HDRN Canada

Public Trust, Literacy and Health Data Foundations in Canada

Glossary of health data and related terms

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Réseau de recherche sur les données de santé du Canada

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Introduction

This glossary accompanies the foundational paper *Public Trust, Literacy and Health Data Foundations*, developed by Health Data Research Network Canada in collaboration with the Public Health Agency of Canada. The glossary aligns with priorities outlined in the *Working Together to Improve Health Care for Canadians Plan*, the *Pan-Canadian Health Data Charter*, and the *Joint FPT Action Plan on Digital Health*. It includes health data terms as well as broader concepts relevant to the paper's content, such as terms related to public trust and digital/data literacy. Where possible, terms and definitions are drawn from existing glossaries, and sources are noted. While created for this paper, the glossary also serves as a standalone resource to support data collaborations and discussions around public trust in the context of health data collection, sharing, and use.

The glossary is organized into the following categories:

Data Management

Access request: an automatic or manual request for access to one or more data sources

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

CARE principles: CARE Principles for Indigenous Data Governance focus on ensuring that data practices respect and support Indigenous Peoples' rights, interests, and worldviews. They aim to address power imbalances and historical injustices by advocating for Indigenous control over their data and ensuring that its use benefits Indigenous communities in culturally appropriate ways. These principles promote Indigenous self-determination, innovation, and the right to manage and create value from their data within their own knowledge systems.

- *Collective Benefit:* Data ecosystems designed and function in ways that enable Indigenous Peoples to derive benefit from the data.
- *Authority to Control:* Indigenous Peoples' rights and interests in Indigenous data must be recognized and their authority to control such data be empowered. Indigenous data governance enables Indigenous Peoples and governing bodies to determine how Indigenous Peoples, as well as Indigenous lands, territories, resources, knowledge and geographical indicators, are represented and identified within data.
- *Responsibility:* Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples' self-determination and collective benefit. Accountability requires meaningful and openly available evidence of these efforts and the benefits accruing to Indigenous Peoples.
- *Ethics:* Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.

Source: Global Indigenous Data Alliance (https://www.gida-global.org/care)

Data collection: the process of gathering data, typically in the context of a research project or for ongoing surveillance and tracking. There are many methods of data collection including manual and automated, and the methods typically depend on the intended outcomes to be measured and analyzed. Data can be collected through forms or survey instruments; video or audio recordings; qualitative interviews or focus groups; extractions from electronic health record data; measurements from sensors, scales, and other lab or clinical equipment.

Source: Adapted from National Library of Medicine Data Glossary (https://www.nnlm.gov/guides/data-glossary/data-collection)

Data custodian (data trustee): as defined in Canadian health legislation, an individual or organization responsible for the secure collection and/or storage of health data and the curation of health data use, disclosure, retention, and disposal. Primarily concerned with security and privacy of health data. **Data custodianship** is the formal discipline for keeping data safe.

Source: Adapted from Expert Advisory Group (2021). Pan-Canadian Health Data Strategy: Building Canada's Health Data Foundation (*https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation.html*)

Data disclosure: the act of sharing or providing access to data with an individual or group

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data governance: refers to diverse arrangements, including technical, policy, regulatory or institutional provisions, that affect data and their cycle (creation, collection, storage, use, protection, access, sharing and deletion) across policy domains and organisational and national borders

Source: The Organisation for Economic Cooperation and Development (*https://www.oecd.org/en/topics/sub-issues/data-governance.html*)

Data institution: a group or organization that manages data

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data integrity: maintenance and assurance of data accuracy and consistency over time in the absence of permissible data alteration

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data linkage: a method of connecting data from different sources for the purpose of analysis

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data repository: physical or digital storage location that can house, preserve, manage, and provide access to many types of digital and physical materials in a variety of formats

Source: CODATA RDM Terminology (2023, v0001). DOI *10.5281/zenodo.10626169*

Data retention (policy): established protocol of an organisation for retaining information for operational or regulatory compliance needs. The objectives of a data retention policy are to keep important information for future use or reference, to organise information so it can be searched and accessed at a later date, and to dispose of information that is no longer needed

Source: CODATA RDM Terminology (2023, v0001). DOI *10.5281/zenodo.10626169*

Data sharing: The Digital Governance Council's Health Data and Information Lexicon defines this as the practice of exchanging data between individuals or groups to support health programs and services. Other sources include that data sharing is a process of making the same data available to multiple users without any effect on **data integrity**. Data sharing does not necessarily imply moving data, as technological innovations such as **trusted environments** enable sharing by allowing users to view and use but not remove data.

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data storage: the methods and systems used to securely save and preserve collected data in a way that ensures its integrity, accessibility, and confidentiality over time. This includes both digital and physical storage solutions, as well as the ethical and legal requirements for maintaining data privacy and security

Source: Adapted from Government of Canada Tri-Agency Statement of Principles on Digital Data Management (*https://science.gc.ca/site/science/en/interagency-research-funding/policies-and-guidelines/research-data-management/tri-agency-statement-principles-digital-data-management*)

Data subject: a person or entity to whom data relates. For example, data may represent information about a person who completed a survey

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Databank: a large repository of data on a particular topic, sometimes formed from more than one database, and accessible by many users (Oxford dictionary)

Adapted from Oxford Dictionary (*https://www.oed.com/search/dictionary/?scope=Entries&q=databank*)

Database: a structured set of data stored electronically designed to be easily accessed, managed and updated

Source: Adapted from Oxford Dictionary (*https://www.oxfordreference.com/display/10.1093/oi/authority.20110803095701352*)

Disaggregated data: Disaggregated data are data that provide sub-categories of information, for example by ethnic group, gender, occupation or educational status. These are sometimes called demographic categories. This information is usually **anonymized** or **de-identified**—stripped of personal information like name or date of birth—and used in statistical analysis. Unlike aggregated data, which groups information together, disaggregated data can reveal inequalities and relationships between categories.

Source: Adapted from British Columbia's Office of the Human Rights Commissioner (2020). Disaggregated Demographic Data Collection in British Columbia: The Grandmother Perspective (*https://bchumanrights.ca/resources/publications/publication/datacollection/*) and Right To Education (2017) Glossary. (*https://www.right-to-education.org/monitoring/content/glossary-disaggregated-data*)

Distributed data: data stored across multiple organizations, institutions, or data centres

Source: Health Data Research Network Canada (2024). Federated Analysis Learning Series (*https://www.hdrn.ca/wp-content/uploads/Federated-Analysis-Learning-Series-Topic-1-Federated-Analysis-101_Jan2024.pdf*)

FAIR principles: An industry standard to allow the reuse of data by making sure it is Findable, Accessible, Interoperable, and Reusable.

- *Findable*: Metadata and data should be easy to find for both humans and computers. Machine-readable metadata are essential for automatic discovery of datasets and services.
- *Accessible*: The user needs to know how the data can be accessed, possibly including authentication and authorisation.
- Interoperable: The data usually needs to be integrated with other data. In addition, the data needs to interoperate with applications or workflows for analysis, storage, and processing.
- *Reusable*: Metadata and data should be well-described so that they can be replicated and/or combined in different settings.

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Five safes: An internationally recognized framework for evaluating access to privacy-sensitive data. The basic premise of the model is that data access requests are evaluated against a set of five 'risk' (or access) dimensions:

1. *Projects*: Is this use of the data appropriate?
2. *People*: Can the data user be trusted to use the data in an appropriate manner?
3. *Data*: Is there a disclosure risk in the data itself?
4. *Settings*: Does the access facility limit unauthorised use of the data?
5. *Outputs*: Are the statistical results non-disclosive?

Source: Adapted from Population Data BC - Eligibility and the Five SAFEs model (*https://www.popdata.bc.ca/data_access/requirements/eligibility*)

Health data governance: the formalization of health data stewardship into a set of structures and rules to ensure effective data management practices in compliance with legislation and regulation.

Source: Federal, Provincial and Territorial Health Data Stewardship Working Group (2024). Advancing Health Data Stewardship through Federal, Provincial, and Territorial Collaboration. Working Group Report #1: Pan-Canadian Framework for Health Data Stewardship [Unpublished manuscript].

Health data policy: organizational guidelines or rules that describe how data is to be managed and used

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Health data steward: a professional role responsible for operationalizing health data governance

Source: Federal, Provincial and Territorial Health Data Stewardship Working Group (2024). Advancing Health Data Stewardship through Federal, Provincial, and Territorial Collaboration. Working Group Report #1: Pan-Canadian Framework for Health Data Stewardship [Unpublished manuscript].

Data stewardship (health): a formal discipline for ensuring health data are managed and used for the public good and for fostering trust in data practices

Source: Federal, Provincial and Territorial Health Data Stewardship Working Group (2024). Advancing Health Data Stewardship through Federal, Provincial, and Territorial Collaboration. Working Group Report #1: Pan-Canadian Framework for Health Data Stewardship [Unpublished manuscript].

Individual health data control: a process that allows patients to easily access their own health information, review it, see who has access to it, and when appropriate, set limits for who can access their data

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Individual health data ownership: a legal principle that the patient has a vested and ongoing interest in the information contained in their health record, while the healthcare provider owns the physical (digital) record

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Information governance: a process of ensuring that rules and oversight are in place to uphold legal, ethical and practical requirements when handling information

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Interoperability: the capacity for seamless sharing of health data and information between health sector stakeholders by means of policy, governance, workflow and, especially, technical alignment

Source: Expert Advisory Group (2021). Pan-Canadian Health Data Strategy: Building Canada's Health Data Foundation (*https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation.html*)

Population descriptors: the grouping or categorization of people based on a common or similar characteristic, such as by race, ethnicity, or ancestry

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Quality assurance (data): the systematic evaluation and improvement of health data to maximize its capacity to improve health and wellbeing

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Registry: a database of organized and structured information that is typically stored electronically in a computer system that holds information about a certain disease, diagnosis, or intervention

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Third-party: a person, group, or public authority other than the data subject, controller, or others that have permission to work with the data

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Trustee: a person or an organization who has authorized control of information and is responsible for managing it

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

General Data

Administrative data (also known as routinely-collected data): data generated through the routine administration of programs. Administrative databases are designed to collect and store this type of data. While not originally intended for research, administrative data can be a rich source of information.

Source: University of Manitoba - Manitoba Centre for Health Policy Concept Dictionary and Glossary (*http://mchp-appserv.cpe.umanitoba.ca/viewDefinition.php?definitionID=102209*)

Aggregate data: a collection or combination of data from multiple individuals within a population that is used to make conclusions about the population

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data: facts, figures, observations, or recordings that can take many different forms, for example, numbers, statistics, words or pictures. Data are collected to learn new things and draw conclusions

Source: Adapted from Statistics Canada (2011) (*https://www150.statcan.gc.ca/n1/edu/power-pouvoir/ch1/definitions/5214853-eng.htm*); Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023).

Data lifecycle: the sequence of stages that data goes through from its creation to its disposal

Source: Federal, Provincial and Territorial Health Data Stewardship Working Group (2024). Advancing Health Data Stewardship through Federal, Provincial, and Territorial Collaboration. Working Group Report #1: Pan-Canadian Framework for Health Data Stewardship [Unpublished manuscript].

Data literacy: data literacy is about collecting, analyzing, understanding and using information from data. It means knowing how to read, analyze, and share data, and understanding how data helps in making decisions

Source: Adapted from PT&DL lexicon adapted from Bonikowska, Sanmartin & Frenette (2019). Data Literacy: What it is and how to measure it in the public services (*https://epe.bac-lac.gc.ca/100/201/301/weekly_acquisitions_list-ef/2019/19-33/publications.gc.ca/collections/collection_2019/statcan/11-633-x/11-633-x2019003-eng.pdf*); Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023).

Data quality: the characteristics of optimized health data, including completeness, consistency, uniqueness, timeliness, validity, and accuracy, integrity, and conformity

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Genomic data: data that includes information like the sequence of molecules in an organism's/person's genes. It is related to the structure and function of an organism's/person's **genome**. From potatoes to puppies, all living organisms have their own genome. Your genome is the operating manual containing all the instructions that helped you develop from a single cell into the person you are today. It guides your growth, helps your organs to do their jobs, and repairs itself when it becomes damaged. And it's unique to you.

Source: Adapted from the National Human Genome Research Institute (*https://www.genome.gov/About-Genomics/Introduction-to-Genomics*) and Amazon Web Services (*https://aws.amazon.com/what-is/genomic-data/*)

Health data: refers to data about a person's health or the health of a community. It can include their health conditions, information relating to maternity and children, causes of death, and quality of life. Health data includes, for example: patient health records, studies about the health of groups of people, data from blood or tissue samples, imaging data, and data from health and fitness devices.

Source: Adapted from Expert Advisory Group (2021). Charting a Path Towards Ambition (*https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-01-charting-path-toward-ambition.html*); Data Saves Lives (2021). Health Data 101: Understand and communicate about the power of health data (*https://static1.squarespace.com/static/5cc8208b90f904c71c744000/t/6616504b0bef933039ea3964/1712738380781/Data-Saves-Lives-Toolkit-Part-One.pdf*); Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023).

Integrated dataset: a set of data from different sources that brings together different pieces of data from different people

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Metadata: data that describes other data and helps answer questions about one or more aspects of the data to help make managing, tracking, and working with specific data easier

Source: Adapted from Global Alliance for Genomics and Health (2016). Data Sharing Lexicon Version 1.0 (*https://www.amed.go.jp/content/000050950.pdf*)

Patient data (personal health information): health data or information that is specific to a unique and identified individual

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Secondary data use: using data in a way that differs from the original purpose for which they were generated or collected

Source: Global Alliance for Genomics and Health (2016). Data Sharing Lexicon Version 1.0 (*https://www.amed.go.jp/content/000050950.pdf*)

Social services data (or "health-related" data): refers to information about non-medical determinants of health such as behaviours, living and working conditions, personal resources and environmental factors, or connected services received by a person (e.g., community housing)

Source: Adapted from Canadian Institutes of Health Research (2017). Health Research and Health-Related Data Framework and Action Plan (*https://cihr-irsc.gc.ca/e/50182.html*)

Synthetic data: a form of fake data that is often computer generated, altered, augmented or replaced to make it look and feel like real personal information in order to protect individual privacy

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Health System

Community care: health care services that people receive at home, rather than in a hospital or long-term care facility, delivered by regulated health care professionals (e.g., nurses), non-regulated workers, volunteers, friends and family caregivers. Community care also includes community-based programs (e.g., drop in care for seniors)

Source: Adapted from Government of Canada (2016). Home and Community Health Care (*https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html*)

Electronic health record (EHR): the systematized collection of patient and population electronically-stored health information in a digital format

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Electronic medical record (EMR): a computer-based patient record specific to a clinical practice

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Health care provider: a licensed person or organization that provides health care services. Examples of health care providers include doctors, nurses, therapists, pharmacists, laboratories, hospitals, clinics, and other health care centers

Source: National Institutes of Health - National Cancer Institute Dictionary (*https://www.cancer.gov/publications/dictionaries/cancer-terms/def/health-care-provider*)

Learning health system: a type of health system that drives better outcomes for individuals and populations by leveraging health data and personalized insights, while improving overall system quality, population health, evaluation, planning, and public health, aligned with data user needs and supporting equitable health

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Patient portal: a digital platform that enables an individual to have safe and secure online access, and sometimes the ability to manage their personal health information

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Patient (person)-generated data: patient or person generated health data is personal health or wellness-related data that is created, recorded, or gathered by or from patients or caregivers to help manage, maintain and/or improve health and wellness

Source: Adapted from Patient Advisors Network - Person-generated Health Data Principles (*https://www.patientadvisors.ca/wp-content/uploads/2021/11/pghd_principles_sep_302019_.pdf*)

Personal information: information about an individual that can be used to reveal their identity

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Primary care: a model of care that supports first-contact, accessible, continuous, comprehensive and coordinated person-focused care. It aims to optimize population health and reduce disparities across the population by ensuring that subgroups have equal access to services. An example of a primary care provider is a family physician.

Source: Adapted from the World Health Organization (*https://www.who.int/teams/integrated-health-services/clinical-services-and-systems/primary-care*)

Quality of care: The degree to which health services for individuals and populations increase the likelihood of desired health outcomes.

Source: World Health Organization (*https://www.who.int/health-topics/quality-of-care#tab=tab_1*)

Remote patient monitoring: the delivery of health care to patients outside of conventional care settings (e.g., a patient's home), made possible by connecting the patient and a health care provider through technology. It involves the electronic transmission of patient data (e.g., symptoms, vital signs, outcomes) from a remote home location to the provider, as well as the supporting services and processes required to conduct data review, interpretation and potential alteration of the patient's course of care.

Source: Canada Health Infoway (*https://www.infoway-inforoute.ca/en/component/edocman/3472-an-evaluation-of-a-remote-patient-monitoring-solution-within-eastern-health/view-document*)

Telemedicine: the use of electronic information and communications technologies to provide and support health care when distance separates the participants

Source: National Institutes of Medicine - Telemedicine: A Guide to Assessing Telecommunications in Health Care (*https://www.ncbi.nlm.nih.gov/books/NBK45440/*)

Person-centric data: a robust personal health information (or data) record that is designed to follow an individual over time and across locations for the entire course of their health journey

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Personal health data: data about an individual's health and wellbeing that can be used to identify them

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Privacy

Anonymization: the process of removing or altering data that identifies an individual or could, foreseeably, identify an individual in the future. The degree to which data are anonymized depends upon the sensitivity of the information, what it is being used for and who has access to it

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Anonymized data: data that are completely stripped of information that can be used to directly identify individuals ("direct identifiers"), meaning the risk of re-identification of individuals from any remaining indirect identifiers is low or very low

Source: Adapted from Portage Network Sensitive Data Expert Group (2020). Sensitive Data Toolkit for Researchers Version 2 (*https://zenodo.org/records/4088946*)

Anonymous data: data that have never had direct identifiers from the point of original collection; the risk of identification from indirect identifiers is low or very low

Source: Portage Network Sensitive Data Expert Group (2020). Sensitive Data Toolkit for Researchers Version 2 (*https://zenodo.org/records/4088946*)

Assent: In Canadian research involving minors or individuals with limited decision-making capacity, "assent" is distinct from full consent and indicates a participant's voluntary agreement to participate in a study. When children or adults of limited cognitive capacity participate in research, researchers must secure the assent of the potential participant as well as the permission of the parent or guardian (in place of the consent of the participant)

Source: Carlton University Office of Research Ethics (2017). (*https://carleton.ca/researchethics/cu-faq/consent-and-assent/*)

Confidentiality: the protection of data from unauthorized access and disclosure

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Consent: the permission to have, use or share data, granted freely and without coercion. Consent can be either communicated explicitly, on, or implied, through actions and precedent

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Consent revocation (or consent withdrawal): the withdrawal of the right to have, use or share data over time

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

De-identification: the process of removing or altering data that identifies an individual or could, foreseeably, identify an individual in the future to lower the possibility of re-identification. The degree to which data is deidentified depends upon the sensitivity of the information, what it is being used for and who has access to it.

Source: Expert Advisory Group (2021). Pan-Canadian Health Data Strategy: Building Canada's Health Data Foundation (*https://www.canada.ca/en/public-health/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation.html*)

De-identified data: data that have identifying information removed or changed so that it no longer identifies an individual

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Identifiability: the degree to which an individual might be re-identified through their data

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

Identifier: an element of data that helps identify a person

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

Implied consent: an unwritten agreement between a patient and another person or organization that allows personal health data to be collected, used, and shared

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

Informed consent (in research): human participants in research are provided all the information necessary for them to make an informed decision about participating in the research

Source: Adapted from Government of Canada (2024). Research Ethics Board: Consent Process (https://www.canada.ca/en/health-canada/services/science-research/science-advice-decision-making/research-ethics-board/consent-process.html)

Opt-in (explicit consent): this consent model requires individuals to actively agree to the collection or use of their data. Typically, opt-in consent is explicit—such as signing a form or clicking a checkbox to confirm understanding and agreement. Opt-in consent is voluntary, and documented, allowing individuals to withdraw consent at any time if they change their mind

Source: Adapted from Office of the Privacy Commissioner of Canada (2019). Consent. (https://www.priv.gc.ca/en/privacy-topics/collecting-personal-information/consent)

Opt-out consent: this model presumes consent unless the individual takes action to withdraw it. Opt-out consent is used when obtaining opt-in consent is impractical or in situations where implied consent may suffice. The opt-out process should still ensure individuals are fully informed, with methods available to withdraw their data if desired

Source: Adapted from Office of the Privacy Commissioner of Canada (2019). Consent. (https://www.priv.gc.ca/en/privacy-topics/collecting-personal-information/consent)

Personally identifiable data: a term to describe personal data about identified or identifiable individuals

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Privacy: refers to persons and their interest in controlling the access of others to themselves (their personal information). Data privacy applies to any data, objective or subjective, that can identify us, either on its own or when combined with other details. This kind of information is called personal data

Source: Adapted from Canadian Association of Research Ethics Boards (2024) Glossary of Terms (*https://careb-accer.org/resources-section/n2-careb-accer-reb-sops/*)

The Personal Information Protection and Electronic Documents Act (PIPEDA): sets the ground rules for how private-sector organizations collect, use, and disclose personal information in the course of for-profit, commercial activities across Canada

Source: Office of the Privacy Commissioner of Canada (2018). Summary of Privacy Laws in Canada (*https://www.priv.gc.ca/en/privacy-topics/collecting-personal-information/consent)(https://www.priv.gc.ca/en/privacy-topics/privacy-laws-in-canada/02_05_d_15/*)

Pseudoanonymous: data where any identifying information is replaced with a pseudonym, or, in other words, a value which does not allow the individual to be directly identified

Source: Data Protection Commission (*https://www.dataprotection.ie/en/dpc-guidance/anonymisation-pseudonymisation*)

Sensitive personal information (SPI): data that if used inappropriately, could promote inequities, or endanger personal health, wellbeing, or assets

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Public and Patient Engagement

Community-based participatory research (CBPR): collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities

Source: Kellogg Foundation (1992). Community-based public health initiative. Battle Creek, MI: Kellogg Foundation and Jull, Giles & Graham (2017). Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge. DOI: *10.1186/s13012-017-0696-3*

Patient and caregiver partners; patient partner; persons with lived experience: patients, their caregivers and families, and members of the public and health care providers who actively collaborate in the research process to ensure that research focuses on patient/public-identified priorities

Source: Adapted from Canadian Institutes of Health Research (2025) Patient Partnership. (*https://cihr-irsc.gc.ca/e/53242.html*)

Patient-oriented research: patient-oriented research is about engaging patients, their caregivers, and families as partners in the research process. This engagement helps to ensure that studies focus on patient-identified priorities, which ultimately leads to better patient outcomes

Source: Canadian Institutes of Health Research (2023), Strategy for Patient Oriented Research (*https://www.cihr-irsc.gc.ca/e/41204.html*)

Public/patient engagement (PPE): planned two-way discussions with individuals, organizations, or groups, designed to gather input, clarify information and foster understanding among those interested and affected by an issue, decision or action, and to better inform decision-making. Also known public and patient involvement (UK) and consumer involvement (Australia).

Source: Health Canada and the Public Health Agency of Canada (2023). Guidelines on Public Engagement 2023 (*https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/health-canada-public-health-agency-canada-guidelines-public-engagement/health-canada-public-health-agency-canada-guidelines-public-engagement.pdf*)

Public participation: any process that involves the public in problem-solving or decision-making and that uses public input to make better decisions

Source: International Association for Public Participation (*https://www.iap2.org/page/ethics*)

Social contract: unstated agreements that individuals and groups make in contexts, communities, and relationships. Often used in the data privacy context, can be described as mutually beneficial and sustainable agreements within a community

Source: Adapted from Martin, K. Understanding Privacy Online: Development of a Social Contract Approach to Privacy. J Bus Ethics 137, 551–569 (2016). (*https://doi.org/10.1007/s10551-015-2565-9*)

Social licence: the ongoing acceptance or approval of an organization or industry's operations by its stakeholders, particularly the local community, broader public, and other key actors in society. In the context of health data, social licence refers to which data-related activities members of the public support, and under what conditions

Source: Adapted from Verhulst and Saxena (2022). The need for new methods to establish the social licence for data reuse (*https://medium.com/data-policy/the-need-for-new-methods-to-establish-the-social-license-for-data-reuse-e7c67bdc4aff*) and Boutilier and Thomson (2011). Modeling and Measuring the Social License to Operate: Fruits of a Dialogue between Theory and Practice (*https://socialicense.com/publications/Modelling%20and%20Measuring%20the%20SLO.pdf*)

Spectrum of engagement: a tool developed by the International Association for Public Participation (IAP2) that acknowledges that public engagement occurs at several levels and assists with the selection of which level the public should be engaged. The stages of the spectrum include Inform, Consult, Involve, Collaborate, Empower.

Source: International Association for Public Participation (*https://www.iap2.org/page/pillars*)

Research/Analytics

Algorithm: a set of rules or instructions for solving a problem or finishing a task used in information technology, which plays a major role in automated systems

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Artificial Intelligence (AI): a wide-ranging branch of computer science that applies advanced analysis and other techniques that mimic human intelligence in order to interpret events, support or automate decisions, and take actions

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Automated decision system: a technology that helps or replaces the judgment of a person using an algorithm, statistical process or other technique

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

Clinical research: a type of research intended to improve the diagnosis and treatment of disease and injury to optimize the health and wellbeing of individuals and populations

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

Data analysis (analytics): the process of developing answers to questions through the examination and interpretation of data. The basic steps in the analytic process consist of identifying issues, determining the availability of suitable data, deciding on which methods are appropriate for answering the questions of interest, applying the methods and evaluating, summarizing and communicating the results

Source: Statistics Canada (https://www150.statcan.gc.ca/n1/pub/12-539-x/2009001/analysis-analyse-eng.htm)

Digital health: an information technology (IT) system or device used in providing healthcare, including the use of wearable devices, mobile health, telehealth, health information technology, and telemedicine

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

Digital identity: an electronic representation of a person or group to access services with trust and confidence

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/)

eHealth: an overarching term used today to describe the application of information and communications technologies in the health sector. It encompasses a whole range of purposes from purely administrative through to health care delivery

Source: Government of Canada (2010) (https://www.canada.ca/en/health-canada/services/health-care-system/ehealth.html)

Health informatics: the science of how to use data, information, and knowledge to improve human health and the delivery of health care services

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Machine learning: A branch of artificial intelligence (AI) that involves teaching computers to identify patterns and learn from data to make decisions or predictions, without being pre-programmed with rules to perform the task

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Real World Data (RWD): data relating to patient health status and/or the delivery of health care routinely collected from a variety of sources. Examples of RWD include data derived from electronic health records, medical claims data, data from product or disease registries, and data gathered from other sources (such as digital health technologies) that can inform on health status.

Source: US Food and Drug Administratration (*https://www.fda.gov/science-research/science-and-research-special-topics/real-world-evidence*)

Real World Evidence (RWE): a form of clinical evidence regarding the usage and potential benefits or risks of a healthcare application derived from analysis of Real World Data

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Secure (or trusted) research (analytical) environments: secure physical or digital environments which can only be accessed by approved researchers

Source: Research Data Scotland (*https://www.researchdata.scot/engage-and-learn/data-explainers/what-are-trusted-research-environments/*)

Security

Authentication: a security mechanism used to verify the identity of a user or device attempting to access a system or application

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Biometric verification: the verification of an individual's identity using anatomical or physiological characteristics, such as face, fingerprints, retinas, or behavioural characteristics, such as keyboard stroke timing, or walking style

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Cyber security: the protection of digital networks, devices, and data from unauthorized or criminal use, or attack

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data breach: a security violation, in which sensitive, protected, or confidential data is copied, transmitted, viewed, stolen, altered or used by an individual or group unauthorized to do so

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data security: a method or methods used to keep data safe from destructive forces and unwanted actions of unauthorized users in order to protect the information

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Data suppression: refers to the process of withholding or removing selected information. The process of suppressing data is often conducted to protect the privacy of individuals

Source: Adapted from University of Manitoba - Manitoba Centre for Health Policy Concept Dictionary and Glossary (*http://mchp-appserv.cpe.umanitoba.ca/viewDefinition.php?definitionID=102209*)

Encryption: a process of changing information from one form to another to hide the content and prevent access by unauthorized individuals and groups

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Firewall: a security tool that acts like a gatekeeper for a computer network. It decides what data is allowed to come in or go out based on a set of rules. This helps protect the network from unwanted or harmful traffic

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Multi-factor authentication: a way to confirm someone's identity using two or more authentication factors

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Unauthorized access (data): a process whereby a person or organization gains physical or logical access to a network, system, or data without permission

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Unauthorized use: the use of data that is not allowed or explicitly authorized

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Health Equity and Social Justice

Accessibility: making sure everyone can use and benefit from information or services fairly. It involves things like making sure places are easy to reach, fees are reasonable, and there are no unnecessary rules or barriers. It's also about providing information in different ways and transforming and translating the messages so that different people can have equal access to the information, no matter their situation or abilities

Source: Adapted from Unicef (2019). Availability, Accessibility, Acceptability and Quality framework (*https://gbvguidelines.org/wp/wp-content/uploads/2019/11/AAAQ-framework-Nov-2019-WEB.pdf*); Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023).

Anti-racism: the active process of identifying and eliminating racism by changing systems, organizational structures, policies and practices and attitudes, so that power is redistributed and shared equitably

Source: Government of Canada (2023) Anti-racism lexicon (*https://www.canada.ca/en/department-national-defence/services/systemic-racism-discrimination/anti-racism-toolkit/anti-racism-lexicon.html*)

Collective rights: rights generally recognized to be exercisable by collectives (or groups of individuals) and not reducible to the individual.

Source: Oxford University Press (*https://www.oxfordreference.com/display/10.1093/oi/authority.20110803095624350*)

Colonialism: colonization is not only a process of taking political control over Indigenous lands, but also a system designed to maintain power and influence (e.g., imposition of colonial institutions of education, health care and law)

Source: Czyzewski (2011). Colonialism as a broader social determinant of health (*https://doi.org/10.18584/iipj.2011.2.1.5*)

Data justice: a set of ideas that addresses the way in which people are represented and/or harmed through their data being made visible to others, or conversely, excluded from the public eye, sites of power, and the process of decision-making. It confronts and challenges structural biases in the ways that we think about, collect, steward, and use data

Source: Royal Roads University (2024) (*https://libguides.royalroads.ca/datajustice*)

Discrimination: an action or a decision that treats a person or a group badly for reasons such as their race, age or disability

Source: Canadian Human Rights Commission (*https://www.chrc-ccdp.gc.ca/en/about-human-rights/what-discrimination*)

Distinctions-based approach: acknowledges that each community has a unique culture, territory, history, and relationship with the Government of Canada, as well as unique strengths to build on and challenges to face. A distinction-based approach means working independently with First Nations Peoples, Inuit, Métis Peoples and Intersectional Peoples in recognition of their unique attributes.

Source: Government of Canada (2023). Visions for Distinctions-based Indigenous Health Legislation (*https://www.sac-isc.gc.ca/eng/1667579335081/1667579367781*)

Engagement, Governance Access and Protection (EGAP) Framework: a framework that envisages Black communities gaining control over their collective data. At the heart of the EGAP Framework is a desire for data sovereignty for Black communities.

- *Engagement*: Genuine, cyclical, accessible consultation with communities regarding data collection, management, analysis and use.
- *Governance*: Community decision-making about engagement processes and data collection, management, analysis, and use, achieved through the establishment of Community Governance Tables.
- *Access*: The rights of communities to access their collective data and to determine who else can access it, along with the capacity building required to enable this right.
- *Protection*: The safeguarding of all individual rights and types of data, including identifiable, de-identified, and anonymized data.

Source: Black Health Equity Group (2021). A Data Governance Framework for Health Data Collected from Black Communities in Ontario (*https://blackhealthequity.ca/wp-content/uploads/2021/03/Report_EGAP_framework.pdf*)

Equity stratifiers: a characteristic such as a demographic, social, economic or geographic variable that can identify population subgroups for measuring differences in health and health care that may be considered unfair or unjust. Inequalities between subpopulations can be identified by disaggregating health indicators using equity stratifiers

Source: Canadian Institute for Health Information (*https://www.cihi.ca/en/equity-stratifiers*)

Health equity: when all people (individuals, groups and communities) have fair access to, and can act on, opportunities to reach their full health potential and are not disadvantaged by social, economic and environmental conditions, including socially constructed factors such as race, gender, sexuality, religion and social status. Achieving health equity requires acknowledging that some people have unequal starting places, and different strategies and resources are needed to correct the imbalance and make health possible. Health equity is achieved when disparities in health status between groups due to social and structural factors are reduced or eliminated.

Source: National Collaborating Centre for Determinants of Health (2022). Glossary of Essential Health Equity Terms (*https://nccdh.ca/learn/glossary*)

Health equity data: data products that provide information on health equity-associated factors such as: income, social status, race, gender, education and physical environment

Public Health Ontario (2024). (*https://www.publichealthontario.ca/en/Data-and-Analysis/Health-Equity*)

Indigenous data: any information that is from or about any Indigenous person or their community, territory or nation, including but not limited to their languages, knowledges, customs or traditions, intellectual property and ideas

Source: University of Toronto (2024). Research Guide - Indigenous Data Sovereignty (*https://guides.library.utoronto.ca/indigenousstudies/datasovereignty*)

Indigenous data sovereignty: the concept of Indigenous authority, right, power to govern as sovereign Nations and make decisions or laws on the ownership, control, collection, access, analysis, application, possession, and use of their own data

Source: First Nations Information Governance Centre (2020). A First Nations Data Governance Strategy (*https://fnigc.ca/wp-content/uploads/2020/09/FNIGC_FNDGS_report_EN_FINAL.pdf*)

Intersectionality: considers how systems of oppression (e.g., racism, classism, sexism, homophobia) interact to influence relative advantage and disadvantage at individual and structural levels. An intersectional orientation recognizes that the experience of multiple forms of discrimination and disadvantage has a cumulative negative effect that is greater than the sum of the parts. The intersectional nature of oppression and privilege means that people may have privilege in one or more forms even if they experience oppression in other domains

Source: National Collaborating Centre for Determinants of Health (2022). Glossary of Essential Health Equity Terms (*https://nccdh.ca/learn/glossary*)

Inuit Qaujimajatuqangit (IQ): Traditional knowledge: ᐃᓅᖃᑎᒌᑦᓯᐊᕐᓂᖅ - Inuuqatigiitsiarniq, Respecting others, relationships and caring for people; ᑐᙵᓇᕐᓂᖅ - Tunnganarniq, Fostering good spirit by being open, welcoming and inclusive; ᐱᔨᑦᓯᕐᓂᖅ - Pijitsirniq, Serving and providing for family and/or community; ᐋᔩᖃᑎᒌᓐᓂᖅ - Aajiiqatigiinniq, Decision making through discussion and consensus; ᐱᓕᒻᒪᒃᓴᕐᓂᖅ - Pilimmaksarniq, Development of skills through observation, mentoring, practice, and effort; ᐃᑲᔪᖅᑎᒌᓐᓂᖅ - Ikajuqtigiinniqi, Working together for a common cause; and ᖃᓄᖅᑑᕐᓂᖅ - Qanuqtuurniq, Being innovative and resourceful.

Source: Nunavut Impact Review Board (*https://www.nirb.ca/inuit-qaujimajatuqangit*)

OCAP®: principles of data governance that describe how First Nations' data and information should be collected, protected, used, and shared. OCAP is an acronym for Ownership, Control, Access, and Possession. In the context of OCAP these terms refer to:

- *Ownership*: the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.
- *Control*: First Nations, their communities, and representative bodies are within their rights to seek control over all aspects of research and information management processes that impact them. First Nations' control of research can include all stages of a particular research project - from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.
- *Access*: First Nations must have access to information and data about themselves and their communities regardless of where it is held. The principle of access also refers to the right of First Nations' communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.
- *Possession*: While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.

Source: Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

OCAS: principles of data governance that describe how Métis citizens' data and information should be collected, protected, used, and shared. "OCAS" is an acronym for Ownership, Control, Access, and Stewardship. In the context of OCAS these terms refer to:

- *Ownership*: the legal possession of something, in this case, the Métis Population Data-Base (MPDB). The Métis Population Data-Base was developed for the Métis Health Status and Health Services Utilization study (Martens, Bartlett et al., 2010) and consists of over 90,000 anonymized individuals.
- *Control*: the power to make decisions about something and decide what should happen.
- *Access*: the right or opportunity to use something that will bring benefits.
- *Stewardship*: speaks to issues of responsible planning and management of resources. A responsibility to Métis to ensure that research that is completed is in their best interests, will result in positive changes in Métis health and health service delivery, and is done in as rigorous and ethical manner as possible.

Source: Adapted from Digital Governance Council (2024). Health Data and Information Lexicon First Edition (*https://dgc-cgn.org/standards/find-a-standard/standards-in-health-data/health-data-lexicon/*)

Racism: includes thoughts or actions that establish or reinforce the superiority or dominance of one racialized group over another. Racism exists on a spectrum and acts on multiple levels — internalized, interpersonal and systemic

Source: Canadian Institute for Health Information (2022). Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada (*https://www.cihi.ca/sites/default/files/document/race-based-and-indigenous-identity-data-supplementary-report-en.pdf*)

Social determinants of health: the non-medical factors that influence health outcomes. The social determinants of health are the interrelated social, political, and economic circumstances in which people are born, grow up, live, work and age. The social determinants of health do not operate as a list or in isolation. It is how these determinants intersect that causes conditions of daily living to shift and change over time and across the life span, impacting the health of individuals, groups and communities in different ways.

Source: National Collaborating Centre for Determinants of Health (2022). Glossary of Essential Health Equity Terms (*https://nccdh.ca/learn/glossary*)

Sociodemographic data: encompasses a broad array of characteristics, including but not limited to age, sex, gender, racialized group, ethnicity, income, education, language, housing status, employment, and geographic location. These data points not only provide a snapshot of individuals' social identities but also offer critical context for understanding the multifaceted determinants of health within communities and for measuring differences in health and health care that may be considered unfair or unjust.

Source: Canadian Institute for Health Information (2018). In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality (*https://www.cihi.ca/sites/default/files/document/defining-stratifiers-measuring-health-inequalities-2018-en-web.pdf*)

Structural determinants of health: structural determinants of health are processes that create inequities in money, power and resources. They include political, cultural, economic and social structures; natural environment, land and climate change; and history and legacy, ongoing colonialism and systemic racism. Structural determinants, also known as structural drivers, shape the conditions of daily life (social determinants of health) including education, work, aging, income, social protections, housing, environment and health systems.

Source: National Collaborating Centre for Determinants of Health (2022). Glossary of Essential Health Equity Terms (*https://nccdh.ca/learn/glossary*)

Other Related Terms

Bioethics: the study of ethical, social, and legal issues that arise in biomedicine and biomedical research. Bioethics includes medical ethics, which focuses on issues in health care; research ethics, which focuses issues in the conduct of research; environmental ethics, which focuses on issues pertaining to the relationship between human activities and the environment, and public health ethics, which addresses ethical issues in public health.

Source: National Institute of Environmental Health Sciences (https://www.niehs.nih.gov/research/resources/bioethics)

Digital literacy: being able to use electronic devices such as computers, smartphones, tablets and other digital tools to find, understand and use information

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023), Government of British Columbia (https://www2.gov.bc.ca/gov/content/education-training/k-12/teach/resources-for-teachers/digital-literacy)

Disinformation: false information which is deliberately intended to mislead—intentionally misstating the facts.

Source: American Psychological Association (https://www.apa.org/topics/journalism-facts/misinformation-disinformation)

Health data literacy: having the skills to: understand information presented in various forms (written, media, digital, etc.); evaluate data to spot when it's used in misleading and wrong ways; collect and handle data that's relevant to specific situations; use data to make decisions about personal and public health; extract useful information from data. Health data literacy helps individuals and communities use data to make informed decisions about health. It gives people the power to understand and use information effectively

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023)

Health literacy: the ability to understand, communicate and use health information to make informed decisions about health

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023), World Health Organization (2023) (https://www.who.int/news-room/fact-sheets/detail/health-literacy)

Information accessibility: information that can be easily understood by the person or group that it is meant for

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023)

Information credibility: the extent to which one believes information to be true

Source: Adapted from McKnight & Kacmar (2007). Factors and effects of information credibility. Conference Proceedings - 9th International Conference on Electronic Commerce. (*https://doi.org/10.1145/1282100.1282180*)

Misinformation: false or inaccurate information (i.e., getting the facts wrong)

Source: American Psychological Association (*https://www.apa.org/topics/journalism-facts/misinformation-disinformation*)

Public trust (institutional trust or public confidence): refers to the extent to which the public believes institutions, organizations, and individuals who hold positions of authority, power or responsibility act in a way that serves and protects the public's interests

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023), Kerasidou, A., Kerasidou, C. Data-driven research and healthcare: public trust, data governance and the NHS. BMC Med Ethics 24, 51 (2023). *https://doi.org/10.1186/s12910-023-00922-z*; van der Sloot, B., Jeymolen, E. Can we trust trust-based data governance models? Data & Policy, 4 (2022). DOI: *https://doi.org/10.1017/dap.2022.36*

Public trust related to data: how much the public believes that groups or individuals in positions of authority are handling personal and population data responsibly, ethically, and legally. This includes collecting, managing, analyzing, and sharing data in ways that align with the public good and the goal of fairness

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023)

Reliability: the ability of governments to minimize uncertainty in the economic, social and political environment of their citizens, and to act in a consistent and predictable manner

Source: Organisation for Economic Co-operation and Development (2013). Trust in government - Assessing the evidence, understanding the policies. *https://one.oecd.org/document/GOV/PGC(2013)1/en/pdf*

Transparency: when public institutions are open about their decisions and actions, and proactively release non-personal data to the public, to help counter misinformation and build trust

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023)

Trustworthiness: the quality of being deserving of trust. A trustworthy organization is relied upon by people. In uncertain circumstances, people are likely to take a leap of faith and trust in that organization's decisions

Source: Federal, Provincial and Territorial Public Trust and Data Literacy Working Group (2023)