



WDS response to the Foundational Paper on Public Trust and Data Literacy - Health Data Glossary Public Consultation

Deadline: February 14, 2025

Website Details:

<https://www.hdrn.ca/en/news/health-data-glossary-promotes-public-trust-transparency/>

Overview:

In an effort to build trust in health data and improve data literacy among members of the public, HDRN Canada is developing a health data glossary in collaboration with the Public Health Agency of Canada (PHAC). The goal of the glossary is to standardize terms used to discuss and describe health data to promote common language across a range of users, including researchers, policymakers and the public.

How to participate:

1. Complete [public consultation survey](#). Proposed glossary terms are embedded within the survey.

Questions

Thank you for your interest in reviewing this health data glossary, which is a critical component of a foundational paper on public trust and health data literacy being developed by Health Data Research Network Canada (HDRN Canada) in collaboration with the Public Health Agency of Canada (PHAC). An accompanying glossary will ensure that the included terms are broadly understood in the context of the paper, and it is also intended to be used as a standalone resource to ground health data initiatives in a standardized framework.

Following an initial consultation focused on the terms themselves, we are now seeking feedback on the **associated definitions** of the proposed terms, with a focus on plain language and clarity. The definitions are divided into **9 separate groupings** (listed below), and you may choose to respond only to whichever terms and/or groupings of terms that you wish to - no responses are mandatory. To skip a grouping, scroll to the bottom of the page and press "next". The full survey should take you about 30-40 minutes to complete. If you have any questions or concerns, please reach out to julia.burt@hdrn.ca



Groupings:

Group 1: **Data management** (terms related to how data are collected, used, stored and governed, e.g., data linkage, data governance)

Group 2: **General data terms** (e.g., types of data)

Group 3: **Health system** (data-related and broader health system terms e.g., electronic health records, primary care providers)

Group 4: **Privacy** (terms related to consent, anonymization, etc.)

Group 5: **Public and patient engagement** (methods and related concepts e.g., patient-oriented research, social licence)

Group 6: **Research/analytics** (terms related to artificial intelligence)

Group 7: **Security** (data security terms e.g., firewall, data suppression)

Group 8: **Health equity and social justice** (data-related and broader health equity/social justice terms e.g., accessibility, racism, data justice)

Group 9: **Other related terms** (terms related to the paper's focus on trust and data literacy e.g., trustworthiness, mis- and dis-information, transparency)

WDS International Program Office

c/o WDS-IPO @ UT-Oak Ridge Innovation Institute

University of Tennessee, Knoxville

Tel. 865-974-7909

wds-ipo@utk.edu | www.worlddatasystem.org



Group 1: Data Management

Access control: a procedure to establish who is permitted to see or use the data, which is often reinforced through security measures

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Access control is more of a set of definitions or rules that outline the connection between data objects, usernames, and permissions.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

CARE principles: Complementary to the *FAIR 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.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Under Collective Benefit, the term "shall be" is missing. It should read "Data ecosystems shall be designed and function ..."

Common data model: provides a common language to govern data across all jurisdictions, standardizes the structure and content of health data to enable various data uses, and allows data and its meaning to be shared consistently across jurisdictions

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The definition should also include that a model is a structure or schema for a dataset



Data collection: act or process of creating, recording, acquiring, or linking to data or type of data. Includes the specification of file formats, naming conventions, data structure, and what provisions have been made for version control, data re-use, sharing, and long-term access to the data. Data collection can be used in the context of research, ongoing surveillance and tracking, and to inform health care or policy decisions

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The version control, data re-use, sharing, and long-term access provisions are later stages of the data life cycle (not part of the collection).

Data controller: a legal person, business, enterprise, public authority, agency or other body that determines the purposes and means of processing personal data. In other words, the data controller decides the how and why of a data processing operation.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Data ethics: a branch of ethics that looks at how data may affect people and society, with an aim to ensure it is used for morally just purposes

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Missing the mention of data processes such as collection, storage, accessibility, ownership rights, and uses that have the potential to affect people and society. The definition should also explicitly mention that it includes concerns about using data to train algorithms and AI.

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



Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The term "diverse arrangements" may not be easily understood by members of the public. The definition should be clearer: Data governance is about exercising authority, control, and shared decision-making regarding all types of data assets.

Data institution: a group or organization that manages data

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: At least some data institutions do more than manage data. This is a rather vague term, as nearly all organizations can claim to manage data to some degree. What value does this term offer, or what is its intended use?

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Data integrity also includes completeness and validity of data

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



Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: A data repository is the combination of digital infrastructure, personnel, policies and practices that govern the curation and preservation of data. Data repositories may be discipline-specific, institutional, regional or general.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The data retention policy defines how long the data will be kept and maintained, ie needs to consider both the data's value over time and the subjective data regulations. The current definition could be interpreted that some data is kept indefinitely when that usually is not the case.



Data sharing: the practice of exchanging data between individuals or groups to support health programs and services

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: We suggest revising the definition to “The practice of exchanging data between individuals, groups or machines, to support health programs, services and research.”

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The methods and systems used to securely save and preserve collected data in a way that ensures its integrity over time. This includes both digital and physical storage solutions, which should be designed to meet ethical and legal requirements for maintaining data privacy and security. While storage solutions may provide bit-level preservation solutions, active preservation for long-term accessibility requires re-appraisal and activities such as format migrations and metadata schema updates, such that access can continue to be guaranteed.

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other: If this definition only encompasses human health, the term entity might be too broad and thus more prone to misinterpretation. Consider stating "an individual to whom data relates" instead.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Consider revising the definition: "A large database on a particular topic, sometimes formed from more than one data source, and accessible by many users."

Database: a structured set of data held in a computer, especially one that is accessible in various ways

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The term "structured" can be misinterpreted to refer only to relational databases. Consider referencing CODATA's definition: "A Collection of data that is organized according to a conceptual structure/model describing the characteristics of these data and the relationships among their corresponding entities, supporting one or more application areas."



Disaggregated data: data that has been taken from aggregated data and broken down into smaller information units. Collective or aggregate data can be broken down or disaggregated, for instance, by: gender, urban/rural location, income, socio-cultural or ethnic background, language, geographical location, political units, or age groups. Fully disaggregating data helps to expose hidden trends, it can enable the identification of vulnerable populations, or it can help establish the scope of the problem and can make equity-deserving groups more visible to policy makers

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Not everyone may understand the terms 'aggregated data' and 'information units'. Consider just focusing on the fact that it's a dataset divided into smaller parts. The example is still helpful.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Should include multiple machines.

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.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The FAIR principles are not a standard and are not just about reuse. They are rather a set of guidelines to ensure that research data and its metadata are findable, accessible, interoperable, and reusable by both humans and machines.

The Findable definition should include the fact that the metadata should be clear and consistent and include unique dataset identifiers, Additionally, consider replacing 'automatic' with 'automated'.

The Accessible definition should be rephrased as it's more about the data than the user. Perhaps the 'data is retrieved through a standardized protocol, with the metadata including access information such as any restrictions or licensing requirements.'

The Interoperable definition should be rephrased, It's not that the data needs to be integrated with other data, Rather the data should be able to be combined with data from other sources without significant effort from the researcher, through the use of common formats and vocabularies. The data is also machine readable allowing for automatic processing and analyzing.

The Reusable definition should include that the metadata should have information regarding the dataset origin, quality, limitations, and usage rights that outline how exactly the data can be used and shared.

Federated analysis: analysis of data across multiple datasets that are stored in different locations (i.e., distributed data), without moving or combining the data into one place. For federated analysis to work, the data need to be connected in some way - for example, by using a common format or through statistical methods. Federated analysis is especially valuable in today's complex data environment, where information is stored



in many different places and formats. It makes it possible to collaborate more effectively within Canada (where each province and territory collects and governs data differently), and internationally (where sharing data across borders can be challenging)

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: It may be advisable to add some language that federated data systems facilitate federated analysis in a more streamlined way. (e.g., harvesters that pull data from disparate sources with an intention to deliver data in a common format and metadata schema).

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 Researchers 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?

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Not everyone may understand the defining question for Outputs. May want to consider something similar to the one on the fivesafes.org website, "Is the confidentiality maintained for the outputs?" Also, the addition of 'lawful, ethical, and sensible" should be included in the defining question for Projects.



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.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The phrase "operationalizing health data governance" may not easily be understood by the general public.



Health data stewardship: a formal discipline for ensuring health data is managed and used for the public good and for fostering trust in data practices

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Consider rephrasing "capacity for seamless sharing of" to "ability to easily share" for better general public understanding.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The term and definition are mismatched. The term suggests the definition is more general. The definition suggests the term is specifically regarding health and medical registries, eg patient registry, medical registry, clinical data registry, and disease registry.

Surveillance (health): a form of tracking and predicting health events through the collection, analysis and reporting of data. Data collection is often in real-time to identify, and inform actions to diminish, public health events

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Consider replacing "diminish public health events" with "reduce significant impacts of public health events" to be more easily understood by the general public.



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



Group 2: General data terms

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. Administrative health data is generated through the routine administration of health care programs. Administrative health databases, developed by provincial governments as a result of universal medical care insurance, are designed to collect and store this type of data.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Big data: semi-structured and unstructured data in a wide variety of formats, in large volumes, and produced at high speed. "Big" data, by virtue of their volume, velocity, or variety cannot be easily stored or analyzed with traditional methods. Things like sensors, Internet of Things (IoT) devices, and social media all create "big" data



Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The first part of the definition disregards the structured form that big data can take on. Instead, the first sentence should simply state big data are datasets containing large volumes of data produced at high speed that vary in structure and format.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The sentence "a large repository of data on a particular topic, sometimes formed from more than one database, and accessible by many users", seems beyond the scope of a data definition and more fitting with the above data collection definition. However, we'd further note that data may be collected for other purposes such as troubleshooting, auditing, and decision-making.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Suggest rephrasing to "from its creation to its long-term preservation or ultimate disposal"



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Data literacy also involves the understanding of data practices, interpreting and translating the data into useful information, and the ability to recognize misleading data

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition should include the fact that data quality measures the condition of a dataset, often using characteristics such as completeness, consistency, timeliness, validity, accuracy, and integrity. As stated in the CODATA definition data quality is "Perception or assessment of a dataset's fitness to serve its purpose in a given context."

Genomic data: a set of data or instructions that is produced by sequencing a human genome

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Not everyone may understand the term 'sequencing a human genome'. Consider



replacing it with 'analyzing a human's DNA structure'

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.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Health information: A group of health data that collectively carry logical meaning.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No



Other: Needs additional detail.

Meta-data: 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition can be simplified into metadata is data or information that describes other data to improve the managing, tracking, understanding and use of the specific data.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Real world data (RWD): a category of data relating to patient health status and/or the delivery of health care routinely collected from a heterogeneous patient population in an operational health setting

Do you agree with this definition? If not, explain why in the "other" box

Yes



- No
- Other: Some members of the general public may not understand the term 'heterogeneous patient population'. Additionally, if this definition is specific to healthcare, the term should be updated accordingly, eg real-world patient data or real-world health data.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Social services 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)

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other:



Group 3: 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)

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: EHR is more of a longitudinal collection of health information for patients and populations stored in a digital format.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes



- No
- Other:

Healthcare 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other: It's not clear what the online access grants. Consider rephrasing to something similar to 'an individual to safely and securely view, and sometimes manage their personal health information.'

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Quality of care: care that is safe, timely, efficient, effective, equitable, integrated and patient-centric

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition is better aligned with the term quality care rather than quality of care. As per the WHO, Quality of care is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes."

Remote patient monitoring: the use of digital devices to monitor a patient's health. Using remote monitoring, patients and providers can manage acute and chronic conditions by collecting and sharing health information

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Should be clear that this is done in between visits or without the patient needing to visit the health provider.



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The word participants is vague and has more room for misinterpretation. Consider replacing participants with health providers and patients.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



WDS International Program Office
c/o WDS-IPO @ UT-Oak Ridge Innovation Institute
University of Tennessee, Knoxville
Tel. 865-974-7909
wds-ipo@utk.edu | www.worlddatasystem.org



Group 4: 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes



- No
- Other:

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)

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Confidentiality: the protection of data from unauthorized access and disclosure

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Might be simpler to phrase it as 'the removing the right to have, use, or share data over time'.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition should include that the process retains the reusability of the data and depends on who will have access to the data in the cases where it will be shared.

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



Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: In the current definition it is ambiguous how much identifying information needs to be removed. De-identified data is a dataset where enough identifying information is blocked or removed so that the remaining information does not and cannot be used to identify an individual.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Identifier: an element of data that helps identify a person

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The definition should include that identifiers are either direct (eg. fingerprints, personal health number, or full name) or indirect (eg age, address, health condition).

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



Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Not always unwritten. Consider a definition similar to: a patient's actions, circumstances, or communication suggest they agree to the collection, use, and sharing of their personal health data, even if they haven't explicitly given permission.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition is missing the part about participation being completely voluntary, without external influence, and having the information to drop out at any time.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This term is more about data that can be used alone or in combination to identify an individual.

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other: The first part of the definition should include a person's right to control the access to their personal information.

The Personal Information Protection and Electronic Documents Act (PIPEDA): 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other:



Group 5: Public/patient engagement

Community governance tables: decision-making bodies that provide oversight of engagement processes, data collection, management, analysis and use, and make determinants on applications for data access in Black communities as part of the Engagement, Governance, Access and Protection Framework (EGAP)

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition does not emphasize that this specifically applies to black communities as per the EGAP framework. Consider rewording so that the mention of EGAP is near the beginning to make the specific application clearer for the reader.

Community-based participatory research: 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition implies that this group only exists among those who participate in research or that they all participate in research. The definition should be rephrased to state that they are valuable resources that can be drawn upon to ensure research is patient-centric.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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).

Do you agree with this definition? If not, explain why in the "other" box

- Yes



- No
- Other: Consider saying 'meaningful involvement' instead of 'two-way discussions' since engagement can take on more forms than just discussions.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



Group 6: 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Consider slightly rephrasing to make the definition easier for less technical people to understand and acknowledge that algorithms exist outside the field of information technology. Perhaps similar to "a set of rules or instructions for solving a problem or finishing a task. In information technology, these play a major role in automated systems"

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The definition should include the capability of AI programs to self-improve over time and be capable of efficiently process, analyze, and identify patterns in large datasets.

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



Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Rephrasing would make the definition easier to understand. Consider “a technology that uses a set of rules or calculations to help or even replace human judgment.”

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The scope of clinical research is not limited to disease and injury. Consider “Clinical research is a type of research that aims to improve health and well-being across all stages of life. This includes finding better ways to prevent, diagnose, and treat diseases and injuries, as well as improving rehabilitation, palliative care, and the overall delivery of healthcare. Clinical research is essential for discovering new knowledge, developing effective treatments, and improving health outcomes for individuals and populations.”

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Digital health is not just an IT system or device. It's more of a discipline that makes use of IT systems and devices. Consider "the use of technology to improve health and wellness. This includes a wide range of tools and applications, such as wearable devices, mobile apps, telehealth, and electronic health records. Digital health empowers individuals to take control of their health, connects them with healthcare providers, and helps improve the quality and efficiency of care."

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Without the inclusion of the examples provided on the Government of Canada website, this seems like it could be confusing. Consider rephrasing to be similar to the definition on the Indigenous Services Canada website: "eHealth is the use of information and communication technologies to support, educate, inform and connect health care professionals and the people they serve."

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes



- No
- Other: The definition should include that computers are trained to sort information, along with the ability to identify patterns and make predictions, and that the datasets are often large.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The use of 'healthcare application' is too vague and may not be easily understood by the public. Consider rephrasing to be more similar to the definition on Canada's Drug Agency's website: "evidence about the use, safety, and effectiveness of a medical product, technology, or drug that is based on or derived from analysis of data generated in a real-world health care setting".

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



Group 7: Security

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The last part of this definition is out of place. Consider rewording the definition to be "a method or methods used to protect data from destructive forces and unwanted actions of unauthorized users". Additionally, the definition could include that data security is applied or lasts throughout the data lifecycle and examples of both threats (hacking attempts, data breaches, and exploitation) and examples of data security (data encryption, firewalls, virus protections, and authorizations).

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Encryption is specifically about scrambling or transforming sensitive data or information into a secret code that only authorized users can solve.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes



- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition is a bit too vague. It does not include accessing data without explicit permission, using data other than the intended purpose, and sharing of data without proper permission.



Group 8: 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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)

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other: This definition is confusing and does not clearly explain the relationship between colonialism and colonization. Consider rephrasing so that it is clear that colonialism is the system of oppression that enables colonization.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

WDS International Program Office

c/o WDS-IPO @ UT-Oak Ridge Innovation Institute

University of Tennessee, Knoxville

Tel. 865-974-7909

wds-ipo@utk.edu | www.worlddatasystem.org



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes



- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

OCAS: principles of data governance that describe how Métis peoples' 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.

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: Based on a Google search, this text seems to be copied from the University of Manitoba document and without the same context, it seems like ownership only applies within the MPDB. Consider rephrasing the definition to be higher level or include the mention of the Manitoba Metis Federation.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The definition is missing environment as a social determinant

Sociodemographic data: data about the social and demographic characteristics of a specific group of individuals, such as age, gender, education level, and income. Collecting sociodemographic data collecting sociodemographic data can organizations to better understand the populations they serve and how health care access and utilization differ across equity-deserving groups

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: It seems some typos and words are missing in the middle of the definition, the phrase "Collecting sociodemographic data collecting sociodemographic data can organizations to better understand" does not make sense.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



Group 9: Other related terms

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This definition seems to be duplicated and also in section 6.

Digital health literacy: the ability to search for, locate, understand and evaluate health information from electronic sources and apply the knowledge gained to address or resolve a health issue. This refers to the application of health and digital literacy skills to confidently and accurately use tools and information to manage health-related issues

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: It is unclear what "This" in the second sentence references.

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other: Consider rephrasing the definition so that it's more about using the devices confidently and effectively, and broadening the scope to include using the tools for critical evaluation, communication, and creation.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

Health data literacy: having the skills to: understand information presented in various forms (like 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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This has too much detail. Need to rephrase it to be simpler. Consider referencing the Health Data Collective's definition of "the ability to understand, interpret, and use health data effectively. This includes: understanding key terms, interpreting data, and making decisions."



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The definition should be rephrased to be more about information being available and useable by everyone, regardless of any abilities or disabilities.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: This implies that the term is solely subjective when there are other objective factors, such as accuracy, evidence, and source expertise, that are also important.



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: To clearly separate this from the term disinformation, consider adding that it is false information shared, regardless of intent to deceive.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:



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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other: The definition should also consider the government's ability to fulfill promises, act with integrity, be transparent, and be responsive. The term is also confusing as from a data perspective, reliability also means the probability that the same results would be observed with data collected from another population sample.

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

Do you agree with this definition? If not, explain why in the "other" box

- Yes
- No
- Other:

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

Do you agree with this definition? If not, explain why in the "other" box



- Yes
- No
- Other: Suggest rephrasing to “the quality of being deserving of trust through demonstration of evidence, transparency and honesty. A trustworthy organization is credible and dependable. In uncertain circumstances, people are thus likely to take a leap of faith and trust in that organization's decisions.”