



DATA GLOSSARY FOR NONPROFITS

Data has become a vital part of nonprofit operations and engagement. It is a tool that can help us tell our stories and make sense of our world, helping us build a plan to meet our missions and better support our communities.

This glossary defines and explains dozens of terms related to data and data management that are relevant to the nonprofit sector, quoting a specific source from the web, which you can follow for more information. It is not intended to be a complete document; as we at ONN come across new terminology or as language around data shifts, we will try to update this glossary to reflect those changes.

Suggestions? Comments? Contact us: info@nonprofitresources.ca

Administrative data: "operational records that governments and service providers keep on the people they serve. Administrative data can provide rich information about communities, creating new opportunities for outcomes evaluation, service delivery, and evidence-based advocacy. Examples of administrative data include: physician visit records, high school completion records, birth and death records, and tax returns." <u>Data Policy Coalition</u>

Aggregated data: "summed and/or categorized data that can answer research questions about populations or groups of organizations. The data has been compiled from record-level data to a level that ensures the identities of individuals or organizations cannot be determined by a reasonably foreseeable method." What is aggregate-level data?

Artificial Intelligence (AI): "enables machines or the in-build software to behave like human beings which allows these devices to perceive, analyze data, reason, talk, make decisions and act." <u>Information and Communications Technologies Canada</u>

Anonymized/anonymous vs de-identified data:

- "De-identification is the general term for the process of removing personal information from a record or data set. De-identification protects the privacy of individuals because once de-identified, a data set is considered to no longer contain personal information." Information and Privacy Commissioner of Ontario
- "Anonymizing data removes all links to the individual, as well as links across
 datasets. However, as with all de-identification methods, it may still be possible to reidentify individuals through indirect identifiers and/or links to related datasets."
 University of British Columbia Library: Anonymization.

Application Program Interface (API): "a tool to build software applications. APIs specify ways for software to access a dataset." <u>Emerging Data Practices for the Philanthropic Sector</u>, PFC. A good API makes it easier for developers to connect data from multiple sources to build new applications.

Automated Decision System (ADS): "computer systems that automate part or all of an administrative decision-making process." <u>Statistics Canada</u>

Awarded Grant data: "refers to the records of grants given by funders. At its most basic, it consists of dollar values, recipient, funder, and a date. However, as more information is added, grant data can become very powerful. Adding grant descriptions, for example, can allow grant data to be used for tracking the types of projects going on in the sector." Emerging Data Practices for the Philanthropic Sector

Data: "facts, figures, observations, or recordings that can take the form of image, sound, text or physical measurements." <u>Statistics Canada</u>

Data dashboard: A way of visualizing data, often to show progress or status, how or whether objectives are being met, or to help users see connections or patterns in what is being measured. "[A] dashboard communicates key performance indicators (KPIs) to a specific target audience." <u>CARL Data Visualization Toolkit</u>.

Data deficit: "a lack of statistical and other information, often understood in relation to a specific sector, industry, or area of knowledge." <u>The Philanthropist</u> For instance, a lack of data on specific communities, such as <u>urban Indigenous</u> People, <u>LGBTQI2S</u> people, and other groups, can make it difficult to plan community-level interventions.

Data equity: "refers to the consideration, through an equity lens, of the ways in which data is collected, analyzed, interpreted, and distributed. It underscores marginalized communities' unequal opportunities to access data and, at times, their harm from data's misuse." <u>Data Equity: What Is It, and Why Does It Matter?</u>

Data infrastructure: can be understood as physical and virtual supports, as well as organizational processes and types of knowledge needed to manage data. "Data infrastructure consists of:

- Data assets, such as datasets, identifiers, and registers.
- Standards and technologies used to curate and provide access to data assets.
- Guidance and policies that inform the use and management of data assets and the data infrastructure itself.
- Organizations that govern the data infrastructure.
- The communities involved in contributing to or maintaining it, and those who are impacted by decisions that are made using it." <u>State of Open Data</u>

Data Integration Units (DIUs): Part of the Ontario **Freedom of Information and Protection of Privacy Act (FIPPA)** sets out ways "de-identified" data (data that can't be used to identify specific individuals) can be shared across provincial ministries and other publicly funded organizations. This is to be done through bodies called **Data Integration Units**. Ontario Public Service Data Integration Units

Data linking: "used to bring together information from different sources in order to create a new, richer dataset." <u>Data Linking Information Series Sheet 1: What is data linking?</u>

Data sets: "groupings of data that have common definitions of observation units and variables." <u>Statistics Canada</u>

Data (publishing) standard: "a specification for a common type of data, which describes what information to publish, how to structure it, and the format in which to release it. These standards can be very complex depending on the subject, but a simple example is an agreement such as requirements gathering and specifications to always list the date a grant was made as the first column in a spreadsheet, in the YYYY-MM-DD format." Emerging Data Practices for the Philanthropic Sector

Data sovereignty: "the concept that information in binary form [essentially raw or unconverted] is subject to the laws of the nation-state where the data is located. The geographical locations where data can legally be stored - as specified by a business, government or industry body - is called *data residency*. The regulations that specify how data can be collected, processed, stored or transferred within a specific nation-state are referred to as *data localization* laws." <u>Data Sovereignty</u>

Digital deficit/divide, also known as digital poverty: "the gap that exists between individuals who have affordable internet access and the skills to use modern information and communication technology and those who do not." <u>Mapping Toronto's Digital Divide</u>.

Digital literacy and access are strongly connected to other social determinants of health. "[G]reater reliance on digital tools has the potential to increase disparities between those who have skills and access to digital tools and those who do not and thereby existing health disparities." <u>Digital inclusion as a social determinant of health</u>

Disaggregated data: "has been extrapolated (taken) from aggregated data and divided 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, or age groups." The lmportance-of-Disaggregated-Data

Freedom of Information and Protection of Privacy Act (FIPPA): "applies to Ontario's provincial ministries and most provincial agencies, boards, and commissions, as well as community colleges, universities [and Ontario Health and other public "institutions" under the Act]. The Act requires that the government protect the privacy of an individual's personal information existing in government records. It also gives individuals the right to request access to government-held information, including general records, and records containing their own personal information." Information and Privacy Commissioner

General Data Protection Regulation (GDPR): "privacy and security legislation passed [in 2018] by the European Union (EU) that imposes obligations onto organizations anywhere, so long as they target or collect data related to people in the EU." What is GDPR, the EU's new data protection law?

Homeless Individuals and Families Information System (HIFIS): "a web-enabled Homelessness Management Information System (HMIS) that can provide communities with the information they need to further their efforts with addressing homelessness. It allows multiple service providers from the same geographic area to implement coordinated access using real-time information about people experiencing homelessness and the resources they need to find and keep a home." Homelessness Learning Hub

Indigenous data sovereignty: "is linked with Indigenous peoples' right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as their right to maintain, control, protect and develop their intellectual property over these." <u>Indigenous Data Sovereignty: Towards an Agenda</u>

Information: "is made up of data. Information is data that has been processed or analyzed within a context to make it useful. In this way, data are the facts that create information." An Open Future: Data Priorities for Nonprofits

Information and Communications Technology: "includes technologies such as desktop and laptop computers, software, peripherals and connections to the Internet that are intended to fulfil information processing and communications functions." <u>Statistics</u>
<u>Canada</u>

Metadata: "data that defines and describes other data and it is used to aid the identification, description, location or use of information systems, resources and elements." <u>Government of Canada</u>

Municipal Freedom of Information and Protection of Privacy Act (MFIPPA): "the local government equivalent of FIPPA and covers municipal institutions such as municipalities, cities, towns, school boards, police services and many other local government entities." Freedom of Information and Protection of Privacy Manual

Open data: "data that can be freely used, re-used and redistributed by anyone - subject only, at most, to the requirement to attribute and share alike." <u>Open Data Handbook</u>

Personal Health Information Protection Act (PHIPA): "sets out rules for the collection, use and disclosure of personal health information. These rules will apply to all health information custodians operating within the province of Ontario and to individuals and organizations that receive personal health information from health information custodians." A Guide to the Personal Health Information Protection Act

Personal Information Protection and Electronic Documents Act (PIPEDA): "applies to private-sector organizations across Canada that collect, use or disclose personal information in the course of a commercial activity. Organizations covered by PIPEDA must generally obtain an individual's consent when they collect, use or disclose that individual's personal information." <u>PIPEDA in Brief</u> Nonprofits may be subject to the Act if they engage in "commercial activities" (<u>Why Charities and Nonprofits Should Comply with PIPEDA</u>) - while proposed legislation in Ontario could regulate nonprofits and charities similarly to the private sector (<u>Modernizing Privacy In Ontario</u>)

Platform: "a group of technologies that are used as a base upon which other applications, processes or technologies are developed." <u>Platform</u> Some platforms are proprietary (controlled by a single (often for-profit) organization or provider, like <u>Google</u>), while others are open or cooperative (like <u>Mozilla's</u> Firefox web browser, or the home-sharing platform <u>Fairbnb</u>).

Registries: "live lists of data managed by one custodian from the government organisation responsible for maintaining the register's data. Each register is the most reliable list of its kind. Creating a register means that the list of data becomes easier for others to find and use." <u>UK Government Digital Services (GDS)</u>

Registry, Business: "An online portal that allows businesses and nonprofits to incorporate, register, and update information." <u>Ontario Business Registry</u>

Service Provider/Consumer Electronic Service Provider (defined in PHIPA): "a person who provides electronic services to individuals at their request, primarily for the purpose of allowing those individuals to access, use, disclose, modify, maintain or otherwise manage their records of personal health information [PHI]." Personal Health Information Protection Act, 2004 "Potential examples of such consumer electronic service providers could include entities who provide services related to the processing of PHI to individuals through their mobile apps, online portals or smart devices providers." Amendments to Ontario's health information legislation bring new obligations and penalties