

Declaration of Personal Health Data Rights in Canada

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Introduction

Personal health data are key enablers of value-based healthcare. In Canada, there is inconsistent understanding and consensus among healthcare stakeholders, including patients themselves and data custodians from all sectors, about fundamental principles of personal health data, such as who owns the data and what are the associated rights that flow from data ownership. In an effort to build consensus on personal health data rights, patient groups created the Declaration of Personal Health Data Rights in Canada.

Methods

Through a patient and caregiver-led Data Working Group established from the fifth annual Patients Redefining the Future of Healthcare in Canada Summit in November 2019, a small group of people from diverse patient organizations, those with lived experiences as patients or as caregivers, including some with expertise in health analytics, decided to tackle the fundamental questions of “who owns personal health data” and “what does this mean for patients’ access to those data.” After a brief scan of relevant reports, national, provincial and European legislation, plus discussions with Canadian health law and privacy experts, they drafted the Declaration of Personal Health Data Rights in Canada. Incorporating feedback from patient, caregiver, and citizen groups, the Declaration is being finalized. The Working Group is next going to seek endorsement of the Declaration from diverse patient groups across Canada before engaging in knowledge mobilization with data custodians to build understanding and consensus.

Results

The Working Group determined that the Supreme Court of Canada has affirmed that individuals own their personal health data, while custodians possess the records (whether hard copy or digital). From that data ownership flows a series of eleven rights, namely: (1) to be informed; (2) to consent; (3) to access, portability, and correction; (4) to de-identification; (5) to benefit; (6) to object to processing; (7) to restrict processing; (8) to a complaint process; (9) to privacy and security; (10) to erasure; and (11) to engagement. The Declaration has received broad support from diverse patient groups across Canada.

Conclusions

This process has confirmed the confusion that exists around the fundamental ownership of data, which then lends itself to confusion about what rights and responsibilities apply and to whom. It has worked to co-create a consensus-building document to clarify these principles. Once the Declaration of Personal Health Data Rights in Canada are endorsed by patient groups from across the country, a knowledge mobilization plan that aims to reach key stakeholders from all relevant sectors across Canada will be co-developed and co-implemented in order to increase awareness and promote behaviour change among data custodians. Until greater trust with patients can be established and earned on an ongoing basis by data custodians from healthcare providers, governments, research institutions, and private corporations, the meaningful implementation of value-based healthcare will be challenged. With growing trust through good practices, personal health data will finally enable the greater uptake of PROMs and outcomes-based performance management that are vital to achieving value for patients across Canada.

Endorsements as of June 14, 2021

Organizations



Individuals

Alan Huang, Vancouver, British-Columbia
 Alies Maybee, Toronto, Ontario
 Amy Ma, Montréal, Quebec
 Andrea Redway, Ottawa, Ontario
 Gilles Caron, Mont-Tremblant, Quebec
 John Sawdon, Whitby, Ontario
 Margriet Eygenraam, Brampton, Ontario
 Michael Eygenraam, Brampton, Ontario
 Robin Sully, Ottawa, Ontario