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Public Trust, Literacy and Health Data Foundations in Canada

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Public trust in governments, organizations and institutions that collect, protect, share and use health data is critical. Health data refers to information that describes a person's health, their health care or anything about their health status or condition. It can be about individuals (personal health data or information) or about populations (population health data). Access to timely and reliable health data, by health care providers, systems and patients, is the foundation of providing high quality health care services to individuals and public health services to populations. Access to health data is also critical for health system planning, management, public health, evaluation, research and innovation. These uses often involve combining or linking data sets, and in the case of research and innovation, includes interests from the public, non-profit and private sectors.

Canada's constitutional federation gives power over large parts of public health and health care to provinces and territories. This creates a fragmented health data ecosystem. New federal funds for provinces and territories were negotiated with provinces and territories, in exchange for commitments to modernize health systems with standardized health data and digital tools. Bi-lateral agreements with provinces and territories were aligned with the Pan-Canadian Health Data Charter which outlines a shared vision for health data in Canada. The 10 principles of the Charter put people and populations at the centre of health data management. The Charter starts with principles of person-centred data design, inclusive data governance, and distinctions-based approaches to data sovereignty as defined by First Nations, Inuit and Métis Peoples, their governments, representatives and expert/technical organizations.

Building on the Charter, this paper on public trust and health data expands on these principles. It highlights important considerations for public trust and identifies the risks and benefits of data sharing as well as the protections interest holders identify to maximize benefits and minimize risks (noting that data sharing does not necessarily imply moving data, and that we use the term interest holders as an alternative to stakeholders). It includes considerations around the uses of health data in clinical care and patients' access to their own health data (often referred to as "primary uses"), as well secondary uses that include but are not limited to health system planning, assessment, evaluation, improvement, research and innovation.

This work is meant to help different levels of government and health system organizations work together to earn public trust in and understanding of health data. It can also be useful to other organizations, both inside and outside Canada, that hold and use health data.

We reviewed relevant grey (e.g., policy reports, working papers, guidelines) and peer-reviewed literature, held focus groups and interviewed key informants. Focus groups and interviews add perspectives from individuals who have expertise related to public trust, public engagement and health data protections, and those who have experience as users of healthcare and public health services. Opportunities for review and comment on key paper materials were included at several different points in the process, including two rounds of public consultations on the health data glossary.

We find that trust is complex, and public trust in health data collection, sharing and use can fluctuate depending on many factors, including the broader political and social context in which health systems operate. Data literacy should be viewed as one of several foundational elements that create the possibility of trust, alongside other important elements, such as transparency and public benefit. Trust comes from trustworthy practice and requires reciprocity. Organizations and institutions that collect, use and share health data need to demonstrate trustworthy practices that are guided by well-developed principles, including those identified in the Pan-Canadian Health Data Charter.

We identify six recommendations for trustworthy practice that include: ongoing, inclusive public engagement; reconciliation that includes respect and support for Indigenous data sovereignty; the alignment of health data

use with public benefit; clear rules and supports for data sharing, access and use; technology standards for safe and seamless data sharing; and transparency, communications and reciprocal learning.

The multitude of interests involved in both primary and secondary uses of health data make clear that there is no simple one-size-fits-all solution for trustworthy practices. The processes used to govern data collection, protection, sharing and use must align with their intended purpose. They will need to evolve over time, as data, technology, analytic approaches, and public expectations also evolve. Public trust must be earned and can easily be lost. Trust is based on relationships that are mutual and require ongoing attention.

Trustworthy practices should be transparent, and part of that transparency is showing accountability for both successes and failures in meeting the intended practices. Trust itself should be measured and monitored over time, as part of an ongoing dialogue between the public and the governments, institutions and organizations that have responsibility for health data.

Earning and keeping public trust is both a laudable and achievable goal. It will require changes in practice, including adopting new models of data stewardship and creating more interoperability in technologies, policies, standards, and relationships across organizations and geography. The principles of the Health Data Charter provide a common goal, and trustworthy practices can help earn the public trust that will be essential for getting there.

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