

## Ensuring Participant Inclusivity in Research | Social, Cultural, and Linguistic Diversity

Research ethics applications include questions about inclusion and exclusion criteria in order to ensure that particular individuals, groups or communities are neither unfairly included nor excluded from opportunities to benefit from research. Quite often, because of how inclusion criteria are framed or the terms used in research plans and supporting documents, some groups may be inadvertently excluded or discouraged from participating. The [TCPS 2](#) 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.” ([Article 4.1](#)) This document is designed to expand on the principles stated in the TCPS2 in the context of ethnicity, culture, ancestry, and membership in a racialized community. A separate document on inclusivity in the context of [gender, sex and sexual orientation](#) is also available.

While the Behavioural Research Ethics Board (BREB) considers the principles of inclusion during the review of research ethics applications, it does not typically prescribe language usage. The BREB reviews research descriptions in the context of the research being proposed. Research that focusses on a particular participant group should use language that is most appropriate for that group.

Researchers are encouraged to educate themselves on community standards and cultural practices in order to ensure that they do not exclude or stigmatize particular groups: either due to their methods of engagement or as a result of the language they use (e.g., how eligible participants are described in recruitment materials).

### ***Know your terms***

There is considerable discussion about categories and terms that designate social, cultural, and linguistic diversity. The BREB encourages researchers to do their own reading to deepen their understanding about how best to apply the terms and concepts in their research. For a discussion of terms, see the BREB [Glossary of Common Terms –Ethnicity](#).

### ***When should researchers be thinking about equity, diversity and inclusion?***

Diversity and inclusion should be considered when researchers are designing their research and confirming its scope. The following considerations may help in your planning and follow through:

**a. Study aims and participant selection.** Researchers should be able to explain, in relation to their research questions and specific field of research: why they chose the proposed study population; the relevance of demographic characteristics being selected; what community consultations occurred; and how the participant sample reflects the population of interest. Researchers should also account for geographic and cultural norms and the expectations and sensitivities of the involved participants. (*Box 5.1.B of the Ethics Application, if not included in the study proposal attached to Box 9.1*)

**b. Criteria for inclusion and exclusion.** Researchers will need to justify any exclusions based on scientific, ethical or safety concerns. When necessary, you should develop alternative approaches to minimizing risk that do not result in excluding a diverse participant sample. Excluding a population for convenience or financial reasons, for example, requiring that participants speak fluent English

to avoid the need for interpreters or translated documents, is generally not accepted. (*Boxes 5.2 and 5.3 of the Ethics Application*)

**c. Identifiability.** Consider how your methods for collecting demographic information can increase the identifiability of data (additional data points may result in reidentification). For example, if you are asking a small group of participants to identify both their ethnicity and gender, consider whether including ethnicity data will increase the chances of participants being made identifiable in your findings and reports. (*Boxes 4.5.B and 6.2 of the Ethics Application*)

**d. Recruitment Methods.** Design your recruitment methods to attract a diverse and balanced study population. For example, if participants are meant to be between the ages of 18-25 but the research team is only recruiting through university student organizations, the research population will not be representative of that age range in the general population. (*Box 5.4 of the Ethics Application*)

**e. Study Accommodation.** Ensure that study procedures are flexible and designed to accommodate the needs of participants. This could include, for example, ensuring that the technology required does not exclude participants based on their economic resources, that the research sites are accessible, that any participant's needs for infectious disease protocols have been addressed, and that research documentation is provided in plain language. The BREB generally recommends using a Grade 7 (age 12) Level as a benchmark. Asking a non-academic family member or friend to critique your participant documents is a good test of whether they are written to an appropriate level and are free of jargon. (*Box 6.10 of the Ethics Application*)

**f. Study Conduct.** Ensure research staff who will engage with participants are trained to work respectfully with diverse populations. Provide appropriate cultural supports for participants based on advice from the community or knowledge holders. Where warranted, translate key participant documents into the languages spoken by the research population. If feasible, offer interpretation services as needed. (*Boxes 6.2 and 6.10 of the Ethics Application*)

**g. Participant Compensation.** Although many behavioural studies are unfunded, researchers should - at a minimum - ensure that participants are not carrying any financial costs for their participation. Compensation should be adequate to cover actual costs (such as for travel or daycare). Where financial compensation is not possible, consult with members of the participant community about what types of non-financial compensation or recognition would be appropriate. (*Box 6.5 of the Ethics Application*)

**h. Recruitment goals in the context of continuing review.** When completing their annual renewals, researchers should review their goals for achieving diversity in their study population. If they are not on track, they should consider whether corrective action is needed.

### ***Collecting Data on Diversity: Ethnicity, Ancestry, and Membership in Racialized Communities***

The demographic categories used in studies should be relevant to the goals of the research. Studies concerned with the social relationships of participants should refer to ethnicity or an individual's ethnic, cultural, linguistic, and/or religious affiliations. Ancestry (the study of the biological relatedness of individuals based on either genealogical documentation or genetic testing) should be distinguished from ethnicity.

"Race" is an ambiguous and antiquated term for social classification and is not appropriate as a demographic category for scholarly research. While it is used in popular discourse and some

bureaucratic settings to differentiate people based principally on physical traits and skin colour, it is not based on science or biology. In public discourse, it creates societal distinctions, with consequences on people's lives and livelihoods. It can obscure demographically relevant distinctions of biological ancestry, and cultural and social affiliation.<sup>1</sup>

The BREB requires clarification in the inclusion criteria (Boxes 5.2 and 5.3) if specific social or cultural identities will be included/excluded. The rationale for the inclusion/exclusion must also be provided. Review your terms for potentially exclusionary language or assumptions about ethnicity, ancestry, or membership in a racialized community. Researchers who study the effects of membership in a (socially constructed) racialized group will need to justify the terms being used in their ethics application.

Questions about ethnicity or cultural affiliation should be framed in the context of the research population and research goals. As an example, do not use "First Nations" as short-hand for all Indigenous, Métis and Inuit populations. Although the BREB recommends – as a starting point – the terminology used by Statistics Canada, it may not be appropriate for some research. In most cases, you should be able to find a recent public source for the term/s used by the community being referred to. If you are using categories borrowed from other survey instruments, consider the extent to which those categories align with the identities of the population you are studying; for example, do not use "African-American" if you are only surveying Canadian residents. Where feasible, you may want to enable participants to self-identify using their own chosen terminology by providing a mixture of standard categories and open-ended questions about ethnicity.

### ***Research with First Nations, Inuit and Métis populations***

The terminology for identifying Indigenous people and communities has evolved, with some terms being rooted in governmental policy (First Nations, Métis, Inuit, Aboriginal, Status Indian) and other terms originating in Indigenous communities (for example, Indigenous, native, and the names of specific nations). The language commonly used in a specific Indigenous community may be different from what is used in government statistics or academic literature. The terms used by social groups within a community may also differ; for instance, terms used by youth may differ from those used by older generations. For further discussion, and if you are intending to work with Indigenous communities, please review TCPS 2 [Chapter 9](#) – Research Involving the First Nations, Inuit and Métis Peoples of Canada.

Researchers engaging with Indigenous communities also need to educate themselves about the distinct governance structures within the community; this will help to ensure that their outreach and collaboration is happening in a respectful manner and through appropriate channels. See Complex Authority Structures, [Article 9.5](#).

Please note that in community-based research, considerable preliminary relationship building work is often needed before recruitment methods can be finalized and potential participants approached. This preparatory outreach activity does not require research ethics approval; it should result in clear procedures and materials for recruitment and consent and these will need to be attached to the ethics application before submitting for review.

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<sup>1</sup> Carleton University Research Ethics Guidelines on the use of race and ethnicity in demographics:  
<https://carleton.ca/researchethics/wp-content/uploads/Research-Ethics-Guidelines-on-the-use-of-Race-and-Ethnicity-in-Demographics.pdf>

### ***Recommendations for designing demographic questions***

Researchers should know the reasons why self-reported ethnicity or ancestry data needs to be collected for their study and how they will be used, so that the demographic questions asked will be relevant to the study purpose. Researchers may need to collect data about ethnicity, ancestry, or membership in a racialized community for a variety of reasons. They may be investigating the social affiliations of people in particular geographical locations. They may be looking for social factors, such as self-reported ethnicity or cultural affiliation to identify patterns in access to services or discrimination in other contexts. Biological background may be valuable in understanding risk for disease, prognosis of disease, or responses to therapy based on disease. Given the underlying complexity of self-reported ethnicity terminology and given the various different reasons for which researchers might want to collect demographic data about social and cultural diversity, UBC BREBs recommend using the following categories:

- Social Affiliation (Ethnicity)
- Biological Relatedness (Ancestry)
- Racialized discrimination (Racialized Group Membership)

**Ethnicity** is a form of relatedness based on a person's social or cultural affiliations, connecting them to contemporaries as well as to ancestors. Individuals may have multiple ethnic affiliations. The ethnic identity a person presents or acknowledges may be affected by social context and by the audience that may accept or reject those claims.<sup>2</sup> Data related to ethnicity can be captured by questions such as, "What social, cultural or ethnic identities do you have?"

**Ancestry** can be genealogical, based on an individual's knowledge of their family history, and genetic, based on the results of genetic testing.<sup>3</sup> These data can be captured by questions such as, "Where are your ancestors (i.e., parents, grandparents, etc.) from?" or by accessing commercially-available genetic testing results.

**Racialized group membership** describes groups that have been affected by social, economic, and political policies and practices of racism. This term is preferred over "race" to describe this group because it acknowledges the process of racialization.<sup>4</sup> Race may be used as a category if the study is examining official policies and programs that define groups in these terms.

### ***Additional recommendations for developing research questions***

1. Consult with the participant communities before constructing your demographic survey.
2. Do not ask for demographic data that is not needed for your analysis.
3. Provide an explanation to participants of why demographic data are being collected and allow their collection to be optional whenever possible. Specify what will be collected and explain how it will be used in analysis. This information can be included in the consent form (suggested wording: "We will be asking some questions about your family background in order to...") and in the survey itself (suggested wording: "Ethnic origin data will be used to...").

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<sup>2</sup> Barth 1969.

<sup>3</sup> Arsdale 2019; Benn Torres 2020; National Academies of Sciences 2023; Stanbrook and Salami 2023.

<sup>4</sup> Gans 2017

4. Offer multiple/alternate options when collecting demographic data, for example: “prefer not to answer”; “population group not listed”; “don’t know.” Provide additional space for respondents to add details relevant to them.
5. Use language that is most appropriate for the particular participant group. If you are in doubt, consult with the participant communities before constructing your demographic survey.
6. Even if you are using standard instruments for your research, ensure that your demographic questions are specifically relevant to your research and to your research population. Since ethnic identity may involve a number of attributes (language, place, etc.), where possible, ask specifically for those that are most relevant to your research. In other words, only ask for the information you intend to use.
7. If participants may be excluded due to questions about ethnicity or languages spoken, explain this up front and place any “excluding” questions at the beginning of your survey. It is frustrating for participants to be “bumped” out of a survey after they have spent time answering the questions because their demographic group is over-represented. (The Research Participant Complaint Line has received calls from survey takers who believed they were bumped from receiving compensation after completing a survey, because the last questions in the survey identified them as being of the “wrong” ethnicity.)

***Recommended format for ethnic origin questions***

Q. What is your cultural background? Choose all that apply.

- African
- European
- East Asian<sup>5</sup>
- South Asian<sup>6</sup>
- South East Asian<sup>7</sup>
- First Nations or Indigenous (please specify) \_\_\_\_\_
- Hispanic or Latina/Latino<sup>8</sup>
- Middle Eastern<sup>9</sup>
- Other (please specify) \_\_\_\_\_
- Prefer not to answer

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<sup>5</sup> China, Mongolia, North Korea, South Korea, Japan, Hong Kong, Taiwan, Macau. [www.worldatlas.com](http://www.worldatlas.com)

<sup>6</sup> Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Sri Lanka ([wikipedia.org](http://wikipedia.org))

<sup>7</sup> Brunei, Burma (Myanmar), Cambodia, Timor-Leste, Indonesia, Laos, Malaysia, the Philippines, Singapore, Thailand, Vietnam (<https://www.niu.edu/cseas/resources/countries.shtml>)

<sup>8</sup> Canadian census 2016 used “Latin, Central and South American,” which includes Hispanic: [https://www12.statcan.gc.ca/census-recensement/2016/ref/dict/app-ann/a5\\_1-eng.cfm](https://www12.statcan.gc.ca/census-recensement/2016/ref/dict/app-ann/a5_1-eng.cfm). “Latinx” has been selectively adopted as a gender-neutral term but is not widely recognized or used outside academia.

<sup>9</sup> Ibid. Used “West Central Asian and Middle Eastern.”



Q. What is your ancestral lineage?<sup>10</sup> Where are your ancestors from? Check all that apply.

- Central Asia (please specify) \_\_\_\_\_
- South Asia (please specify) \_\_\_\_\_
- Africa (please specify) \_\_\_\_\_
- Europe (please specify) \_\_\_\_\_
- South or Central America (please specify) \_\_\_\_\_
- Indigenous (please specify) \_\_\_\_\_
- Pacific Islander
- Don't know
- Prefer not to answer
- Other \_\_\_\_\_

Be consistent in how the inclusion criteria are described in recruitment and consent materials as well as in demographic data collection tool/materials.

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### Resources

Indigenous Peoples: Language Guidelines (2018 Version 2.0)

[https://assets.brand.ubc.ca/downloads/ubc\\_indigenous\\_peoples\\_language\\_guide.pdf](https://assets.brand.ubc.ca/downloads/ubc_indigenous_peoples_language_guide.pdf)

Statistics Canada. [Ethnic Origin Reference Guide](#), Census of Population, 2016

Arsdale, Adam P. Van. 2019. "Population Demography, Ancestry, and the Biological Concept of Race." *Annual Review of Anthropology* 48 (1):227-241. doi: 10.1146/annurev-anthro-102218-011154.

Barth, F. 1969. "Introduction." In *Ethnic Groups and Boundaries*, edited by F. Barth. Oslo: Universitetsforlaget.

Benn Torres, Jada. 2020. "Anthropological Perspectives on Genomic Data, Genetic Ancestry, and Race." *American Journal of Physical Anthropology* 171:74-86.

Gans, Herbert J. 2017. "Racialization and Racialization Research." *Ethnic and Racial Studies* 40 (3):341-352. doi: 10.1080/01419870.2017.1238497.

National Academies of Sciences, Engineering, and Medicine. 2023. *Using Population Descriptors in Genetics and Genomics Research: A New Framework for an Evolving Field*. Washington, DC: The National Academies Press.

Stanbrook, Matthew B., and Bukola Salami. 2023. "Cmaj's New Guidance on the Reporting of Race and Ethnicity in Research Articles." *Canadian Medical Association Journal* 195 (6):E236-E238. doi: 10.1503/cmaj.230144.

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<sup>10</sup> Use this question only if your research is studying biological factors. If you are screening for a specific ancestral origin, explain the purpose of asking this question.