Centre for Addiction and Mental Health

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Submission of

Centre for Addiction and Mental Health

to

The Standing Committee on General Government

on

Bill 31: Health Protection Privacy Act, 2003

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A PAHO/WHO Collaborating Centre

Un Centre collaborateur OPS/OMS

Affiliated with the University of Toronto

Affilié à l'Université de Toronto

Introduction to CAMH

The Centre for Addiction and Mental Health (**CAMH**) is the largest mental health and addictions facility in Canada. It was created in 1998 through the successful merger of the Addiction Research Foundation, the Clarke Institute of Psychiatry, the Donwood Institute and the Queen Street Mental Health Centre. CAMH is a teaching hospital fully affiliated with the University of Toronto and has been recognized internationally as a Pan-American Health Organization and World Health Organization Collaborating Centre.

Building on the legacies of four outstanding organizations, CAMH offers a unique model for understanding and helping people with addiction and mental illness, for preventing substance abuse and for promoting mental health. We operate central clinical and research facilities in Toronto, Ontario, as well as 26 satellite offices across the province that work with partners to improve the quality and accessibility of services within the addiction and mental health system. While CAMH's work focuses on the needs of Ontario communities, our impact extends across the country and internationally.

CAMH brings together internationally recognized biological, clinical and social research with the most advanced clinical treatment and out-patient services, a range of professional training and a province-wide network of community program staff. As a result, we have a unique capacity to focus our research agenda on the most pressing needs and to translate new knowledge into action.

CAMH advocates for services that are accessible, effective and adequately funded for all people needing help. We are also working towards the elimination of the stigma that is faced by those with mental illness or substance use problems.

Privacy Rules in the Mental Health and Addictions Context

Privacy is an important component of basic human dignity and respect. People with mental health and addictions histories frequently experience stigma and their lives can be impaired forever by an episode of mental health or addiction treatment. The greatest fear our clients have about increased access to information about their status is that this will inevitably add to the stigma and discrimination they already experience. The therapeutic relationship, which is a vital component of care for our clients, is founded upon trust. Protecting the information they entrust to us is of the utmost importance.

Since 1978, the mental health system of Ontario has had legislated rules regarding the use and disclosure of, and access by clients to, clinical mental health records. These rules provide clear, if somewhat inflexible, direction to psychiatric facilities. Because of this experience, we have excellent systems in place to respond to patient requests for access to clinical records and checks and balances for disclosing clinical information. CAMH supports the extension of rules similar to those in the *Mental Health Act* to other parts of the health system.

We are always very concerned about the terrible effects of stigma on people with mental illness and addictions. This makes us cautious about information being more easily shared as information can be misused by others to discriminate against our clients and deny them the basic rights of citizenship and full participation in society. Such

discrimination severely limits our clients' capacity to overcome the effects of their illnesses, with the assistance of our treatments and services, and to live more fulfilling lives. Therefore, privacy legislation must be crafted so that there is an ability to share information in a way that facilitates patient access and movement to and through all parts of the system, respects clients' rights to confidentiality with appropriate safeguards and does not exacerbate stigma.

Some of the problems we have historically experienced under the *Mental Health Act* rules seem to be addressed in Bill 31, such as:

1. The rules of the *Mental Health Act* have created barriers to developing a continuum of care and an integrated mental health and addictions system because most transfers of patient information, even between health care providers, require a consent to disclosure (in the form of a "Form 14") or documentation between CEOs of health care facilities - Bill 31 will allow more timely and fluid exchange of information strictly within the "circle of care";

2. Having distinct rules relating to "clinical records" in psychiatric facilities and not to personal health information held outside the clinical record (e.g. for research, community programs, homes for special care, etc.) has meant that the protection of such information is uneven - Bill 31 redirects our focus to personal health information regardless of where it is held;

3. Not all psychiatric facilities are as well informed as they should be about their duties under the *Mental Health Act* because they are part of general hospitals that operate under different rules pursuant to the *Public Hospitals Act* - Bill 31 creates common rules regardless of where service is provided; and

4. Community mental health and addictions programs have not been subject to the *Mental Health Act* and therefore there has been lack of consistency and protection for clients of the sector regarding privacy - Bill 31 creates common privacy rules for all health information custodians and this will lead to greater clarity and hopefully greater compliance with the rules.

CAMH Response to Bill 31

CAMH supports:

1. Consistent rules for the collection, use and disclosure of personal health information across the health care sector;

2. Provincial legislation specifically designed for the health care sector as opposed to the application of the federal legislation, the *Personal Information Protection and Electronic Documents Act*, to the health care sector;

3. The inclusion of community mental health and addictions health care providers in the definition of "health information custodians" and the greater flexibility to disclose personal health information within the circle of care for health care purposes in order to dismantle continuity and access barriers;

4. The protection of personal health information collected for research purposes and the role of Research Ethics Boards to review proposed projects involving personal health information;

5. Common rules across the health care sector regarding clients' rights to access and correct the personal health information held by an organization;

6. The participation of substitute decision-makers to make decisions regarding the collection, use, or disclosure of or access to personal health information on behalf of incapable individuals; and

7. The protection of "quality of care information" in order to encourage and foster open internal dialogue for ways to improve health care delivery.

CAMH is concerned that:

1. Bill 31 is extremely complex and it will take time and intensive study to fully understand all the possible implications of the various provisions, especially how restrictive provisions interact with permissive provisions; this is necessary in order for hospitals such as ours to fully understand and meet our obligations to protect confidentiality; it will be even more difficult for community programs with whom we regularly need to exchange information to get up to speed on the implications of the legislation for them;

2. The complexity of Bill 31 will make compliance challenging and we will all need educational materials and common templates created by the government and the Information and Privacy Commissioner of Ontario to succinctly explain the changes the legislation will have on existing practice in the health care sector and the new obligations created by the legislation;

3. The implementation timetable and costs will make compliance challenging - July 1st is an unrealistic date for implementation - at least another six months will be needed for the regulations process to be truly consultative and complete, and this first set of regulations should be very carefully done;

4. We are concerned about the particular costs related to:

    a. Amending our information management systems and practices;
    b. Reviewing and revising our existing policies on clinical records;
    c. Attracting and hiring staff with the appropriate expertise to fulfill privacy-related functions;
    d. New signage and communications tools to educate our clients and staff and to fulfill the notification requirements of the legislation; and
    e. Training our staff to understand their obligations under the legislation;

5. To clarify the scope of information-sharing in the mental health and addictions system, it would be helpful to have provisions similar to the ones for community treatment orders in section 35.1 of the *Mental Health Act* for the purposes of developing discharge plans and transfers of clients into community programs,

(such as ACT teams, housing and employment programs); this is necessary because the definition of community service in subclause (vii) of paragraph 3 of the definition of "health information custodian" in section 3 would not always include all the agencies with which we work as such agencies may not be providing health care in the usual sense, but such agencies offer a resource to our clients that is crucial to their continuity of care, and information needs to be shared between CAMH and these community agencies in order to complete applications, consider discharge planning and to determine whether the services are suitable for the person;

6. The permitted disclosure for risk of harm provisions (s. 39(1) & (2)) could result in pressure on hospitals and physicians to disclose more information to the police and other authorities, and custodial facilities than is really necessary for fear of liability for not disclosing such information;

7. The withdrawal of consent provision (s. 19) could result in our inability to rely on any consent (whether it is express or implied) for fear that an individual could withdraw his or her consent even after we have acted on the consent to collect, use or disclose the personal health information; the effect of withdrawal of consent should be clearly spelled out to state that withdrawal does not have any retrospective effect; where information has been collected, used or disclosed lawfully, withdrawal of consent should not invalidate actions taken in reliance on the consent;

8. It is not clear whether the legislation is intended to allow individuals to expressly restrict the use of their personal health information through a "lockbox" for the permitted uses as listed in section 36 (such as for teaching and research purposes); if that is the intended result, we have significant concerns about the negative impact such restrictions would have on, among other things, our research program, risk management efforts and the education of our clinicians; we seek clarification of this issue;

9. The application of the consent, use, disclosure and access provisions to personal health information that is research data will result in a significant change for researchers, and may not be realistic in the context of research practice; while most personal health information that is collected in the course of research is done with the consent of research subjects, research databases have not been considered health records and have not been treated as such by the hospitals and universities where researchers work; this will be a major issue of implementation for information managers and will entail significant costs;

10. The rules regarding fundraising could negatively impact on our foundation's ability to raise critical funds to support our projects and programs and we hope the government will continue to work with organizations such as ours to identify appropriate alternatives to fundraising that meet acceptable privacy practices;

11. The rules of Bill 31 must not interfere with the obligations of our clinicians or CAMH to disclose personal health information to the Ontario Review Board for the ongoing assessment and care of our forensic clients as well as to enable the Board to make its orders and dispositions with full knowledge of the patient's

heath status and behaviours, and we require assurance that the rules will not have such an unintended effect; and

12. Creating an offence (s. 70(3)) that holds officers, employees or agents liable regardless of whether the corporation has been prosecuted or convicted is unreasonable and should be redrafted.

We look forward to working collaboratively with the government to finding solutions to these kinds of concerns and on the development of regulations, templates, forms and materials for implementation.

Recommendations:

CAMH recommends that:

1. There be an extension of at least 6 months for the coming into force date to allow for a reasonable period of time for implementation;

2. The government consult and collaborate on the development of regulations, forms, templates and educational materials and include CAMH in these activities with regard to the mental health and addictions system;

3. The government fully analyze and consider the costs of health information custodians changing their information management systems before implementing new requirements (for example, forms for audit and reporting);

4. The legislation allow for specific disclosure by health information custodians for the purposes of discharge planning drawing on language that is similar to section 35.1 of the *Mental Health Act* for community treatment orders;

5. Section 19 be amended to clarify that withdrawal does not have any retrospective effect and that where information has been collected, used or disclosed lawfully, withdrawal of consent shall not invalidate actions taken in reliance on the consent;

6. The proceedings sections and Mental Health Act amendments sections be amended to explicitly allow information to be disclosed to the Ontario Review Board and the Consent and Capacity Board to ensure continuity in those processes;

7. The government will continue to work with organizations such as ours to identify appropriate alternatives to fundraising that meet acceptable privacy practices; and

8. Subsection 70(3) be deleted.

CAMH Contact Person

We would welcome the opportunity to work closely with the government and Ministry officials to further develop the suggestions made in this submission.

If you have any questions with respect to this submission, or if you require further information about our response, please contact Gail Czukar, Executive Vice President of Policy and Planning and General Counsel to CAMH at 416-535-8501 ext. 6923 or gail_czukar@camh.net.