

Participant inclusivity in research | Ethnicity and race¹

The TCPS 2 (2018) 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](#)) All these categories may be intertwined; intersecting social categories often can and should work together in research. For example, the recent introduction of the term “Latinx” to replace “Latina” and “Latino” arose out of a desire to create a gender-neutral term to refer to Latin American cultural and ethnic identities.

This document is designed to expand on the principles stated in the TCPS2 in the context of ethnicity, race and culture. 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 a lot of rich discussion of these terms, as well as multiple definitions and thoughts on how they should be applied. While offering the definitions below, 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.

Ethnicity. As stated in the Statistics Canada reference guide: “Ethnic origin refers to a person's ‘roots’ and should not be confused with citizenship, nationality, language or place of birth. For example, a person who has Canadian citizenship, speaks Punjabi (Panjabi) and was born in the United States may report Guyanese ethnic origin.”²

See also the [Statistics Canada](#) page that records out-of-date standards (statcan.gc.ca/eng/concepts/definitions/previous/preethnicity).

Race. “The idea that the human species is divided into distinct groups on the basis of inherited physical and behavioral differences.” <https://www.britannica.com/topic/race-human>. See also <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3057432/>.

¹ The BREB would like to thank Dr. Sarah Hunt for her generous contributions to this guidance.

² Ethnic Origin Reference Guide, Census of Population, 2016. <https://www12.statcan.gc.ca/census-recensement/2016/ref/guides/008/98-500-x2016008-eng.cfm>

Racialize. The process of attributing “racial meaning to people’s identity and, in particular, as they relate to social structures and institutional systems, such as housing, employment, and education.” This process results in a racialized group or individual. (Yee, J. (2008). Racialization. In R. T. Schaefer (Ed.), *Encyclopedia of race, ethnicity, and society* (Vol. 1, pp. 1111-1111). Thousand Oaks, CA: SAGE Publications, Inc.
<https://sk.sagepub.com/reference/ethnicity/n455.xml>.

Collecting data on ethnicity and race

Categories of ethnicity and race are often used to separate non-white people from the “norm” (i.e. populations of western European origin), so it is important for researchers to consider if they are asking all participants to identify their ethnicity/racial background, or if they are only providing options for those who are racialized.

Researchers who study race as a relevant (socially constructed) factor in accounting for exposure to racism and other determinants of inequity will need to ensure that the terms being used are justified in their ethics application.

The BREB requires clarification in the inclusion criteria (Box 5.2) if specific cultural identities will be included/excluded and the rationale for the inclusion/exclusion must also be provided. Review your terms for potentially exclusionary language or assumptions about ethnicity.

Although the BREB recommends – as a starting point – the terminology used by Statistics Canada, it may not be appropriate for some research. Questions about ethnicity or cultural origins should be framed in the context of the research population and the research goals. As examples, do not use “First Nations” as short-hand for all Indigenous, Métis and Inuit populations. Similarly, do not use “African-American” if you are only surveying Canadian residents. In most cases, you should be able to find a 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. Where feasible, you may want to provide opportunities for 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 (e.g. 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 [Module 9](#) Research Involving the First Nations, Inuit and Métis Peoples of Canada.

Researchers engaging with Indigenous communities also need to be informed of 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. As noted in the TCPS 2, Module 9:

Every community has its own authority structure. Some authority structures are more complex than others, involving formal and informal mechanisms within communities to guide decision-making. Within a single community there may be an elected leadership body, respected elders, advisory bodies and specialized knowledge-keepers.

Please note that, in community-based research, considerable preliminary outreach work may be needed before participants can be identified and contacted. This outreach activity does not require research ethics approval; it should result in clear processes and materials for recruitment and consent that will need to be attached to the ethics application for review.

Recommendations for designing demographic questions

1. Do not unintentionally conflate “race” with “ethnicity.” The term “race” is still often misapplied to refer to ethnic or cultural identity; but it can be appropriate in some circumstances, for example, when researchers are studying the social construct of race as a factor in health care access.
2. If you are in doubt about the appropriate terms, consult with the participant communities before constructing your demographic survey.
3. Depending on the level of sensitivity around questions of ethnicity and/or cultural identity, include an explanation of why the question is being asked, either in the consent form (“we will be asking some questions about your family background in order to...”) or in the survey itself (“Ethnic origin data will be used to...”).
4. Offer a “prefer not to answer” option.
5. Even if you are using standard instruments for your research (e.g., HHS survey tool), 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.
6. If participants may be excluded due to demographic questions about ethnicity or languages spoken, explain this up front and place “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 question format | ethnic origin

- Q. What is your cultural background? Choose all that apply.
- African
 - European
 - East Asian³

³ China, Mongolia, North Korea, South Korea, Japan, Hong Kong, Taiwan, Macau. www.worldatlas.com



- South Asian⁴
- South East Asian⁵
- First Nations or Indigenous (please specify) _____
- Hispanic or Latinx⁶
- Middle Eastern⁷
- Other (please specify) _____
- Prefer not to answer

Q. What is your racial origin/lineage?* What race would you identify yourself as? Check all that apply.

- Asian
- Black
- Caucasian
- Hispanic
- Indigenous⁸ (please specify) _____
- Pacific Islander
- Don't know
- Prefer not to answer

* Use this question only if your research is studying biological racial factors. If you are screening for a specific racial origin, the BREB recommends that you explain the purpose of asking this question.

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

(see: <https://blogs.scientificamerican.com/voices/what-role-should-race-play-in-medicine/>)

Resources

Indigenous Peoples: Language Guidelines (2018 Version 2.0)

https://assets.brand.ubc.ca/downloads/ubc_indigenous_peoples_language_guide.pdf

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

⁴ Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Sri Lanka ([wikipedia.org](https://en.wikipedia.org))

⁵ Brunei, Burma (Myanmar), Cambodia, Timor-Leste, Indonesia, Laos, Malaysia, the Philippines, Singapore, Thailand, Vietnam (<https://www.niu.edu/cseas/resources/countries.shtml>)

⁶ 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.

⁷ Ibid. Used "West Central Asian and Middle Eastern."

⁸ TCPS 2 Chapter 9 continues to use the generic term "Aboriginal" to designate First Nations, Inuit and Métis.