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PCGL Reference Survey for Participant Sociodemographic Data

Version 1.0 | April 07, 2025

Corresponds to *PCGL Data Dictionary* version 1.0_2025-05-05

Corresponds to *PCGL Guidance Document for Participant Sociodemographic Data* version 1.0

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Revision History

This section/table is necessary for most documents in order to track who has been modifying it, how, and when. This is a living document that will be reviewed and modified in time. The revision history is available below.

Date (YYYY-MM-DD)	Version	Description	Author
2025-03-31	0.1	Created draft with initial content	Alexander Chan
2025-04-05	0.2	Revised content to incorporate suggestions from: Justin Pelletier, Taila Hartley, Arian Omeranovic, Mouna Ben Amor, Kimberly Begley, Ma'n Zawati, Yann Joly, Hermann Nabi, Yvonne Bombard, Guillaume Bourque.	Alexander Chan Amirah-Iman Hicks Claude Bhérer
2025-04-07	1.0	Finalized content, draft ready for publication	Alexander Chan Amirah-Iman Hicks Claude Bhérer

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PCGL Reference Survey for Participant Sociodemographic Data

Version 1.0, Released: 07 April 2025

Corresponds to *PCGL Data Dictionary* version 1.0_2025-05-05

Corresponds to *PCGL Guidance Document for Participant Sociodemographic Data* version 1.0

As part of its commitment to equity in genomics, the Pan-Canadian Genome Library (PCGL) is developing standards for collecting, depositing, and sharing individual-level sociodemographic data to support data harmonization and reproducible research on social determinants of health in Canada. This survey represents an integral part of these efforts, introducing a Pan-Canadian standard for harmonized sociodemographic data collection and reporting in alignment with Canadian and international guidelines (as outlined in the sections below). Importantly, this work reflects the 2021 resolution adopted by the 74th World Health Assembly (WHA74.16), which encourages Member States to integrate social determinants of health into public policies and programmes[1].

I. REFERENCE SURVEY METHOD DEVELOPMENT

The PCGL developed this survey to provide guidance for studies on how to collect information on eight key sociodemographic variables defined by the Canadian Institute for Health Information (CIHI): age, race, ethnicity, gender, sex assigned at birth, education, income, and geographic location[2–4]. These variables allow researchers to divide data into population subgroups based on known social determinants of health, which influence a person's overall health, access to care, and health outcomes throughout their life. We propose questions and response options to collect information on these sociodemographic variables, which are considered "required" variables in the PCGL. In addition, we recommend studies consider adding questions to collect information on religion, disability status, sexual orientation, and housing accommodations when relevant. We propose questions and permissible response options for these optional variables.

The questions and response options were developed with reference to existing Canadian standards (including CIHI and Statistics Canada) and informed by international frameworks outlined within the National Academies of Science, Engineering, and Medicine *Rethinking Race and Ethnicity in Biomedical Research* foundational report[5], the *All of Us* Research Program[6], and the UK Biobank[7].

II. INTENDED USE

We share this survey for prospective studies to use as a reference. Studies interested in depositing their data into the PCGL are strongly encouraged to retain questions and response options as defined here.

These response options allow harmonization and reproducibility across studies and map to corresponding reporting categories in the PCGL data dictionary version 1.0. The PCGL may change some of these questions and response options in the future; however, they are valid as of April 07, 2025. If changes are to occur, the PCGL will share mapping to version 1.0 (this version) of the reference survey and the equivalent PCGL data dictionary. Similarly, projects that alter the PCGL provided reference questions and response options are responsible for ensuring harmonization to PCGL standards and should provide mapping to the appropriate PCGL-developed standards.

We encourage projects to employ multiple mediums when conducting this survey to minimize barriers related to survey collections and ensure universal accessibility. These mediums include sign-language interpretation, voice-to-text, audio versions of the survey, and large text versions.

Any questions can be directed to Amirah-Iman Hicks (amirah-iman.hicks@mcgill.ca), PCGL Equity, Diversity, and Inclusion advisor.

III. TEMPLATE PREAMBLE

This preamble is intended to inform study participants why their sociodemographic information is collected. Where necessary, this text may be adapted by prospective studies. Nevertheless, the key element of the following text is to explain why the data is being collected and that there are no right or wrong answers.

This survey gathers information on eight key sociodemographic variables defined by the Canadian Institute for Health Information (CIHI): age, race, ethnicity, gender, sex assigned at birth, education, income, and geographic location. These variables, also known as social determinants of health, influence a person's overall health, access to care, and health outcomes throughout their life.

To support this work, this survey asks about you: your background, your lived experiences, and your current situation. Your responses will help us understand the sociodemographic makeup of participants in Canadian genomic research. Collecting this information alongside your genetic data ensures that future discoveries in genetics research will benefit all Canadians equitably, helping researchers understand why some groups may be more affected by certain diseases or respond differently to certain treatments.

This survey will take about 10-15 minutes to complete. While there are no right or wrong answers to these questions, we ask that you respond honestly to as many questions as possible. We are interested in your personal experiences and perspectives. If you are unsure how to answer a question, please choose the option that most accurately reflects your life and lived experiences.

BEFORE YOU BEGIN!

These questions are meant to be answered by you. A parent or legal guardian should complete this survey for you if you are under the age of majority (at the time of survey completion).

The first 10 questions ask about your background information.

Q1. [REQUIRED] What is today's date (YYYY/MM/DD)?

				/			/		

Q2. [REQUIRED] What is your year and month of birth (YYYY/MM)?

				/		

Q3. [REQUIRED] In our society, people are often described based on race or racial background. There is no scientifically supported biological basis for discrete racial groups. Rather, race is a sociopolitical construct based on perceived differences in physical appearance. This influences the way we are treated by individuals and institutions and may affect our health.

With this in mind, which category(ies) best describes you? Select all that apply:

☐ Black
☐ East Asian
☐ Indigenous (First Nations, Inuk/Inuit, Métis)
☐ Latin American
☐ Middle Eastern or North African
☐ South Asian
☐ Southeast Asian
☐ White
☐ Do not know
☐ Prefer not to answer
☐ None of these fully describe me (i.e., another race/racial category)
  Branching Logic: when "None of these fully describe me" selected, then:

　　Please specify:
　　(display optional free text)

Q4. [REQUIRED] Ethnic or cultural origin refers to the multi-dimensional concept of community belonging and a shared cultural group membership. It can include language, religion, country of origin, nationality, cultural traditions, and migration history of a person's ancestors (biological parents, grandparents, etc.). For examples of ethnic or cultural origins, visit Statistics Canada's Examples of ethnic or cultural origins web page.

What were the ethnic or cultural origins of your ancestors? Specify as many origins as applicable using capital letters:

[*Display free text*]

Or,

☐ Do not know
☐ Prefer not to answer

Q5. [OPTIONAL] Religion refers to a person's connection or affiliation with any religiously defined community, denomination, or system of belief. Religion is not limited to formal membership in a religious organization or group. For examples of denominations and religions, visit Statistic Canada's Examples of religions and religious groups / denominations web page.

What is your religion, if any? You may include a religion you feel reflects your identity or background even if you are not currently a practising member of that group.

[*Display free text*]

Or,

☐ No religion
☐ Do not know
☐ Prefer not to answer

Q6. [REQUIRED] Gender refers to the socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people. A person's gender may be the same as or different from their assigned sex at birth and may change over time.

Which category best expresses how you currently describe your gender identity?

☐ Man
☐ Woman
☐ Another Gender
Branching Logic: when "Another Gender" selected, then:

> **Please specify:** (*for example, Non-binary, Two-spirit, Trans, etc.*)
> *(display optional free text)*

☐ Prefer not to answer
☐ Not applicable
*Response option provided when the question of gender is not appropriate to ask (e.g., newborn studies). This response option should **NOT** be provided to adult participants.*

Q7. [OPTIONAL] Do you self-identify as a person of minority sexual orientation or gender identity (2SLGBTQIA+)?

☐ Yes
☐ No
☐ Prefer not to answer

Q8. [REQUIRED] What was your biological sex assigned at birth?

☐ Male
☐ Female
☐ Intersex
☐ None of these describe me
Branching Logic: when "None of these describe me" selected, then:

> **Please specify:**
> *(display optional free text; can include clinician comments if relevant)*

☐ Prefer not to answer

Q9. [OPTIONAL] Do you self-identify as a person with a disability (significant or persistent physical, mental, sensory, psychiatric or learning impairment)?

- [ ] Yes
- [ ] No
- [ ] Prefer not to answer

Q10. [REQUIRED] What is the highest level of schooling you attained? Include qualifications obtained in Canada or outside Canada.

- [ ] No formal education
- [ ] Elementary school or equivalent
- [ ] High school (secondary school) diploma or equivalency certificate (for example, General Education Development, or Adult Basic Education)
- [ ] Certificate of Apprenticeship, Certificate of Qualification (Journeyperson's designation), or other trades certificate or diploma (for example, hairstyling, cooking, electrician, carpentry)
- [ ] College, CEGEP, or other non-university certificate or diploma (for example, accounting technology, industrial engineering technology, legal assistant)
- [ ] Bachelor's degree (for example, B.A., B.A.(Hons.), B.Sc., B.Ed., LL.B.)
- [ ] Degree in medicine, dentistry, veterinary medicine or optometry (M.D., D.D.S., D.M.D., D.V.M., O.D.)
- [ ] Master's degree (for example, M.A., M.Sc., M.Ed., M.B.A.)
- [ ] Doctoral degree (for example, Ph.D.)
- [ ] Post-doctoral fellowship or training
- [ ] Prefer not to answer
- [ ] Not applicable

The next 6 questions are about your employment status, income, and place of residence.

Q11. [REQUIRED] What is your current personal income from all sources *after* taxes last year?

- ☐ Less than $15,000
- ☐ $ 15,000 - $ 19,999
- ☐ $ 20,000 - $ 29,000
- ☐ $ 30,000 - $ 49,999
- ☐ $ 50,000 - $ 69,999
- ☐ $ 70,000 - $ 84,999
- ☐ $ 85,000 - $ 99,999
- ☐ $ 100,000 - $ 124,999
- ☐ $ 125,000 - $ 149,999
- ☐ $ 150,000 or more
- ☐ Prefer not to answer
- ☐ Not applicable

Q12. [OPTIONAL] What is your current employment status? Please select 1 or more of these categories.

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Self-employed
- ☐ Parental leave of absence
- ☐ Out of work for 1 year or more
- ☐ Out of work for less than 1 year
- ☐ Looking after home and/or family
- ☐ A student
- ☐ Retired
- ☐ Unable to work (for example, because of sickness or disability)
- ☐ Prefer not to answer
- ☐ Not applicable

Q13. [REQUIRED] What is your current address of residence?

While your postal code is the main information we use, we also ask for your city, and province/territory to help clarify your address in certain instances where postal codes may be less specific – for example, institutional residences, First Nations lands, and Inuit land claim agreements.

Address Line 1 (*optional*)	
Address Line 2 (*optional*)	
City	
Province/Territory	
Postal Code	
Country (*optional*)	

Q14. [OPTIONAL] Do you own or rent the place where you live?

☐ Own
☐ Rent
☐ Other Arrangement
Branching Logic: when "Other Arrangement" selected, then:

Please specify: (*for example, live in accommodation rent free, sheltered accommodation, care home, mobile or temporary structure, etc.*)
(display optional free text)

☐ Prefer not to answer
☐ Not applicable

Q15. [OPTIONAL BUT REQUIRED IF USING Q14] Please describe your current housing arrangements.

☐ Person living alone
☐ On a college/university campus dormitory
☐ With a roommate
☐ With family
☐ Motel/hotel
☐ Hospital, rehabilitation centre, drug treatment centre, or other temporary institution
☐ In a group home, nursing home, or other residential facility
☐ Transitional housing
☐ Emergency shelter or shelter for the unhoused
☐ Anywhere outside (for example, street, vehicle, abandoned building)
☐ Other
  Branching Logic: when "Other" selected, then:

  Please specify:
  (display optional free text)

☐ Prefer not to answer

Q16. [OPTIONAL] How many years have you lived at your current address?

☐ Less than 1 year
☐ 1-5 years
☐ 6-10 years
☐ 11-20 years
☐ More than 20 years
☐ Prefer not to answer

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