

Health Data for All of Us:

Sharing Ideas & Priorities



Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

Glossary of Terms

Health Data Research Network Canada (HDRN Canada)

HDRN Canada is a non-profit corporation that facilitates data sharing and data access for health researchers conducting multi-regional research. HDRN Canada connects individuals and organizations across the country to share expertise, identify opportunities for collaboration, and foster innovation in data access and use in ways that respect privacy law, public expectations and Indigenous data sovereignty. The network includes provincial, territorial, and multi-regional organizations that hold and manage health data.

Health data

Health data is a general term that can include information about the health status of individuals and the health services that individuals receive. Examples of health data include visits to health care providers or health facilities, prescription medications, laboratory test results, demographic, and social determinants of health.

Social determinants of health

Social determinants of health refer to a range of social and economic factors that shape the health of an individual and the population. These factors include income, education, employment, housing, and experiences of discrimination, racism and historical trauma.

Administrative health data

Administrative health data are generated through routine encounters with health care programs and services. Examples include information generated through physician visits, hospital admission and discharge data, care homes, and prescription medications. This is different from clinical data which pertains to patient-level medical information.

De-identified data

De-identified data refers to data from which all identifying information has been removed. This is different from anonymized data (the difference will not be discussed).

Health data ecosystem

Health data ecosystem refers to the technological infrastructure and governance structure that supports the environments in which health data are generated, stored, analyzed, shared and used.

Data-intensive health research

Data-intensive health research is a form of research that uses population health data for large-scale data linkage (bringing de-identified information on the same individual from different sources together) and analysis.

Social licence

Social licence is the perceived approval or consent of the public that grants permission for organizations to perform certain kinds of work. In the context of health data, this term describes the acceptable uses and users of health data that members of the public support.

Health equality

Health equality means that every individual is given the same resources or opportunities.

Health equity

Health equity means that every individual has a fair opportunity to achieve optimal health, regardless of age, income, education, or any other social determinants of health.

Equity-deserving groups

Equity-deserving groups are communities that experience significant and collective barriers due to disadvantage and structural discrimination, and actively seek social justice and reparation. This term is gradually replacing “equity-seeking groups”.

Disaggregated data

Disaggregated data are data that have been broken down into smaller information units. In the context of health data, this means breaking down individuals’ policy-relevant attributes such as gender, language, ability, ethnicity, and Indigenous identity.

Indigenous Data Sovereignty

Indigenous Data Sovereignty refers to the right of Indigenous peoples to govern the collection, ownership, and application of data about Indigenous communities, peoples, lands, and resources.



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