Public Trust, Literacy and Health Data Foundations in Canada

A foundational paper developed by HDRN Canada in collaboration with the Public Health Agency of Canada

Public trust in health data and data literacy have been identified as key priorities of governments across Canada. HDRN Canada, funded by the Public Health Agency of Canada, developed a foundational paper which identifies an **emerging set of principles-based recommendations for trustworthy health data practices**. Find the paper at *hdrn.ca* (available May 15, 2025), or email *info@hdrn.ca*.

Key Messages

> 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. 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*.

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We identify **six recommendations** for trustworthy practices 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.

Health data collection, sharing and use can result in significant benefits as well as risks. Trustworthy practices should focus on maximizing benefits while minimizing risks through proper protections and guardrails.

True person-centred health data, as outlined in the *Pan-Canadian Health Data Charter*, implies that a broad range of interests should have influence over health data design, access, sharing and use.

Transparency about trustworthy practices and accountability for those practices are essential to earning and maintaining public trust.

Principles-based recommendations for trustworthy data practices

Organize ongoing, inclusive **public engagement**

Create **technology standards** that will make data safe and sharing seamless

Support reconciliation, and support and respect **Indigenous data sovereignty**

Be **transparent** and create opportunities for **reciprocal learning**

Ensure health data use aligns with **public benefit**

Create clear **rules** and supports **for data sharing** and access and use

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