in the research process for their emotional labour? If not, how do we plan on compensating them?
  - How will we communicate with the people involved in the research process to ensure that the compensation they will receive is something they want in return for their participation?
- **Is the collection of data being sponsored or funded?**
  - Who is funding the data collection and project?
  - Is the funding source conditional? Is the funding source sustainable? Does it need to be?
    - What will happen once the project is complete? Who will keep the data, and how will it be stored?

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(10) Francis, "Gender+ and COVID 19 Data for Justice Teach-In," *UBC ORICE*.

# COMMUNITY-BASED PROJECTS

Community-based projects can have many different topics and sizes as they largely depend on the community and their needs. Most community-based projects are done to centre and support the lives of those in the community. However, regardless of the community and how many people it may include, it is important to consider the following questions in relation to the intentions behind these projects as well as how to encourage the active involvement of the community members themselves:

- **Is this a community-driven project?**
  - Who in the community is involved in this project? Is their involvement voluntary?
  - How involved will the community be? In what ways do the community participants and our organization interact and know each other.
  - How will community members benefit from this project?
    - How might these benefits continue to be beneficial in the future?
  - How will we benefit from their project?
  - Is community involvement conditional?
    - What are the conditions for their involvement?
    - Do these conditions make their participation more or less meaningful?

All of the questions mentioned above touch upon the need for an equitable approach when collaborating with community members. These questions are especially important when working with populations who have historically had a negative experience with traditional research practices. Equitable relationships require that power and knowledge are shared between and among everyone involved, including resources and results (11). This reflects our reciprocity and reflexivity principles, both of which emphasize the need to approach research, reflection, and action as an iterative and cyclical point of community building and connection. The Manitoba Research Alliance (MRA) points out that while university scholars bring an expertise to a project, they are not the experts (12). They take an approach that centres the voices of the oppressed and work to walk beside instead of ahead of the community. This requires developing relationships and responding to research ideas that emerge from the community.

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(11) Boilevin et al., "Research 101: A Manifesto for Ethical Research in the Downtown Eastside."

(12) D'Ignazio and Klein, "Data Feminism," 115.

# SAFETY AND INCLUSIVITY

In the context of research, safety and inclusivity are broad terms used to ensure that the involvement of participants is respected (13). When integrated into the project well, it can create sustainable relationships and build upon existing ones. However, when done poorly, it can fracture relationships and prevent participants from trusting anyone involved in the research process. While the considerations in this section may be more relevant for organizations working with vulnerable communities, it can nevertheless be valuable for all organizations to reflect on these topics as we think about how we want to relate to our communities and research participants.

To avoid the possibility of manipulating someone and exploiting their story for the benefit of data collection, consider the following questions:

- **What is the power dynamic between data collectors and participants?**
  - Is the relationship a top-down approach?
  - Do participants have a say in how their data is being collected and used?
- **How can we ensure that questions are coming from a place of empathy?**
  - How will we try to understand someone's experience on their terms without judgement?
  - Are we asking questions in the language of the participants? Are we able to provide a translator?
  - Are we taking cultural considerations into account when necessary?
- **How will we collect data that is inclusive?**
  - Who might not be able to provide their data? Why?
  - How will we know if we are asking questions relevant to the community-based research? Are we open to their feedback if not? How can we build their feedback into the process?
  - What kinds of data might participants be more or less willing to give? Why? Are there ways for us to overcome this? Do we need to?
- **How can we prioritize researcher and participants' health and healing in data collection?**
  - Is there a safety plan in place (both for the researcher(s) and the participant(s))?
  - Have the participants been included in the development of this plan? Is there a need to?
  - What resources and support systems are in place for individuals and communities organizing and participating in the project?

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(13) D'Ignazio and Klein, "Data Feminism," 115.

A safety plan is a personalized plan to help the participants feel safe while conducting research. The plan should aim to be practical and prepare the participant for various scenarios in which they may encounter trauma while participating in a research project. Part of the plan may include compiling resources and support networks a participant can choose to rely on if they encounter trauma.

While the definition of a safety plan for this guide is broad, specific safety plans can be made for specific concerns, such as if participants are experiencing domestic/intimate partner violence. According to Verywell Mind, Safety planning “requires carefully thinking through possible scenarios and determining how best to cope with the abuse, tell friends and family members, and reach out for legal assistance.” (14)

For more resources about safety plans, see the National Domestic Violence Hotline.

## BIASES AND INTERSECTIONALITY

Bias can occur anywhere in a data-based project. Although a bias broadly refers to a strong preference that someone may have for or against a particular group, biases are also present in many different forms when working with data (15). There are historical biases, representation biases, measurement biases, evaluation biases, aggregation biases, and more biases that can all arise when collecting and working with data. There are often many different biases that influence the outcome of a data-based project (16). When collecting data, it is important to critically recognize and acknowledge internalized biases when working with a community we are seeking to serve, as biases can cause people and important stories to be left out (17).

“Where data [is] missing, people are missing.” (18)

To decrease the risk of missing out on important perspectives, adopting an intersectional approach to research can be useful to engage with bias in your project. Intersectionality refers to the interdependent and overlapping identities that an individual and group may carry due to their own experiences (19). The resulting access to power and privileges that come from this is ultimately an analysis of power. Identities include (but are not limited to) race and ethnicity, gender and sexual orientation, class and income, education level, and dis/ability.

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(14) D'Ignazio and Klein, “Data Feminism,” 115.

(15) D'Ignazio and Klein, “Data Feminism,” 115.

(16) Suresh and Gutttag, “A Framework for Understanding Sources of Harm throughout the Machine Learning Life Cycle.”

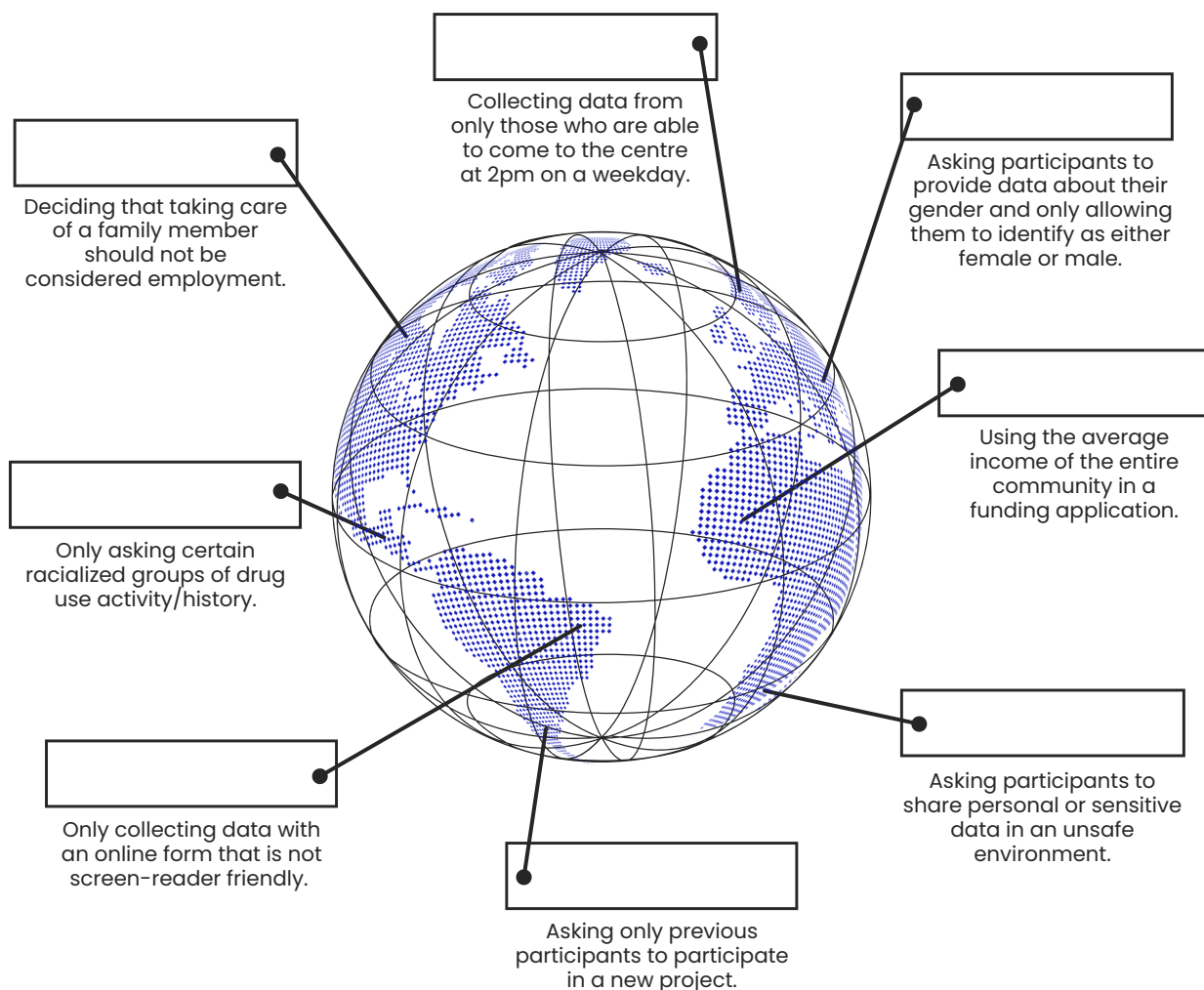
(17) King et al., “Addressing Missing Data in Substance Use Research,” 454; Taylor, “What Is Data Justice?” 2.

(18) “Addressing Missing Data in Substance Use Research,” 454.

(19) Collins, *Black Feminist Thought*; Crenshaw, *The Urgency of Intersectionality*; Darity, *International Encyclopedia of the Social Sciences*.

# RECOGNIZING POTENTIAL SOURCES OF DATA BIAS

\*There are often multiple solutions, due to intersecting experiences of oppression.



**Evaluation Bias**

**Representation Bias**

**Racial Bias**

**Historical Bias**

**Ableism Bias**

**Aggregation Bias**

**Measurement Bias**

**Gender Bias**

This list is not complete. Try to think of more biases that can arise and other situations where you could see such biases coming up!

There are biases in all aspects of our world and it is our responsibility to be aware of these biases so as to avoid perpetuating them. This is particularly true when working with data. Can you identify some of these potential sources of data bias?

The term intersectionality was coined by lawyer, civil rights advocate and critical race theory scholar Kimberlé Crenshaw to describe the "various ways in which race and gender intersect in shaping structural and political aspects of violence against women of colour" (20). Our identities can create overlapping and interdependent systems of oppression, marginalization and discrimination. We can use this understanding to be aware that oppression cannot be reduced to one fundamental type and that oppressions work together in producing injustice.

Before beginning the project, engaging with these questions can help to collect data that is less biased:

- **What pre-existing biases do we have about the participants? What are they?**
- **If I am doing research with marginalized groups of people, are we centring their trauma without considering their resilience and full humanity?**
- **How might the questions that are being asked be seen as discriminating? Do they further marginalize particular populations?**
- **Could the data being collected be used to discriminate based on class, for example?**
- **Is it necessary to ask about income? Why?**
- **How are the questions influenced by biases?**
  - Are we considering other axes of identity?
  - How will the data that is being collected reflect the population the project seeks to serve or speak to?
  - How can we analyze the data from multiple perspectives and intersections of identity?

## RACE AND ETHNICITY

Race is defined as a socially and politically constructed category, but it is not natural, nor is it biological (21). Society groups people into races based on their physical differences, such as their skin tone and features. Race is "a deeply complex sociopolitical system whose boundaries shift and adapt over time" that was historically, and continues to be, used to organize society and its resources along racial lines." (22)

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(20) Crenshaw, "Mapping the Margins." Although intersectionality is credited to Kimberlé Crenshaw (1989), earlier Black feminists including Sojourner Truth, Patricia Hill Collins; Joyce King; Audre Lorde, Cherrie Moraga and Gloria Anzaldúa also contributed to the advancement of intersectionality.

(21) Lyon, "Lecture on the Sociology of Race and Ethnicity."

(22) Sensoy and DiAngelo, Is Everyone Really Equal?

Categorizing and grouping people by race was done to support worldviews that viewed some groups of people as superior and some as inferior. This is known as racialization. Race is a category created to concentrate power within one racial group and legitimize dominance over other racial groups; racialization involves attributing racial differences, which are based on physical characteristics, and then acting on those differences (23).

Racism is discrimination of a person based on race through prejudices and power. It is a set of ideas that implies the superiority of one social group over another based on perceived biological or cultural characteristics (race). This affects individuals in criminal justice, employment, housing, health care, political power, education, and all other areas. Racism is both institutional and systemic, and the actions of an individual can also be racist. Racism involves the different treatment of different racialized groups that limit opportunities or privileges (24).

There is no one right way of collecting or not collecting race-based data. There is also no rule saying when to collect it and when not to. Still, it is important to engage with and consider why this data might be collected for this project and to continuously centre the community's needs.

On one hand, historical instances of "colourblind" data (ie. not including racial data) have led to insufficient and inappropriate responses in times of crisis, inadequate funding for certain programs, inadequate services for certain communities, and so on. For example, the COVID-19 pandemic disproportionately affects racialized communities, especially Black and Indigenous people in Canada. However, the true extent of these effects is unknown due to the Canadian government not collecting racial data. "Colourblind" data often leaves inequalities unaddressed and has led to inadequate responses in times of crisis, inadequate funding for certain programs, inadequate services for certain communities, and so on (25).

On the other hand, there are many instances where including this data may not be relevant to the project at hand. To help determine whether race-based data is relevant or helpful to your project, consider the following questions:

- **Do the project goals benefit from asking what someone's race is? Why?**
- **How are we prefacing this question? (ie. Do we explain why it's useful to research participants?)**
- **Are we making questions about race optional or required? Why?**
  - What information will this provide? How do we plan to use this information?
- **Could the data being collected be used to discriminate based on race?**
- **Could asking for cultural background or similar be a suitable alternative?**
- **Are participants able to self-identify?**
- **Are we aware of racial bias that could appear in the data?**
- **How can we make sure this data does not cause (further) harm to the community?**

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(23) "Glossary." in Racial Equity Tools.

(24) Blauner, *Racial Oppression in America*.

(25) Francis, "Gender+ and COVID 19 Data for Justice Teach-In," *UBC ORICE*.

# GENDER AND “SEX”

Gender is composed of the socially constructed roles, expressions, behaviours, and identities of different individuals, often in relationship with cultural concepts of masculinity and femininity (26). Gender exists on a spectrum outside the binary male/female, man/woman model and can change over time. Gender identities include, but are not limited to, those of “woman,” “Two-Spirit,” “non-binary,” “genderqueer,” “agender,” and “man.” Subcomponents of gender can include:

- Gender assignment (assigned to an individual at birth).
- Gender roles (behavioural expectations based on gender).
- Gender attribution (how other people read someone’s gender).

Gender exists separately from the sex assigned at birth. There is diversity in how different people experience, understand, and express gender, and how gender is institutionalized within a society (27).

Sexism is discrimination of a person based on their sex. Sex refers to a person’s biological status and is often categorized as intersex, female, or male, yet biological sex is not easily categorized and gender and sex are entangled (28). Prejudices and gender stereotyping are harmful and directly related to gender discrimination.

The categories we choose to represent in our data have long-standing consequences; for example, they become the basis on which we allocate resources and make policies. While there are inherent limits to trying to capture the full gender spectrum into a few discrete, measurable categories for data collection it does not mean we shouldn’t collect gender-based data and try our best to represent the diversity of the gender spectrum in our data.

Consider, for example, a feedback form in which participants are asked to provide input about the effectiveness of a bike co-op program. The form asks for the gender of the respondent and only offers “male” and “female” as options. Not only can this take an emotional toll on the respondents who do not fit into these categories, it may also invisibilize valuable data about the effectiveness of the bike co-op program for different kinds of people. If, for example, non-binary users are not captured in the survey it might be hard to make a case for or demonstrate need for specialized programming or dedicated hours for gender non-binary co-op members.

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(26) Canadian Institutes of Health Research, “What Is Gender?”

(27) Lyon, “Lecture on the Sociology of Race and Ethnicity.”

(28) Albert and Delano, “This Whole Thing Smacks of Gender.”

# ASKING ABOUT "SEX" OR Gender

GENDER EXISTS SEPARATELY FROM THE SEX ASSIGNED AT BIRTH. THERE IS DIVERSITY IN HOW DIFFERENT PEOPLE EXPERIENCE, UNDERSTAND, AND EXPRESS GENDER, AND HOW GENDER IS INSTITUTIONALIZED WITHIN SOCIETY.

DO YOU WANT TO COLLECT DATA ABOUT "SEX" OR **Gender**?

Gender

**Gender** IS COMPOSED OF THE SOCIALLY CONSTRUCTED ROLES, EXPRESSIONS, BEHAVIOURS, AND IDENTITIES OF DIFFERENT INDIVIDUALS, OFTEN IN RELATIONSHIP WITH CULTURAL CONCEPTS OF MASCULINITY AND FEMININITY. GENDER EXISTS ON A SPECTRUM OUTSIDE THE BINARY MALE/FEMALE, MAN/WOMAN MODEL AND CAN CHANGE OVER TIME.

"SEX"

WILL THE BIOLOGICAL SEX OF THE PERSON CHANGE HOW THEY ARE TREATED/THE ACCESS THEY HAVE TO RESOURCES/SOMETHING ELSE?

YES

NO

ASK FOR "BIOLOGICAL SEX" DATA AND USE INTERSEX, FEMALE AND MALE AS OPTIONS. ALSO EXPLAIN HOW THIS DATA WILL BE KEPT CONFIDENTIAL BECAUSE THIS INFORMATION CAN BE CONSIDERED PRIVATE.

I CAN DO ALL OF THIS!

I CAN'T DO THESE THINGS

ASK!

DON'T ASK!

SOME INSURANCE PROVIDERS OFTEN REQUIRE BIOLOGICAL SEX INFORMATION. IT CAN BE HELPFUL TO ASK "WHAT SEX OR GENDER IS LISTED ON YOUR MEDICAL INSURANCE?"

IN SOME COMMUNITIES AND SETTINGS, COLLECTING DATA ABOUT TRANSGENDER EXPERIENCES IS IMPORTANT. ASKING "ARE YOU TRANSGENDER?" ALONGSIDE ASKING ABOUT GENDER CAN HELP. AGAIN, MAKE SURE THE PARTICIPANTS KNOW THAT PROVIDING THIS INFORMATION IS OPTIONAL, THE REASONS THAT THIS INFORMATION IS BEING COLLECTED, AND HOW IT WILL BE STORED AND KEPT CONFIDENTIAL.

IS THIS FOR A DIVERSITY STATISTIC?

NO

DON'T ASK!

YES THIS IS WHAT I WANT!

YES

ASK ABOUT GENDER!

I DON'T WANT THIS.

START AGAIN AND PICK "SEX"

SUBCOMPONENTS OF GENDER CAN INCLUDE:

- GENDER ASSIGNMENT AT BIRTH
- GENDER ROLES (BEHAVIOURAL EXPECTATIONS BASED ON GENDER).
- GENDER ATTRIBUTION (HOW OTHER PEOPLE READ SOMEONE'S GENDER).
- GENDER EXPERIENCE (PERSONAL)

WHEN ASKING ABOUT GENDER, MAKE SURE THIS IS AN OPTIONAL RESPONSE, ALLOW PARTICIPANTS TO SELF IDENTIFY THEIR GENDER, AND DESCRIBE WHY YOU ARE USING THIS INFORMATION AND HOW IS IT BEING STORED AND KEPT CONFIDENTIAL.

I CAN'T DO THESE THINGS

I CAN DO ALL OF THIS!

DON'T ASK!

ask!

form :)

What is your gender identity?

- ☐ Woman
- ☐ Man
- ☐ Non-Binary Person
- ☐ Self identify:
- 
- ☐ Prefer not to answer

This information is being collected to help us provide better resources for our community. This information will be anonymized and stored for up to 1 year after submission. Please contact us to remove or modify the data you are sharing.

That being said, there are many reasons why people and communities may prefer to remain invisible and would prefer not to provide details on their gender identity. To help determine whether gender-based data is relevant or helpful to your project, consider the following questions:

- **How is this project categorizing sex and/or gender? Why?**
- **Are we asking about the gender of the individual? Why?**
- **Do we allow participants to self-identify?**
- **Does the data being collected discriminate based on gender or identity?**
- **Is it necessary to ask the assigned biological sex at birth of a person? Why?**
  - Are intersex categories included?

## BARRIERS

Barriers to participation in data-based projects can cause unequal participation and which can result in collecting data that does not represent your community as best as it can (29).

- What barriers to data collection may come up, and how are we planning to address them?

There are many barriers to participation in data-based projects, and they often are community-specific. This list includes some common barriers to engage with to try and answer the above question, but should not be considered complete. Examples of barriers in data-based projects include:

### Privacy/Confidentiality Barriers

Participants may be hesitant to participate in a data-based project due to privacy concerns. Participants may be unsure what the data will be used for. Participants may fear their data will be misinterpreted or misused, and any individual has the right to refuse to participate. Privacy/confidentiality barriers can be reduced by providing detailed information about how the data is being collected, which platforms (if any) are being used, and for how long the data will be kept, providing contact information so participants can change or remove their data, anonymizing the data (see section 2), and allowing participants to give data in a private space (30). Consent to participate should be active and ongoing. Active and ongoing consent is consent that is not presumed to exist but is actively sought out, and is reaffirmed with each new step in the project (see Data Process Step 2).

### Barriers to Reporting Violence

This can include shame, fear, inequitable power distribution, lack of trust in institutions, failing institutions, retraumatization when reporting/going through the criminal justice system, etc. Reporting violence barriers can be reduced by using the healing-centred lens (see appendix) can help everyone involved in the research project to develop shame resilience collectively (31).

(29) Shorter, "Barriers to Accessing/Sharing Data."

(30) D'Ignazio and Klein, "The Power Chapter"; Jang, Chang, and Tsai, "Smartphone Security"; "The First Nations Principles of OCAP®."

(31) D'Ignazio and Klein, "The Numbers Don't Speak for Themselves"; Martin and Walia, "Red Women Rising."

**Financial Barriers**

Financial barriers can include limited resources to pay those collecting data or giving data, limiting the capacity of communities to collect data. In addition, those collecting data might have limited resources in terms of software for data storage, collection, modification, or sharing (32). Even with limited financial resources, a community-based approach offers many other advantages and may ultimately do a better job at collecting target data than a larger institution.

**Accessibility Barriers**

If collecting information digitally, there are many accessibility concerns to consider (e.g., website accessibility, internet access, knowledge of internet software). If collecting information in-person, there can also be many other community-specific accessibility concerns (location is not accessible by public transit, participants are unable to take time off work, the building is not wheelchair accessible, etc.).

Accessibility barriers can be reduced by providing compensation to participants for taking the time to give their data, providing compensation to participants for transportation costs, going to the participant vs. them coming to you, and providing alternative ways for participants to provide their data (over the phone, printable documents, conversation).

**Language Barriers**

It is important to make sure questions are clear and understandable to the entire community. Asking clear questions will help get the best data from all members of the community. Language barriers can be reduced by providing questions in multiple languages, seeking translation services, asking straightforward questions, providing example responses to support understanding.

**Environmental Barriers**

An uncomfortable location or setting in which the participant does not feel comfortable sharing their data can impact the quality of the data and results of the data-based project. It is important to consider how the space you are using for data collection might be perceived by your community. Spaces hold different experiences and meanings for different people. Consider, for example, interviews conducted by a teachers union of high-school youth participating in after-school programs. The only empty room available that day is the board room where the principal and vice-principal normally meet with students for behavioural, conflict resolution, and academic issues. Participants may be under the impression that they are being disciplined and therefore be less inclined to participate or be nervous when responding. Thinking ahead about the space you are using can help to address potential environmental barriers.

**Fatigue as a Barrier**

Both participants and those collecting data can be impacted by the length, the level of engagement, and the emotional labour of the data collection. For example, if you anticipate your study or survey will take a long time to complete, consider alternative formats like an audio-assisted survey, to alleviate some of the potential fatigue participants and researchers might experience.


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(32) "Data Feminism," 42, 142.

Some questions to consider when thinking about potential barriers to participation and improving accessibility include:

- **Who are we including and excluding by using a specific platform?**
  - Is it necessary to do data collection online?
  - Can using this platform reduce the representation of the community?
- **Can we distribute our surveys through multiple platforms (email, social media, flyers, etc.)?**
- **Are other methods of contact for the participant being provided? (an address or phone number might not be available)**
- **Are we compensating participants for their time?**
  - Will participants be offered compensation for travel?
- **Are the questions understandable to the community?**
  - Are we providing example responses or scenarios to support understanding?
  - Will participants be allowed to ask clarification questions?
  - Will participants have access to audio files to listen to the questions?
- **Is the language/choice of words for the questions being asked suitable for the community?**
- **Will participants be able to provide data verbally or in other various formats? Will a translator or interpreter be made available?**
- **When are we scheduling data collection (e.g. structured interviews, tabling, phone calls)? Do we offer multiple times/days to participate?**
  - Would participants who are unable to take time off work still be able to participate?
- **Where are we doing data collection?**
  - Is it accessible by transit?
  - Is the building physically accessible? Are there ramps, elevators, railings etc...?
  - Would a public or private space be better suited to the data collection process?

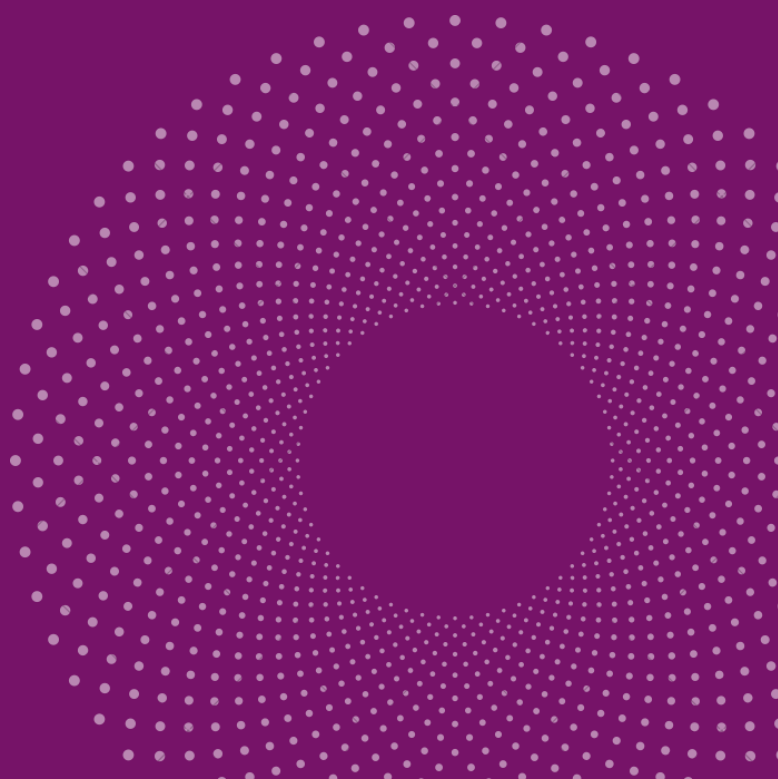




*the field work.  
setting out to collect.  
existing in a state of wonder at  
what surrounds you, while  
remaining focused on the task set  
out for you. taking only what you  
need, and nothing more.*

## DATA PROCESS STEP 2: COLLECTING DATA

After our plan is made, the next step is to collect the data. Below are questions to ask ourselves. This step is important because you will be working with members of the community of whom you are collecting data from. While all principles are important, let's review the principles of reciprocity and reflexivity here. Reciprocity refers to the mutual exchange of privileges between researchers and participants. Reflexivity refers to the personal examination of one's own beliefs and judgements and how these may have influenced the research itself. Consider how we could provide something in return to participants who are providing us with data, foster relationships, and establish boundaries.




# COLLECTING DATA

A few questions to consider at this stage include the following:

- **From whom is the data coming from?**
- **How is the data being collected? Is this a secure way to collect data?**
- **Who is involved with the data collection?**
  - Are they from a community the same as or similar to that from which data is being collected? If not, can this happen? If not, how do we ensure data collectors are sensitive to the needs of this community?
  - Are there opportunities for training community members to collect the data? To become project leaders?
- **Are we respecting our own boundaries and providing ourselves with structures of support during the data collection process?**
- **Are we respecting the participants' boundaries and providing structures of support during the data collection process?**
  - Are we providing a way for participants to 'leave' at any point without penalty/without a reason/and still be entitled to compensation?
  - Can participants request for their data to be removed at any time?
- **Does the data collector have proper resources to support the community members who are sharing their experiences and data?**
- **To respect consent, how will the participants' ownership over their experiences be upheld?**
- **Who will collect and have access to the data?**
- **Is the information that is being collected sensitive?**
- **How are we valuing our own ongoing consent throughout the data collection process?**
  - How will we ensure consent is fully informed and freely given to participate in this project?
  - How will people who share their data provide informed consent?
- **How is consent, with regards to data collection and data use, being addressed when collecting data?**
  - Will there be any privacy concerns with the information requested? How will this be handled?
  - Could someone in the community get into trouble with the information they are providing?

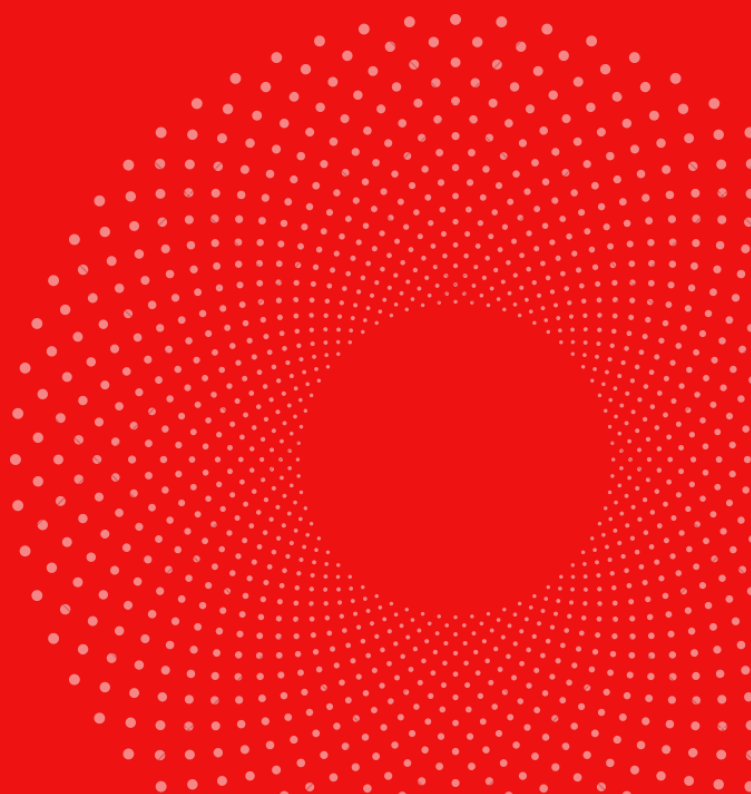


A large, solid red circle is centered on the page. Inside the circle, there is a paragraph of text in a light gray, italicized font.

*the sacred task of processing and  
cleaning that which is yours to  
steward. prioritizing tenderness in  
the manual and automated steps  
that are necessary to sift through  
the bruises and impurities in order  
see clearly.*

## DATA PROCESS STEP 3: PROCESSING AND CLEANING DATA

What we choose to include or not to include, what we decide to report or not report, can be a source of bias. At this stage, bias does not stem from the data, but rather it can emerge from the cleaning and analysis conducted by both humans and non-humans. “Data validation” ensures that the collected data is both accurate and correct before it is processed. “Cleaning data” refers to the detection and correction of any inaccuracies in the data collected. Inaccuracies can stem from input errors on computers to human error when inputting, and more. Cleaning qualitative data – like interviews – can look like ensuring consistency between the transcription and the audio recordings.



# PROCESSING AND CLEANING

“Cleaning” involves collecting, organizing and validating data into a useful and readable format (33). Readable can mean different things depending on the type of data, the nature of the project, and how the data will be analyzed (often software dependent). There may be many ways that data can be collected (verbally, on forms, digitally) and to put all the data into one uniform format is “cleaning the data.” “Cleaning” can also include discarding data that is not considered valid or complete.

The process of validating data ensures that the collected data is both accurate and correct before it is processed. Validating data requires sensitivity, however; there are obvious barriers that arise when asking people from whom data is collected to prove that what they are saying is true. In the appendix we discuss trauma sensitivity in greater depth.

- **How might the data be validated?**

- Does the data need to be validated in the first place?
- Could the validation process be invasive?
- Would validating the data make it more valuable? How and why?
- Who will be the validators? What are the power dynamics there?

To aggregate data is to group together one or more values to represent one value. Values can be age, gender, race, income, and more. If we would like to find the average income of the entire community, we would aggregate the age, gender, and race values. By doing this, we can make the differences in income depending on age, gender, and race no longer visible/clear.

For example, race-disaggregated data would be data that was collected and analyzed separately based on race. This can be important in healthcare settings when systematic inequalities lead to differences in health insurance, access to services based on race (34).

- **Will the data be aggregated (combined)?**

- If combining data, what will and will not be visible by choosing to aggregate data?
- If choosing disaggregated (separate subcategories) data, what categories will I include or exclude?
- What (or who) will or will not be visible?
- What counts as invalid data?
- Who is deciding what is a category and what does and does not fit into it? What biases are present in these decisions? (gender, race, sexuality, employment)

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(33) “Data Equity Framework”; *Data Feminism Reading Group - Week 1 - Introduction*.

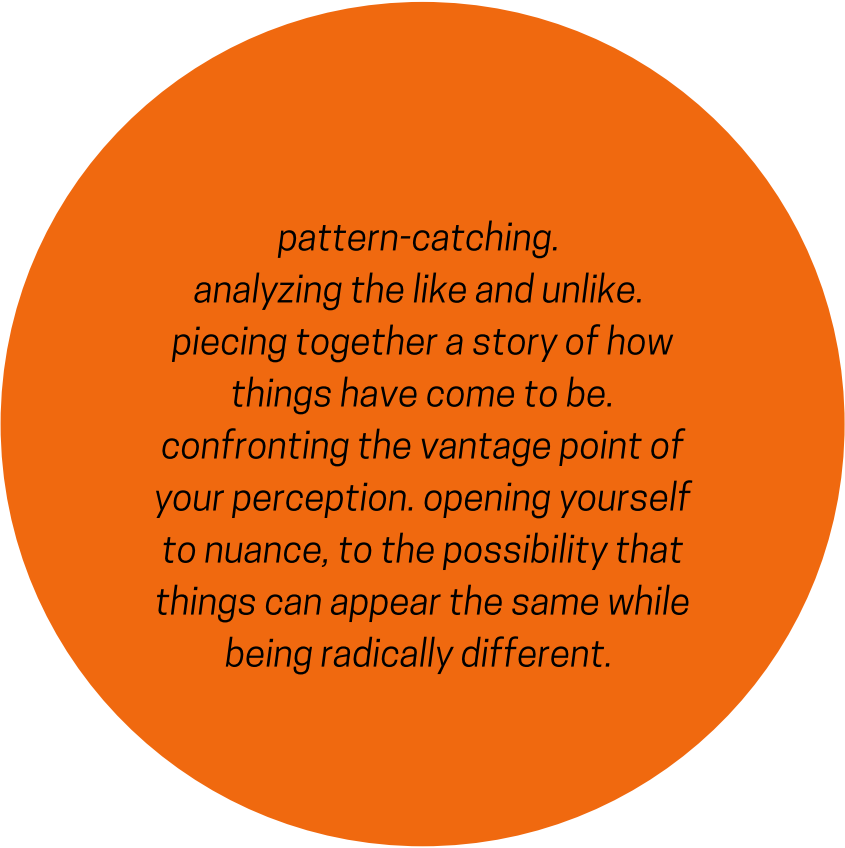
(34) “Black In BC Mutual Aid - The Need for Race-Based Data Collection”; Lindsay, “B.C. ‘actively Discussing’ Collecting Race-Based Data on COVID-19.”

To anonymize data (to get data that is anonymized) is to make changes in the method of data collection and data storage to ensure that the data/information participants have given cannot be identified with them. This can be done by not collecting identifiable information, such as names, addresses, telephone numbers, by assigning specific ID numbers to individuals (these also need to be kept secure). There are other methods to anonymize data such as data masking (changing the specific values to a single character or digit to hide the real entry), data swapping (mixing up columns and rows but keeping all the data collected to ensure the same results from the analysis), generalization (removing parts of the entries such as the street name but keeping the neighbourhood), and more.

Anonymizing data is one way to ensure data privacy. Data can include sensitive information such as addresses and health information, and individuals who are providing this data may be concerned about its confidentiality. Privacy concerns are very valid as privacy is about power. It is important, however, to consider the degree to which anonymity will be used to maintain confidentiality in a data project. At this stage of decision-making, it can be useful to re-centre project goals while prioritizing confidentiality in your research team's approach, regardless of whether you decide to anonymize the data or not.

- **Who is organizing/processing/cleaning the data? Who will have access to the data?**
- **Are the transcriptions clear? If we are using transcription software, are we sure that it is picking up all words?**
- **If we are cleaning an audio interview for better analysis, are we sure we are not erasing any nuances in the participant's words? Are language barriers accounted for?**
- **Will the data be in a digital format? If so, will the platform or software used be secure?**
  - Where will secure information be stored if not on the platform?
- **Is the data anonymized?**

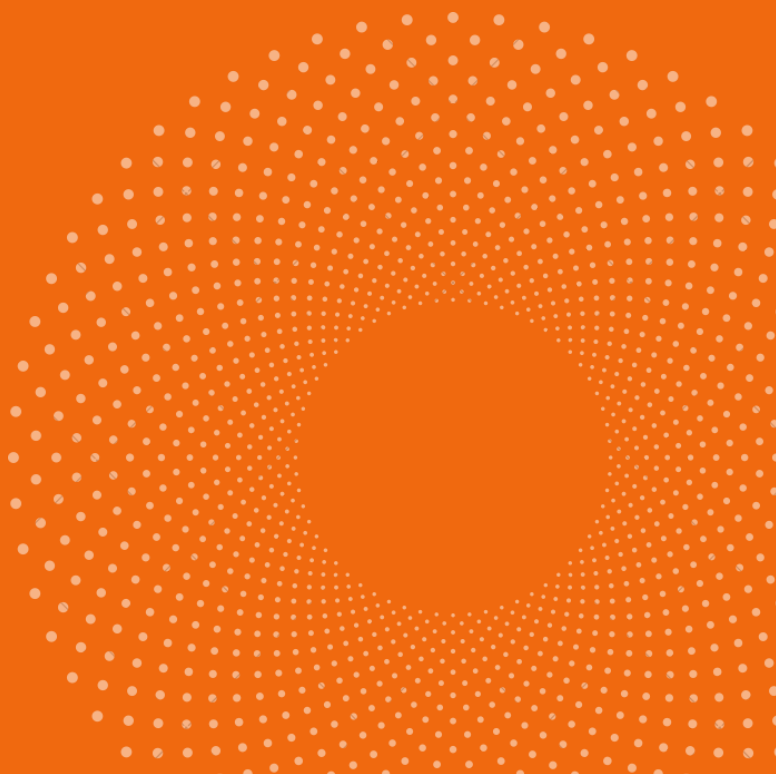




*pattern-catching.  
analyzing the like and unlike.  
piecing together a story of how  
things have come to be.  
confronting the vantage point of  
your perception. opening yourself  
to nuance, to the possibility that  
things can appear the same while  
being radically different.*

## DATA PROCESS STEP 4: ANALYZING DATA


The next step is analyzing the data. This step is where the data that was collected is interpreted to form results. Here, it is important to engage with internalized biases critically, how they may arise in this step, and how to take on a community-centred lens. The principle of anti-oppression is very important here. It is important to centre the voices and experiences of marginalized populations directly impacted and bear the brunt of systemic inequities and state violence. Think about how these systems of injustices uniquely interact with your organization. The people from whom we collect data are equals and peers. Remember they have their own agency, and it is important to seek to find our power with them, rather than over them.



# ANALYZING THE DATA

- **How is the data being analyzed?**
  - Who is analyzing the data?
  - How can the analysis process be documented so that it is transparent and clear?
  - Will this process be shared, and with whom?
- **Could the data be biased and have biased results?**
  - What is considered a success?
  - Can something else be considered a success and have different results? Who has the power to make decisions regarding this? Why?
  - Are there any alternative explanations for the results?
  - Will these explanations be shared, and why?
  - What would the interpretation be if the results were reversed?
- **Are we considering other interpretations?**
- **Are we including the community at this stage?**
- **Is all work clear and understandable?**
- **How long will the analyses be valid?**
- **Is it easy to modify or remove data from the analysis?**
  - Will participants be able to modify or remove their own data to protect their right to withdraw and anonymity, without giving a reason, without penalty, and still be entitled to compensation?





*sharing knowledge with the  
collective. a posture outward.  
a time for the celebration of  
stories. a reverent and authentic  
presentation of what  
has been made together.  
inviting all to share at the table.*

## DATA PROCESS STEP 5: SHARING RESULTS

At this stage, it is very important to centre the principle of reciprocity. Knowledge mobilization through visualization and communication of the data project should be clear and respect the project's goals (35). Dissemination should acknowledge and uplift engaged communities along with your results. In addition, varying levels of technological and institutional access may affect who can access your research. Similar to data collection, sharing of results is also a collaborative process.

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(35) "Knowledge Mobilization – Research Impact Canada."

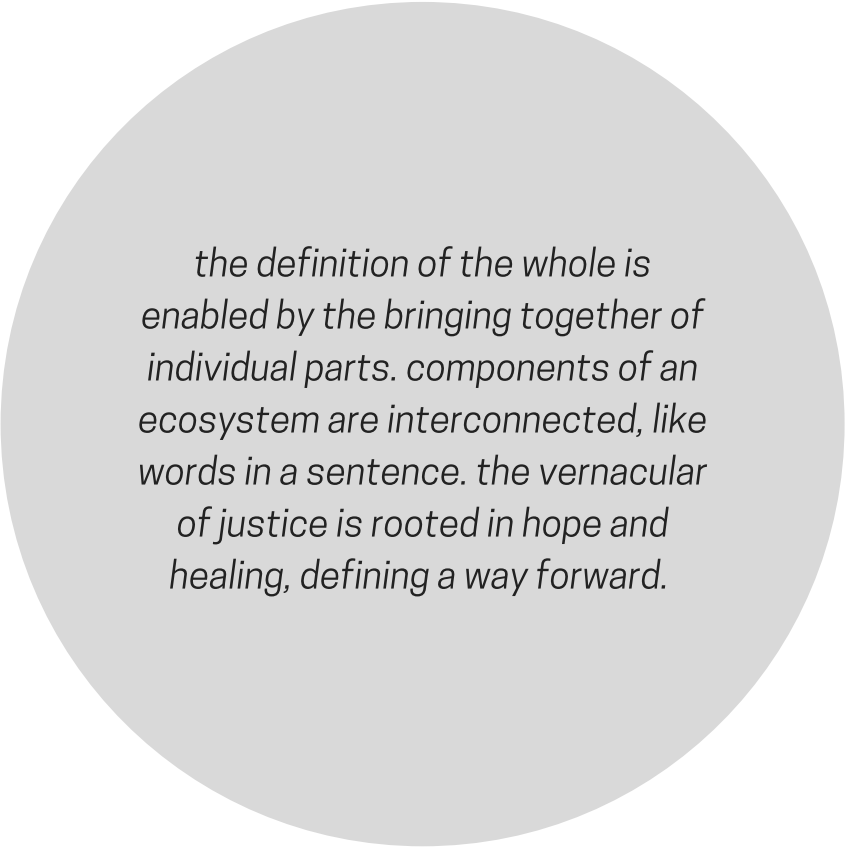
# SHARING THE RESULTS (36)

- **Who will share the results?**
- **How will it be shared?**
- **Where will it be shared?**
  - Will the data be shared in spaces in which the relevant community regularly gathers?
- **Are the distributing tools accessible?**
  - Is an internet connection required to access the data?
  - Is the data in multiple languages relevant to the participants and community?
  - Is the data in multiple forms taking into account hearing and/or sight impairment?
  - Have graphics and illustrations been used?
  - Are the charts easy to understand?
    - Are there text descriptions for the charts that interpret the results?
    - Are the colours/symbols used suitable for those with Colour Vision Deficiencies?
  - Is there text to explain the results?
  - Is the language accessible?
  - Are we using jargon?
  - Have screen reading abilities been considered?
  - How will the information be shared? Does that work for all members of the community?
- **Who will the results be shared with?**
  - Before making the results public, are participants able to access the results?
  - Do we have their consent to share the results?
  - Will everyone involved be able to receive a copy of the results?
- **Have assumptions made during the analysis stage been explained?**
- **Are we sharing the entire process so that the work is transparent and clear?**
- **Have we included financial reports and information about funding or conflicts of interest?**
- **What larger picture or conversation is the data a part of?**
- **How long will people have access to the results?**
  - Have Information Privacy Laws been considered?
- **Can the results be modified, such as if participants request to remove or change their data?**
  - Have we explained how they will be able to do this?

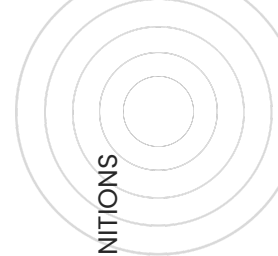
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(36) An iconic example of data sharing and visualization for data justice can be found in the early work of [W.E.B DuBois](#). He used data visualization to undermine common assumptions and prejudices about black people in the early 20th century. This is a great example of how data visualization can itself be an act of resistance or activism.





*the definition of the whole is  
enabled by the bringing together of  
individual parts. components of an  
ecosystem are interconnected, like  
words in a sentence. the vernacular  
of justice is rooted in hope and  
healing, defining a way forward.*



# APPENDIX A: IMPORTANT DEFINITIONS

## Equity vs. equality

Equality is treating everyone the same, regardless of a person's privileges or disadvantages. Equity means treating people differently depending on their needs, abilities, backgrounds, and marginalizations. This can include the redistribution of resources, and depending on someone's need, some people will get more resources to have equal opportunities to those who do not. This is different from equality as equality would mean that resources are distributed equally regardless of other factors. In a data-based project, this can mean needing to provide more or different kinds of support to some members of the community to collect data from them (37).

## Oppression

On a personal level, oppression expresses itself through beliefs (stereotypes), attitudes, values (prejudice), and actions (discrimination) used to justify unfair treatment based on distinct aspects of one's identity, real or perceived. On an institutional level, oppression expresses itself through the denial and limitation of resources, agency and dignity based on one's social identity. These policies, laws, and practices benefit the dominant group with little to no consideration of or care for the longer-term harm inflicted on marginalized individuals and groups. Being aware of how these systems of injustices interact with and within your organization is important to not cause further harm (38).

## Positionality

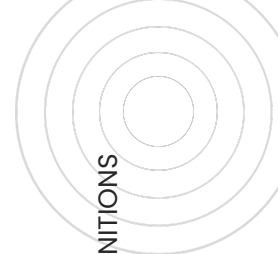
Positionality refers to how differences in social position and power shape identities and access in society. Socially constructed positions in our society shape our identities. In research, positionality refers to the researcher's position in relation to the focus of the study, which can be a citizen, the community, the organization or the participant group. Positionality is important to consider because it can influence how the data-based project is carried out and can determine the outcomes and results (39).

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(37) "Advancing Equity and Inclusion: A Guide for Municipalities"; "Equity & Inclusion Glossary of Terms."

(38) "Terminologies of Oppression."

(39) Coghlan and Brydon-Miller, *The SAGE Encyclopedia of Action Research*; Marisa Elena Duarte, *Network Sovereignty*; Misawa, "Queer Race Pedagogy for Educators in Higher Education"; Sensoy and DiAngelo, *Is Everyone Really Equal?*

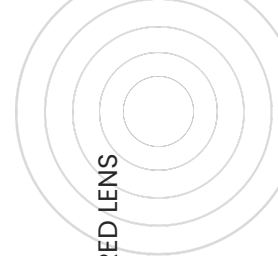


## Data Justice

Data justice is a movement that comes as a response to the historical (and ongoing) ways of collecting and sharing data that erase, invisibilize, misrepresent, or harm marginalized communities. Gathering and using data is inherently political and the 'neutrality of data' is a myth that has allowed for the ongoing marginalization of vulnerable communities. Data justice seeks to prevent (further) harm against marginalized populations by ensuring that the community's interests and participation are at the forefront of each research project.

## Informed Consent

Consent is not just asking for a signature on a legal document. Obtaining informed consent means carefully explaining to a participant what information will be collected, the reason it is being collected, how long it will be stored for, who will be using it, and who can access it.



# APPENDIX B: TRAUMA-INFORMED AND HEALING-CENTERED LENS

## Trauma

"Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being." (40)

Trauma is not just an individual experience but can be connected to wider systemic oppression. Systemic inequities can lead marginalized groups to develop trauma. Examples of systemic inequities: racism, misogyny, queer-phobia, transphobia, classism and poverty, etc. Groups targeted due to their racial, religious, or ethnic identities continue to grapple with the social, economic, and emotional fallout for generations, a concept that's known as historical trauma." (41)

Intergenerational trauma occurs when trauma gets transferred between generations. Example: Indian Residential Schools funded by the Canadian government have left a legacy of intergenerational trauma (42).

People doing research might be influenced by "Vicarious trauma (VT) and Secondary Traumatic Stress (STS)", which are frequently used interchangeably to refer to the indirect trauma that can occur when we are exposed to difficult or disturbing images and stories second-hand." (43)

## Trauma Informed and Healing Centred Lens

Throughout our data collection process, we want to incorporate a trauma informed and healing centred lens. Trauma may not only be an individual experience but also part of wider systemic oppression. Systemic inequities can lead marginalized groups to develop trauma, which may affect other parts of their life. Examples of such trauma include racism, misogyny, queer-phobia, transphobia, and classism and poverty.

To support participants' healing there are structures of support that can be put in place related to the trauma-informed and healing-centred lens. These lenses recognize the impact of trauma in both the researchers and the participants, provide a way for community-based organizations to consider how to accommodate their team better, and are useful to consider when working with people in any context.

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(40) "Section 1: A Review of the Literature."

(41) Padilla, "Beyond Trauma-Informed Care Is a Healing-Centered, Culturally Rooted Approach."

(42) DeAngelis, "The Legacy of Trauma: An Emerging Line of Research Is Exploring How Historical and Cultural Traumas Affect Survivors' Children for Generations to Come."

(43) "Defining Vicarious Trauma and Secondary Traumatic Stress."

- Consider ensuring that everyone involved in the research process develops an understanding about trauma and its impacts on people's physical, mental, emotional, and spiritual health.
- Consider adopting practices that minimize re-traumatization.
- Consider prioritizing the holistic and collective healing of people impacted by trauma. A healing-informed lens is influenced by Indigenous understandings of holistic healing practices, healing justice, and First Nations' practices of Traditional Healing. Holistic healing includes cultural, spiritual, and social justice action-oriented dimensions.
- Consider providing flexibility in care to everyone involved in your research project.

## Using the trauma-informed lens before the data collection:

### **Building a foundation of trust and respect:**

Thank the participants for their time; ask and use participant's correct pronouns.

### **Setting and following personal boundaries:**

Make a shared group agreement to create a safe space.

### **Open and honest communication:**

Talk to the participants about any of their concerns about disclosing their information; explain why you are collecting the data and how you will use it; ask the participants if they have any specific needs or barriers to answering the questions.

### **Validation:**

When participants share any concerns, validate their concerns -- note them down and address them when needed.

### **Accessibility:**

Provide a copy of questions from the data standard to service users to read and review; make this available in multiple formats, in multiple languages, and in multiple formats as needed.

## Using the trauma-informed lens during the data collection:

### **Giving space to reflect:**

Don't rush the participant and provide options to pause or stop.

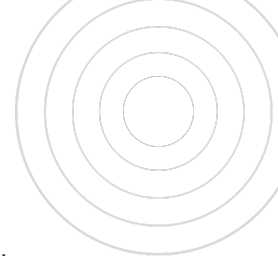
Providing options to choose: Remind participants of their right to skip any question by selecting 'Prefer not to answer.'

### **Intentionality and diversity:**

Actively and intentionally create a safe and inclusive space for diverse identities, and consider how to communicate this so participants feel supported and respected.

### **Avoiding assumptions:**

Avoid making assumptions and respect and accept how people self-identify. For example, someone's gender identity can not be known by looking at them or knowing their names.



## Building a healing centred engagement:

Build empathy. Empathy is a learned skill that involves the ability to 1) “see the world as others see it; 2) be non-judgemental; 3) understand another person’s feelings; and 4) to communicate your understanding of that person’s feelings.” (44)

- Developing people’s ability to “see beyond the condition, event or situation that caused the trauma in the first place.” Develop the ability to dream and imagine, use their agency.
- “Build[ing] critical reflection and take loving action.” (45)

## Elements of Healing-centred engagement: (46)

It is political, rather than clinical

- Communities and individuals have the agency to restore their wellbeing.
- Healing from trauma needs to address the systemic root causes.
- “When people advocate for policies and opportunities that address causes of trauma, such as lack of access to mental health, these activities contribute to a sense of purpose, power and control over life situations.”

It “is culturally grounded and views healing as the restoration of identity” (47)

- “Culture as a way to ground young people in a solid sense of meaning, self-perception, and purpose.”
- Recognizes that people have intersectional identities.
- Focuses on collective healing.
- “Healing centred engagement is the result of building a healthy identity, and a sense of belonging.”
- “Healing centred engagement embraces a holistic view of well-being that includes spiritual domains of health. This goes beyond viewing healing only from the lens of mental health, and incorporates culturally grounded rituals, and activities to restore well-being (Martinez 2001).”

Example: healing circles in Indigenous cultures

- It is “asset driven and focuses on the well-being we want, rather than symptoms we want to suppress.”
  - People are more than the worst things that happened to them.
  - It “builds upon their [people’s] experiences, knowledge, skills and curiosity as positive traits to be enhanced.”
- It “supports adult providers with their own healing”
  - Healing is ongoing.

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(44) Wiseman. “Toward a Holistic Conceptualization of Empathy for Nursing Practice.” *Advances in Nursing Science* 30, no. 3 (July 2007), quoted in Brown. *I Thought It Was Just Me (but It Isn’t): Making the Journey from “What Will People Think?” To “I Am Enough.”* New York: Avery, 2008, 37.

(45) Brown, *I Thought It Was Just Me (but It Isn’t)*.

(46) Ginwright, “The Future of Healing: Shifting From Trauma Informed Care to Healing Centered Engagement.”

(47) Ibid.



## Why is it important to have both the trauma-informed and healing-centred lenses?

The trauma-informed lens recognizes that people may have traumas, which impact their physical, mental, emotional, and spiritual health. With this awareness, researchers can accommodate everyone involved in a research project (including themselves) better. The healing-centred lens recognizes that people are not just their traumas and humanizes them; it centres people's healing rather than the traumas, it prioritizes s with their own healing"

## Why is it important to keep the two lenses distinct, even though there is some overlap?

The trauma-informed lens is distinct from the healing-centred lens because it recognizes that not everything needs to be fixed. Sometimes we cannot heal from trauma when it is ongoing or when we are not removed from the source. Here, the healing-centred lens falls short (48).

### Limitations of trauma-informed lens

- Can centre people's traumas. However, people are not just their traumas.
- Can assume that trauma is an individual, rather than a collective experience.
- May not address the systemic/root causes of traumas.
- "Runs the risk of focusing on the treatment of pathology (trauma), rather than fostering the possibility of (well-being)."

### Limitations of healing-centred lens

- It focuses on healing, which may not be possible in certain circumstances.
- Sometimes we can't heal from trauma when it's ongoing/when we're not removed from the source.

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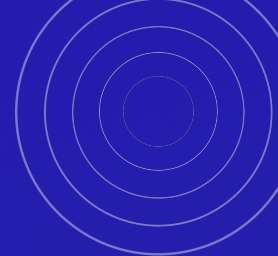
(48) Ibid.

# FINAL REMARKS



The Gender+ team thanks you for learning alongside us. We are grateful for the scholarly lineages on which this guide was built and for the ongoing activism by organizations and communities to centre justice-based approaches to data projects.

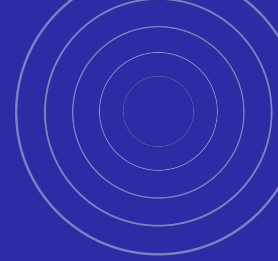
This guide has been created collaboratively by numerous local and international community organizations and diverse teams of students and recent graduates from the University of British Columbia (UBC). As members of the Gender+ Collective, we recognize that we have had many resources and opportunities to interact and engage with community members and organizations who work in community-based research and data justice. However, because of our limited perspectives and capacities, this guide should not be considered complete nor comprehensive. Several questions may remain unanswered, and we encourage readers to make the necessary space to engage in such discussions with other community organizers.



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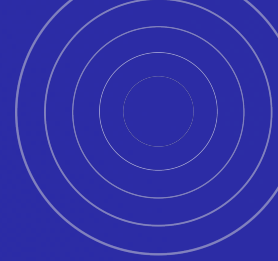
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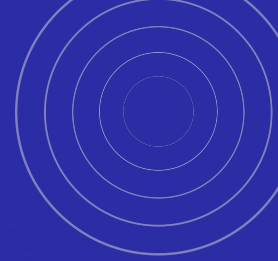
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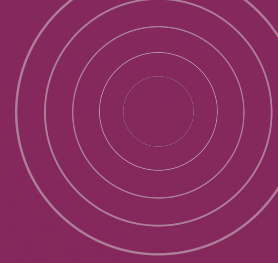
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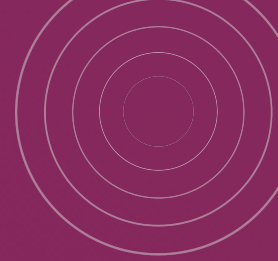
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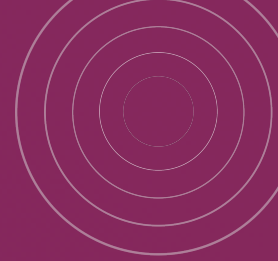
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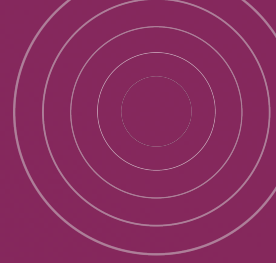
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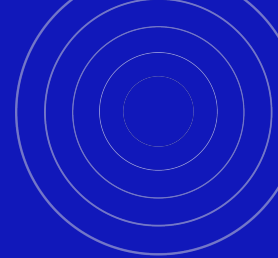


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**Collective for Gender+ in Research**

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