Sociodemographic Data Collection and Use Policy

8-230	
Section:	Registration
Applies to:	All Staff
Approved by:	Board
Date Established:	January 2025
Date Revised:	

Purpose

This policy describes the guidelines and procedures for the secure collection, storage, and management of sociodemographic data. The goal is to ensure that sociodemographic data is handled ethically, securely, and in compliance with applicable laws and regulations.

Scope

This policy applies to the College and staff involved in the collection, management, and analysis of sociodemographic data including racialized group and ethnic identity collected at registration. It covers the processes of data collection, storage, protection, access control, and usage for regulatory and policy development purposes.

Definitions¹:

Sociodemographic Data: Information encompassing a broad array of characteristics, including but not limited to age, sex, gender, racialized group, and geographic location.²

Data Security: Measures taken to protect data from unauthorized access, loss, or corruption.

Confidentiality: The obligation to protect personally identifiable information from unauthorized disclosure.

Race: Race is a social construct used to categorize people based on visible or physical traits, such as skin colour, hair texture, and facial features which are often seen as inherent traits.³

¹Canadian Institute for Health Information Minimum Health Human Resources Data Standard About the 2022 Health Human Resources Minimum Data Set Data Standard

² Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics, Ontario Health, June 2024

³ Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics, Ontario Health, June 2024



Racialized Group Identity: Racialized group is used in this policy to describe those affected by racism. Racialized groups can encounter a range of racisms, which can overlap or intersect with other social, ethnic or cultural groupings.⁴ Racialized Groups are organized along the lines of people and their visible or physical traits and may or may not intersect with geographic location and/or place of origin.

Indigenous Identity: Indigenous identity refers to whether a person identifies with the Indigenous peoples of Canada. This includes those who identify as First Nations (North American Indian), Métis and/or Inuk (Inuit), and/or those who report being Registered or Treaty Indians (that is, registered under the Indian Act of Canada), and/or those who have membership in a First Nation or Indian band. Aboriginal peoples of Canada (referred to here as Indigenous peoples) are defined in the Constitution Act, 1982, Section 35 (2) as including the Indian, Inuit and Métis peoples of Canada.⁵

Guiding Principle(s) of Data Governance⁶:

Regulatory Duties and Sociodemographic Data: In compliance with the Regulated Health Professions Act, 1991 and the Occupational Therapy Act, 1991, the College has an accountability to collect certain personal information in the interests of the public.

Ownership: Registrants retain ownership of their sociodemographic data. They have the right to volunteer certain additional sociodemographic data and know how their data is collected, used, and shared.

Respect for Privacy: All sociodemographic data is collected and stored in a manner that respects individual privacy rights and complies with relevant data protection laws.

Transparency and Accountability: The data collection process is transparent. The College is accountable for how sociodemographic data is used to inform policies and practices.

Non-Discrimination: The data is not used to discriminate against individuals or groups based on racialized group or ethnic identity. It serves as a tool to identify and help reduce disparities in healthcare outcomes.

Data Minimization: Only the data necessary to achieve regulatory goals is collected, and personal data is kept no longer than necessary.

⁴ Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics, Ontario Health, June 2024

⁵ Constitution Act, 1982, Section 35 (2)

⁶ Government of Ontario's Anti-Racism Data Standards (Standards) established to help identify and monitor systemic racism and racial disparities within the public sector.



Recognition: The contributions of communities are acknowledged and valued.

Healthcare System Equity: By collecting sociodemographic data about racialized groups, ethnicity, gender identity and other social or cultural background of individuals, the College can better monitor system patterns of health outcomes, access to care, and quality of service across different racial and ethnic communities. Collection of this data enables the College to support and guide practices that reduce disparities, improve healthcare equity, and influence systemic improvements to ensure care is provided in a fair and culturally competent manner.

Systems Level Data Standard and Partner Engagement: The College uses the Canadian Institute for Health Information (CIHI) Health Human Resources Minimum Data Set ("HHR MDS") data standard as a guide to collect the sociodemographic data. CIHI's broad range of health system databases, measurements together with College reports and analysis are used to engage with system partners.

Accurate and Ethical Data Collection: The College is responsible to ensure that this data is collected accurately, ethically, and with respect for registrant privacy. Data collection processes comply with relevant laws and regulations, including those that protect individuals from discrimination and bias. Ongoing training and resources are provided to support the responsible, secure, and effective management of sociodemographic data.

Transparency and Public Trust: The College uses aggregated data to inform evidence-based decisions, guide policy development, and advance accountability in occupational therapy delivery at a system level.

Policy

Data Types:

Regulatory Data: In compliance with the Regulated Health Professions Act, 1991 and the Occupational Therapy Act, 1991, the College has an accountability to collect certain personal information in the interests of the public.

Sociodemographic Data: Data related to racialized group, ethnicity, gender identity and cultural background does not appear on the public register.

Collected sociodemographic data is used to reduce or eliminate systemic inequity, marginalization and other health system barriers. The collection of sociodemographic data provides insight into the degree to which the diversity of the Ontario public is reflected in College registration. The College aims to promote transparency, health equity, and support evidence-based decision-making while safeguarding individual privacy and confidentiality.

Required Sociodemographic Data Collection:

The *Regulated Health Professions Act, 1991* and the College bylaws specify what information about each occupational therapist is to be kept and made available to the public. Find a description of what information is and is not available on the Public Register at

https://www.coto.org/clientsandthepublic/how-to-find-an-ot.

Data Collection:

The College uses the Canadian Institute for Health Information (CIHI) Health Human Resources Minimum Data Set ("HHR MDS") data standard⁷ as a guide to collect the sociodemographic data including Indigenous Identity data-see Appendix 1 for Indigenous Identity Data Standard and Appendix 2 for Racialized Group Data.

When collecting sociodemographic data, care will be taken to ensure:

- 1. The collection of sociodemographic data is integrated into existing and trusted workflows to minimize disruption and enhance efficiency. Data collection prompts are incorporated into the Data registration application and registration renewal forms and registration processes to facilitate systemic data capture.
- 2. Registrants know that provision of this information is optional, and each registrant can choose not to provide the information, without any repercussions.
- 3. Information is collected in ways that are safe, respectful, responsible and do not cause harm (e.g. by providing resources on this topic and developing an FAQ).
- 4. There is appropriate and meaningful engagement with registrants.
- 5. There is transparency and accountability by providing clear information on how the data will be gathered, stored, used and managed.
- 6. There is adequate explanation of the benefits and risks, if any, of collecting this information.
- 7. Each registrant can choose not to answer any of the sociodemographic questions and still continue to complete the renewal registration process.
- 8. No program, service or benefit will be withheld if registrants do not answer the questions.

⁷ Canadian Institute for Health Information Minimum Health Human Resources Data Standard About the 2022 Health Human Resources Minimum Data Set Data Standard

Storage and Management

- 1. Data is stored in a secure system and access will be limited to a small number of College staff.
- 2. Data provided by each registrant will be kept confidential.
- 3. Each registrant can withdraw their consent about additional sociodemographic data and request that the College remove or stop using their information at any time.
- 4. Registrants will not be able to be identified by the data they choose to submit because the data will be reported aggregately.

Data Use

Data will be used to:

- 1. Provide a baseline measurement of the sociodemographic of occupational therapists to better understand sociodemographic trends and inform efforts and strategies to promote equality and diversity in the profession.
- 2. Develop programs and practice support that will assist registrants in better serving communities.
- 3. Help the College meet its current strategic plan objectives and values which commit to integrating equity, diversity and inclusion ("EDI") practices throughout the organization and the occupational therapy profession.
- 4. Highlight and track disparities and systemic barriers that equity-deserving groups face in accessing health care services or joining the profession.
- 5. Support evidence-based decision making aimed at reducing or eliminating discrimination in the profession.
- 6. Heed the Truth and Reconciliation calls to collect data so that progress can be measured especially on increasing the number of indigenous health professionals, based on the belief that only what is measured can be effectively understood and improved.
- 7. Provide more robust data to the Canadian Institute for Health Information (CIHI), in turn allowing the organization to aggregate Canadian data regarding the profile of Canadian OTs.

Limited Use

Data will not be used:

- 1. In any way that could identify an individual registrant.
- 2. With the intention to impact, harm or discriminate against a registrant.
- 3. To deny registration or be checked against a registrant's safe practice registration requirement.
- 4. By the College in complaints or discipline processes.
- 5. To perpetuate stereotype of specific groups.

Responsibilities

The College:

- Ensures compliance with laws and ethical guidelines in all stages of data collection, storage, and management.
- Ensures clear guidance is provided to staff regarding the types of sociodemographic data to be collected, the appropriate data fields or forms to use, and the preferred methods for data entry.
- Provides staff with regular training on data security, privacy protection, and ethical use of sociodemographic data.
- Ensures that clear procedures are in place for data access, including who can access and modify data, and under what circumstances.
- Monitors the implementation of this policy to ensure data is being handled appropriately and securely.
- Ensures engagement of people with "lived reality" who are most affected through two-way or multi-directional communication
- Ensures the contributions of people and communities are acknowledged and valued.

Staff:

- Follow established procedures for collecting, storing, communicating about and managing sociodemographic data.
- Always maintain the confidentiality of sociodemographic data.
- Report any breaches of data security or potential risks to the Privacy Officer immediately.
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Procedure

Data Collection:

- 1. Sociodemographic data is collected at registration and annual registration through a secure application and renewal process.
- 2. The sociodemographic data collection repository includes at a minimum, the 30 core data elements identified in the CIHI HHR MDS Data Dictionary to enable the College to submit HHR data under agreements with CIHI and other government agencies including but not limited to Indigenous Identity⁸ and Racialized Group See Appendix 1 and Appendix 2.
- 3. Digital consent is obtained from individuals with clear language explaining how the data will be used.
- 4. Provision of sociodemographic data in the COTO Portal by registrants is voluntary through purpose-built applications providing for digital consent and use of non-mandatory fields.

Data Storage and Protection

Secure Storage:

- 1. All sociodemographic data is stored in secure, encrypted systems to prevent unauthorized access.
- 2. Physical storage devices (e.g., hard drives, backup tapes) containing sociodemographic data are kept in secure, access-controlled locations.
- 3. Electronic data is stored in secure databases that comply with the highest standards of cybersecurity.
- 4. Regular backups of all data are performed to ensure data integrity and recovery in case of system failure.
- 5. Data is aggregated and anonymized in reports to minimize the risk of identification of individuals.

Access Controls:

1. Data access is restricted to authorized personnel only.

⁸ Canadian Institute for Health Information Minimum Health Human Resources Data Standard About the 2022 Health Human Resources Minimum Data Set Data Standard



- 2. Role-based access controls are implemented to ensure that only individuals with a legitimate need can access specific types of data.
- 3. All data access is logged and monitored to detect and respond to unauthorized access attempts.
- 4. Regular audits of access logs and security systems are performed to ensure compliance with security protocols.

Data Retention:

- 1. Sociodemographic data is retained to fulfill the regulatory or policy objectives with reference to the Document Retention and Destruction Policy.
- 2. Data is securely destroyed or anonymized to prevent unauthorized use.

Reporting, Accountability and Communication:

- 1. Individual sociodemographic data is reported on the Public Register as required by the Regulated Health Professions Act, 1991 and the Occupational Therapy Act, 1991.
- 2. Aggregate and anonymous data is provided in HHR data reports under agreements with CIHI and other government agencies.
- 3. As part of the strategic plan, the College:
 - 1. Shares aggregate data and analysis with registrants and system partners to impact both regulatory and healthcare system outcomes.
 - 2. Engages in multi-directional communications with people and registrants with "lived reality" including but not limited to: key community advisors; Citizens' Advisory Group; the Equity Perspectives and Indigenous Insights Advisory Committees.
- 4. Contributions by people and communities are acknowledged and recognized as part of regular communications and processes including but not limited to meeting agendas, reports and newsletter items.
- 5. Questions or concerns from the public and registrants regarding the use of sociodemographic data are escalated to the Program Director and Privacy Officer.

Confidentiality and Privacy Protection

Confidentiality Agreements:

- 1. All staff members and third-party vendors with access to sociodemographic data sign confidentiality agreements to protect sensitive information.
- 2. Any breaches of confidentiality are immediately reported and addressed in accordance with established protocols with regards to Privacy.

Privacy Rights:

- 3. Individuals are informed of their right to access, correct, or withdraw their sociodemographic data at any time, in compliance with applicable data protection laws.
- 4. Individuals can request their data or file complaints about how their data is being handled by contacting the Program Director and Privacy Officer.

Data Breach Response

Incident Reporting:

- 1. In the event of a data breach or security incident, the Program Director and Privacy Officer is notified immediately.
- 2. Affected individuals are notified promptly in accordance with legal requirements and the Privacy Code.
- 3. Necessary remedial actions are taken to mitigate harm under the direction of the Program Director.

Corrective Actions:

- 1. Following any breach or failure in data management, the College will review and update policies and procedures to prevent similar incidents from occurring in the future.
- 2. Staff training is updated regularly to reinforce best practices in data security and confidentiality.

Compliance and Enforcement

1. The College conducts regular audits to ensure compliance with this policy and relevant data protection laws.



2. Any violations of the policy, including improper data handling or security breaches, are addressed promptly and may result in disciplinary action.

Policy Review and Updates

This policy will be reviewed and updated annually, or more frequently, if necessary, to account for changes in legal, technological, or ethical standards related to sociodemographic data collection, storage, and management.

Legal Requirement and Resources:

- Canadian Institute for Health Information Minimum Health Human Resources Data Standard <u>About the 2022 Health Human Resources Minimum Data Set Data Standard</u>
- The *Regulated Health Professions Act, 1991 (RHPA)*, allows health regulatory colleges to collect personal information from members, "as reasonably necessary for the purpose of health human resource planning or research".
- Constitution Act, 1982, Section 35 (2)
- The Ontario Human Rights Commission (OHRC) notes that Canada's human rights legislative framework supports collection of such data on code grounds for a code-consistence purpose.
- Government of Ontario's Ontario's *Anti-Racism Data Standards* (Standards) established to help identify and monitor systemic racism and racial disparities within the public sector.
- Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics, Ontario Health, June 2024



Appendix 1: CIHI Indigenous Identity Data Standard ⁹

Question:

Do you identify as First Nations, Inuk/Inuit and/or Métis?

<u>Response:</u>

Categories (select all that apply):

- Yes, First Nations
- Yes, Inuk/Inuit
- Yes, Métis
- No
- Do not know

⁹ About the 2022 Health Human Resources Minimum Data Set Data Standard



Appendix 2: Racialized Group¹⁰ Data Collection (Based on CIHI HHR MDS, 2022 and Ontario Health Data Standard, 2024)¹¹

Question:

Which racialized group best describes you? Check all that apply and/or indicate another category:

Response category

- Black
- East Asian
- Indigenous
- Latin American
- □ Southwest Asian/North African
- South Asian
- White
- □ Another racialized group category Optional-please specify: [open text]
- Do not know

¹⁰ Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics, Ontario Health, June 2024

¹¹ About the 2022 Health Human Resources Minimum Data Set Data Standard