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Public trust, literacy and health data foundations in Canada

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Objectives

Public trust in health data and data literacy are identified as key priorities of governments across Canada. Health Data Research Network 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.

Method

The foundational paper was developed through a review of relevant grey and peer-reviewed literature. Two online focus groups (with 8 individuals each) and four online key informant interviews were conducted to add real-world perspectives from patient partners and people with expertise in relevant areas including data privacy, trust and Indigenous data sovereignty. Focus group and interview participants were identified based on previous engagements and working relationships with the study team. Honoraria were provided to patient partners. A health data glossary was developed from existing Canadian glossaries and two rounds of public review to accompany the paper.

Results

Through existing literature, underlined by feedback from focus groups/ interviews, we noted several well-developed principles associated with trust in primary and secondary uses of health data, including transparency and public benefit. Participants underscored the importance of distinguishing trust from related concepts (e.g., dependence) and highlighted that trust is not equal across sub-populations. Health data literacy was identified as one of several pre-conditions for earning public trust.

Five emerging recommendations for trustworthy data practices emerged, including: 1) putting people at the centre – prioritizing ongoing, inclusive public engagement; 2) supporting Indigenous data sovereignty and reconciliation; 3) ensuring alignment with public benefit; 4) using identified frameworks for health data sharing and use; and 5) creating transparent and ongoing methods of communications.

Conclusion

A common framework for earning public trust and enhancing health data literacy is essential for a consistent approach to policy development across Canada. This work aligns with priorities of Canadian governments, both informing a coordinated policy approach and serving as a public resource for understanding the Canadian health data landscape.

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