



MEDIA RELEASE

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Government Wants Carte Blanche Over Your Personal Health Information: Privacy advocates take aim at BC Government's eHealth Legislation

The Province's recently introduced eHealth Bill (Bill 24) will receive its second reading within the next two weeks, allowing the Provincial Government to create massive electronic databanks of citizens' personal health information and to override citizens' long-cherished rights to privacy and to doctor/patient confidentiality. An informal coalition of health and privacy groups is joining forces to decry the Bill 24.

The BC Persons With AIDS Society (BCPWA), BC Freedom of Information and Privacy Association (FIPA), BC Civil Liberties Association (BCCLA) and BC Coalition of People with Disabilities have been involved with the eHealth consultation process for the last two years and say that the failure to enshrine meaningful control for citizens over their personal health information makes the government's assurances of privacy meaningless.

"The Bill enables the government to create vast databases containing our most sensitive personal information," said Darrell Evans of FIPA. "This opens the door to massive security breaches; they are happening all the time. We're talking drug histories, genetic information, medical test results, you name it. And once your personal information gets out or on the Internet, it's there forever, beyond anyone's control."

The Bill gives government sweeping powers to access and utilize private and confidential medical information gathered from a variety of sources including community health clinics, women's clinics, pharmacies, medical labs, hospitals and other public health bodies. Massive registries of health information are controversial and have seen organized medical and community opposition in the United Kingdom.

Since at least 2003, the Provincial Government has been working on the electronic health record system known as eHealth. The stated intention is to provide better care to the citizens of British Columbia. However, the Bill in front of the legislature, which would make the eHealth system a reality, has failed to address the privacy and confidentiality concerns that have been raised. If passed, it would allow the government, not the individual, to decide who can access confidential medical information and how it may be distributed.

“Essentially Bill 24 says that the government will decide what is good for you, in terms of protecting your medical privacy,” says Richard Rosenberg, of BCCLA. “Even if the government is currently to be trusted in promising privacy protections today, under this legislation, it can take those protections away tomorrow.”

The groups are calling for Bill 24 to be redrafted with the right of patient consent and control enshrined, with only strictly limited exceptions for emergencies and audits. The groups also say that sensitive health information should never leave Canada without express consent and that citizens should have an absolute right to prevent their health information from being used for research purposes.

“The government claims there will be benefits to eHealth, but whatever those benefits might be, they come with the risk for security and disclosure disasters,” says Glyn Townson, Chair of BCPWA. “To ensure citizen confidence we need real privacy protections built into the system, not airy promises that they might come down the road”.

BILL 24 — 2008
**E-HEALTH (PERSONAL HEALTH INFORMATION ACCESS
AND PROTECTION OF PRIVACY) ACT**

Bill 24:

- Repeals and replaces sections 10.1 to 10.7 of the *Health Act* in respect of health information banks
- Provides no guarantee of any patient control over the collection, use and disclosure of their personal health information.
- Provides the Ministry of Health with the powers to decide how individuals' health information is collected, disclosed and used.

Bill 24 gives the government carte blanche over personal health records. Under this Bill:

- An individual's constitutional right to privacy is at risk.
- The ministry can access, at their discretion, any individuals' records in the E-Health System. However, it does not guarantee individuals the right to access their own records electronically.
- Information can be collected from every health information bank, except doctors' own records. However community clinics are captured by the legislation. Therefore all records, including doctors' notes, belonging to individuals without a regular general practitioner may be collected.
- Information can travel to the United States "for maintenance purposes," where it could be accessed, under the Patriot Act, by the Federal Bureau of Investigation.
- A Data Stewardship Committee will be appointed to manage disclosure, for the purpose of health planning and research. This committee is appointed by the Minister and therefore, also under her or his control. There is no effective patient representation structure to this committee.
- Disclosure directives are introduced as a way to seemingly create doctor, patient confidentiality electronically. However, the Minister can override these directives, completely negating confidentiality and privacy.

Disclosure Directives:

- Definition – "individual disclosure directives, whereby some or all of an individual's personal health information is "masked" (not available to users of the system) at the individual's request."
- The making of a disclosure directive is not a right under this legislation, it is a privilege.

- Clause 9 (5) reads: “If the Minister amends a designation order in respect of the authority to make a disclosure directive, any part of a disclosure directive that is inconsistent with the amendment is deemed to have been revoked.”
- The Ministry can retroactively alter a disclosure directive established by an individual over his or her records.
- Subsection (e) allows for an override of a disclosure directive "if prescribed circumstances apply." This condition is so huge and vague that it completely negates the idea of patient consent.
- Sec 26(2)(e) indicates that the Cabinet can “prescribe circumstances, in which a person may collect, use or disclose personal health information despite a disclosure directive,” completely removing the power of disclosure directives.
- The effect of disclosure directives is neither more nor less than the Minister or the Cabinet say it is, and traditional guarantees for privacy and confidentiality are non-existent.
- Sec 18(1)(a) refers to section 33.2(c) of the Freedom of Information and Protection of Privacy Act (FIPPA); this section of the FIPPA allows disclosure “to an officer or employee of the public body or to a Minister, if the information is necessary for the performance of the duties of the officer, employee or Minister.” This means there is no guaranteed privacy at the Ministry of Health.

Recommendations

- **The bill should define** an explicit right of citizens to impose disclosure directives concerning the collection, use and disclosure of their personal health information.
- **This right should not** be subject to the will of the Minister or the L-G in council.
- **This right should be** subject to limited overrides for public health, emergency and audit purposes. Citizens should have total discretion over the use of their public health information for research purposes.

Declaration of Medical Privacy Rights

The Right to Privacy is a human right and is fundamental to my dignity as a human being.

My right to privacy extends to all my personal health information, regardless of the format in which it is recorded.

Any personal health record maintained on me by any health care provider is created through a special relationship, with the expectation that my information will remain confidential. The confidential nature of this relationship exists to safeguard and promote my physical and mental health. Any violation of this confidential relationship may adversely affect my health and is a violation of my right to privacy.

The right to privacy affirms my right to control access to and use of my personal health information. Any access or use without my consent is a violation of my right to privacy.

Fundamental to my right to privacy of health information is the right to:

- a) be told why specific information is requested and if it will be part of a physical record,
- b) know who will have access to any of my health information and for what purpose,
- c) refuse access to all or portions of my information,
- d) expect an audit trail that will identify who has accessed my health information,
- e) expect my health information will be maintained in a secure environment that will prevent any unauthorized access,
- f) request and receive an accurate and complete copy of my health records in a timely fashion,
- g) have corrected any factual error in the records. If there is a disagreement about the accuracy of the records, it is my right to have the disputed information clearly identified and to append to the records what I believe to be the correct information,
- h) expect the information will be retained for a length of time appropriate only to the primary reason for which it was obtained. Any retention beyond this length of time must be done with my consent, and
- i) seek an effective remedy should any of these rights be violated.



For more information:

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Organizations in Opposition to Bill 24

BC Persons With AIDS Society

The British Columbia Persons With AIDS Society (BCPWA Society) is dedicated to empowering persons living with HIV disease and AIDS through mutual support and collective action. It is Western Canada's largest AIDS organization with a membership of more than 4,400 HIV-positive individuals. Unique among major HIV/AIDS agencies in Canada, BCPWA Society's Board of Directors is composed entirely of HIV-positive members. The Society provides support and advocacy services, treatment information and volunteer opportunities for its many diverse members.

The Freedom of Information and Privacy Association

FIPA is a non-partisan, non-profit society that was established in 1991 to promote and defend freedom of information and privacy rights in Canada. Its goal is to empower citizens by increasing their access to information and their control over their own personal information. They serve a wide variety of individuals and organizations through programs of public education, public assistance, research, and law reform.

BC Civil Liberties Association

The B.C. Civil Liberties Association was established in 1962 and is the oldest and most active civil liberties group in Canada. The organization is formed by a group of citizens who volunteer their energy and talents to fulfill the organization's mandate: to preserve, defend, maintain and extend civil liberties and human rights in British Columbia and across Canada. The BCCLA is an autonomous, non-partisan charitable society.

BC Coalition of People with Disabilities

The BC Coalition of People with Disabilities is a provincial, cross-disability advocacy organization. Its mandate is to raise public and political awareness of issues that concern people with disabilities. The organization hopes, through its work, to facilitate the full participation of people with disabilities in all aspects of society and to promote independence.