



OFFICE OF THE
INFORMATION &
PRIVACY COMMISSIONER
for British Columbia

Protecting privacy. Promoting transparency.

A Prescription for Legislative Reform

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As Information and Privacy Commissioner for British Columbia, my role is to inform the public about their information and privacy rights, and bring forward issues and new developments affecting these important rights. Today I am issuing a special report, *A Prescription for Legislative Reform*, to promote an informed dialogue between patients, health practitioners, researchers, and government about the collection and use of personal information in the health care system.

This dialogue is urgently needed. While the drive to improve health outcomes and new technologies are creating new opportunities in the research and treatment of disease, government's current legal framework for the use of personal health information is strained by this new reality.

We are rapidly moving into the age of digital health care and electronic records. When a patient seeks care today, a digital medical history is likely at her physician's fingertips via a computer or mobile device. The results of her lab tests can be accessed online through a patient portal. She can track her own health and fitness with a wearable device that beams results to her smart phone. And for about \$1,000 her genome can be sequenced in a laboratory, identifying potential health risks and tailoring treatments to her unique genetic make-up.

Digitizing multiple facets of a person's health and storing them in databases creates the potential to improve patient care, but it also creates the potential for inappropriate use of data and improper access by those not authorized to see or use it. If expected privacy protections fail, patients will very quickly lose trust in the technology and in the health care system as a whole.

B.C. is one of the few provinces without comprehensive health privacy legislation governing the many generators of personal health information. Our legislation was designed for a paper-based system and health information governance is fragmented between more than a dozen separate laws. Some of the rules are difficult to understand, even by privacy and legal experts, because they are opaque, complex, inconsistent and incomplete.

For the public, this patchwork means a lack of transparency – those with questions or concerns about how personal health information is collected, used or disclosed must identify which one of B.C.'s laws and regulations applies to the personal health information in question.

Doctors treat the whole patient and not a specific condition; similarly, government needs to take a holistic approach to the collection, use, disclosure and protection of personal health information and patient data by introducing a health information law with clear and consistent rules for the public and the private sector. This is one of 21 recommendations I am making to ensure B.C.'s health information and privacy rules are up to the challenge of the digital age.

Just as we must strive for excellence in the protection of patient data, we must also ensure that our laws promote innovation in health research. B.C. is well known for its pioneering work in the fields of HIV/AIDS research, cancer treatment, personalized medicine, and genomics to name a few.

Earlier this week, an international conference drew more than 400 researchers from around the world to Vancouver, to engage in dialogue about how to facilitate global and local health research linkages.

My office has been an active promoter of privacy-positive health research. In recent years we have hosted two health research roundtables – one in partnership with the Ministry of Health – where disparate parties came together in dialogue to find solutions to the research challenges inherent in the current system.

A Prescription for Legislative Reform builds on these roundtables with recommendations to address some of the key issues facing health researchers. My proposals include a streamlined ethics approval process, centralized data stewardship oversight model, and a one-stop research platform that would create a secure and controlled environment in which to conduct this vital health research.

British Columbia has the opportunity to embrace innovation and protect privacy at the same time. We can keep pace with digital technologies, facilitate life-saving research, and improve health outcomes. All of these things can be achieved with a comprehensive and modern approach to regulating personal health information that I am confident will benefit all British Columbians who access our health care system.

At this critical juncture, I hope that this prescription will stimulate dialogue, legislative action and meaningful reform. To read the report, visit: www.oipc.bc.ca.

Elizabeth Denham is Information and Privacy Commissioner for British Columbia.