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Dr. Brian Emerson
Medical Consultant
Ministry of Healthy Living and Sport
4-2,1515 Blanchard Street
Victoria, BC V8W 3C8

Dear Dr. Emerson

RE: Proposed Communicable Disease Regulation (CDR) Amendment

Introduction

1. I am writing on behalf of the British Columbia Civil Liberties Association (BCCLA) in response to a request for submissions on proposed amendments to the Communicable Disease Regulation confidentiality provisions.
2. The BCCLA is the oldest and most active civil liberties organization in Canada. We have spent nearly 50 years working to preserve, defend, maintain and extend civil liberties and human rights in British Columbia and across Canada. We have longstanding and extensive involvement in working to ensure proper balancing and respect for patients' rights in the many difficult legal and ethical issues that arise in the provision of health care.

Executive Summary of the BCCLA Response

3. **We are opposed to the proposed amendments, for the reasons we give below.**
4. **We recommend that:**
 - a) **the CDR be retained as it currently reads;**
 - b) **that proposals be received for amendments to Schedules A and B, in order to address the concern that not all the diseases listed warrant inclusion;**

- c) **that a systemic review of medical and sociological scholarship be undertaken in order to provide the basis for evidence-informed policy making on the issue of confidentiality concerns as a barrier to accessing testing.**
- 5. **We are also concerned about aspects of the process. In particular, we are concerned that the request for the views of selected stakeholders provided so little information on:**
 - a) **the perceived problem with the current privacy regime,**
 - b) **the purported benefits of the proposal and**
 - c) **the research that has been undertaken by the Ministry, particularly regarding likely harms of the proposal.**

No Pressing Problem Identified

- 6. The primary rationale for the proposed amendments that is cited in the invitation for comment is that section 6.1 of the Public Health Act Communicable Disease Regulation is “not aligned with the reality of modern clinical practice”. The relevant provision reads:

6.1 Where a person voluntarily submits himself to testing or examination for a communicable disease and, as a result of that voluntary test, another person is required to make a report to the medical health officer under section 2 or 3, no person shall disclose or permit to be disclosed to any person other than the medical health officer information contained in the report or the results of an examination or test, without the written consent of the person who so volunteered.
- 7. The short explanation of the proposed changes states that a “clarification” is required to make s. 6.1 applicable only to public health staff, so that the provision would be limited to medical health officers. In other words, health care providers would not be subject to the requirement for written consent for disclosures of information on patients’ reportable diseases.
- 8. The request for submissions contends that “new realities” require the removal of barriers “to the flow of important clinical information in to PLIS [Provincial Lab Information Solution]” and offers the opinion that the requirement for patients’ written consent for disclosure of medical information pertaining to reportable diseases is an unworkable impediment to the system of centralized electronic health care information that is currently underway in British Columbia.

9. The request for submissions states (without citing a source) that “[t]he CD regulation confidentiality provision is not recognized by clinicians as relevant to their practice”. While it not clear in what sense the CDR is not considered “relevant”, it is also not clear in what sense the CDR presents an unworkable difficulty, especially in light of the information provided that making HIV reportable in 2003 (bringing it under the CDR), “did not change how this information was being handled in clinical practice.”
10. The letter requesting submissions on this topic highlights that the CDR “does not differentiate among communicable diseases with respect to sensitivity of the information”, thus HIV and mumps fall under the same heightened privacy requirements. However, what is proposed is even more undifferentiated and what we might term “a race to the bottom” in terms of privacy protections. While it certainly arguable that mumps is not generally considered as medically sensitive as other CDR applicable conditions such as HIV, viral Hepatitis, sexually transmitted infections and leprosy, that fact is in no way an argument for lowering privacy standards for information that is acknowledged to be highly sensitive.
11. The fact is that the “new realities” of centralized electronic health information already severely reduce patient and practitioner’s control over the disclosure of personal health information. At this time in British Columbia there is effectively no information generally available to patients on how they can apply a disclosure directive to their personal health information and no option for record level masking of the data. In light of the increasing exposure of patients’ health information through e-Health, the CDR may be one of the most important residual controls on dissemination of particularly sensitive medical information. And if the contention is that not all conditions currently listed in the schedule require that degree of confidentiality, then the answer is to propose a revised list, not eliminate the confidentiality protections of all listed conditions.

No Clear Explanation of Benefits

12. The request for submissions does not explicitly state what benefits can be expected from the proposal. It could be inferred from the proposal that the benefits would be that 1) practitioners will save time by being able to forego having to get written consent from a patient for disclosure of information about their reportable disease, and 2) information on reportable diseases would be available to practitioners who need the information, but would otherwise not have it because patients would not grant consent for the disclosure or would not be able to provide consent in a timely manner.
13. We do not believe that a requirement for written consent for disclosure of information about a patient’s reportable disease constitutes an undue burden on a practitioner. Most health information is disclosed on an implied consent

model to those in the circle of care, and presumably many patients would consider the provision of consent for disclosure a formality. However, the requirement for express consent affords a critical protection to those patients who do not wish for their information to be disclosed.

14. And it cannot be ignored that the “new reality” in centralized electronic health information is that disclosure extends well beyond the “circle of care” parameters of implied consent. Disclosure to a health information bank (HIB) provides access to thousands of people; every health care practitioner in the province who falls under the access model.
15. The access model is still in development at this time and is subject to change. Further, the access model for the direct provision of health care is only one avenue of access. The e-Health Act provides for some government officials and researchers to have access to personal health information and how far access may ultimately be provided with amendments to the e-Health Act is an open and deeply disturbing question. In our latest communication with government officials on the subject, we were told that the government is currently unprepared to promise that the e-health system won't ultimately be linked to other Ministries (communication with Paul Shrimpton, Ministry of Health, CIAC meeting, January 13, 2010).
16. Thus, it is an entirely false analogy to say that disclosing information to the e-health system is like disclosing within the circle of care and should fall within an implied consent model. And where there is heightened concern for confidentiality, as we see with many of the CDR regulated diseases, then the implied consent model within an e-Health framework is even more woefully inadequate.
17. We fully expect some significant percentage of patients to withhold consent for disclosure of their privacy-sensitive, reportable condition and the fundamental and critically important principle of patient autonomy should allow for this. An argument of automated efficiency cannot override such a fundamental right.
18. Additionally, we do not believe it is sufficient to claim that patient's health care is compromised without health care practitioners having access to health information that patients do not consent to providing. Simply put, a forced disclosure model could arguably extract data that might be useful or needed by a clinician for patient care in some rare cases. However, we agree with clinicians who maintain that the effective provision of healthcare is predicated on a relationship of trust, not forced disclosures.
19. Countering the argument for forced disclosures is the very real concern that some patients will avoid certain medical testing altogether because of

institutionalized failures to provide confidentiality. And there is good reason to believe that of the people who will find forced disclosure a barrier to healthcare, many will be citizens who are socially marginalized and medically vulnerable.

No Evidence of Research into Likely Harms

20. Public health initiatives are dependent on the trust of patients. Initiatives to provide accessible, youth-friendly, confidential sexual health services are an example of the kind of outreach and patient-trust building that is considered imperative for effective diagnosis and treatment of communicable diseases. It should come as no surprise that the vastly expanded access to patient records afforded by centralized electronic health records reduces many patients' trust in the confidentiality of their medical information and thus is a barrier to their accessing medical services.
21. Those were the entirely predictable results of a recent Scottish study published in the journal, *Sexually Transmitted Infections* and reported in Aidsmap News ("Electronic record sharing inadvertently erect barriers to HIV and STI treatment and care", Dec. 11, 2007). In that study, almost two-thirds of sexual health clinic patients reported that they did not want their GP informed of their visit and one in four patients said that they would be less likely to attend sexual health clinics if their records were shared via electronic databases.
22. That study concludes as follows:

We therefore need to be cautious when endeavouring to adopt common systems for the purpose of service improvement, that we are not erecting barriers to access. It appears that, 90 years on from the establishment of the first venereal disease clinics in the UK, there is still a need to reserve the option of separate GUM records and data systems to enable desired levels of patient anonymity, while trying to improve communication with GP colleagues.
23. While there has been a concerted effort in recent years to reduce the stigma and shame of certain medical diagnosis, those laudable efforts have not reduced the need for medical confidentiality. There have been many advances in treatment for people living with HIV, and yet it is still the case that medical confidentiality fears are a serious barrier to access testing.
24. A study published in the *International Journal of STD and AIDS* and reported in Aidsmap News ("Why are gay men reluctant to test for HIV?" Nov. 7, 2008) found concerns about the confidentiality of HIV testing to be the second most important factor cited by Australian gay and bisexual men who had not recently been tested for HIV.

25. The particular threats to patient confidentiality that occur because of the vastly expanded data-sharing through centralized electronic health records was the subject of a special report from the National AIDS Trust in the UK. The report cites the “legitimate worries” about information held on central databases, and the exacerbation of such concerns because of massive public health sector data breaches. Certainly e-health data breaches are now a regular feature of the news; this week’s top e-health data breach story being the decision not to prosecute a Scottish doctor for illegally accessing the medical data of several well-known people (“Large databases can never be secure”, *The Guardian*, Jan. 20, 2010).
26. The point here is that in the UK there have been special reports looking at the question of confidentiality in healthcare for people living with HIV under an e-health system that arguably contains many more privacy protections than BC’s e-health system, including an opt-out provision and a range of masking capabilities, including an option for a “locked box” masking feature that is invisible on the summary record, so that only practitioners with the patient’s permission are able to see that such a locked box even exists.
27. The e-health system underway in the BC provides very little reason for people living with HIV to be confident about their medical confidentiality and to date, there is no commitment by the Ministry to implement the recommendations of the e-Health HIV Medications Task Group.
28. In short, there is every reason to be concerned that the e-health system is likely to create an inadvertent barrier to accessing testing for communicable diseases and certainly no effective privacy protection should be *withdrawn* in such a scenario, unless and until meaningful and effective confidentiality protections are fully operational.
29. We submit that this is a matter that requires the kind of careful (‘first do no harm’), systemic study that constitutes best practice in evidence-informed health policy making. Not only do we not know of any such undertaking, we have cited some of the empirical evidence that supports the proposition that forced medical data disclosures are a barrier to accessing medical testing.
30. We do not believe that the proposed ‘solution’ of anonymous testing is particularly workable or indeed readily available. We are not aware that anonymous testing is “an option for people being tested for *any* disease” [emphasis added]. We are aware of there being some “non-nominal” testing for HIV and STI’s at specialized clinics. Such clinics are very desirable, but their availability throughout British Columbia is limited.
31. For example, a recent study showed that in British Columbia “geography isolates many youths from testing service times or services and present privacy concerns, especially for rural youth” (Shoveller, J. et al, “Youth’s

experiences with STI testing in four communities in British Columbia, Canada”, *Sexually Transmitted Infections* 2009, 85: 397-401).

32. While we certainly support “anonymous” testing options, we submit that such an option is not an effective substitute for the CDR.

Conclusion and Recommendations

33. The move to a centralized electronic health data system inherently challenges patient privacy rights by vastly expanding the scope of access to patient’s health information and limiting the options for patient and health care provider control over disclosures.
34. Many of the pressing medical confidentiality challenges in this new environment have not yet been addressed (i.e. how to effectively inform the public of disclosure directives; how to provide effective privacy protection for HIV patients whose HIV-specific medications have to date been excluded from PharmaNet; record-level masking, etc.).
35. We believe that patient privacy rights are negatively impacted by the e-health system that is currently underway (see attachment: “The Real Impact of the e-Health Act”) and we are firmly opposed to further diminishing of patient privacy rights by amending the CDR.
36. Thus, we are opposed to the proposed amendments.
37. We recommend that:
 - a) the CDR be retained as it currently reads;
 - b) that proposals be received for amendments to Schedules A and B, in order to address the concern that not all the diseases listed warrant inclusion;
 - c) that a systemic review of medical and sociological scholarship be undertaken in order to provide the basis for evidence-informed policy making on the issue of confidentiality concerns as a barrier to accessing testing.
38. We are also concerned about aspects of the process. In particular, we are concerned that the request for the views of selected stakeholders provided so little information on:
 - a) the perceived problem with the current privacy regime,
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- c) **the research that has been undertaken by the Ministry, particularly regarding likely harms of the proposal.**

Respectfully submitted,



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Policy Director

- cc Ms. Deb McGinnis, Executive Director, eHealth Privacy, Security and Legislation
Mr. Paul Shrimpton, Executive Director, eHealth Electronic Health Record
Mr. Warren O'Briain, Executive Director, Communicable Disease and Addictions
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Office of the Information and Privacy Commissioner for British Columbia
Options for Sexual Health – BC Branch
Health Information Privacy and Security Council
BC Centre for Excellence in HIV/AIDS
BC Coalition for People with Disabilities
BC College of Physicians and Surgeons
BC College of Registered Nurses
BC Freedom of Information and Privacy Association
BC Medical Association
BC Ministry of Citizens Services