EQUITY, DIVERSITY & INCLUSION GUIDANCE DOCUMENT FOR CONDUCTING RESEARCH AT BRUYÈRE AND THE BRUYÈRE RESEARCH INSTITUTE

This document will be a living document, subject to recurring evaluation, review, and revision.

PREAMBLE

The Bruyère Research Institute and the Bruyère Research Ethics Board respects and values the dignity, rights, and diversity of all those who work, study, volunteer, and participate in research across our organization. The principles outlined in this guide are a reflection of our values as an institution, and our efforts to remove barriers and biases in order to create a safe, equitable, accessible, diverse and inclusive space for those who conduct research and those who participate in it.

As a Catholic organization, we are inspired by the values and legacy of our foundress, Mother Elisabeth Bruyère, and have the following values:

- Respect – Welcoming diversity
- Compassion – Care and empathy
- Collaboration – Striving to create a supportive environment
- Accountability – Fostering social responsibility
- Learning – Valuing and encouraging lifelong learning

1. BACKGROUND AND DEFINITIONS

*(Please note that the **Canadian Centre for Diversity and Inclusion** (CCDI) is the most exhaustive and up to date source for the following definitions and should be consulted to ensure accuracy. In the case of a discrepancy, please refer to CCDI: https://ccdi.ca/. The definition list below is not exhaustive, and is derived from a number of sources. Some wording includes direct quotes, and some is a hybrid wording from a variety of sources. The direct quotes have not been put in italics; however, all sources used are referenced in the **Resources and References** section at the end of this document).*

Embracing an equitable, diverse and inclusive research framework creates the foundation for exceptional, transformational, and impactful research, which opens the door for all individuals, regardless of their situation or circumstances, to participate in research.

Adopting a common language, and embracing a shared understanding of equity, diversity and inclusion, helps to strengthen research, inspire creativity, and encourage and support open dialogue.

Equality Versus Equity

Equality refers to equal rights, responsibilities and opportunities for all people. However, equality of opportunity by itself does not guarantee equal outcomes for different groups. Equity refers to fairness, impartiality and justice in the distribution of benefits and responsibilities, and aims to eliminate disparities and disproportions that are rooted in historical and contemporary injustices and oppression. Unlike equality, which simply provides for equality of opportunity, equity explicitly recognizes and actively promotes measures to address historical and social disadvantages. Equity can also be defined as reaching parity within institutional policies, processes and procedures, and outcomes. The

goal is to attain a representational, resource-based, and mindfulness about equity while considering the impact of access, power, treatment, impact, opportunities, and outcomes. Equity is required to achieve equality.

Diversity
The actual lived experiences, viewpoints and perspectives, and the act of including individuals while being mindful of such considerations such as race, language, ethnicity, gender identity and expression, sex, sexual orientation, socio-economic status, age, disability, neurodivergence, physical appearance, religious beliefs, political beliefs or other ideologies, ancestry, culture, and geographic background.

Identity
The differing and distinct qualities and elements that individuals use to describe and represent themselves within a social context. Key aspects of identity may include sexuality, gender, sexual orientation, race, ethnicity, disability status, religion, beliefs, age, socioeconomic status, geographic location, hobbies, family structure, life experiences, etc.

Disability
Any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment – or a functional limitation – whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a individual's full and equal participation in society.

Indigeneity
This is a global expression that refers to the Original Peoples of a section of land. In Canada, Indigenous typically refers to people of First Nation, Inuit, and/or Métis descent, regardless of where they reside and whether their names appear on an official register. Indigenous groups have distinct histories, cultures, languages, and distinct traditional knowledge, perspectives, and worldviews. When collecting this data, providing options such as 'population group not listed', specify, 'don't know', 'prefer not to answer', and 'multiple/mixed' and a self-description fill-in response can help participants feel more comfortable.

Indigenous
This is an umbrella term for First Nations (status and non-status), Mètis, Inuit and Urban Indigenous Peoples. Researchers must be conscious and respectful of the diverse cultures, traditions, worldviews, languages, governance and value systems, using a distinctions-based approach to research, recognizing the unique differences across each of these groups. Furthermore, research proposals and research documents must recognize the distinction between the different Indigenous groups.

Barriers
Either obvious or subtle obstacle(s) that prevent or impose restrictions on individuals from accessing, using, or doing something that others can readily access, use, or do. Barriers can be either physical, economic, financial, informational, and/or organizational policies/practices.

Sex/Biological Sex
This is a medical term, defined by a set of anatomical and physiological characteristics and biological attributes in humans and animals, including chromosomes, gene expression, hormones, and reproductive or sexual anatomy. While sex is usually categorized as female or male, there is variation in the biological attributes that comprise sex and how those attributes appear.

Gender

The socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people. Gender influences how people perceive themselves and each other, how they act and interact, and the distribution of power and resources in society. Gender identity is not confined to a binary (girl/woman, boy/man) nor is it static; it exists along a continuum and can change over time. There is considerable diversity in how individuals and groups understand, experience and express gender through the roles they take on, the expectations placed on them, relations with others, and the complex ways that gender is institutionalized in society.

Race

A social construct, classifying people into different groups according to common physical characteristics, regardless of language, culture or nationality.

Ethnic and Cultural Origin

The ethnic or cultural origins of the individual's ancestors. Ethnic groups share common identity, heritage, ancestry, or historical past, often with identifiable cultural, linguistic, and/or religious characteristics.

2. RACE, ETHNICITY AND OTHER CONSIDERATIONS IN RESEARCH

TCPS2 Article 4.1 states that researchers shall not exclude individuals from the opportunity to participate in research on the basis of attributes such as culture, language, religion, race, disability, sexual orientation, ethnicity, linguistic proficiency, gender or age, unless there is a valid reason for the exclusion.

Researchers must give consideration for elements of diversity in their research and incorporate it into all aspects of the research process, such as designing the research documents, participant recruitment, inclusion and exclusion criteria considerations, data collection, analysis, storage, and sharing and publishing data outcomes.

Race and ethnicity are two separate representations and cannot be used interchangeably. Thus, researchers need to specify in their research what kind of data they are interested in collecting, and use the appropriate language.

When asking about racial origin or lineage, or what race a participant would identify as, consistent with the goals of the study, researchers may choose to include the options derived from the Statistics Canada website, as well as the Canadian Centre for Diversity and Inclusion.

Disabilities

These are often overlooked in the research setting in relation to individuals having adequate access to the research, and the research itself being accessible-friendly. Barriers can be anything – including physical, architectural, technological or attitudinal, that is based on information or communications or anything that is the result of a policy or a practice – that hinders the full and equal participation in society of persons with an impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment or a functional limitation.

Likewise, researchers must give consideration to cultural and geographic norms, and participant expectations and sensitivities. The collection of demographic information must keep in mind that additional data may lead to identifiability or re-identification of participants.
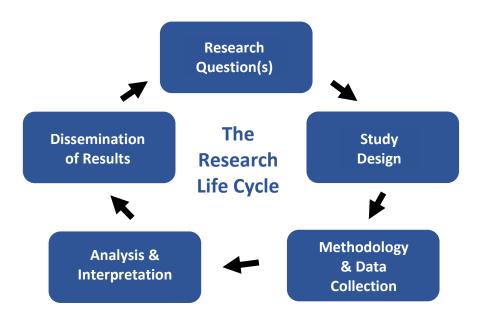
3. INDIGENOUS RESEARCH CONSIDERATIONS

When conducting research that involves Indigenous communities, and/or peoples, researchers must recognize the importance of Indigenous self-determination and self-governance, understand the barriers they face based on their identity, and design research in collaboration with the Indigenous community/individuals, and in ways that respect the governance, needs, and specific data-related practices and principles of the communities/individuals. Researchers also must follow Indigenous research ethics principles, and ensure Indigenous applications do not face systemic barriers in the peer review process.

Please consult the following resources when conducting research with Indigenous peoples and communities *(please note, this list is not exhaustive):*
1. CARE Principles for Indigenous Data governance: https://www.gida-global.org/care
2. TCPS2 – Chapter 9: Research Involving the First Nations, Inuit and Metis Peoples of Canada: https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html
3. The First Nations Principles of OCAP: https://fnigc.ca/ocap-training/
4. The First Nations Information Governance Centre (FNIGC). Fundamentals of OCAP®. https://fnigc.ca/ocap-training/take-the-course/
5. CIHR Defining Indigenous Health Research: https://cihr-irsc.gc.ca/e/50340.html
6. Gareau, P. L. Indigenous Canada: Online Course. *University of Alberta.* https://www.coursera.org/learn/indigenous-canada
7. Indigenous Knowledges & Data governance Protocol: https://indigenousinnovate.org/downloads/indigenous-knowledges-and-data-governance-protocol_may-2021.pdf
8. Inuit Qaujimajatuqangit Governance: https://www.gov.nu.ca/culture-and-heritage/information/inuit-qaujimajatuqangit

4. INCORPORATING EDI INTO THE RESEARCH LIFE CYCLE

The incorporation of EDI language and considerations must be evident in *all* stages of the life cycle of the research study, and there are numerous benefits to the wider community when EDI is carefully considered and integrated, such as:

- Introducing a wider application of findings, along with novel technologies, to a greater societal audience;
- Mitigating existing and new biases', along with challenging societal assumptions, norms and stereotypes;
- Equitable and fair benefits to communities impacted by the research;
- Reduction and prevention of overgeneralizing study findings, which can result in harm;
- Allowing for the opportunity of reproducibility of research findings and outcomes.

Researchers should ask themselves the following questions during all stages of their research:

- How do I be emotionally caring and compassionate? What can I put in place to support this?
- What supports can I put in place for participants who are retraumatized through the research?
- How do my lived experiences impact how I do research?

a. RESEARCH QUESTION(S) & FUNDING CONSIDERATIONS

The incorporation of EDI inclusion into a research study must begin with the research question, and long before applying for funding. Developing and focusing your research question(s) require careful consideration to any, and all, possibilities of how you can design your study within an EDI framework, demonstrating reflection and consideration of perceived and real barriers of groups who may experience underrepresentation and/or discrimination. Researchers must be cognizant and proactive in relation to the context of their research.

Many funding agencies that adjudicate research proposals within an EDI framework have specific requirements. Researchers should be careful to follow these and be prepared to communicate what they have already done during the initial study development stages to reflect EDI integration.

Researchers need to incorporate sufficient research funds into their research applications to address EDI-related factors where applicable, such as ensuring adequate financial reimbursement for participants who are required to travel farther in order to participate in the research.

b. STUDY DESIGN, AUTHORSHIP & STAFFING

Incorporating an EDI framework into the research design of a study, which will include research questions, methods, theoretical frameworks, literature reviews, analyses, and the interpretation and dissemination of findings, reveals complexities about the lived experiences and histories of different groups and individuals. Researchers need to ask themselves how their research design can be strengthened by considering diversity and identity factors such as, but not limited to, age, disability, education, ethnicity, gender expression and gender identity, immigrant and newcomer status, Indigenous identity, language, neurodiversity, parental status/responsibility, place of origin, race, religion, sexual orientation and socio-economic status.

While underrepresentation can have many implications as outlined above, researchers need to give equal consideration to the over-inclusion of vulnerable or disempowered groups. Disproportionate participation should be mitigated in accordance with TCPS2 Article 4.7, such as not putting undue burden of participation on particular groups, or the exclusion of certain groups.

Researchers must carefully consider their approach to the design of their research, such as gender-based analysis plus (GBA+), intersectionality and antiracist approaches. Researchers must be careful to consider who will be impacted (including unintended impacts) the most by their research, and base their research discipline, methodology and topic on this.

To promote EDI in research, it is highly suggested to include one to two paragraphs in the study methodology section on EDI considerations in the proposed research, on the similar lines as TRI-COUNCIL requirements on EDI consideration in the grant applications. This should also be reflected in the BREB applications and related protocols.

i) Authorship

When researchers are designing their study, authorship must be considered as part of the EDI conversation. The very beginning stages of research design should include the development of a predefined criteria for authorship within an EDI context.

ii) Staffing Considerations

The Principal Investigator(s) should recognize their role in embracing and reflecting diversity, along with capacity-building within their own research teams and collaborations. Just as researchers must be mindful about not excluding marginalized groups from participating in research, they must also strive for diversity within their own research teams and collaborations.

Collaboration on a research study is typically a necessary component of the research itself in health research, providing a crucial contribution towards the integrity of the research, and data analysis. These collaborations may consist of other researchers, advisors, patients or family members, third party entities, volunteers, etc. Incorporating representation of individuals with lived experience into what is being studied is another factor to consider in the development of the research team and the project. EDI principles and diversity of viewpoints/expertise must be considered in the identification of these individuals and the building of these relationships.

Equally important are the staff hired to work on the research study. Researchers must be mindful when hiring staff, ensuring they are making every effort to incorporate equity, diversity and inclusion principles into their recruitment and selection process.

For more guidance on this topic, please refer to the CIHR unconscious bias training module: https://www.chairs-chaires.gc.ca/program-programme/equity-equite/bias/module-eng.aspx

c. METHODOLOGY AND DATA COLLECTION

Collecting information about participant ethnicity, cultural origin, race, sex, gender, Indigeneity, etc., needs to be justified as to the relevance, explaining how it fits in with the research objectives (without excluding other groups/identities), as well as how, and where, the information is integral to the analysis. Researchers must adhere to the Core Principles outlined in the TCPS2 (Respect for Persons, Concern for Welfare, and Justice), while being conscious of collecting too much, or too little, demographic data.

i) Ethnic and Cultural origins

When collecting race and ethic demographic data, researchers need to be sensitive to the potential for stigmatization, and unequitable or unfair treatment. The focus needs to be on ***asking***, rather than presupposing the varying demographics of the participants, while giving consideration to the geographic and cultural norms and protocols. It is often helpful to explain to participants why you're asking specific demographic questions. It's also important to keep in mind the fluidity of socio-political and geographic contexts by offering checkboxes that allow for multiple responses, rather than requiring individuals to choose one option.

Please refer to the link below for suggested wording:

Statistics Canada, Ethnic or cultural origins: Technical report on changes for the 2021 Census: Appendix 2 – 2021 Census linked list of examples of ethnic and cultural origins
https://www12.statcan.gc.ca/census-recensement/2021/ref/98-20-0002/982000022020001-eng.cfm#a7

ii) Inclusive Language

It's important to keep in mind that research participation should be motivated by the inclusion and exclusion criteria of the context, objectives, and focus of the research.

Asking participants about their gender identity, researchers need to be careful when offering options in selecting gender, or gender identity. It is generally good practice to avoid using 'other' as an encapsulating term, as people may experience this category as 'othering' and underestimating the unique experiences of that person's demographic background on the research. Options such as 'I don't identify with any option provided,' 'something else' and 'I prefer not to answer' are good options for researchers to consider.

Suggested wording when asking about, or referring to, gender identity *(this list is non-exhaustive)***:**

a) Gender-fluid
b) Man
c) Nonbinary
d) Trans man
e) Trans woman
f) Two-Spirit
g) Woman
h) Humankind, not mankind
i) Staffing the office, not manning the office
j) Ancestors, not forefathers
k) Working hours, not man-hours
l) Artificial, synthetic or constructed, not man-made

Researchers are expected to use bias-free language within the research context, such as referring to participants by the name that they use in reference to themselves. The use of pseudonyms should be done respectfully and appropriately, avoiding the use of 'female' or 'male,' as the attribution of sex and/or gender, as the individual may be unknown. Using 'Mr' or 'Mrs' should generally be avoided if the researcher is not aware of the pronoun in which the participant wishes to be addressed. Asking the participant for their pronouns is encouraged, and viewed as a good practice generally;

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however, researchers must be mindful of creating barriers between the participant and research staff. They must also carefully consider the cultural, geographic, or linguistic contexts in this regard, and endeavor to use respectful and appropriate language relevant to their circumstances.

Likewise, when referring to an occupation where gendered terms are commonly used, it is recommended to use **non-gendered language**, such as using 'police officer,' or 'weather person.'

d. ANALYSIS AND INTERPRETATION/DISSEMINATION OF RESULTS

Researchers must give careful consideration to their analysis process, and *who* is doing the analysis. They must ask themselves the following questions:

- Does my analysis team always consist of the same gender and/or ethnicity? If so, how does this impact the analysis?
- Am I bringing a diverse approach to my analysis?
- Am I de-identifying, or not linking the master code list to my participants, prior to conducting analysis?

5. CONFIDENTIALITY

Researchers must give consideration to the anonymity, security and identifiability of collected data that contains race, Indigeneity, ethnic or cultural origins and/or any other attributing properties that may or may not pose a threat to participant safety or security. The consent process needs to include an explanation to participants how their data (especially identifiable data) will be protected, including retention, sharing, storage and destruction, and the technological and physical measures that will be taken to safeguard the data.

Researchers are being increasingly encouraged to make their data available through data repositories and other opportunities for re-use by others. Researchers must consider the data requirements of their funder and study parameters through the use of a robust data management plan that takes into account the confidentiality requirements of the data and participant populations they are working with.

Questions about data retention, sharing, and re-use can be directed to the Bruyère REB: REB@bruyere.org and the Office of Research Services: briirb@bruyere.org

Additional information can be found here:

- Tri-Agency Research Data Management Policy https://science.gc.ca/site/science/en/interagency-research-funding/policies-and-guidelines/research-data-management/tri-agency-research-data-management-policy

- Bruyère Research Data Management Strategy Bruyère - Research Data Management (bruyere.org)

Bruyère

1. Accessible Canada Act/Justice
   https://accessibilitycanada.ca/aoda/definitions/#:~:text=For%20people%20with%20disabilities%2C%20barriers,movements%2C%20senses%2C%20or%20activities

2. Bruyère Mission, Vision and Values
   https://www.bruyere.org/en/mission-vision-values

3. Canadian Centre for Diversity and Inclusion
   https://ccdi.ca/

4. Canadian Institutes of Health Research. Research Involving First Nations, Inuit and Métis Peoples of Canada webinar
   https://na1se.voxco.com/SE/?st=10PfBH%2fDtvG2UCCsjH7WKUsVljYzaEv6Bj6WcCIBIcc%3d

5. CARE Principles https://www.gida-global.org/care

6. CIHR Diversity and Inclusion Training: Online Course
   https://www.chairs-chaires.gc.ca/program-programme/equity-equite/bias/module-eng.aspx

7. CIHR: What is Gender? What is Sex?
   https://cihr-irsc.gc.ca/e/48642.html

8. CIHR Defining Indigenous Health Research
   https://cihr-irsc.gc.ca/e/50340.html

9. Gareau, P. L. Indigenous Canada: Online Course. *University of Alberta.* https://www.coursera.org/learn/indigenous-canada

10. Indigenous Knowledges & Data governance Protocol https://indigenousinnovate.org/downloads/indigenous-knowledges-and-data-governance-protocol_may-2021.pdf

11. Inuit Qaujimajatuqangit Governance
    https://www.gov.nu.ca/culture-and-heritage/information/inuit-qaujimajatuqangit

12. NSERC guide on integrating equity, diversity and Inclusion Considerations in Research
    https://www.nserc-crsng.gc.ca/NSERC-CRSNG/Policies-Politiques/EDI_guidance-Conseils_EDI_eng.asp#a5

13. Ontario Human Rights Commission. Call it out: racism, racial discrimination and human rights: Online Course.
    https://www.ohrc.on.ca/en/learning/elearning/call-it-out
    Glossary: https://www.ontario.ca/document/data-standards-identification-and-monitoring-systemic-racism/glossary

14. Ontario Standards for Participant Observer Information (POI) of Race
    https://www.ontario.ca/document/data-standards-identification-and-monitoring-systemic-racism/standards-participant-observer-information-poi-race

15. Race-based and Indigenous identity data

https://www.cihi.ca/en/race-based-and-indigenous-identity-data

16. Statistics Canada Website (2021)
    https://www12.statcan.gc.ca/census-recensement/2021/ref/98-20-0002/982000022020001-eng.cfm#a7

17. Stats Canada
    https://www12.statcan.gc.ca/census-recensement/2021/ref/98-20-0002/982000022020001-eng.cfm#a7

18. TCPS2 – Chapter 4: Fairness and Equity in Research Participation
    https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter4-chapitre4.html

19. TCPS2 – Chapter 9: Research Involving the First Nations, Inuit and Metis Peoples of Canada
    https://ethics.gc.ca/eng/tcps2-eptc2_2018_chapter9-chapitre9.html#a

20. The First Nations Principles of OCAP
    https://fnigc.ca/ocap-training/

21. The First Nations Information Governance Centre (FNIGC). Fundamentals of OCAP® https://fnigc.ca/ocap-training/take-the-course/

22. Tri-Agency Research Data Management Policy
    https://science.gc.ca/site/science/en/interagency-research-funding/policies-and-guidelines/research-data-management/tri-agency-research-data-management-policy

23. USAI Research Framework
    https://ofifc.org

24. Queens University. Indigenous Community Research Partnerships: Online Course.
    https://www.queensu.ca/indigenous/decolonizing-and-indigenizing/community-research-partnerships-training

25. Queens University. Inclusive Language
    http://www.queensu.ca/brand-central/writing-style/inclusive#:~:text=Inclusive%20language%20respects%20and%20promotes,or%20less%20valued%20than%20others