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How to use race-based data to advance mental health equity

Knowledge Institute
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Table of Contents

Purpose

This resource offers evidence-based suggestions for using race-based data to enhance mental health equity in Ontario's child and youth mental health and addictions sector (the sector). Mental health equity is achieved when everyone can attain their full potential for mental health and wellbeing (World Health Organization [WHO], 2022). In this document, we:

- provide a rationale for using race-based data.
- explain the ethics related to collecting, analyzing and using this data.
- describe how to measure mental health equity using race-based data throughout the data cycle.
- recommend tools that can be used throughout different phases of the data cycle to advance mental health equity.

Rationale

To advance mental health equity, we must strive for the highest possible standard of mental health for all persons. We need to recognize and address inequities in mental health. Mental health equity is linked with the concepts of justice and fairness, and what is considered just and fair depends on social norms (Penman-Aguilar et al., 2016). This means that mental health equity cannot be measured directly.

There are two common ways of measuring mental health equity:

- The absence of that which is inequitable (WHO, 2021). Inequity does not refer generally to any disparities between any population groups; instead, it refers very specifically to disparities between groups of people categorized according to important features of their underlying social position (Braveman, 2003, p. 182).
- The absence of differences in health and its social determinants and structural determinants that are associated with lower social positions (WHO, 2021).

Social determinants of health are non-medical factors that influence mental and physical health (Braveman, Egerter, & Williams, 2011). They include factors such as race, gender, ethnicity, education level, income level, racism, discrimination, stress level and employment status (Alegría et al., 2019; Braveman et al., 2011).

Social determinants have large effects on mental and physical health, accounting for 30% to 55% of health outcomes (Penman-Aguilar et al., 2016). The reverse is also true: mental health can affect social determinants. Symptoms of mental health difficulties can have a negative impact on socioeconomic status, educational performance, employment capacity and justice involvement (Alegría et al., 2019).

Structural determinants of health are different. These structural determinants include governance, economics, decision-making, policies, and programs that influence health outcomes (Penman-Aguilar et al., 2016).

To measure mental health equity, we must first identify characteristics of different groups of people. These characteristics are associated with different levels of power and privilege, as well as social positions. The next step is to collect, analyze and interpret differences in health and determinants between groups (Penman-Aguilar et al., 2016).

Race is considered a social determinant of health. Race is the categorization of people based on physical characteristics, such as skin colour and hair type (Kurzawa et al., 2021; Canadian Institute for Health Information [CIHI], 2020). Race is not considered to be determined by biology. It is a socially constructed system of classification created by socially dominant groups that reflects the attitudes of these groups (CIHI, 2020; Government of Ontario, 2018; OHRC, 2009). Racism and racial discrimination are considered social determinants of health (Berry et al., 2021).

Racism is ingrained within governance, economics, decision-making, policies, and programs (Penman-Aguilar et al., 2016). This is called systemic racism. Race is, therefore, also a structural determinant of health. When race and racism combine with other social and structural determinants of health in other sectors, it can prevent groups of children and young people from attaining their full potential for mental health and wellbeing. It can also cause further inequities in the child and youth mental health and addictions sector.

In Ontario, “data collection and analysis should be undertaken where an organization or institution has or ought to have reason to believe that discrimination, systemic barriers or the perpetuation of historical disadvantage may potentially exist” (OHRC, 2009, p. 32).

To advance mental health equity, race-based data should be collected, analyzed and used across the sector. The main purpose for collecting and using race-based data is to identify, remove, prevent and mitigate the outcomes and power imbalances resulting from racial discrimination, racism and systemic racism.

Data ethics

We need to focus on ethics when it comes to race-based data. Research shows that power issues are part of the process of collecting, analyzing, managing and using data (Datnow & Park, 2018). Individuals in higher-level positions of power can influence which data is prioritized and how data is interpreted and acted on (Coburn & Turner, 2011).

Racism marginalizes racialized[1] persons and First Nations, Inuit and Métis communities. There is a risk that race-based data could be used by racial groups in higher social positions to maintain their power and to perpetuate racial prejudice, racial discrimination and racism. There is also the risk of race-based data being used toward persecution.

Both historically and present-day, there is evidence of misuses and abuses of research and data on racialized communities and Indigenous peoples globally and in Canada.

Data ethics for race-based data includes two main components:

- The key principles of privacy, confidentiality and informed consent
- The approaches of anti-racism, anti-colonialism, whole of society and transformative participation (See Appendix A: Glossary).

Privacy principle

Respect the privacy of individuals, groups and communities (Government of Ontario, 2018).
Act in accordance with relevant legislation, law and policy, such as:

- Ontario Human Rights Code (Government of Ontario, 1990a)
- Ontario Human Rights Commission policy and guidelines on racism and racial discrimination (OHRC, 2009)
- Data Standards for the Identification and Monitoring of Systemic Racism (Government of Ontario, 2018)
- Freedom of Information and Protection of Privacy Act (Government of Ontario, 1990b)
- Municipal Information and Protection of Privacy Act (Government of Ontario, 1990c)

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[1] Racialization is “the process by which societies construct race as real, different or unequal in ways that matter to economic, political and social life” (OHRC, 2021). A racialized person is a person who is categorized or differentiated by race.

- Personal Health Information and Protection Act (Government of Ontario, 2004)

Conduct a privacy impact assessment when designing or starting a project to identify privacy implications, risks and mitigation strategies (Government of Ontario, 2018; Information and Privacy Commissioner of Ontario, 2015).

Tool:

- For guidance on conducting a privacy impact assessment, see *Planning for Success: Privacy Impact Assessment Guide* published by the Information and Privacy Commissioner of Ontario (2015).

Confidentiality principle

Protect the confidentiality of personal information.

- The ethical duty of confidentiality includes obligations to protect information from unauthorized access, modification, loss, disclosure, use, or theft (Government of Canada, 2018).

Informed consent principle

Individuals should provide their personal information voluntarily. They should understand why the data is being collected, how it will be analyzed and how it will be used. As fully as reasonably possible, they need to also understand any risks and potential benefits to the data collection.

Consent should be ongoing: individuals provide consent each time their information is collected and can withdraw their consent at any time. If an individual withdraws consent, they can request that their data be withdrawn as well (Government of Canada, 2018).

First Nations, Inuit and Métis peoples in Canada have been subject to medical and social experiments, as well as data collection and use, without their consent (Government of Ontario, 2018). To this day, many people — especially racialized individuals and First Nations, Inuit and Métis persons — are misinformed about research and how data is collected and used (Crouse Quinn et al., 2012).

Anti-racism approach

Around the world, people are persecuted by governments and other actors because of their race (United Nations High Commissioner for Refugees [UNHCR], 2011). Many people come to Canada to escape persecution, including persecution based on their race (Immigration and Refugee Board of Canada, 2021). Individuals who have been persecuted, as well as individuals whose family members and friends have been persecuted, may be reluctant or unwilling to have their personal data collected and used (UNHCR, 2015). This is especially relevant in collecting race-based data when the individual's persecution was based on race.

Racialized peoples and First Nations, Inuit and Métis peoples also experience racial discrimination and racism within Canada (Government of Ontario, 2018), and may have concerns about race-based data being used in a way that maintains or worsens racial discrimination and racism.

The collection and use of race-based data must be guided by an anti-racism approach. Anti-racism is a proactive approach that recognizes the historic and cultural contexts of racism, especially systemic racism, and aims to ensure that unfair treatment does not exist (Government of Ontario, 2018).

Anti-colonialism approach

First Nations, Inuit and Métis peoples in Canada have an extremely difficult history associated with data collection and use. Since the Confederation in 1867, the Government of Canada has implemented laws and policies aiming to destroy the identities and cultures of First Nations, Inuit and Métis peoples (Government of Ontario, 2018; Truth and Reconciliation Commission of Canada [TRCC], 2015). The federal Indian Act (1876) and the Indian Residential Schools (1870s-1990s) (TRCC, 2015) are two key examples of this (Government of Ontario, 2018; TRCC, 2015). The Government of Canada also assigned names and identification numbers, and collected and used data to monitor populations, to control the movements of First Nations, Inuit and Métis peoples and to limit their access to services (Government of Ontario, 2018; TRCC, 2015). To this day, most data collection and analysis in Canada is based on European perspectives (Government of Ontario, 2018). This means that coloniality[2] continues to be a pervasive issue in data collection and use in Canada

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[2] See Appendix A

today.

Anti-colonialism involves the “recognition of Indigenous peoples’ inherent rights and sovereignty, which are protected by Aboriginal and Treaty rights, and right to self-determination in accordance with the United Nations Declaration on the Rights of Indigenous Peoples” (Government of Ontario, 2018).

Whole of society approach

A whole of society approach should be adopted for activities related to using race-based data to advance mental health equity. This approach “promotes partnership and contributions by a wide range of stakeholders to collective impact” (Kindomay & Kocaata, 2019). It ensures openness, inclusivity and diversity. This approach provides the basis for ongoing, genuine dialogue leading to a deeper understanding and mutual respect. Particular attention should be given to engaging racialized and First Nations, Inuit and Métis communities.

Transformative participation approach

Transformative participation balances decision-making between a highly diverse range of participants and helps them to engage deeply and meaningfully in a wide range of activities and tasks (Cousins & Chouinard, 2012). Racialized and First Nations, Inuit and Métis peoples should be engaged as partners for all activities related to measuring race-based mental health inequities and using race-based data. Their participation should empower them to construct and represent their own knowledges (Freire, 1970). Through ongoing learning, partners of all races should further develop their knowledge and skills related to advancing mental health equity. Through critical reflection, everyone involved should question and consider a broad range of factors, including their own assumptions and biases, as they relate to race and mental health equity.

Tools:

- For more on meaningfully engaging young people and families, see:
- Knowledge Institute on Child and Youth Mental Health and Addictions (2021a). *Quality standards for youth engagement*.
- Knowledge Institute on Child and Youth Mental Health and Addictions (2021b). *Quality standards for family engagement.*

Using race-based data to advance mental health equity

To date, race-based data has rarely been part of Canadian health information systems. However, many health stakeholders are becoming more committed to collecting, analyzing and using race-based data (CIHI, 2020). It is important for agencies in our sector to have a clear strategy in place to ensure race-based data is used toward advancing mental health equity. Here, we present strategies to support how your organization can best:

- measure race-based mental health inequities
- act to address race-based mental health inequities
- monitor and evaluate processes and actions used to promote mental health equity

Plan and prepare

Planning and preparing is the first step. It includes all the strategies your organization needs to prepare for future stages of the data cycle.

Identify stakeholders and convene working groups

When taking a whole of society approach and transformative participation approach to guide activities related to using race-based data, it is necessary to identify stakeholders and convene working groups for meaningful engagement. Depending on the size of your organization and your goals, you may establish one or more working groups.

To develop a working group, you may wish to try these strategies:

- Obtain approval, financial support and commitment from your organization's leadership (Lingras, Alexander, & Vrieze, 2021).
- Speak with the communities served by your organization to build buy-in.
- Recruit members. This could be done via an open invitation to data stakeholders and users (organization members, community representatives) and may or may not require an application (Lingras et al., 2021). It may also be through selective invitation, where potential participants are invited based on factors such as their experience with data collection and use, interest in mental health equity, or ability to commit to long-term participation (Hawn Nelson & Zanti, 2020). No matter how members are recruited for your working group, it is important to ensure that a range of racial groups is represented.

- Establish leadership and membership terms (Lingras et al., 2021).
- Create a culture of inquiry (Parks, 2018).
- Establish meeting formats and work logistics (Lingras et al., 2021). Some meetings may be closed so that only group members can attend, while other meetings may be held openly for public deliberation (Hawn Nelson & Zanti, 2020). Public deliberation might be used when the working group wishes to consider diverse perspectives in order to come to a decision and build broader stakeholder buy-in (Hawn Nelson & Zanti, 2020). Set agendas for meetings that establish rationales and expectations for data-related processes and to structure collaboration (Parks, 2018).
- Establish a common language and develop norms, guidelines and suggestions for discussions about race and mental health equity (Hawn Nelson et al., 2020; Parks, 2018).
- Communicate activities and initiatives of the working group to the broader organization and community (Lingras et al., 2021).
- Consider collaborating with other groups within your organization and external partners to emphasize that advancing mental health equity is everyone's responsibility (Lingras et al., 2021).

Tools:

- For a tool for identifying stakeholders, see Toolkit Activity 1 of Hawn Nelson et al. (2020). *A toolkit for centering racial equity throughout data integration*. Philadelphia, PA: Actionable Intelligence for Social Policy, University of Pennsylvania.
- For guidance on leading conversations about equity-related data, see Parks (2018). Leading data conversation moves: Toward data-informed leadership for equity and learning. *Educational Administration Quarterly, 54*(4), 617-647

Develop understanding of contexts, strengths, past harms and future opportunities

Collecting and using race-based data without understanding the racial, social and historical contexts of an organization and the people it serves can augment existing inequities and create new ones (Hawn Nelson et al., 2020). Understanding these contexts involves recognizing the strengths and resiliency of racialized communities and First Nations, Inuit and Métis communities (Wutunee, 2019). It also involves recognizing past harms from misuses of race-based data (CIHI, 2020) and determining which groups have been over-surveilled through data collection, both historically and to present day (Hawn Nelson et al., 2020). Additionally, it is important to understand which groups may be suspicious of efforts to collect and use data, and the reasons for their suspicions (Government of Ontario, 2018).

Be transparent with stakeholders about the racial, social and historical contexts of your organization and the people you serve. Developing this understanding is a first step toward adopting anti-racism and anti-colonial approaches. It is a responsive approach to your organization's communities. Ways of appropriately and respectfully developing this understanding may vary depending on the community. For instance, oral histories and narratives may be appropriate ways to provide context on mental health inequities experienced by various First Nations, Inuit and Métis communities within Canada (Wutunee, 2019).

Tool:

- For a tool for developing understanding about racial, social and historical contexts, see Oregon Education Investment Board, Equity and Partnership Subcommittee (2015). Community engagement framework.

Establish explicit, clear and measurable goals

All processes related to collecting, analyzing, managing and using race-based data should be clearly and explicitly linked to mental health equity goals. There are three overarching goals related to advancing mental health equity by using race-based data:

- support continuous improvement and organizational learning
- challenge beliefs
- ensure accountability (Mandinach & Schildkamp, 2021; Datnow & Park, 2018)

The primary purpose of measuring race-based mental health inequities should be to support continuous improvement and organizational learning (CIHI, 2020). Data should be used to identify, monitor and address mental health inequities potentially stemming from racism. Instead of just using data to inform services and programs to "treat" racialized communities and First Nations, Inuit and Métis communities experiencing mental health inequities, data should be used to question and change systems (Hawn Nelson et al., 2020).

Another main goal should be to use data to challenge racial bias, prejudice and racist beliefs (Mandinach & Schildkamp, 2021). If challenging beliefs is not a goal, then data may be used to confirm racial bias. Confirming racial bias through data use would perpetuate discrimination, systemic barriers and/or historical disadvantage and further entrench inequities within the sector. This is the opposite of what using race-based data should do.

A third goal should be to ensure accountability to staff, clients, partners and the community for mental health equity. Being accountable to different groups may create tensions, so establishing goals for accountability on race-based mental health equity should involve collaboratively identifying potential sources of conflict and implementing processes to address them proactively (Hackman, Malin, & Ahn, 2019).

The goals selected during the planning stage should guide all your organization's subsequent activities.

Conceptualize race-based data

Because race is a social construct, there is not one standardized way of conceptualizing racial groups (CIHI, 2020, p. 8). People are generally classified into racialized groups based on perceived physical differences like facial features and skin colour (CIHI, 2020). People may be multi-racial, which means they are classified into more than one racial group.

When conceptualizing race-based data, you can use the opportunity to raise your own awareness and challenge assumptions about race. This is an opportunity to consider multiracial identities and to reflect critically on the ways race intersects[3] with other social categorizations to shape mental health inequities.

It is important to keep in mind the distinctions between, and the intersections, of:

- race and ethnicity
- race and immigration status
- race and nationality

Race, ethnicity, immigrant status and nationality tend to be grouped together in mental health data and research in Canada. Unfortunately, this grouping can create inaccuracies in data and inform inappropriate responses when addressing health inequities (McKenzie et al., 2016).

Ethnicity, like race, is a social construct. Ethnicity refers to a sense of belonging within a group based on shared characteristics such as cultural traditions, language, religion and/or geographic origins (CIHI, 2020, p. 10).

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[3] Intersectionality refers to the network of connections between social categories such as race, ethnicity, nationality, class, gender, sexuality, ability and age, especially as they create overlapping and interdependent systems of discrimination or disadvantage for a given individual or group (Hill Collins, 2015; Oxford Languages, 2021).

Immigrant status refers to whether a person is a non-immigrant, an immigrant, or a non-permanent resident in Canada (Statistics Canada, 2016). In Canada, these categories refer to the following persons:

- Non-immigrant category: “Persons who are Canadian citizens by birth” (Statistics Canada, 2021).
- Immigrant category: “Persons who are, or who have ever been, landed immigrants or permanent residents. Such persons have been granted the right to live in Canada permanently by immigrant authorities. Immigrants who have obtained Canadian citizenship by naturalization are included in this category” (Statistics Canada, 2021).
- Non-permanent resident category: “Persons from another country with a usual place of residence in Canada and who have a work or study permit or who have claimed refugee status (asylum claimants). Family members living with work or study permit holders are also included, unless these family members are already Canadian citizens or landed immigrants/permanent residents” (Statistics Canada, 2021).

Nationality refers to a legal bond between a State (a country or nation) and an individual. A national is a person who is a member of a State. Most States grant key rights to nationals, such as the right to live in the State’s territory and the right to participate in political processes. These rights also include certain obligations for nationals — for example, a requirement to pay taxes or serve in the military (Office of the High Commissioner for Human Rights [OHCHR], 2021). Nations can give and sometimes take away nationality (OHCHR, 2021). A person who is not considered a national by any State is referred to as stateless (OHCHR, 2021).

Distinguish the racial categories your organization will use from categories that refer to First Nations, Inuit and Métis peoples. There may be some commonalities between these concepts, such as experiences of racism and cultural belonging. However, First Nations, Inuit and Métis are constitutionally recognized sovereign nations with inherent rights to self-determination (CIHI, 2020, p. 11). The categories of First Nations, Inuit and Métis peoples may not reflect the names that they use for their specific nation and community nor their preferred conceptualizations of race (CIHI, 2020, p. 11).

Create ethical guidelines

There is a heightened need to focus on ethics when it comes to race-based data. It is important that your organization has ethical guidelines for collecting, analyzing, interpreting, using and reporting on race-based data. These guidelines should address how to respond to any potential negative consequences or harm of such work within your organization and beyond. For example, information about clients' social determinants could potentially lead providers and insurers to assume less responsibility for client outcomes, use the information against clients, or stigmatize clients (Alegría et al., 2019).

Using data for equity purposes runs the risk of focusing on needs or deficits, and entrenching deficit-based views of already marginalized racialized groups (Bertrand & Marsh, 2021; Wutunee, 2019). Ethical guidelines might help address how data can be used to show not only needs, but also strengths, capabilities and circumstances.

Tool:

- For more information about research ethics and free online modules, see the Government of Canada (2018) *Tri-council policy statement: Ethical conduct for research involving humans – TCPS 2.*

Establish data governance policies and processes

Ensure that your organization's policies and processes employ best practices for the collection, privacy, usage, synthesis/analysis, control, publication, storage and archiving/disposal of race-based data (Standards Council of Canada, 2021). Data governance processes should also include measures related to security of personal information and quality assurance (Government of Ontario, 2018).

It is important to recognize, respect and act in partnership with Indigenous sovereignty and governance structures (Government of Ontario, 2018). The First Nations principles of ownership, control, access and possession (OCAP®) guide all activities related to First Nations data in keeping with each First Nation's world view (Government of Canada, 2021b). It is important to collaborate with those First Nations, Inuit and Métis communities wishing to be visible in, and use, data (Wutunee, 2019).

Tools:

- For a six-part learning series on key issues in and recommendations for data governance, see Government of Canada (2021a) *Data governance and standardization series*
- For a course on the First Nations principles of ownership, control, access and possession, see First Nations Information Governance Centre (2021) *The First Nations principles of OCAP®.*

Determine the methods and measures

It is important to consider the implications of choices made about analysis in measuring race-based mental health inequities because they can introduce bias (Penman-Aguilar et al., 2016). Bias can stem from the value preferences informing the choice of methods and measures, as well as data presentation approaches (Penman-Aguilar et al., 2016). It is recommended that your organization use different measures on the same data to map mental health inequities (Penman-Aguilar et al., 2016).

Measures are often clinical outcomes like mental health symptom improvement (Adler et al., 2016). Other measures might also be important to various stakeholders (Alegría et al., 2019). There is a need to address the concurrent multiple mental and physical health conditions in a population in research on the social determinants (Rose-Clarke et al., 2020). Your organization may wish to consider measures related to both mental and physical health, if in the position to do so.

Measuring race-based mental health equity involves comparing data between different racially defined groups. As a first step, determine the reference point from which differences will be measured. The reference point could be:

- the total population
- the largest racial group
- the racial group with the most favourable rate for a mental health outcome
- the racial group with the most favourable rate for a social determinant of mental health
- the racial group with the greatest social advantage
- another target group selected during the planning process (Penman-Aguilar et al., 2016; Keppel, Pamuk, Lynch, et al., 2005; Braveman, 2003)

Next, determine whether:

- differences will be measured on an absolute or relative scale (Penman-Aguilar et al., 2016). An absolute scale represents the original values as measured by an instrument (the number of people in a racial group with a particular health outcome). A relative scale represents values in relation to others (a ratio of the number of people in one racial group with a particular health outcome to the number of people in another racial group with the same mental health outcome).
- the sizes of the social group will be accounted for (Penman-Aguilar et al., 2016).
- differences will be evaluated with using a pairwise or summary approach (Penman-Aguilar et al., 2016).
- extra emphasis should be given to social group(s) that are of greater concern through differential weighting (Penman-Aguilar et al., 2016).

Pairwise comparisons are methods for analyzing multiple population means in pairs to determine whether they are significantly different from one another (Salkind, 2010). Pairwise approaches are often used to analyze mental health equity because the general population is typically broken down into three or more groups for analysis (Penman-Aguilar et al., 2016).

A summary approach uses descriptive statistics to summarize and describe data for each group individually.

Consider different designs and their strengths and limitations (Alegría et al., 2019). Many studies of social determinants of health use cross-sectional designs (Rose-Clarke et al., 2020; Gruebner et al., 2017). However, longitudinal qualitative and quantitative studies are particularly needed to examine social determinants of health and to understand and address mental health inequities (Rose-Clarke et al., 2020; Alegría et al., 2019; WHO, 2014).

Experiences and impacts of social determinants of mental health vary across life, influence people at different ages and stages of life in particular ways, and can be transferred intergenerationally (WHO, 2014, p. 18). Longitudinal studies are needed to assess causality, to examine trends over time, and to consider the cumulative effects of multiple social determinants of health (Rose-Clarke et al., 2020; Alegría et al., 2019).

Provide reasons for these choices and clarify their implications.

Tool:

- For guidance on determining methods and measures, see pages 6-9 of Penman-Aguilar et al. (2016). Measurement of health disparities, health inequities, and social determinants of health to support the advancement of health equity. *Journal of Public Health Management Practices, 22*(1), 1-17. DOI: 10.1097/PHH. 0000000000000373.

Select information technology systems and tools

Consult with your organization's data team to discuss the possibilities of capturing race-based data within existing and alternative Information Technology (IT) systems (Sinai Health Systems, 2017). Explore interoperable functions. If possible, work with and develop flexible IT and data systems that adapt to changes in contexts and systems (Hawn Nelson et al., 2020).

Decide what, if any, algorithms your organization will use to analyze race-based data. Algorithms are a series of instructions in statistical tool packages that adjust analyses based on human behaviour (Hawn Nelson et al., 2020). Algorithms are developed by programmers, and they reflect the biases of those who create them (Hawn Nelson et al., 2020). This means that algorithms are not race-neutral. If your organization is going to use algorithms to analyze race-based data, use strategies and tools to assess biases and determine the potential consequences of applying the algorithm (Hawn Nelson et al., 2020). You can also create and publish a social impact statement on algorithms (Fairness, Accountability, and Transparency in Machine Learning, 2017).

Tools:

- For guidelines on developing and using algorithms and recommended steps for making a public impact statement about the algorithm, see Fairness, Accountability, and Transparency in Machine Learning (2017) *Principles for accountable algorithms and a social impact for algorithms.*

- For a toolkit of assessing and managing algorithm risk, see Anderson, Bonaguro, McKinney, Nicklin, & Wiseman (2018). *Ethics & algorithm toolkit*.

Plan for communicating and building buy-in with staff and stakeholders

Consider developing a communications strategy specific to mental health equity that addresses racial equity. This strategy could be aligned to your organization's overall communications strategy.

Health inequities associated with race should be framed as the result of structural inequities stemming from racism. Race should not be positioned as a client vulnerability (Adler et al., 2016). Explanations of health inequities focusing on racialized individuals or groups suggest the responsibility to overcome barriers lies with them, rather than with organizations and society (Alegría et al., 2019). Framing health inequities as a society-wide problem is critical for changing attitudes and challenging stereotypes (Alegría et al., 2019).

Your communications strategy may be accompanied by an implementation support document, such as a work plan. This plan can include a schedule for important communications related to advancing racial equity in mental health.

Tool:

- For recommendations for reporting and communicating about findings and uses of race-based data, see pages 31-39 of Hawn Nelson et al. (2020). *A toolkit for centering racial equity throughout data integration.* Philadelphia, PA: Actionable Intelligence for Social Policy, University of Pennsylvania.

Provide learning and development opportunities

Identify the learning needs of staff and stakeholders related to collecting, analyzing and using race-based data to advance mental health equity. When planning for staff's professional development, consider using data literacy definitions and frameworks laying out the knowledge, skills and dispositions that staff working in different positions need to collect, analyze and use data effectively (Mandinach & Schildcamp, 2021). Data literacy can be presented along a continuum ranging from novice to expert and describing the knowledge and skills that a person at each phase of the continuum demonstrates (Mandinach & Schildkamp, 2021).

Develop and deliver appropriate training and support resources tailored to different audiences (staff in different roles, stakeholders, partners) (Government of Ontario, 2018). Training and support formats might include professional learning communities, coaching, train the trainer programs, workshops, symposia, e-learning modules, in-person training, and events to share learning and experiences (Sinai Health Systems, 2017; Datnow et al., 2021).

Tools:

- For guidance on developing a new training curriculum, see Thomas et al. (2015). *Curriculum development for medical education: A six-step approach.* Baltimore, MA: Johns Hopkins University Press.
- For examples of educational materials and resources for collecting client demographic data – including race-based data, see Sinai Health System Health Equity Office (2021). *Measuring health equity: Demographic data collection in health care.*

Collect data

Include staff and stakeholders in data collection

Involve your organization's staff and stakeholders in defining what data to collect, and how and when it should be collected (Hawn Nelson et al., 2020). Develop clear definitions of data items and include these definitions in all communications about the data (Alegría et al., 2019). Data can be collected from online applications for programs and services, client intake paperwork, service payment records, patient surveys, or any other place where data have been collected to administer or evaluate programs and services (Hawn Nelson et al., 2020, p. 18).

Adapt best practices to fit with existing workflows

Develop a strategy for collecting race-based data focused on adapting best practices to fit within existing workflows (Sinai Health Systems, 2017). This should involve speaking with staff in different positions, assessing their workloads, and tailoring data collection procedures to be integrated as seamlessly as possible in their everyday activities.

Collect only the data that you need

Collect only the race-based data your organization needs to advance mental health equity. Any data collected should be collected for a specific use that is tied to a measurable mental health equity goal.

Collect data from clients who provide informed consent

Equity can only be achieved if efforts to use data are focused on everyone (Datnow & Park, 2018). This means that data should be collected from all clients who provide informed consent and, where applicable, assent.

When clients are considering providing consent and assent, ensure they have access to a staff member to ask any questions (Sinai Health Systems, 2017).

Although everyone should be invited to have their race-based data collected and used to advance mental health equity, not everyone will provide consent (and assent, where applicable). This can result in authorization bias (Beebe, Ziegenfuss, Jenkins, Haas, & Davern, 2011). Authorization bias means the people who provide consent and assent are significantly different from those who do not provide consent and assent in terms of attributes important to mental health equity (Beebe et al., 2011). Historical and present-day misuses and abuses of the data of racialized communities and First Nations, Inuit and Métis peoples have led in many places to authorization bias. It is important to demonstrate exemplary ethics with data — especially race-based data — to foster trust and potentially reduce future authorization bias.

Include a preamble

When collecting personal information related to race, your organization can ask individuals to self-report race as a social description or category instead of as a reflection of their personal identity (Government of Ontario, 2018). As systemic racism is shaped by how society categorizes individuals into racial groups, this approach helps to identify and monitor systemic racism (Government of Ontario, 2018).

Tool:

- For more on writing a preamble to collect personal information about race, see Standard 14 (page 25) of Government of Ontario (2018). *Anti-racism data standards – Order in Council 897/2018: Data standards for the identification and monitoring of systemic racism.*

Collect data on other social determinants of health

Consider collecting data on other social determinants of health, in addition to race. Examples include socioeconomic status, gender, immigration status and language proficiency. This will:

- allow you to do an intersectional analysis (disaggregated analysis across two or more factors) to see if inequities are due to racism or other related social determinants of health (CIHI, 2020; Penman-Aguilar et al., 2016).
- enable a more holistic view of clients (for example, a whole-child view) (Hawn Nelson et al., 2020).
- provide nuanced information about subgroups within racial groups to help challenge prejudiced and racist beliefs that all people from one racial group are the same (Hawn Nelson et al., 2020).

Tools:

- For more on other social determinants of mental health, see:
- Compton, M.T., & Shim, R.S (2015) The social determinants of mental health. *Focus: The Journal of Lifelong Learning in Psychiatry, 13*(4), 419-425.
- Rose-Clarke et al. (2020). Rethinking research on the social determinants of global mental health. *The Lancet Psychiatry, 7*(8), 659-662.
- Alegría, M., NeMoyer, A., Falgas, I., Wang, Y., & Alverez, K. (2019). Social determinants of mental health: Where we are and where we need to go. *Current Psychiatry Reports, 20*(11), 1-13.

Manage data

Maintain and promote secure systems and processes for retaining, storing, archiving and disposing of data (Government of Ontario, 2018). Limit access to and use of personal information (Government of Ontario, 2018). This might involve:

- categorizing data as open, restricted and unavailable (see Appendix A: Glossary), having policies for managing each of these categories of data, and communicating these policies to staff and stakeholders (Hawn Nelson et al., 2020). For instance, a policy could be that access to individual-level personal information linked to race-based data is unavailable (Hawn Nelson & Zanti, 2020).
- having clear policies against sharing or linking data across institutions that have patterns of institutional racism and that have historically committed or may presently be committing racialized harm, without sufficient data safeguards in place (Hawn Nelson & Zanti, 2020). Such policies may require data-sharing agreements with organizations to address data safeguards.

Implement quality assurance and quality improvement processes to ensure the quality of data (see definitions in Appendix A: Glossary). There are often problems with quality of data on social determinants of health, particularly race (Cook, Sachs, & Weiskopf, 2021). Quality issues associated with race-based data commonly include accuracy, completeness (whether data are missing) and conformance (whether data are compatible) (Cook et al., 2021). Race-based data being inaccurate or incomplete can lead to misclassification bias (Cook et al., 2021).

Tools:

- For examples of positive and problematic practices in managing race-based data, see:
- Page 5 of Hawn Nelson, A.L., & Zanti, S. (2020). A framework for centering racial equity throughout the administrative data life cycle. *International Journal of Population Data Science, 5*(3), 1-10.
- Pages 21-25 of Hawn Nelson, A., Jenkins, D., Zanti, S., Katz, M., Berkowitz, E., et al. (2020). *A toolkit for centering racial equity throughout data integration*. Philadelphia, PA: Actionable Intelligence for Social Policy, University of Pennsylvania.
- For recommendations on mitigating issues with data quality, see pages 5-7 of Cook, L.A., Sachs, J., & Weiskopt, N.G. (2021). The quality of social determinants data in the electronic health record: a systematic review. *Journal of the American Medical Informatics Association, 00*(0), 1-10. Doi:10.1093/jamia/ocab199.

Analyze and interpret data

Analyze the data using the methods and measures selected during the plan and prepare stage. Recommendations for your organization include the following.

- Use different measures on the same data (Penman-Aguilar et al., 2016).
- Analyze data on all clients from your organization, rather than just on the individuals you have personally treated or supported. This approach promotes shared responsibility (Datnow & Park, 2018).
- Compare groups classified by two or more social determinants of health (for example, racial group by socioeconomic status) and analyze the relative contribution of the different factors to the identified mental health inequities (CIHI, 2020; Hawn Nelson et al., 2020; Penman-Aguilar et al., 2016). Without disaggregating by subgroups, analysis can gloss over inequities (Hawn Nelson et al., 2020). However, it is important to be careful when disaggregating by subgroups because this can make the analysis focus on a specific population that is likely already over-surveilled (Hawn Nelson et al., 2020).

Mental health equity data is inherently ambiguous and has multiple meanings. It is important to make sense of and interpret the data in collaboration with management, staff and stakeholders (Knapp et al., 2018; Mandinach & Schildkamp, 2021). This collaboration could take place through a working group established during the plan and prepare phase.

Consider the data based on the goals established during the plan and prepare phase to generate insights[4] (Dykes, 2016). These insights will be used in the next phase to influence decisions and actions (Dykes, 2016). Remember that there are three overarching goals related to advancing mental health equity using race-based data. Determine whether the data provide insights related to these goals:

- support continuous improvement and organizational learning
- challenge beliefs
- ensure accountability (Datnow & Park, 2018; Mandinach & Schildkamp, 2021)

Be mindful of the ways in which data analysis and interpretation are influenced by many factors, including interests, experiences, ideologies and institutional contexts (Mandinach & Schildkamp, 2021; Knapp et al., 2018).

Measuring mental health equity involves comparing data between racially defined groups. Regardless of the ways in which mental health equity is measured and race-based data is analyzed, interpretations should indicate that all populations must be faring well for mental health equity to be demonstrated (Penman-Aguilar et al., 2016).

Put the data into action

The next step is to put the data into action. Certain pieces of data may provide insights about on a given situation. However, they do not necessarily tell us how to address an issue (Knapp et al., 2018). When it comes to using data to advance mental health equity, a lot of thought and discussion with staff and stakeholders must go into deciding what insights to act on and how exactly to act on them and then implementing these actions.

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[4] Insights are what is generated by analyzing data and drawing conclusions (Dykes, 2016).

Create an action plan for advancing mental health equity. Your organization's action plan should be based on:

- the goals of advancing mental health equity using race-based data that were established in the plan and prepare phase. Again, these goals should be tied to the following overarching goals:
- support continuous improvement and organizational learning
- challenge beliefs
- ensure accountability
- the insights generated by analyzing and interpreting the data in the previous phase
- the understandings and expertise that staff and stakeholders have from their experiences, recognizing that there may not be high-quality data related to these experiences yet (Knapp et al., 2018)

Consider what actions should to be taken, continued or stopped within your organization to advance equity. These actions should be linked to one or more of the three overarching goals:

- **Goal 1:** Support continuous improvement and organizational learning
    - Consider how data can be used to improve access, experiences and outcomes for clients (Sinai Health Systems, 2017). It is, however, important to note that if your organization is interested in tailoring services to be more responsive to clients, then it may be more relevant to collect and use ethnicity-related data (CIHI, 2020). For example, data on preferred languages could be used to anticipate language services needed.
    - Use data to inform training and professional development.
    - Use data for planning. This might involve developing client profiles, identifying disparities, determining benchmarks for improvement and developing capacity for targeted improvements in services (Sinai Health Systems, 2017).
- **Goal 2:** Challenge beliefs
    - Consider how the data can be used to encourage staff to challenge biases and to reflect critically on policies, programs and practices (Datnow & Park, 2018).
    - Consider how to prevent the data from being used to confirm racial biases.

- **Goal 3:** Ensure accountability
    - Incorporate equity into reporting structures.
    - Consider profiling who is being served to ensure your organization is accountable to them. Develop different messages for different audiences. Use appropriate lengths, language, formatting and levels of detail. Write your messages using active, person-centred language. (Hawn Nelson et al., 2020).
    - Provide clear documentation of processes, rationales for choices made throughout the entire data use process (e.g. planning and preparation, data collection, analysis, interpretation, use) and explanations of the implications of choices made (Hawn Nelson et al., 2020; Penman-Aguilar et al., 2016).
    - De-identify data sets and results of analyses before making information public (Government of Ontario, 2018). De-identifying data removes personal information that could be used to identify individuals (Knowledge Institute on Child and Youth Mental Health and Addictions, 2022).
    - Acknowledge structural racism and other harms to communities that may be embedded in data and data-related processes (Hawn Nelson et al., 2020).
    - Discuss proposed actions with staff and stakeholders to determine if your plans are ready for implementation or if they require further research (Menger et al., 2016).
    - Report on the data, the insights generated from the data, and the actions to be taken based on the data and insights to staff, clients and partners (Hawn Nelson et al., 2020).

Make each intended action point as clear as possible by explicitly identifying the who, what, where, when, why and how:

- Who has a role or responsibility related to the intended action?
- What specific action is required or encouraged of each intended actor?
- When and where will the action be implemented?
- What tools will support the implementation of the action? These might include policies, funding, incentives, training and professional development, tip sheets, working groups, monitoring and evaluation tools, etc.

Tools:

- For tips on de-identifying data, see Knowledge Institute on Child and Youth Mental Health and Addictions (2022). *How to de-identify personal information when sharing data.*

Monitor and evaluate actions

Throughout the entire process of using race-based data to advance mental health equity, conduct impact analyses based on the core question: Does this work mitigate, worsen or ignore inequities? (Hawn Nelson et al., 2020).

Before implementing actions informed by insights generated from race-based data, create a plan to monitor and evaluate whether the actions advance mental health equity. Monitoring and evaluation should centre on these questions:

- Are the processes used and the actions undertaken mitigating, worsening, or ignoring inequities? These inequities may be in opportunities and outcomes for different groups of clients (Hawn Nelson et al., 2020).
- Has your organization achieved the goals set in the plan and prepare phase? (Mandinach & Schildkamp, 2021)
- Implement the plan to monitor and evaluate actions.

Implement the plan to monitor and evaluate whether the actions advance mental health equity.

Summary

The main purpose of using race-based data should be to advance equity in Ontario's child and youth mental health and addictions sector.

As a sector, we need to focus on ethics when it comes to race-based data. This involves respecting the key principles of privacy, confidentiality and informed consent and using the approaches of anti-racism, anti-colonialism, whole of society and transformative participation.

It is important that agencies that collect and use race-based data have a clear, evidence-based strategy in place to ensure that data is used toward advancing equity. This strategy should include processes to plan and prepare for data collection and use, collect and manage data, analyze and interpret data, act using insights generated from data, and monitor and evaluate these processes and their outcomes. All processes related to race-based data should be clearly and explicitly linked to measurable mental health equity goals. Agencies may wish to establish specific goals for their organization that are linked to these three overarching equity-related goals:

- support continuous improvement and organizational learning
- challenge beliefs
- ensure accountability

Mental health equity will be achieved when everyone can attain their full potential for mental health and wellbeing in Ontario.

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Appendix A: Glossary

Anti-colonialism

Anti-colonialism is the recovery of traditional Indigenous knowledges as a strategy to resist the replacement of Indigenous ways and knowledges with Eurocentric ways and knowledges, the interpretation of experiences of colonized peoples on their own terms, and the evocation of understandings not forced through Eurocentric lenses (Carlson, 2016; Hart, 2009; Dei, 2006).

Anti-oppression

Anti-oppression refers to actions, theories, frameworks and strategies that challenge injustices and inequities that occur at different levels in society (for example interpersonal, institutional, systemic) and allow certain groups of people to overpower other groups of people (Coleman, n.d.; Canadian Race Relations Foundation, 2019).

Anti-racism

Anti-racism is the active process of identifying individual, institutional and systemic racism. It seeks to challenge and change or eliminate racially inequitable outcomes and the structures that sustain inequity. (Coleman, n.d.; Ontario Human Rights Commission, 2015; Ontario Health, 2020

Assent

An indication of agreement by an individual not able to give legal consent to participate.

Confidentiality

The obligation of an individual or organization to safeguard information. The ethical duty of confidentiality includes obligations to protect information from unauthorized access, use, disclosure, modification, loss, or theft" (Government of Canada, 2018).

Colonialism

"A political doctrine that advocates or seeks to justify the exploitation of a colony, territory, or country by a foreign state [that] relates to the past expansion of the colonizing countries" (Tomicic & Berardi, 2018, p. 153).

Coloniality

Colonial situations in the present period (Grosfoguel, 2007).

Consent

An indication of agreement by an individual who can provide legal consent to participate. The term means free, voluntary, informed, and ongoing consent. (Government of Canada, 2018).

Data ethics

"Ethical issues that arise from recognizing that the evaluation of data collection, sharing, and use practices has the potential for adverse impacts. In order to minimize adverse impacts of data processes, ethical concerns should be addressed at all stages of the data life cycle" (Hawn Nelson et al., 2020, p. 68).

Data governance

Data governance includes the collection, privacy, usage, synthesis/analysis, control, publication, storage, and archiving/disposal of data.

Equity

Achieving equity requires identifying and addressing unfair barriers to opportunity. Equity can be defined as both a process and an outcome. As a process, equity can be achieved in many ways, such as co-developing with communities the policies and practices that impact their lives, or applying an equity lens or framework to programs and services. As an outcome, equity is the absence of differential outcomes based on social, economic, demographic or geographic characteristics. It is important to note that equity is not the same as equality (Canadian Race Relations Foundation, 2019; Center for Social Inclusion, n.d.)

Individual racism

Individual racism is the explicit and implicit beliefs, attitudes, and actions that support or sustain racism by individual people (National Museum of African American History and Culture, n.d.)

Informed consent

Ongoing, voluntary decision to participate based on a clear understanding of what participation entails.

Insights

Insights are generated by analyzing data and drawing conclusion based on the data (Dykes, 2016).

Institutional racism

Institutional racism is racial inequity within institutions and systems of power, such as workplaces and government agencies. It is carried out by individuals directed by prejudiced people or a prejudiced system. Institutional racism can be expressed through discriminatory treatment, policies and practices as well as inequitable opportunities and outcomes (The Annie E. Casey Foundation, 2020; Alberta Civil Liberties Research Centre, n.d.)

Interpersonal racism

Interpersonal racism is the public expression of racism that occurs between people. This includes slurs, biases, or hateful words or actions (YW Boston, 2017).

Intersectionality

Intersectionality refers to the fact that social categories such as race, ethnicity, nationality, class, gender, sexuality, ability and age connect and combine to create overlapping and interdependent systems of discrimination or disadvantage and shape inequities (Collins, 2015). It is a framework that recognizes that people are disadvantaged by many sources of discrimination that result in unique forms of oppression and harmful outcomes. Multiple identity markers do not exist independently, and they are not simply additive (YW Boson, 2017).

Multiracial

Having parents or ancestors of different races.

Open data

Data that can be shared openly, either at the aggregate or individual level, based on state and federal law (Hawn Nelson et al., 2020, p. 21).

Privacy

"An individual's right to be free from intrusion or interference by others. Individuals have privacy interests in relation to their bodies, personal information, expressed thoughts and opinions, personal communications with others, and spaces that they occupy. An important aspect of privacy is the right to control information about oneself." (Government of Canada, 2018)

Quality assurance

All planned and systematic activities implemented in a quality system so that quality requirements for a product or service will be fulfilled.

Quality improvement

"All actions taken throughout the organization to increase the effectiveness and efficiency of activities and processes in order to provide added benefits to both the organization and its customers." (Council of Accreditation, Ontario Child Welfare Quality Network, 2009).

Race

Race is the categorization of people based on physical characteristics, such as skin color and hair type. It is a socially constructed system of classification of socially dominant groups that reflects the cultural attitudes of colonial Europeans and is not considered to be determined by biology (Ontario Health, 2020).

Racialization

"The process by which societies construct race as real, different or unequal in ways that matter to economic, political and social life" (Ontario Human Rights Commission, 2021).

Restricted data

Data that can be shared, but only under specific circumstances, with appropriate safeguards in place (Hawn Nelson et al., 2020, p. 2)

Security

Measures to protect information, including physical, administrative, and technical safeguards (Government of Canada, 2018).

Structural racism

Structural racism is racial inequity that occurs across society and is rooted in the operation of major social institutions that excludes people from certain groups. It differentiates people based on their race through laws, policies, institutional practices, cultural representations and other ways (Canadian Race Relations Foundation, 2019; Ontario Health, 2020; Alberta Civil Liberties Research Centre, n.d.).

Systemic racism

Systemic racism is the interplay between individual, institutional, and structural racism which functions as a whole system. It is a dynamic system that produces and replicates discrimination and exclusion of individuals across levels of society that creates unfair barriers and disadvantages access and opportunity for racialized groups and First Nations, Inuit and Métis peoples (Canadian Race Relations Foundation, 2019; The Annie E. Casey Foundation, 2020; Ontario Health, 2020)

Transformative participation

Transformative participation balances decision making between a highly diverse range of participants and supports intended beneficiaries and stakeholders to participate deeply and meaningfully in a wide range of activities and tasks (Cousins & Chouinard, 2012).

Unavailable data

Data that cannot or should not be shared, either because of law, lack of digital format, or data quality or other concerns (Hawn Nelson et al., 2020, p. 21).

Appendix B: Recommended tools by phase of the data cycle

Data ethics

- For guidance on conducting a privacy impact assessment, see *Planning for Success: Privacy Impact Assessment Guide* published by the Information and Privacy Commissioner of Ontario (2015).
- For more on meaningfully engaging young people and families, see:
    - Knowledge Institute on Child and Youth Mental Health and Addictions (2021a). *Quality standards for youth engagement*.
    - Knowledge Institute on Child and Youth Mental Health and Addictions (2021b). *Quality standards for family engagement.*

Plan and prepare

- For a tool for identifying stakeholders, see Toolkit Activity 1 of Hawn Nelson et al. (2020). *A toolkit for centering racial equity throughout data integration*. Philadelphia, PA: Actionable Intelligence for Social Policy, University of Pennsylvania.
- For guidance on leading conversations about equity-related data, see Parks (2018). Leading data conversation moves: Toward data-informed leadership for equity and learning. *Educational Administration Quarterly, 54*(4), 617-647
- For a tool for developing understanding about racial, social and historical contexts, see Oregon Education Investment Board, Equity and Partnership Subcommittee (2015). *Community engagement framework*.
- For more information about research ethics and free online modules, see the Government of Canada (2018) *Tri-council policy statement: Ethical conduct for research involving humans – TCPS 2*.
- For a six-part learning series on key issues in and recommendations for data governance, see Government of Canada (2021a) *Data governance and standardization series*
- For a course on the First Nations principles of ownership, control, access and possession, see First Nations Information Governance Centre (2021) *The First Nations principles of OCAP®.*
- For guidance on determining methods and measures, see pages 6-9 of Penman-Aguilar et al. (2016). Measurement of health disparities, health inequities, and social determinants of health to support the advancement of health equity. *Journal of Public Health Management Practices, 22*(1), 1-17. DOI: 10.1097/PHH. 0000000000000373.

- For guidelines on developing and using algorithms and recommended steps for making a public impact statement about the algorithm, see Fairness, Accountability, and Transparency in Machine Learning (2017) *Principles for accountable algorithms and a social impact for algorithms.*
- For a toolkit of assessing and managing algorithm risk, see Anderson, Bonaguro, McKinney, Nicklin, & Wiseman (2018). *Ethics & algorithm toolkit.*
- For recommendations for reporting and communicating about findings and uses of race-based data, see pages 31-39 of Hawn Nelson et al. (2020). *A toolkit for centering racial equity throughout data integration*. Philadelphia, PA: Actionable Intelligence for Social Policy, University of Pennsylvania.
- For guidance on developing a new training curriculum, see Thomas et al. (2015). *Curriculum development for medical education: A six-step approach*. Baltimore, MA: Johns Hopkins University Press.
- For examples of educational materials and resources for collecting client demographic data – including race-based data, see Sinai Health System Health Equity Office (2021*)*. Measuring health equity: Demographic data collection in health care.

Collect data

- For more on writing a preamble to collect personal information about race, see Standard 14 (page 25) of Government of Ontario (2018). *Anti-racism data standards – Order in Council 897/2018: Data standards for the identification and monitoring of systemic racism.*
- For more on other social determinants of mental health, see:
    - Compton, M.T., & Shim, R.S (2015) *The social determinants of mental health. Focus: The Journal of Lifelong Learning in Psychiatry, 13*(4), 419-425.
    - Rose-Clarke et al. (2020). *Rethinking research on the social determinants of global mental health. The Lancet Psychiatry, 7*(8), 659-662.
    - Alegría, M., NeMoyer, A., Falgas, I., Wang, Y., & Alverez, K. (2019). *Social determinants of mental health: Where we are and where we need to go. Current Psychiatry Reports, 20*(11), 1-13.

Manage data

- For examples of positive and problematic practices in managing race-based data, see:
    - Page 5 of Hawn Nelson, A.L., & Zanti, S. (2020). A framework for centering racial equity throughout the administrative data life cycle. *International Journal of Population Data Science*, *5*(3), 1-10.
    - Pages 21-25 of Hawn Nelson, A., Jenkins, D., Zanti, S., Katz, M., Berkowitz, E., et al. (2020). *A toolkit for centering racial equity throughout data integration*. Philadelphia, PA: Actionable Intelligence for Social Policy, University of Pennsylvania.
- For recommendations on mitigating issues with data quality, see pages 5-7 of Cook, L.A., Sachs, J., & Weiskopt, N.G. (2021). T*he quality of social determinants data in the electronic health record*: a systematic review. *Journal of the American Medical Informatics Association, 00*(0), 1-10. Doi:10.1093/jamia/ocab199.

Put the data into action

- For tips on de-identifying data, see Knowledge Institute on Child and Youth Mental Health and Addictions (2022). *How to de-identify personal information when sharing data.*

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