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Thursday 28 August 2008

Standing Committee on Social Policy

Review of the Personal Health
Information Protection Act, 2004

Chair: Shafiq Qaadri
Clerk: Katch Koch

Assemblée législative
de l'Ontario

Première session, 39e législature

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Jeudi 28 août 2008

Comité permanent de la politique sociale

Examen de la Loi de 2004 sur la
protection des renseignements
personnels sur la santé

Président : Shafiq Qaadri
Greffier : Katch Koch

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ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

STANDING COMMITTEE ON SOCIAL POLICY

COMITÉ PERMANENT DE LA POLITIQUE SOCIALE

Thursday 28 August 2008

Jeudi 28 août 2008

The committee met at 0903 in committee room 1.

The Clerk of the Committee (Mr. Katch Koch): Good morning, honourable members. It is my duty to call upon you to elect an Acting Chair. Are there any nominations?

Mr. Peter Shurman: I nominate the member for Etobicoke–Lakeshore, Laurel Broten.

The Clerk of the Committee (Mr. Katch Koch): Are there further nominations? There being no further nominations, I declare the nominations closed and Ms. Broten elected as Acting Chair.

SUBCOMMITTEE REPORT

The Acting Chair (Ms. Laurel C. Broten): Thank you for joining us this morning as the Standing Committee on Social Policy reviews the Personal Health Information Protection Act, 2004, pursuant to subsections 75(a) and 75(b) of the act.

I'd like to call upon one of the members to provide the report of the subcommittee on committee business dated Wednesday, June 25, 2008. Ms. Jaczek.

Ms. Helena Jaczek: Your subcommittee on committee business met on Wednesday, June 25, 2008, to consider the method of proceeding on the review of the Personal Health Information Protection Act, 2004, pursuant to subsections 75(a) and (b) of the act, and recommends the following:

(1) That the committee meet in Toronto for the purpose of holding public hearings on August 28, 2008.

(2) That the clerk of the committee post information regarding the hearings on the Ontario parliamentary channel and the Legislative Assembly website.

(3) That interested people who wish to be considered to make an oral presentation on the review should contact the clerk of the committee by August 8, 2008, at 5 p.m.

(4) That the clerk of the committee provide a list of all interested presenters to the subcommittee following the deadline for requests.

(5) That the Information and Privacy Commissioner of Ontario be invited to make a presentation to the committee.

(6) That the deadline for written submissions be August 28, 2008, at 5 p.m.

(7) That the committee meet on September 4, 2008, for report writing.

(8) That the clerk of the committee, in consultation with the Chair, be authorized prior to the adoption of the report of the subcommittee to commence making any preliminary arrangements to facilitate the committee's proceedings.

The Acting Chair (Ms. Laurel C. Broten): Any discussion with respect to the subcommittee report? Seeing none, shall the subcommittee report pass, as reviewed by Ms. Jaczek? Carried.

REVIEW OF PERSONAL HEALTH INFORMATION PROTECTION ACT, 2004

Review of the Personal Health Information Protection Act, 2004, pursuant to subsections 75(a) and 75(b) of the act.

INFORMATION AND PRIVACY COMMISSIONER/ONTARIO

The Acting Chair (Ms. Laurel C. Broten): We are now ready to hear our first deputant. I'd like to call to the front of the room, please, the Information and Privacy Commissioner of Ontario, Dr. Ann Cavoukian.

Welcome, and thank you for joining us this morning. Perhaps as you take your seat you can start by letting us know who has joined you, and I'll let you know that you have 20 minutes to provide your remarks to the committee this morning.

Dr. Ann Cavoukian: Thank you very much for your time and attention.

Let me begin by thanking the Standing Committee on Social Policy for inviting me to make a presentation here today during the review of the Personal Health Information Protection Act. I'm joined today by my two assistant commissioners, Ken Anderson and Brian Beamish, and of course I could not carry out any of my functions without them; I'm very, very fortunate to have them with me.

As you are aware, I'm charged with the responsibility of overseeing compliance with PHIPA, the Personal Health Information Protection Act. This includes reviewing, investigating and adjudicating complaints that individuals have been denied access to their health records; complaints alleging that health information has been collected, used or disclosed in an unauthorized manner, contrary to the act; and a number of other areas.

It also includes conducting reviews and investigations at my own initiative, in the absence of a complaint, where I have reasonable grounds to believe that a person has contravened or is about to contravene the act.

I have to tell you, I'm not here only in my capacity as a commissioner; I am also, I think, uniquely qualified to speak to you about PHIPA today because I'm a patient again and again. I seem to find myself in and out of hospitals with some regularity, and I just had some surgery a few weeks ago. So I feel I am uniquely qualified to speak to this subject, because I think we can't lose sight of the fact that the patient is at the heart of this legislation, and the needs of the patient. So I will speak to you both as a patient and as a commissioner.

After almost four years of discharging my responsibilities under this act, I can personally attest to the fact that the act clearly appears to strike the right balance between protecting the privacy of individual patients with respect to their health information and the equally important objective of ensuring the continued delivery of effective, efficient and timely health care.

0910

I always say, because I do have a focus as a patient, that first you focus on delivery of health care services and then you wrap a very strong layer of privacy around it. You must have both, but I assure you, when you're at emergency as a patient, your first concern is the delivery of health care services. And this act strikes the right balance. Overall, in my view, the act is working very well, and does not require significant amendments.

The act was the culmination, as you know, of extensive consultations with a broad range of stakeholders, including patient advocacy groups, regulatory colleges, health care providers, health care associations, professionals and researchers. The Legislature of Ontario should be applauded for its efforts in this regard, and for ensuring that stakeholders continue to have input by requiring an open and transparent regulation-making process. This success of the act can, I think, largely be attributed to this invaluable input from all stakeholders.

You should know that when the act was first proclaimed, my office met with all the regulatory colleges and the professional associations, and recently, in the last couple of weeks in preparation for this meeting, we met with a number of them. We met with the College of Physicians and Surgeons and the Ontario Hospital Association. We spoke to lots of stakeholders. We wanted to prepare. I think that kind of ongoing consultation is very important.

Another reason that the act has been able to balance the competing interests is because it is a consent-based statute. It gives individuals and patients control over when, whether and under what circumstances their health information will be collected, used and disclosed. It differentiates among the circumstances in which express consent of the individual is required, the circumstances in which consent of the individual may be assumed to be implied, and the circumstances in which health information may be collected, used or disclosed without consent.

I'm a big advocate of the implied consent model of the act. People are sometimes surprised at that because I am the privacy commissioner. But as I said, as a patient, I assure you, when you're in need of health services, the last thing you want to chip away at your invaluable time with your health care provider are unnecessary obstacles such as seeking express consent when it's not necessary. It's clear: You're there to see your health care provider, and you are disclosing the information for purposes of getting health care. It can be easily implied under those circumstances.

In general, the act permits health care providers to seamlessly share health information with one another because of this construct for the purpose of providing health care to an individual. These provisions have come to be referred to as the circle of care. Although "circle of care" is not a defined term in the act, it is a very useful term for understanding how things work under the act. Unless an individual expressly indicates otherwise, within this trusted circle of care, health care providers may provide and share health information without the explicit consent of the individual, thereby ensuring the effective, efficient and timely delivery of health care services. However, in general, outside of this trusted circle, health information may only be shared with the express consent of the individual. For example, express consent is required prior to sharing health information with what you might think of as people outside of the circle of care: insurers, employers, market researchers. Clearly, you wouldn't envision them as being part of the circle of care of your health care providers. There, strong, explicit consent is required, and should be.

Further, the act recognizes that there are certain circumstances where the greater public interest requires that health information be shared at times without consent; for example, where it is necessary to eliminate or reduce a significant risk of serious bodily harm to a person or group of persons. You think of the SARS epidemic, you think of those situations.

It's also important to point out that Ontario's act has served as a model for health privacy legislation across Canada, including the recently introduced Personal Health Information Act of Newfoundland and Labrador.

Further, in a recent report of the New Brunswick task force on personal health information, to whom I spoke a few years ago, their mandate is to provide recommendations on health privacy legislation to the Minister of Health for New Brunswick. The task force stated that it "regards the Personal Health Information Protection Act of Ontario as the 'gold standard' among PHI privacy statutes in Canada." They recommended that the drafting of their legislation in New Brunswick be guided principally by our act here in Ontario. I think we can all be very proud of that and I think that really stands very loud and clear as an example of what an excellent act we have here.

In addition, Ontario's act is the only health privacy legislation in Canada that has been declared to be substantially similar to the federal act, the Personal

Information Protection and Electronic Documents Act. This happened a number of years ago, since 2005. You can't underestimate the importance of this. The effect of this determination is to exempt health care providers in Ontario from the application of federal privacy rules that were, first of all, never designed to address the unique needs of the health sector. Can you imagine that if we didn't have this substantially similar designation, health care providers in Ontario would not only have to follow PHIPA, they'd have to somehow follow the federal law as well, which is competing with PHIPA? It would have been a nightmare. You can't have two different sets of rules. Fortunately, we don't have that problem.

One of the reasons our act was declared to be substantially similar to the federal legislation is the fact that it is a consent-based statute. I can't emphasize the importance of that. Integral to the concept of consent is the notion that individuals not only have the ability to consent, but also have the ability to withhold consent or withdraw consent. The provisions of our act that provide individuals with the statutory right to withhold or withdraw consent to the collection, use or disclosure of their health information have come to be referred to commonly as the lockbox provisions, although, once again, the term "lockbox" does not appear in the act.

The statutory right of individuals to lock their health information, however, is certainly not absolute and is subject to very important exceptions. In particular, individuals cannot lock their health information where the effect would be to prohibit or restrict their health care provider from recording health information that is required to be recorded by law or by standards of professional or institutional practice—for example, standards published by regulatory colleges. Further, individuals cannot lock their health information where the collection, use or disclosure is otherwise permitted or required by the act to be made without consent—for example, where there are reasonable grounds to believe that the disclosure is necessary to eliminate or reduce a significant risk of serious bodily harm.

I'm going to acknowledge that this lockbox requirement has presented some challenges for legacy systems—the older information systems of electronic health records—that were designed to provide unrestricted access across the board within health care facilities. However, having said that, my office has taken a very flexible approach to the implementation of this lockbox provision. Specifically, I've indicated again and again, and in a fact sheet that my office has actually issued on this topic, that health care providers may achieve compliance with the lockbox provisions through a wide variety of means. You can do it manually, you can do it through policies and procedures and you can do it through paper-based processes and solutions that you set up, not just technology-related ones. So you haven't been required to accept the very costly burden of changing your legacy systems. You don't have to do it. If you want to do it, of course that's your choice, but it's not been imposed by my office. I think this is a sensible approach because the number of cases that arise are very few. Why go to all this time and trouble and cost unnecessarily? In due course, the systems are going to be updated anyway. Change them at that point, but in the meantime, deal with it. Find a paper-based solution, and we have a number of examples we can give you of how that has proved to be very successful. Health care facilities are not required to go to the enormous expense of retrofitting their legacy systems to manage this lockbox requirement. Since there have been very few instances where individuals have actually exercised their right to lock their information, such requests can effectively be managed outside of these legacy systems.

I should also note that over four years of experience with the act, I'd suggest that the ability of health care providers to comply with the lockbox provisions has not been a significant issue. Of the roughly 1,000 complaints that my office has dealt with to date, only a handful—less than five—have been based on the failure of a health care provider to comply with a lockbox request, and of that handful, all of them were resolved to the satisfaction of both the individual involved and the health care provider through informal discussions and mediation provided by my office. It's not a problem. We can deal with it.

0920

If the Legislature of Ontario were to alter these consent provisions of the act in any way, including eliminating or modifying the lockbox provisions, it would jeopardize the designation of our act as being substantially similar to the federal statute that I mentioned earlier. As a result, health care providers in Ontario would be required to not only comply, as I mentioned, with the privacy rules in our act, but also the privacy rules in the federal legislation, which, as I've also indicated, were never designed to address the unique needs of the health care sector but rather to address the needs of electronic commerce. This would result in a great deal of unnecessary confusion. We don't need to go there, so I just wanted to draw attention to that.

I also want to emphasize to the committee that, since the act has come into effect, health care providers have largely embraced their obligations under the act. To date, my office has investigated over 960 complaints under the act. However, on only five occasions have I had to resort to actually issuing an order. I often joke about how we fought very strongly for having order-making power, and then I don't go and use it all the time. But that's the whole point: When you have order-making power, you have the strength that you need to make sure that the act will be complied with in the way it should be. You don't want to abuse that right. When you need to do it, you do so, and we've used it five times. It's a great testament to health care providers' willingness to work co-operatively with my office in investigating and adjudicating complaints. A large percentage of cases that come to us are self-reported cases from hospitals and health care providers, much to their credit, and we work with them very closely.

My office has always stressed what I call the three Cs: consultation, collaboration and co-operation. That's how we try to deal with health care providers, preferring to resolve complaints informally through mediation rather than the issuance of orders. On the five occasions when we have issued an order, it was not because the health care provider needed to be forced to comply with their obligations under the act. Rather, it was because the complaints involved potentially systemic issues, very broad issues that, in my view, other health care providers would benefit from the guidance provided by issuing an order. It sets the standard of practice, if you will, and you want to disseminate that very widely.

For example, one of my most recent orders involved an investigation relating to a stolen laptop belonging to a hospital which contained the unencrypted health information of 2,900 patients. In this order, I found that the hospital had contravened the act because reasonable steps had not been taken to ensure that this information was protected against theft, loss and unauthorized disclosure.

I further held that if health care providers felt that they had to store identifiable health information on mobile devices such as laptops or BlackBerries, then you just had to encrypt the information and code it in a way that, if someone stumbled on it or accessed it in an unauthorized manner, they would get garbage. So if you take health information outside of your health care facility in a mobile device, you either encrypt it or you don't take it, full stop; those are the choices. I issued an order there. Again, the hospital was wonderful. They co-operated, they absolutely said they would do this, but I wanted the message to go out very loud and clear to everyone.

Finally, I'd like to conclude by very briefly discussing the amendments to the act that are being recommended by my office and which have been circulated to committee members earlier today. My proposed amendments to the act have three purposes, and they're very minor in nature. First, they aim to ensure that the proper balance continues to be struck between the rights of individual patients with respect to health information and the delivery of effective, efficient and timely health services. Second, they attempt to ensure that the exercise by individuals of their rights under the act continues always to be respected. Third, we want to ensure that my office has the powers necessary to independently review and adjudicate complaints under the act.

In particular, the amendments requested are designed to guarantee the continuity of individual rights and the continuity of health care providers' obligations under the act upon changes in their practice, such as bankruptcy, insolvency or the cessation of their practice. Both my assistant commissioners and I would be happy to tell you the details of some of these. I'm not going to go into it right now, but I'd be happy to take questions on it with my assistant commissioners.

Our amendments also seek to protect the rights of individuals under the act, including their right to access their health information, from any improper conditions or restrictions. I can't tell you how important it is, again, as a patient—especially if you're a patient dealing with multiple health care providers in different facilities. You become the manager of your own information. You've got to have everything at your fingertips. If there's any imposition on your ability to get your information, which you have a right to, this can impose a real barrier. I'm really asking for your assistance in making sure health care providers don't impose any imposition to people getting their own health information.

I never have a problem, of course—that may not surprise you—getting my information, but I think, again, I'm unique. Sometimes, health care providers ask patients for their reasons: "Why do you want the information? Why do you want a copy"—

The Acting Chair (Ms. Laurel C. Broten): Commissioner, we only have a couple of minutes left, so if I could ask you to reach your conclusion. Thank you.

Dr. Ann Cavoukian: See? That's what always happens when I go off-script. I only have two paragraphs left. I'll turn back to the script.

The amendments also attempt to ensure that the process for conducting reviews and for investigating and adjudicating complaints prescribed in the act is consistent with the reality of the circumstances in which such reviews and investigations are undertaken. We'd be happy to expand upon that during question period.

In closing, please permit me to reiterate that the act is working very well and does not, in my view, require any significant changes. Thank you very much once again for providing me with the opportunity to appear before the committee today and for considering my office's proposed amendments to the act. My assistant commissioners and I will be happy to answer any questions that you may have. Thank you very much.

The Acting Chair (Ms. Laurel C. Broten): Thank you very much. Watching the time closely, unless there are some very specific questions of clarification, we have exceeded our time for your presentation and don't have time for questions.

Dr. Ann Cavoukian: Just by one minute. Can I just—

The Acting Chair (Ms. Laurel C. Broten): We run a very tight ship; we have a very long day.

Dr. Ann Cavoukian: Just one more thing, and you will be so excited to hear this: We have the best structure here in Ontario. Today in the news clips, California just indicated that they're setting up a new state office. It's called the Office of Health Information Integrity. Why? Because they don't have an Office of the Information and Privacy Commissioner. They're setting this up, and the hospitals are to draft a plan to safeguard patient information, because they don't have the protections that we enjoy here under PHIPA and our office. We're very fortunate in this province, and I thank you very much for that.

The Acting Chair (Ms. Laurel C. Broten): That was a nice way to start our day. Thank you.

ARCH DISABILITY LAW CENTRE

The Acting Chair (Ms. Laurel C. Broten): I'd like to now call upon our next presenter, ARCH Disability Law Centre. Good morning. If you could please identify yourself before the committee. I'll let you know that you have 15 minutes for your presentation, and that includes our time to ask questions.

Ms. Ivana Petricone: Yes. I will try very hard to stay within that time. Good morning. My name is Ivana Petricone. I am the executive director of the ARCH Disability Law Centre.

I'd like to begin my remarks by telling you a little bit about ARCH. ARCH Disability Law Centre is one of the community legal aid clinics in Ontario. We specialize in serving people with disabilities throughout Ontario. ARCH represents people with disabilities in a number of ways. We engage in test case litigation, we provide summary advice, and we also provide public legal education and engage in law reform activities on behalf of people with disabilities. ARCH is, as I said, one of a number of community legal clinics that serve people with low income in Ontario. Our membership consists of more than 60 disability consumer and service organizations, and our staff report to a consumer-based volunteer board of directors.

At ARCH, we continually hear concerns from clients and the community of people with disabilities regarding health information privacy. Health information privacy legislation is of particular importance to people with disabilities, and I'd like to describe that to you. Compared to the general population, an enormous volume of health records and information is compiled regarding people with disabilities. Such information is collected, used and distributed in a host of different contexts. Access to and privacy of health information has a strong impact on the ability of people with disabilities to participate fully in society. People with disability rely on their health information not only for medical treatment and research, but for most other aspects of their lives, which include employment, education, insurance, access to government services, income support and transportation. Decisions that will determine whether or not an individual receives government disability payments or other income maintenance benefits, accessible transportation, private disability insurance or accommodations at work are all reliant upon the person's health records.

0930

Given the importance of access to personal health information by persons with disabilities, that information must be easily accessible by the person concerned. The access should not cost very much—in fact, it should cost as little as possible—and the individual should face no barriers to information concerning themselves.

The right to privacy and confidentiality of that information is another most important element of health information privacy legislation for people with disabilities. If an unauthorized disclosure occurs, even of the simple existence of the disability, this can easily result in discrimination against that person. It is essential, therefore, that PHIPA provide scrupulous protection of unauthorized dissemination of personal health information.

Since its enactment, PHIPA has gone a long way in achieving these important goals for people with disabilities. Today, I'd like to highlight for you some areas that ARCH believes require revision by the Legislature to come closer to achieving these goals.

The first area I'd like to discuss is the applicability of PHIPA to non-health-sector persons and organizations. As you may know, many people with disabilities, particularly those with intellectual or developmental disabilities, live in supportive housing or what are called group homes. The service providers in these residential settings are often custodians of personal health information. The status of these facilities is unusual under the Long-Term Care Act. Therefore, it is unclear under the current legislation whether PHIPA applies to these service providers, particularly in section 3 of the act, which contains the definition of "health information custodian" and which is not entirely clear.

In addition to these residential settings, detailed personal health information is collected in a host of other non-health-sector contexts, such as in workplaces, insurance, educational institutions and service agencies. This information is equally sensitive, personal and important outside the health sector as within it. Inappropriate disclosure or refusal of first party access is as damaging to the individual in these contexts as it is in health professionals' offices and hospitals.

All health information should be protected equally, regardless of the location in which it is kept.

It is ARCH's recommendation that all custodians of personal health information be governed by PHIPA, including those who are not in a purely "health care" sector. The legislation should include directly all persons and entities who collect, use and disclose personal health information regardless of whether they are part of the health sector.

ARCH has expressed concern in the past regarding non-health information that is frequently attached to personal health information records; for example, in community care access centre records, which contain information regarding eating, transferring, or meal preparation, in addition to financial information, which often is kept regarding a person's eligibility for particular services. Subsection 4(3) of PHIPA deals with "mixed records" and states that personal health information about an individual includes identifying information that is not personal health information. Identifying information is also defined in section 4, but it is unclear what information is covered by this definition or whether it would cover the examples that I've given you. There should be more clarity in these areas so as to protect the privacy rights of all individuals.

Coming from a community legal clinic, I would like to address with you the issue of fees. Persons with disabilities have a disproportionately greater need for access to medical records, as I've described to you. At the same time, they are disproportionately poor and often not in a position to pay hundreds of dollars to access their own medical records. ARCH frequently receives calls from people who desperately require copies of their health records but for whom the fees charged are prohibitive. Many in the community of people with disabilities have very low incomes and very significant medical expenses. This combination makes it, in most circumstances, impossible for them to afford any significant cost for accessing their records.

At the same time, access to their health records has a major impact on most aspects of their lives, and most importantly, their income. Inability to access these records often means that people with disabilities are denied much-needed social assistance, insurance and accommodations. It is fundamentally unjust and inconsistent with the purpose of privacy law to deny access to health records because an individual cannot pay for them. Therefore, we urge that any fees for accessing health records must be as low as possible, with a mechanism provided by which persons with limited financial means can be exempted from fees altogether.

I'd like to address a little bit the issue of complexity of PHIPA. This is a very complex piece of legislation. I've only been at ARCH for a few months, and it took me considerable effort to work through this law, and I'm an old lawyer, so you can imagine the person in the group home having to work through it. One example is that it's not clear to us at ARCH when reviewing section 8, which relates to freedom of information, which legislation applies, nor is it clear how the Freedom of Information and Protection of Privacy Act and the Municipal Freedom of Information and Protection of Privacy Act apply together. This complexity is only heightened for many people with disabilities often because of the disability that they have. ARCH stresses that the act should be simplified and its applicability expressed in a clearer manner.

In addition, ARCH sees a serious need to incorporate public education about the act into the act. Public education must be communicated in plain language and in accessible formats. The information should be available in places often frequented by persons with disabilities, such as group homes and community care access centres. People with disabilities must be informed of their rights and of what they can do if breaches occur. Custodians of personal health information must advise the person if a breach occurs but should also direct the person who has suffered the breach to a place where they can be advised of their remedies; for example, the Information and Privacy Commissioner, whom you've just heard from, or our legal clinic.

In order to fully participate in society, people with disabilities must have access to their personal health information as well as the assurance that that information will be kept confidential and their privacy rights enforced when there is a breach of that confidentiality. While ARCH views PHIPA as important legislation which achieves many of these imperatives, many issues such as the applicability of PHIPA to non-health-sector persons and organizations, non-health information attached to health information records, accessibility of personal health information to the person concerned, and public education about this complex legislation require more careful attention. The current review presents an important opportunity to address these unresolved issues.

I'd like to thank you for the opportunity that you have afforded ARCH to make these comments today.

The Acting Chair (Ms. Laurel C. Broten): Thank you very much. We have just a couple of minutes if there are any questions. I'll start with you, Mr. Marchese, if you have any questions.

Mr. Rosario Marchese: Thank you, Ivana, for coming. First, a statement around public education: I think all governments fail in that regard with all bills, and while governments may claim they do it, we never do it. So it's a good point to make publicly over and over again because we don't do a good job of that.

Secondly, did you get a chance to talk to the Information and Privacy Commissioner and tell her about your concerns?

Ms. Ivana Petricone: I have not, but when there were hearings for the legislation in 2004, ARCH did speak to the privacy commissioner.

Mr. Rosario Marchese: Did you get a chance to talk to any ministry people about your concerns?

0940

Ms. Ivana Petricone: Yes. The ministry people attended at our office a few weeks ago and we were able to present these concerns.

Mr. Rosario Marchese: It's not as if they agree or disagree; they simply listened to your concerns.

Ms. Ivana Petricone: Yes.

Mr. Rosario Marchese: With respect to the fees, was there any sensitivity to the issue of inaccessibility to records because of how high the fees might be?

Ms. Ivana Petricone: I think there was sensitivity to it. You would have to ask them, but we did make the point. It's an extremely important point, for people to be able to afford, so we've made—

Mr. Rosario Marchese: I agree. I would hope the government would listen to that.

The Acting Chair (Ms. Laurel C. Broten): One last question, Mr. Marchese.

Mr. Rosario Marchese: You heard the privacy commissioner talk about the bill. She's quite happy and doesn't think there are too many changes that are required. Are you familiar with the changes she might be putting forth?

Ms. Ivana Petricone: I'm not. No, I can't address those changes.

Mr. Rosario Marchese: Are you in agreement that the bill is pretty good?

Ms. Ivana Petricone: I am in agreement with that, but for these four areas that I've highlighted today.

Mr. Rosario Marchese: Thank you.

The Acting Chair (Ms. Laurel C. Broten): Mr. Shurman.

Mr. Peter Shurman: Thank you very much for your attendance. Just a couple of questions, primarily pertaining to the centralization or lack thereof in terms of records. How much problem do people who deal with your organization find inherent in the fact that legislation is everywhere? I think of myself, and Commissioner Cavoukian made mention of the same thing—I probably have a hundred different sets of health records everywhere. This act has been around since 2004. The same type of act was contemplated in 2000 by our government.

We agree with this act, by the way, but there's been very little movement on centralization of records in an e-health sense, and so the collection of this data and the dispersal of this data seem to be a problem. I'm interested in your experience with this.

Ms. Ivana Petricone: Certainly, our experience, for people with a disability, reflects your experience with records all over the place, in many different places, and is heightened as well. You can imagine that people with disabilities have even more of these records and they are deposited in different places, not only in their doctor's office but in the several offices that I've mentioned.

We did talk with ministry staff about centralized deposit or holding of the information. Inasmuch as that may make those records more accessible to people with disabilities, we agree with that. However, it's hard to see how having everything in one place is going to make that easier for people to get their hands on.

Mr. Peter Shurman: From my perspective, and again, I'm looking for your view on this, if I walked into a doctor's office and handed a card to the doctor or the doctor's assistant and it was swiped and my records were there, that would make me a lot happier, especially knowing they came from one centralized registry.

Ms. Ivana Petricone: Yes, I agree with that. I think the centralized holding of the information may make the protection of that information easier, but at the cost of accessibility.

Mr. Peter Shurman: Thank you.

The Acting Chair (Ms. Laurel C. Broten): Mr. Naqvi.

Mr. Yasir Naqvi: I just wanted to ask you a quick question, and I believe my colleague Mr. Ramal has a question as well. I was intrigued by your comments about the applicability of PHIPA to the non-health sector, and you referred to section 3 in particular, to supportive housing and the application of the act. I was looking at section 3 and I actually see a specific reference to the Long-Term Care Act in paragraph 3(1)2. In addition to that, the whole concept of a circle of trust in the application of the act—in your opinion, is that not sufficient to cover the non-health sector which may be in possession of the health information of individuals?

Ms. Ivana Petricone: My understanding is that the status of group homes is unclear under the Long-Term Care Homes Act, which makes it unclear under the section that you have just read to me. Our point is that we need to clarify that. We need to make it absolutely clear that that information is protected by these residential settings, which are not really long-term-care facilities; they're homes for people with disabilities. There are supports in the homes. So that status is unclear to us and to many people in the sector. We're simply urging that if that is the intent, if the intent of this section is to capture them, then it should be made more clear in your review.

Mr. Yasir Naqvi: Thank you for your clarification.

The Acting Chair (Ms. Laurel C. Broten): We're out of time. Thank you very much for your presentation.

MINISTRY OF HEALTH AND LONG-TERM CARE

The Acting Chair (Ms. Laurel C. Broten): I'd like to call upon the representatives from the Ministry of Health and Long-Term Care. Please introduce yourself and those individuals who will be joining you at the table. You have 15 minutes for your presentation.

Ms. Carol Appathurai: My name is Carol Appathurai. I'm joined today by Fannie Dimitriadis, who is legal counsel for the ministry. We'd like to thank you for the opportunity to present today.

I'd like to begin my presentation by providing a little bit of context. Public opinion surveys over the years have demonstrated that the privacy of health information is very, very important to the public. In fact, the public sees their personal health information as the most sensitive of all information. That concern is borne out by two statistics that I think are really quite compelling: 1.2 million Canadians have withheld information from a health care provider; and 735,000 Canadians have decided not to see a health care provider because of concerns over whom the information would be shared with or how it would be used. I think that's quite compelling. That really demonstrates the importance of having strong privacy legislation, more so as we go forward with the electronic health record. I'm happy to say, as you've heard earlier from the privacy commissioner, that Ontario's privacy legislation is really seen to be a model of protections that are very well balanced.

We are bringing forward a few recommendations. They're not major changes.

First, we would like to amend the legislation to allow for disclosure of personal health information for quality assurance purposes. When we developed the act in 2004, we put in a provision that allowed health care providers to use the information that they have in their possession for quality assurance purposes, to evaluate the quality of the service they're providing. We did not anticipate at that time that they may need more than that information; that is, they would need follow-up information. I can give you an example: When a hospital that has treated an individual discharges that individual to the community for ongoing treatment, it would be very helpful for the hospital to have feedback on how that individual is doing in the community. It allows the hospital to evaluate whether their diagnosis and treatment were appropriate.

Currently, under the act, there is no provision to allow for that disclosure. So we are asking that we amend the legislation to permit that disclosure. We would put some limitations around it in order to ensure that it was for quality assurance purposes only, and we would achieve that balance between supporting an effective health care system while protecting the privacy of the individual.

Our second recommendation relates to public consultation on proposed regulations. Currently, under the act, we are required to post regulations in the Ontario Gazette for 60 days. That's to allow the public time to give us feedback on their opinion. We are suggesting a change to that: reducing the number of days that the legislation is posted to 30 days. This would bring it into compliance with the Ontario Drug Benefit Act and the Long-Term Care Homes Act. We are also asking that we be able to post this information on the ministry website. We do believe that this would not only bring it into compliance with the other legislation, but it would allow us to move time-sensitive technical regulations through more quickly.

0950

Our third recommendation relates to regulation-making authority related to e-health. Currently in the legislation, we have one section—I think you have it before you—that refers to regulation-making power related to e-health. You can see—I won't read it out for you—that it's fairly narrow in scope. This regulation-making authority dealt with the development related to aspects of e-health that we anticipated in 2004. Since that time, it's become clear that additional applications of e-health, unforeseen in 2004, must be accommodated under PHIPA. We would also like to make PHIPA much more flexible to deal with e-health requirements that we can't anticipate at this time. We took some inspiration from Newfoundland in this. Their privacy legislation includes a comprehensive regulation-making power, and we think this is something that would benefit Ontario.

Our fourth recommendation relates to the consent provisions. You have heard the privacy commissioner explain that Ontario's is consent-based legislation, so that information flows on the basis of implied consent, but that consent can be revoked by the patient, by the individual, in whole or in part. This is commonly known as the lockbox. Implementing the lockbox in old legacy IT systems has been a challenge. It's less of a challenge in newly developed situations.

For example, I remember visiting the Sault Ste. Marie community health centre two or three years ago. They developed an electronic health record, and at that time they had 85% of the community in Sault Ste. Marie on that electronic health record. In developing the record, they heard from psychiatrists and psychologists that some information should not be part of the record and readily accessible to everyone. They heard from the mental health and addictions patients that there was a need to keep some of their information locked away. They also heard from the staff at the centre that they felt they didn't want all of their information necessarily to be accessed by others. They designed—and very nicely designed—an electronic health record that included a box called "social demographics," so that mental health information automatically gravitated there, and individuals who wanted to lock away bits of information could easily do that.

Other jurisdictions are struggling with the challenge of implementing a consent-based model in a technology environment that's not quite there. So you see that Britain has a sealed envelope; you have Finland; you have Australia. All are finding adaptations until we have, as we expect to have fairly soon, appropriate technology. In the interim, as you have heard, the privacy commissioner has come forward with adaptations.

We feel that this consent-based approach is vital to patient trust, and is especially vital as we go forward with the electronic health record.

Our next recommendation relates to breach notification. PHIPA requires that health information custodians notify the individual at the first reasonable opportunity if personal information about the individual is lost, stolen, or accessed by unauthorized persons. This was a first for Ontario, and it has been copied in legislation in other jurisdictions. Some providers have felt that this is particularly onerous. We believe that this provision should be maintained, that it has sufficient flexibility. If you notice, we use the phrase "at the first reasonable opportunity," and that really is quite flexible. We do believe that breach notification is critical to the kind of transparency and accountability that is necessary for instilling patient trust.

Since PHIPA came into force in 2004, we've been working very closely with stakeholders to address their concerns and their issues, and most of those concerns and issues we've been able to address through regulatory change. Recently, we've had requests for changes, for amendment to the legislation to give greater clarity within the legislation. We believe that many—probably the majority—of these requests can be addressed through regulatory change, rather than legislative change, and we're certainly committed to working with stakeholders to address their issues.

We've also heard, as you have, from ARCH and from others as well the need for education for patients on their rights under the legislation and the need for education for stakeholders to ensure that they are aware of their responsibilities under the legislation. We've certainly heard this and we're giving it very careful consideration.

The Acting Chair (Ms. Laurel C. Broten): We only have a couple of moments left, and I have had signals from committee members that they have questions for you, so if you could wrap up, that would be great, and we'll let them ask their questions.

Ms. Carol Appathurai: We've wrapped up.

The Acting Chair (Ms. Laurel C. Broten): Very good. Mr. Shurman.

Mr. Peter Shurman: I just have one question. I'm going to be quite blunt: I'm pretty unimpressed with the work of the ministry in terms of the development of a universal e-health records-keeping system. This act was put together contemplating that, and we're still at a situation where I myself am going for surgery next week and I filled out yet another paper form. I have no idea how many paper forms about me exist; I'm the same as Commissioner Cavoukian. When can we anticipate that the $650 million that's been thrown at this so far will justify, for example, the recommendation you make with regard to clause 73(1)(h), which looks at the Lieutenant Governor in Council having a more comprehensive range of blah, blah, blah on e-health records?

Ms. Carol Appathurai: The ministry is very committed to implementing an electronic health record and they're very actively working towards that.

The Acting Chair (Ms. Laurel C. Broten): Ms. Jaczek.

Ms. Helena Jaczek: Thank you for your presentation. I have two very quick questions. Your recommendation number one related to, as you described it, a follow-up situation, a transfer of information from one health information custodian to another. I have difficulty understanding what would be so difficult in obtaining consent from the patient if it was explained to the patient that custodian number one wishes to have a follow-up discussion with custodian number two. Surely the majority of patients would be only too happy to provide their consent, and therefore you would not need that change within the legislation?

My second question relates to fees. We did hear from ARCH again that although there is the possibility of a health information custodian waiving fees, they have found in their experience that this does not seem to be sufficient, and I notice the ministry does not address that issue.

Ms. Carol Appathurai: I'll answer the second one first, because this is a concern for the ministry. We believe that may be a result of a lack of education on the part of stakeholders. Unfortunately, we've found that there are a number of stakeholders who are not fully conversant with the legislation and we think that education on this issue would go a long way to resolving the problem.

In terms of why you cannot obtain consent, that's an interesting question, because really we went into developing the legislation with the principle that, wherever possible, consent should be obtained. But what we did hear from stakeholders is that it's very, very time-consuming for them to do this and that it's simply more efficient in certain areas to allow the free flow of information.

I'll give you an example. In the newborn screening program in Ontario, where they screen approximately 135,000 babies every year, they would have to obtain consent from each of those parents in order to get feedback information on whether in fact their diagnosis of that infant was correct down the road.

Ms. Fannie Dimitriadis: I just wanted to add to that as well. We've also heard from stakeholders that, in some cases, the need for following up on quality assurance arises after the fact. They don't realize it, and at that point, they've lost touch with that patient. They're no longer seeing that patient. That's what we've heard from some of the stakeholders.

1000

The Acting Chair (Ms. Laurel C. Broten): Mr. Marchese.

Mr. Rosario Marchese: Just a quick few points, Carol. You almost expressed surprise that some people are not aware of the act. For me, it's a given. I would think that all ministry officials would take that as a given in terms of whatever work we have to do. You may be limited in your ability to do it by way of dollars—I'm not sure—but it shouldn't be a surprise.

The other point you make is that 1.2 million people withhold information—I'm assuming you said that's a good thing, because the act works—and that 750,000 did not see a health care provider. Presumably that's good, but I'm not quite sure how that is a positive thing—as a question.

The final one is that you appear to agree with many of the changes that people are recommending by way of regulation. Are there some that you don't agree with? Which ones might they be?

Ms. Carol Appathurai: As we've said in our recommendations, we would not agree with any amendments to the consent or breach of notification, but I would have to actually see all of the recommendations before I could answer that question.

But I may not have been clear in describing the context. I used the 1.2 million and 735,000 examples from the 2007 Ekos survey to illustrate just how sensitive and how concerned people are that they would go as far as withholding information or not seeing a doctor because of that concern about the protection of their information.

The Acting Chair (Ms. Laurel C. Broten): Thank you for your presentation.

STEVE ELSON

The Acting Chair (Ms. Laurel C. Broten): I'd like to call upon our next presenter, the Schizophrenia Society of Ontario, London chapter, if you could introduce yourself. You have 15 minutes for your presentation, including questions.

Mr. Steve Elson: My name is Steve Elson, and I'm a member of the leadership committee of the London chapter of the Schizophrenia Society of Ontario. I'd like to say how very pleased I am to have this opportunity today.

I am a parent of a child who lives with schizophrenia. For the last 12 years, I have been actively involved with the Quinte chapter, and more recently the London chapter, of the Schizophrenia Society of Ontario. For the last three I have served as the London chapter chair.

As a family, we have had our own struggles, and in addition I've had the opportunity to listen to many stories from other family members about their difficulty with finding treatment for their family member.

Recently, based on complaints and frustrations voiced at meetings, I put together a short two-page guide to help family members gain access to information. So while I'm officially here as an individual, unofficially I think I am speaking for many family members, especially parents of family members who are diagnosed and live with a serious mental illness, all across this province.

To put my remarks in context, I would like to say that having access to health care information about a son or daughter, sister or wife needs to be understood within the lifelong context of our relationship with our family member. For example, as parents, these are children we have nourished, raised and lived with from birth. They are people we love and cherish and people we have a profound sense of commitment to. As our children, we have seen them grow up and often flourish into adolescents or young adults, only to have their and our lives irrevocably and profoundly changed forever with the onset of mental illness. I say this because it is important to understand that whatever involvement we have with the health care system and professionals, it pales in comparison to our life experience with these individuals before, during and after any active treatment they receive. Yet all too often, the experience, insights, understanding and, yes, even the love we have to bring to the whole clinical treatment process is discounted. It may be rejected, tolerated or accepted, depending on who we encounter. From our perspective, nothing is predictable.

At the same time, progressive mental health treatment research has documented the significant role that families play and the value they can bring to the treatment, care, healing and recovery process. In terms of the health care system, it's like we are on the outside looking in, while at the same time it is families who have been and will continue to be the primary support system for their ill family member. It's like we're good enough to care and be fully responsible for the well-being of our family member outside of the health care treatment and care process, but not good or valuable enough to be actively involved while they are in it.

So now what? In the context of the hearings today and PHIPA, I think that the legislation as it is being applied serves to exclude families, especially families who are directly involved and committed to their loved ones. For example, it does not recognize the lengths that families sometimes have to go to get their loved one into treatment. If a family member is actively psychotic, then we need to practise the tough love of getting the police or justice of the peace involved. For someone who is actively delusional and has no insight, seeking out treatment is not a voluntary option.

So it's no surprise, in this context, that the parent or spouse is labelled as the enemy. We are often the target of our family member's anger, since it is our intervention that has often resulted in the person being placed in treatment, which they see as being unnecessary. So it's no surprise that the person in treatment might want nothing to do with the family or want to deny them access to information. That's why context is so important.

This is not a one-time event. It is a lifelong condition, and we live with the possibility of having to repeat this scenario if the person goes off their medication. In the long term, some families can get discouraged and burnt out from constantly going it alone. In the worst-case scenario, everybody gives up on the individual and they fade into the world of homelessness and severe personal neglect.

The recent Senate report on mental health, headed up by Senator Michael Kirby, called Out of the Shadows at Last, gave testament to the grim realities faced by family members all across this country. While not all situations are like this, we know that if we don't actively participate in the lives of our loved ones, the consequences can be dire.

Now that I have set the scene, let me offer some observations based on my experience and that of others. While PHIPA has served a very useful role in defining the rules around what information can be shared with whom and has put a special status on personal health care information, it is almost as if protecting the privacy of information is more important than the reason it was collected in the first place. The general rule is that information cannot be shared and only by exception can it be. So the responses we get include: "No, we can't tell you without permission"; "We can't tell you because your family member says he/she doesn't want us to"; "We can't tell you because the ill person is an adult"; "We can't tell you because you are not part of the circle of care"; and "We can't tell you because you are not a substitute decision-maker." You get the idea.

At the same time, from a continuity-of-care perspective, family members can provide a vital link in the provision of support and care, not only before and after hospitalization but during as well, if they are allowed to. I would like to think that the provision of care and the continuity of care take precedence and that privacy provisions safeguard the patient, but not at the expense of addressing the health care needs of the patient.

As an example, if a patient in a hospital were to be discharged into the care of a licensed group home or residential care facility, the group home staff would have access to the information they needed to ensure recommended treatment approaches and medications are maintained and followed. It just makes sense that this happen. Why? Because it is in the best interests of the patient that this occur. So why, if a patient is being discharged home, do the same provisions not apply?

Obviously, I think they should, and I'm glad to say that the province of British Columbia thinks so too. British Columbia has put provisions in their Freedom of Information and Protection of Privacy Act whereby families can be provided with relevant information without the person's consent if "the disclosure is for the purpose for which the personal information was originally obtained or collected; or a use consistent with the purpose for which the personal information was originally obtained or collected."

Here is an excerpt from the Guide to the Mental Health Act, 2005, from British Columbia: "If a client's personal information was collected for health care purposes, public bodies may release necessary information to third parties for 'continuity of care.' This means public bodies may disclose personal information to health care professionals, family members, or to other persons, such as friends and relatives, involved in a client's care for the purpose of that care. The release of the information must be in the best interests of the health of the client."

1010

I would like to conclude by asking that this committee carefully review the provisions that the province of British Columbia has put in place and give serious consideration to amending PHIPA to allow for the sharing of personal health information in the same manner as BC has done.

Thank you for the opportunity to come here today to inform you of my perspective, to voice my concerns and to table a solution for your consideration.

The Acting Chair (Ms. Laurel C. Broten): Thank you for your presentation. Mr. Ramal.

Mr. Khalil Ramal: Thank you for your presentation. You've brought a different perspective to the committee.

I have had a similar experience. Constituents came to my office many times to deal with their daughter, but they weren't able to do so because of the regulations and privacy issues, because she was an adult. What happened then? The daughter killed herself. I'm probably not allowed to mention names, but you're probably familiar with that story. It has happened on a regular basis, and you mentioned it.

You spoke eloquently when you described how parents are allowed to look after their loved ones, but when it comes to health care, because they're dealing with an adult, they're not allowed to know more information about their health care or provide additional information or support in order to treat their loved ones. So you're asking us to extend the ability to provide information to the parents or the circle who will provide that person some kind of care.

What do you think about when we establish electronic records? I didn't get a chance to ask the ministry when they presented to us about the possibility of allowing a person access to his or her record through a special code—especially with the technology now. It gives us that ability, instead of going back to the doctor to pay a fee, because so many people have no ability to pay a fee every single time they want some kind of a record or information about their health care. What do you think about this?

Mr. Steve Elson: First of all, I think there definitely have to be some parameters or some safeguards associated with who gets access to information and that that's clearly enshrined in the legislation. Obviously, one option is to allow family members to be defined as part of the circle of care and to be fairly specific about who those individuals are. That may in fact allow family members to gain access to the information that they're currently not provided. There perhaps are a number of approaches, but there obviously needs to be some authenticity to the requests, in terms of the kind of information that family members require.

In terms of whether it's provided electronically or accessing information electronically, I think that's a secondary concern, from a family member's perspective. What we need is the information that's going to allow us to have some understanding as to the kind of situation and what we need to do to contribute to the ongoing rehabilitation or the ongoing care of the individuals who come back into our homes. When we're guessing or we don't have that information, particularly clinical, available to us, that becomes really problematic.

The Acting Chair (Ms. Laurel C. Broten): Mr. Marchese.

Mr. Rosario Marchese: I really sympathize a great deal with what you're saying. We always struggle with how to balance the interests. Often, we go too far in one way or the other. But I do appreciate what you're saying. I think we've got to find a way to allow parents to get this information, because I understand it's about helping the son, daughter, wife, partner, or whoever it is, and helping yourselves. So I'd be very interested to look at the BC model to see where it has succeeded and where there might be some problems and how we could fix them.

Have you talked to the ministry, and what have they said about how we might deal with this particular issue?

Mr. Steve Elson: Good question. I haven't, personally. When I spoke with the ministry, when I brought this to their attention, they indicated that in fact they would be looking at other legislation in other provinces. I basically left it with the ministry to do that investigation and determine whether or not it was something that was appropriate for Ontario to take under consideration.

Mr. Rosario Marchese: I'm sympathetic to that. I hope we can find a way to help families deal with that problem.

Mr. Peter Shurman: Mr. Elson, thank you for appearing. I follow on my colleague Mr. Marchese's question, because I too find myself very much in sympathy, and I've been an advocate for family members who can't advocate for themselves. Sometimes that decision has to be made absent their ability to give you permission to advocate, so I hear what you're saying. But looking at the quote that you've provided from the BC act, "If a client's personal information was collected for health care purposes, public bodies may release necessary information to third parties for 'continuity of care.'" So far, so good. "This means public bodies may disclose personal information to health care professionals, family members, or to other persons, such as friends and relatives, involved in a client's care for the purpose of that care. The release of the information must be in the best interests of the health of the client."

In whose opinion—how would you contemplate making that determination?

Mr. Steve Elson: Good question. I think that clearly the responsibility for the release of the information belongs with a custodian, the person who has the legal responsibility for the release of that information.

Mr. Peter Shurman: Forgive me, though: In your presentation, it doesn't seem like there necessarily is a custodian in some of these cases. You've got a father and a daughter relationship, perhaps, where the daughter has a problem but maybe you don't have the custodial right. It seems to me in your presentation that came across. What happens then?

Mr. Steve Elson: You're quite correct from that perspective. I was looking at it from the point of view of the person who's the health information custodian. We're missing the context of the word "custodian." The person who has responsibility for the health care information within the health care system—my understanding would be that in fact it's their judgment as to whether or not they do or do not release the information. What we're asking for is allowing that as an option, allowing that information to be released and shared with family members in a predictable fashion so that it doesn't become guesswork as to whether it will or will not be shared with us.

Mr. Peter Shurman: Then let me ask that question one more time: Who makes that determination? Who decides? A court? Who?

Mr. Steve Elson: I would like to think that it's the person who would be the primary custodian of that information, so it might be a physician, it might be the hospital who has the responsibility for that information. That information doesn't belong to us; we're asking for the information that belongs to the patient in that record to be shared with us as family members. It's not under our control; we recognize that. What we're saying is that people who do have control and will therefore make that decision about whether to share it or not, be that the health care provider—that there are clear provisions in terms of enabling them to share that information with us as family members.

The Acting Chair (Ms. Laurel C. Broten): Thank you, Mr. Elson, for your presentation.

COUNCIL OF ACADEMIC HOSPITALS OF ONTARIO

The Acting Chair (Ms. Laurel C. Broten): I'd like to call upon the Council of Academic Hospitals of Ontario. Please introduce yourselves as you join us at the table. You're beginning to understand the drill here. You have 15 minutes. That includes questions, and certainly the time goes very quickly. Please begin when you're ready.

Ms. Mary Catherine Lindberg: Good morning. My name is Mary Catherine Lindberg and I'm the executive director of the Council of Academic Hospitals of Ontario. To my side is my colleague Mary Jane Dykeman, a lawyer specializing in advice to academic hospitals, including on privacy and research matters. In particular, Mary Jane has provided us with considerable advice related to the Personal Health Information Protection Act.

The Council of Academic Hospitals of Ontario acts as a collective voice for Ontario's 25 academic hospitals. Ontario's academic hospitals, in full affiliation with our province's six medical and health science schools, have a threefold mission: They provide specialized and advanced care to patients from within and outside their communities, they teach future health care professionals, and they conduct health research that leads to tomorrow's health care advances. We are the hospitals of last resort, the hospitals that provide the highly specialized acute care.

Our members are also members of the Ontario Hospital Association, and we have worked closely with the OHA in our review of PHIPA. Our council fully supports the positions and recommendations set out in their submission to this committee. I understand that OHA is scheduled to present to you later today. This morning, I will focus on the direct impact the PHIPA legislation has on our members' unique and most significant contribution to the system: health research.

1020

Ontario is the fourth largest health research centre in North America. Twenty-five academic hospitals and affiliated research institutes employ 10,000 researchers and generate over $850 million annually in research activity. Ontario's academic hospitals are home to 80% of all of Ontario's health research. Ontario's health research enterprise is internationally renowned, with some of the world's most highly cited health researchers located within our universities and research hospitals. In this post-genome era, we are developing unprecedented insights into how the human body works and making progress on how to intervene to prevent, treat and cure disease. With chronic diseases on the rise and an increasingly aging population, this new knowledge will be needed more than ever.

Clinical trials are one aspect of health research, and these studies include volunteer research subjects. These studies answer questions about efficacy, safety, impact on quality of life and a host of other crucial issues.

We have recently completed an extensive initiative to standardize clinical trial agreements, with the ultimate result that the academic hospital—the principal investigator in the study—and the drug sponsor now have a common set of ground rules to which they agree. These agreements include the usual contractual language about insurance and other standard terms and conditions; however, they also speak specifically to the standards that must be met to protect individual privacy, as well as the confidentiality of personal health information. Our member hospitals have adopted these principles and present a united front to the industry sponsors on ground rules around health privacy and research, which brings me to the impact of PHIPA on health research in Ontario.

Our primary goal in research is to promote excellence in the delivery of health care without doing harm. Clinical researchers and hospital administrators support safeguards for health information and to prevent its misuse. Researchers have dealt with issues of individual privacy protection and the confidentiality of personal health information for many years. They recognize that the relationship between researchers and research participants, and, by extension, the personal health information of these research participants, must be based on trust and respect. The challenge for legislation such as this is finding the sometimes sensitive balance between privacy concerns and the need for societal advancement in areas such as medical discovery. We need clinical trials. They save lives and they make lives better.

It is the position of our council that the PHIPA legislation, as it is currently written, does support the health research mandate of Ontario's academic hospitals. We ask that this sensitive balance be maintained as the standing committee considers proposed changes. We want to ensure that we maintain an environment within Ontario that ensures a health care system that is continuously improving, while being respectful and protective of the rights of the individuals whom it serves. We would be very pleased to work with you to ensure that an appropriate balance is maintained.

We also understand that there may be some consideration of increasing the transparency of the activities of research ethics boards, including mandatory publication of documents related to clinical trials, such as letters of approval issued by research ethics boards.

For those of you who may not be familiar with research ethics boards, research ethics boards have the responsibility of assessing the ethics of all research that is undertaken within their organization. The purpose of a research ethics board is to ensure that all research involving human subjects is carried out with the highest scientific and ethical standards, and to ensure safeguards are developed which provide the greatest protection to patients and members of the community who serve as research subjects. They are also arm's-length entities.

Ontario's academic hospitals are fully committed to transparency and accountability, but in this area we must offer some caution. In the case of research ethics boards, we believe current requirements already protect patient privacy as well as provide rights to access information. These include:

First, patients interested in participating in a research study must at the outset provide informed consent. As a result, there is an obligation to provide these individuals with full disclosure concerning the study, including potential risks and benefits. This information is provided directly by the research team, and typically, contact information for the principal investigator as well as the research ethics board is provided to the individual in case they have any further questions. In some instances, personal health information may be used or disclosed for research purposes without consent, such as in a retroactive chart review, but only as permitted by the PHIPA, where the research ethics board has turned its mind to whether it's appropriate to permit this to occur. A good example would be a case of epidemiological or longitudinal studies that may be taken over a number of years. In such studies, obtaining individual consent would be impractical—this is part of the criteria set out in PHIPA—but there is a strong public interest in supporting this kind of research.

Secondly, a publicly accessible, searchable Web database of clinical trials already exists to provide additional information to interested parties. This database provides information relating to 60,000 clinical studies across 157 countries, including the trial's purpose, who may participate and its location.

Thirdly, research ethics boards are arm's-length entities: arm's length from hospitals, researchers and industry. There is little evidence to date to suggest that their impartiality has been undermined.

Additionally, section 15 of the regulations to the PHIPA mandates that each research ethics board be constituted in a particular manner in order to serve the public interest. This includes having a member of the board with an express interest in privacy. In practice, research ethics boards are becoming more attuned to privacy matters and incorporate these into their ethics reviews of prospective studies.

Finally, the Information and Privacy Commissioner of Ontario, as the oversight body, continues to have the power to investigate complaints, including those related to research, as well as to initiate investigations in her own right.

A robust research environment is necessarily rooted in innovation and intellectual property. Our recommendation is that we carefully weigh privacy concerns against any solution that may jeopardize the necessary level of confidentiality in health research that promotes and sustains innovation and investment.

Our recommendation, therefore, is to maintain the current requirements for transparency of research ethics boards, as an appropriate balance has been struck between necessary disclosure to patients and the public and the confidentiality required to preserve intellectual property.

We appreciate the opportunity to share our position. We thank you for your careful consideration of this very important issue of patient confidentiality. We would welcome an opportunity to discuss our comments.

The Acting Chair (Ms. Laurel C. Broten): Mr. Marchese, any questions?

Mr. Rosario Marchese: It appears that you support the current legislation; it strikes the right balance, you say. It also appears that you're worried that changes might be made. Do you have reason to believe that changes are coming from somewhere?

Ms. Mary Catherine Lindberg: If everybody starts to review all the other legislation and looks at other things—and there has been some discussion that maybe the research ethics boards should release their approval letters—we're just a little worried that that might complicate some of the things that are happening. We have no positive reinforcement that says that will happen. We're just saying that we want to be cautious and we want to live with what we have.

The Acting Chair (Ms. Laurel C. Broten): Mr. Shurman? Ms. Jaczek.

Ms. Helena Jaczek: Just following up a little bit on the question from my colleague across the way, we did hear from the Ministry of Health this morning, first of all, that in fact four out of five Canadians do value the privacy of their personal health information, but also that the ministry is considering a recommendation related to quality-of-care research, where, potentially, health information would be passed from one health information custodian to another health information custodian for the purposes of follow-up related to quality of care, without seeking the patient's consent for that follow-up. For me, quality-of-care follow-up is a type of health research; it is obviously designed to improve care etc. So, with your background and your knowledge of what you have described very clearly here, the standard research procedures that Canadian academic hospitals follow, would you be in favour of such a change to the legislation, as proposed by the Ministry of Health and Long-Term Care?

1030

Ms. Mary Jane Dykeman: If I could just jump in for a moment, I know that that's been one of the discussions amongst the teaching hospitals and it's been raised by the ministry. My understanding was that some of the focus was on things such as serious adverse events and quality improvement. And you're right; it's an excellent point. There's been an ongoing debate for some time about what is quality improvement versus what is pure research. I think we probably do step aside somewhat in that arena to really focus on quality improvement. I think that's probably not the main focus of CAHO; we think mainly of clinic trials and, again, the use of the information in retrospective chart reviews. But I know that many of the academic hospitals, as well as many of the other health information custodians, would like to do that to ensure that we share the appropriate information about serious adverse events and make proper improvements to the health care. It's not focused specifically on research. So I think there is a distinction to be made.

The Acting Chair (Ms. Laurel C. Broten): Thank you very much for your presentation.

PSYCHIATRIC PATIENT ADVOCATE OFFICE

The Acting Chair (Ms. Laurel C. Broten): I'd now like to call upon the Psychiatric Patient Advocate Office. I would ask you to join us at the table and introduce yourselves as you commence your presentation, please. You have 15 minutes, and that also includes the members' time for questions.

Mr. Ryan Fritsch: Good morning. My name is Ryan Fritsch. I am legal counsel to the Psychiatric Patient Advocate Office, which I will refer to as the PPAO. With me this morning is David Simpson, one of our program managers.

We would like to thank the committee for its invitation to consult in this first statutory review of PHIPA. We are here today to share our perspective as a rights protection organization with over two decades of experience. We also speak from the experience of our network of 60 rights advisers and patient advocates who have worked under PHIPA for the last three years in dozens of hospitals throughout Ontario.

Three years ago, the PPAO appeared before the Standing Committee on General Government and raised a variety of issues with the then-draft version of this legislation. Today, we appear before you to say that many of those same issues persist. We encourage this committee to take this review opportunity and address many of these issues now.

Let me begin this morning by telling you who we are and what we do. The PPAO was established in 1983 as an arm's-length organization of the Ministry of Health and Long-Term Care to protect the civil and legal rights of in-patients in the current and divested provincial psychiatric hospitals. We provide a range of services, including instructed and non-instructed advocacy, systemic advocacy, rights advice and public education.

Since the changes to the Mental Health Act in 2000, the PPAO has been designated by more than 95% of schedule 1 hospitals in Ontario as their rights adviser. Last year, we provided more than 20,000 rights advice visits to patients, did work on more than 4,500 advocacy issues, and contributed to 140 systemic-change concerns. We also had 3.2 million visits to our website, which is full of guides and rights information.

In our experience, there is a huge gap between mental illness, acceptance and understanding in Canada. In our submission, privacy legislation is the key to bridging that gap. Privacy laws protect patients who need help from the discrimination that hurts everyone. By protecting persons from discrimination, privacy laws contribute to social equality, communal empowerment and individual recovery.

As with any significant piece of legislation, PHIPA has its limitations. While we are going to focus on two primary areas in a moment, we would like to draw your attention to a number of key issues that we will not have time to discuss in detail. Two of these issues significantly erode patient rights. These are: (1) barriers to access and disclosure of patient health information records because of an onerous complaints resolution system; and (2) barriers to access and disclosure of patient health information records because of excessive and arbitrary fees.

Two other issues we address in our written submissions include: (1) everyday misuse of the concept of the circle of care as a way of interpreting patient rights under PHIPA that is extralegal and unintended by the legislation; and (2) confusion among health care providers, patients and patient families over the legal test for consent to medical care, and when a patient is providing knowledgeable consent versus implied consent.

Finally, two other issues we raise speak to the need for education and policy guidance. These include, first, that quality-care committees should be reviewed and redefined to better serve their intended function; and two, that many health care providers, particularly outside of major institutions, are unaware of fundamental and basic patient privacy rights. We submit that privacy must be made a part of the health care curriculum and that government must do more to provide plain-language privacy rights resources around the province.

We would be happy to provide the committee with any supplemental material on any of these issues.

You'll find that the first issue we focus on in our written submission concerns the need to strengthen and improve a patient's right to protect their personal health information under the existing lockbox provisions of PHIPA. These concerns are raised between pages 1 and 3 of our written submission.

By way of background, PHIPA sections 20(2) and 37(1)(a) proactively empower a patient with the right to direct limits on the disclosure of specific content in their personal health information record from other health care providers or persons of concern who may come into contact with the record. This so-called lockbox provision protects the patient from the discrimination, stigma, embarrassment and interference that may occur when their mental health diagnosis or treatment regime is unnecessarily disclosed to family members, employers, neighbours, colleagues, landlords, friends or other private or public institutions beyond the privacy of the therapeutic context.

The PPAO was instrumental in advocating that this provision be included in PHIPA during the initial drafting phase of Bill 31. Unfortunately, we find that its protections are still absolutely required. A study published this month by the Canadian Medical Association found that Canadians are 50% more likely to fear telling friends and relatives about a mental illness than any other health diagnosis, including cancer or diabetes.

Some typical examples where a patient would invoke their lockbox right to avoid prejudicial information leaks would include that a mental health facility not share a diagnosis with a family physician; that adult children are protected from having their treatment regime disclosed to family members; that a landlord is not told about the mental illness for a patient receiving housing support under a community treatment plan; or that a patient's neighbour working in the treatment facility not be privy to their health information.

Unfortunately, the self-evident value in such a protective right is being underutilized by patients. In turn, this is keeping the right from becoming a normalized routine in everyday health care. We think the reasons for this are fourfold.

First, many health information custodians take an overly generous interpretation of what information within a patient's health record is "clinically necessary." Sometimes this disclosure takes place in direct contravention of the patient's order. But patients can also get caught between a rock and a hard place when they attempt to enforce their right. On the other end of the spectrum, it does happen that patients are referred to specialists or other doctors who refuse to treat them until they know what health information is within the lockbox.

Second, health information custodians may wrongly conclude that lockbox rights are to be balanced against the circle-of-care principle. This principle does not exist within PHIPA, yet it is commonly used as a shorthand for providing all personal health information to the circle of health care providers and sometimes family members. Unfortunately, this principle is not only extralegal, but it is often given a huge discretionary grey area as to who is and who isn't within the circle of care.

Third, lockbox protections are also usurped when a patient's psychiatric information follows them to new institutions or doctors. Complications arising from such a move can include a continuing presumption of consent at the new institution, or a health information custodian with different standards than the patient has been afforded in the past. Such problems are exacerbated by the lack of standardized consent forms, the patchwork of information retention schedules, and the dispersion of records across many institutions or practitioners. All of this is onerous if not impossible for patients to anticipate and manage, and becomes yet another barrier to health access in a system that is already often slow to respond to mental health care needs.

Fourth, patients are often simply unaware that they have a right to the protection of a lockbox. This calls out for education of patients, their families and health care practitioners alike.

1040

For the most part, we believe these shortcomings can be addressed through legislative clarification that focuses on (1) presumptively restricting a patient's lockbox only to those so authorized; (2) accounting for the circle of care and other grey area health care providers; and (3) requiring that health care providers respect and abide by lockbox provisions over their personal or moral misgivings.

Moving on, you'll find that the second issue we focus on in our written submission is critical of the way police collect, use and retain the personal health information of persons diagnosed with a mental illness. Furthermore, we are concerned with how police analyze and disclose this information for the purposes of conducting police record checks and vulnerable persons screenings. These issues are raised between pages 3 and 7 of our written submission.

Our core concern here is that the patchwork of municipal police services across Ontario is not currently governed by PHIPA in the exercise of these reporting functions. They therefore receive no standardized principles or procedures that would extend the privacy rights and sensitivity given to personal health information in contexts other than this one. Without such protections, police have free range to determine how information related to a mental health diagnosis will be characterized as so-called “information of concern on file” to the public safety, which in turn requires that it be disclosed as part of a records check. As a result, an individual’s personal health information is not only disclosed outside of its therapeutic context, but it is also given a criminal profile that compounds prejudicial and discriminatory attitudes against mental illness. Even more damningly, this can permanently compromise a patient’s ability to obtain employment, volunteer in their communities, obtain health insurance and enjoy civil liberties such as the basic freedom to travel.

The truth is that most police contact with persons having mental illness is non-criminal in nature. Under the Mental Health Act, police are called upon to respond to persons in distress or in need of assistance and effectively act as a mode of transportation to connect them with the health services they require. More recently and increasingly, police are being paired up with a nurse or other health care worker as a mobile response unit to provide the most appropriate health crisis services possible. Out of these encounters, we note how four primary concerns arise that should be dealt with under the PHIPA framework.

First, it is all too easy for the inference to be made that any contact with police is criminal in nature. Unfortunately, our experience is that this already typifies the common practice. When persons with mental illness are temporarily taken into custody and to a place of examination pursuant to the Mental Health Act, it is more often than not wrongly characterized as a criminal arrest. This criminalizing mistake is made even within the judicial system. Within the police service, a record of a series of non-criminal interventions might be characterized over time as a pattern of behaviour that police determine is relevant as information of concern. In our submission, police should not be put in the position of being psychiatrists in blue. Patterns of behaviour should not be inferred from misleading representations of incidents and should not be based on assumptions about the meaning of a health diagnosis or a simple lack of knowledge and understanding.

Second, police might make such a conclusion as to the relevancy of health information without fair consideration of any external referent such as the nature of the inquiry into the background check, the environment in which services are to be provided or the actual risks associated with vulnerable populations within that environment.

Third, police services believe that they are entitled to release this information as pertinent to a records check as it is police information and not personal health information. This is a questionable practice on its face, but also because police record other types of health information, such as injuries and visible disabilities, that they would never consider relevant or proper to release as part of a police records check.

The Acting Chair (Ms. Laurel C. Broten): You only have a couple of minutes left.

Mr. Ryan Fritsch: Thank you.

Finally, we note that the line continues to blur between police services and health services. While we support the role of mobile crisis response units, it is our experience that health information recorded or observed by the attending nurse may also be recorded by the police officer.

In our submission, we believe that this deeply concerning list of privacy violations can be addressed by extending the PHIPA framework to these police functions. Section 4 of the act defines personal health information, in part, as that which “relates to the physical or mental health of the individual.” Based on this definition, it appears that much of the information gathered and released by police services across Ontario would be covered by PHIPA as personal health information.

Additionally, the Ministry of Health and Long-Term Care should provide the necessary direction either in law, regulation or policy to ensure that privacy barriers between health and police services are respected.

As the database grows and as crisis response units become a more common way to assist persons suffering mental illness, the potential for discriminatory information flows will intensify. These privacy concerns must be addressed through province-wide standardization to ensure that the disclosure of information through police record checks at least satisfies the very high test for disclosure of mental health information in the common law, if at all. It is for these reasons that we believe this issue must be addressed as part of the statutory review of PHIPA.

As this concludes my submissions, we invite questions from the committee. Thank you.

The Acting Chair (Ms. Laurel C. Broten): Thank you very much for your presentation. You’ve given us a great deal of information, written information as well, which I’ll ask the committee to review. But we won’t have any time for questions this morning.

FAMILIES AND FRIENDS OF SCHIZOPHRENIA

The Acting Chair (Ms. Laurel C. Broten): If I could call upon the next presenters, the friends and family of schizophrenia.

Ms. Annick Aubert: My name is Annick Aubert, and I was fortunate enough to get copies made of my presentation by the clerk because, as you can tell, after what I just heard I’m a bit emotional.

I consider myself a primary caregiver. I’ve been looking after someone who has had schizophrenia for 28 years. This is weekly and daily. I’d like to tell this gentleman that my family member came home at 2:30 last night. He never comes home any earlier, and yet I was up here at 8 o’clock this morning. As soon as I give my presentation I’m going to rush back, because he has diabetes, and when he takes his blood sugar he often forgets to write it down. When we go to the hospital, they say, “Well, did you keep track of his blood sugar?” I do—so I won’t be long.

I must say that I have the deepest respect for the PPAO’s office as it was in 1983. These gentlemen maybe will remember that at the first PPAO was David Giuffrida. He did wonders at Queen Street. I was in his office if not monthly, weekly. I just realized this morning—and by the way, thank you, Mr. Marchese. I should have thanked everybody else, but thank you in particular, because you listen to me often. I realized this morning that with the new privacy act, I could never have talked to David the way I talked to him 20 years ago. He would have kicked me out. Yet I’m sure that with my feedback, maybe bias, he was helped to make tremendous changes in what was the old Queen Street Mental Health Centre, especially about restraints and locked rooms, because I did report all that to him. Enough of that.

Families are primary caregivers for nearly half of all seriously mentally ill people, and yes, we are not included in the circle of care. Steve said it wonderfully: Each time we tried to help or we wanted information just to make sure we were doing the right thing for our family members, we were told, in the old days, “Did you sign a form 14?” These days, we don’t even know what the new forms are, and anyway, the example by—this lady’s office only mentioned consent to disclose, not consent to collect or use. So when we want to call and say, “Our family member did not come home last night. We don’t know where he is. Has he been admitted because he was ill on the street yesterday?”, we’re told, “We can’t give you that information.” So we go and worry or we go and look for them ourselves, and sometimes we find them—under the Gardiner, on the beaches or on the lakeshore.

The only thing we would really like—and it goes against the PPAO’s wishes—is that we be included and be given enough information to help our family members get better. And they do get better with our help.

We just came back from France. We warned them, “Our family member has schizophrenia. He’s quite seriously ill,” and yet we had three wonderful weeks in France. So we are helpful; we are helping. Please let us help.

I’ll stop here, and you can read my report.

1050

The Vice-Chair (Mr. Vic Dhillon): We’ll start with the official opposition. There’s about five minutes each.

Mr. Peter Shurman: I don’t really have any questions. I just want to express my admiration for you. I think that the kind of care that you can give arguably exceeds the care that could be given by any professional. I congratulate you for what you’re doing.

The Vice-Chair (Mr. Vic Dhillon): Mr. Marchese.

Mr. Rosario Marchese: I did want to ask the Psychiatric Patient Advocate Office a question in relation to what you’re raising and in relation to what the previous parent raised. I understand that there are circumstances when sharing some information with some family members would be worse, but I also understand that there are many times when sharing information with family members is important and is good, and you two parents have indicated why it’s important to strike that right balance. While I seriously respect the rights of individual patients, I also know there are parents like yourselves who want to help, are committed to helping, and there’s nothing else you could do but help, which means you suffer if you’re unable to do so, and the person you want to take care of suffers because your ability to help isn’t there. We’ve got to find a way. That’s the question I wanted to ask the presenter, Mr. Fritsch, to respond to, but we didn’t get a chance. I’m hoping the ministry will look at the British Columbia model to see what works and what doesn’t, as a way of finding the language that allows families to be part of the solution. I hope we find it.

Ms. Annick Aubert: We do not ask for confidential information. What they share with their psychiatrist is none of our business; we don’t want to know any of that. We just want to know, at least, if they’ve been admitted if we’ve been looking for them for years, or when they’re going to be discharged, because sometimes we’re not told when they—and they change their mind all the time. When they refuse consent while hospitalized, they’re often discharged, and even though they don’t want to talk to us, they are on our doorstep and we didn’t know they were there.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Mr. Marchese.

Mr. Rosario Marchese: I just want to congratulate her for being a worried parent who’s giving a lot.

The Vice-Chair (Mr. Vic Dhillon): Government side: Dr. Kular.

Mr. Kuldip Kular: I don’t have any questions. I really want to thank you for presenting here before the committee.

In my experience as a family doctor turned politician, I feel the same way as Mr. Marchese feels: that we have to find the right balance between disclosing the information for family members or caring custodians. But my feeling is, where is that right balance? That would be the most difficult job to bring into the act, and I don’t know how we can do that.

COMMUNITY AND LEGAL AID SERVICES PROGRAM, YORK UNIVERSITY

The Vice-Chair (Mr. Vic Dhillon): Next, we have community and legal aid services program, York University, and Ms. Nadia Chiesa.

Welcome to the committee. You have 15 minutes. Please state your name for the record, and you may begin.

Ms. Nadia Chiesa: My name is Nadia Chiesa. I’m a law student at community and legal aid services program, a student legal aid clinic at Osgoode Hall Law School at

York University. I'm joined today by Amy Wah, legal counsel at CLASP.

CLASP represents clients with mental health needs in many areas, including housing, income support and human rights work, and we work in partnership with agencies serving this community.

Working with the mental health consumer survivor community, we have become aware of the concerns surrounding the current police practice of retaining and disclosing records of detention under the Mental Health Act. Today, I will be addressing this issue in more detail as well as outlining our recommendations.

In recent years, it has become common practice for employers and community groups working with vulnerable persons to require potential employees and volunteers to consent to a police records check. The goal of conducting these background checks is to verify that the individual in question has not been involved in any known activity that may place the agency's client base at risk. Unfortunately, most agencies do not have a clear understanding of the limitations of these inquiries, nor of the type of information maintained on police records that may be disclosed to them.

If an applicant has been detained by police under the Mental Health Act, which means that police have transported him or her to the hospital for psychiatric assessment—or, less commonly, that police have transported him or her between psychiatric facilities—then a police record will exist. A police record is created even if the individual is not admitted to hospital for treatment. A police record is created simply because the individual is transported to hospital by police.

The following example illustrates how these records are created and how this is an issue that can affect everyone, even those with no history of mental illness. A young woman studying social work is experiencing severe depression and recognizes that she needs help, so she calls her sister. Her sister drives her to the hospital, where she receives treatment and is released. She returns to her everyday life. She applies to a job at a children's centre and has to agree to a police records check. She does not have a record and she gets the job.

Another young woman who is also studying social work is experiencing severe depression. She recognizes that she needs help, so she calls 911. The police go to her home and drive her to the hospital, where she receives treatment and is released. She returns to her everyday life. She applies to a job at a children's centre and has to agree to a police records check. She has a police record simply because the police drove her to the hospital. In order to continue with her application, she must disclose the record and the circumstances surrounding it to her potential employer. She does not get the job.

Section 17 of the Mental Health Act authorizes police officers to detain and transport individuals to hospital for examination by a physician in a number of circumstances. A police record is created simply because the police have transported the individual to the hospital.

We are concerned that when a person is detained under the Mental Health Act, that incident can later be disclosed to a potential employer and community agencies during a police records check. After an applicant consents to the police records check, the record itself is sent to the individual, while the employer receives a letter stating that the check has been completed and that there is information on file. The applicant is placed in the compromising position of either disclosing the record—and, by extension, his or her personal health history—or withdrawing from consideration for the position.

This type of police record does not mean that the individual has engaged in criminal activity or even has a diagnosis of mental illness. Employers often, however, do not understand what this record means and withdraw job offers as a result.

We submit that this information should be considered to be personal health information, implicating the individual's personal health at the time of detention, and as such should be protected by PHIPA. The practice of disclosing these records is a serious infringement of an individual's right to privacy.

Detentions under the Mental Health Act are not criminal in nature, yet are maintained in the same category as theft, break and enter, and weapons offences. These mental health police records are retained for five years plus the year of the incident, a longer period of time than some police records in relation to criminal charges.

Further, unlike some criminal police records that a person can request be cleared after a certain period of time, there is no process in place to pardon or clear mental health police records.

Since these detentions are not criminal in nature, most people who find themselves in this situation had no idea that this information might ever be disclosed as part of a police records check, nor should they. Our clients' experiences show that at the time of detention, the person is typically not informed that a record of this police contact will be retained and could be disclosed during a records check in an employment context. Considering that these detentions involved no criminality, it does not occur to those who have had this experience that it would ever be disclosed to a potential employer when they consent to a police records check. Unfortunately, most seem to learn that this incident is on their record only when the police record is sent to them and the employer contacts them to discuss the results of the check. They are then placed in the unenviable position of either disclosing this personal information, which can be a humiliating and traumatic experience, or forgoing the opportunity of employment. This amounts to discrimination based on a disability.

It is important to note that youth are particularly affected by these records, as early onset of mental illness can begin during adolescence. Once a young person has this kind of record, it can adversely affect educational, volunteer and employment opportunities. The record will follow them during their critical formative years. Further, while youth criminal records are often sealed after the age of 18, mental health police records for youth are not. These records will follow a young person into early adulthood.

1100

The practice of releasing this personal health information, which should be protected by PHIPA, criminalizes people with mental health issues and perpetuates the myth that they are dangerous. It is discriminatory in its practice as it reveals non-criminal records related to persons with psychiatric disabilities. It negatively affects an individual’s access to employment and full participation in society.

The practice also impairs an individual’s right to non-discriminatory access to health care. For example, if an individual knows that calling 911 to seek health care during a mental health crisis may result in a mental health police record that could adversely affect employment, education and volunteer opportunities, he or she may be less likely to access the necessary health care.

PHIPA is intended to protect an individual’s right to privacy of his or her personal health information. The practice of releasing records of detention under the Mental Health Act violates this right. The consequences of this violation are severe considering the significant stigma surrounding mental illness in our society. There is overwhelming research demonstrating that people with mental illness face discrimination in all areas of their lives because of the diagnosis. The very fact that potential employers receive a letter from police indicating that a police record exists may be sufficient to cause an employer to withdraw an offer. This is discriminatory when the underlying basis is not criminal conduct. When this information is released to an employer, the individual is forced to either disclose his or her personal health history or forgo the opportunity. It is an extremely difficult decision to make and neither option is satisfactory.

We submit that the police practice of disclosing records of detention under the Mental Health Act to an employer during a police records check violates the individual’s right to the privacy of personal health information under PHIPA. Police should still be able to collect information for the purposes of maintaining business records as long as consent is obtained in accordance with the requirements of the act, but other uses or prejudicial disclosures should be restricted.

We recommend that this committee consider amending PHIPA to specifically enumerate records of detention under the Mental Health Act within the definition of personal health information so these records will be clearly protected by PHIPA. By defining these records as personal health information, the police would no longer be able to release these records as part of a police records check. When an individual consents to the collection of this information at the time of detention under the Mental Health Act, he or she is consenting to the collection of information for the intended use of maintaining police business records. The individual should not be presumed to be consenting to the use or disclosure of the information as part of a police records check. Therefore, when an individual consents to a police records check, he or she should not be presumed to be consenting to the disclosure of mental health police records. This presumption would violate the requirement that consent be knowledgeable, because the individual would not know that his or her police record could contain this personal health information.

We also recommend that records of detention under the Mental Health Act not be subject to any exemptions in the legislation so that an individual’s right to privacy of his personal health information will be guaranteed. Ontarians have the constitutionally guaranteed right not to be discriminated against on the basis of a disability. The current police practice of releasing records of detention under the Mental Health Act violates this right.

We recommend that the Ontario Legislature develop PHIPA in accordance with the Ontario Human Rights Code and the Canadian Charter of Rights and Freedoms, as the courts have indicated that legislation should be interpreted in accordance with national and provincial commitments to human rights legislation and the Constitution.

Amending PHIPA to protect these rights as personal health information, thereby prohibiting the release of these records, would not only preserve the integrity of the legislation but would protect the fundamental human rights of all Ontarians.

I’d like to thank you for having me here today.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. A couple of minutes to each side.

Mr. Rosario Marchese: Yes, a quick comment, Nadia. Are you related to Dino Chiesa?

Ms. Nadia Chiesa: No, I’m not.

Mr. Rosario Marchese: And you noticed how I pronounce Chiesa?

Ms Nadia Chiesa: Yes.

Mr. Rosario Marchese: We’re so lucky to be able to recognize these sounds.

I really appreciate what you’re raising. The other group raised similar points—the Psychiatric Patient Advocate Office. The point about what is personal health versus criminal record is important. You understand the problem. If something should happen or if something was not disclosed in a way that would help people solve a problem, then we as politicians, as legislators, would be liable—somebody would be liable. So what’s the fine line between how you help individuals not be discriminated against, because they would under the circumstances you describe, versus where it should be recorded in such a way that it would allow us to prevent a problem down the line? Do you think that what you present offers that balance for public protection versus personal protection?

Ms. Nadia Chiesa: I believe it does. As I mentioned in my submissions, having a mental health police record does not mean that you are mentally ill or that you suffer from a diagnosis of a mental illness, or that you have engaged in any criminal conduct whatsoever. We're not opposed to the release of criminal records during an employment check. We're concerned that, by releasing mental health police records, police are releasing personal health information that should be protected.

Mr. Rosario Marchese: I'm personally sympathetic to the argument, actually. I'm not sure whether you've discussed that with the ministry people who are here and what they've told you. If you have an answer, let me know.

The Vice-Chair (Mr. Vic Dhillon): Mr. Naqvi.

Mr. Yasir Naqvi: Thank you for your presentation. Is it a possibility that we can get a copy of your presentation?

Ms. Nadia Chiesa: Yes, we'll also be submitting written submissions.

Mr. Yasir Naqvi: That will be great. Thank you very much.

My understanding is that police records are created under the Police Services Act. Am I correct?

Ms. Nadia Chiesa: I believe so, yes.

Mr. Yasir Naqvi: So don't you think that that obligation, whether or not to release police records, would be covered under the Freedom of Information and Protection of Privacy Act and Municipal Freedom of Information and Protection of Privacy Act? Are there not enough safeguards with those two pieces of privacy legislation and what they cover, that we may not require any amendment to PHIPA?

Ms. Nadia Chiesa: Yes, it is true that those two pieces of legislation do apply and that police have not historically been subject to PHIPA. However, we submit that, because the mental health police records deal so distinctly with a person's personal health information—that is, the record is created because of their mental state at the time of detention, and their mental state is the whole reason for the detention—we submit that this information should be considered personal health information and also subject to PHIPA.

Mr. Yasir Naqvi: So do you think that would somehow provide for more added safeguards than already exist in the system?

Ms. Nadia Chiesa: Yes. We hope that if PHIPA were to protect this information, then this information would not be released in the context of an employment police records check, which is what's happening now and is leading to discrimination in terms of employment opportunities.

Mr. Yasir Naqvi: It's interesting, because just today, there was an article in the Globe and Mail that talks about a situation in London, Ontario, where now the Human Rights Tribunal is required not to disclose those police records. The London Police Service, as I understand, will no longer be doing so. This gives me the indication that, obviously, recourse and mechanisms do exist as is, legislatively speaking. And as Mr. Marchese was suggesting, where do we draw that fine balance in terms of this particular piece of legislation? But thank you very much for your submission on this point.

The Vice-Chair (Mr. Vic Dhillon): Mr. Shurman.

Mr. Peter Shurman: I think in one way or another we all share the same concerns. I'm not insensitive to what you're saying, but I find the examples that you gave to be, I suppose purposefully, very simplistic. It's not as cut and dried as somebody has a crisis, goes and gets treatment, and in the case of some kind of a mental depression, as I think you were using as an example, "Let's take a pill and it'll all go away and why should there be a police record kept?" A 911 call is a very, very serious call. So as I started out saying, I'm not insensitive to it, but I certainly would like to hear what mechanism you would recommend besides codifying something, somehow, in PHIPA.

Ms. Nadia Chiesa: Yes, absolutely. I understand your position and your concern. We use the examples that we did today because although there are certainly more serious situations and more long-term ongoing situations, this is the kind of story that we've heard from clients over and over again. It could be one instance, one mental health crisis that leads to this creation of a record that follows someone for at least five years down the line. That's why we see it as being so important that this kind of protection is codified in the legislation.

Mr. Peter Shurman: Well, I will put it to you again: I don't know how we would codify this. Frankly, if I were the employer and the description of your imaginary example puts me in the position of hiring someone who's going to care for children, I want to know that. I want to know that there was a depression for which there was treatment, whether that record is contained on police files or anywhere else. I have yet to hear a convincing argument that says that within five years, I shouldn't.

1110

The Vice-Chair (Mr. Vic Dhillon): Do you have a comment on that? Just very quickly, please.

Ms. Amy Wah: If a person's mental illness is a bona fide occupational concern, I think it would be only fair to someone who is a prospective employee to be asked for that information specifically. It wouldn't be fair and it would be discriminatory if an employer were to get access to this person's mental health status via a request for a criminal records check. I think we need to keep those two things distinct and separate.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We have to carry on.

CANADIAN MEDICAL PROTECTIVE ASSOCIATION

The Vice-Chair (Mr. Vic Dhillon): Our next presentation is from the Canadian Medical Protective Association. Good morning. If you could state your names, you have 15 minutes; any time remaining will be used up evenly for questions. You may begin.

Dr. William Tucker: I'll introduce my companions in a moment, but thank you for hearing our submission.

I'm Dr. Bill Tucker, a neurosurgeon at St. Michael's Hospital here in Toronto, and I'm the president of the Canadian Medical Protective Association, the CMPA. The CMPA is a not-for-profit mutual defence organization operated by physicians for physicians that provides professional liability protection to approximately 73,000 Canadian doctors, including 29,000 here in Ontario. The CMPA also compensates patients who have been shown to have been harmed by negligent medical care. As a not-for-profit organization whose modus operandi is to balance, over time, its costs and revenues, the CMPA has nothing to gain financially or otherwise from the Personal Health Information Protection Act.

I am joined by Dr. John Gray on my right, the CEO and executive director of the CMPA, and on my left, Mr. Domenic Crolla, a partner of the law firm Gowling Lafleur Henderson. A member of the CMPA's general counsel is also with us to be available to answer questions at the end of the presentation.

I'll open my remarks by stating that, on the whole, the CMPA believes that the PHIPA is working well. Physicians understand the importance of doctor-patient confidentiality and their obligation to protect personal health information. This responsibility is drilled into physicians from the very first day of medical school and it remains top of mind throughout one's career. Accordingly, the core values of the act resonate very well with physicians.

The committee staff has received our written submission, which provides additional detail on the three subjects we would very briefly like to highlight for your attention this morning.

The most important item deals with the apparent discrepancy between the act and other legislation concerning an access parent's right to his or her child's personal health information. This discrepancy poses very practical issues that should be addressed.

The second item addresses the protection of quality assurance information, an area where we believe the act works well.

The final topic relates to the personal information of the health care provider, an area not addressed within the current provisions of the act but one that does require attention.

Before passing the microphone to Dr. Gray, let me momentarily take off my hat as an elected member of the CMPA council and speak to you as a practising physician. Few situations are more challenging for a doctor than informing parents about the often difficult decisions to be made regarding treatment for their sick or injured children. The current legislative discrepancies related to an access parent's right to that information add an unnecessary complicating factor to these difficult situations. The current uncertainty is not in the best interests of the child, his or her parents or the health care provider who may be caught in the middle.

I'll now ask our CEO, Dr. John Gray, to speak to these issues in a little more detail.

Dr. John Gray: Thank you, Dr Tucker. Let me preface my remarks by stating that, while I am currently the CEO of the CMPA, I also understand the difficulties that Dr. Tucker described. For 26 years, I practised as a family physician in Peterborough.

As Dr. Tucker has indicated, the association is concerned about the current discrepancies related to an access parent's right to his or her child's health information. PHIPA assumes that a patient is capable of providing consent as it relates to the information's collection, use and disclosure, regardless of age. When a child is less than 16, the act also provides authority to a parent acting on the child's behalf to give, withhold or withdraw consent to the collection, use and disclosure of the child's personal health information. However, in subsection 23(2), the act states that for the purposes of consent, the term "parent" does not include a parent who only has a right of access to the child. Other sections of the act do provide the access parent with access to the child's personal health information, but generally only where an emergency exists. For most non-emergency situations, no such right of access to the information exists. Absent a court order, the access parent is at the mercy of the custodial parent to consent to the disclosure of the child's health information.

While PHIPA is generally clear as to its intent, it runs counter to both the provisions of Ontario's Children's Law Reform Act and the federal Divorce Act. Both of these acts provide that the access parent has "the right to make inquiries and to be given information as to the health, education and welfare of the child." This difference in approach places the treating physician in a very difficult position. While PHIPA does state that it will prevail unless another act specifically provides otherwise—which the Children's Law Reform Act does not—the Divorce Act is federal legislation and might normally be seen to be paramount. However, it only applies to those circumstances in which the parents are or were once married. As we know, this is not always the case these days. The result is a potentially contradictory and certainly confusing situation.

In preparing advice to our members, the CMPA consulted with the Office of the Information and Privacy Commissioner of Ontario and with the College of Physicians and Surgeons of Ontario. The IPC response noted that the office was not able to provide a definitive interpretation or advance ruling, but it did state that subsection 43(1) could be interpreted such that the health information custodian may, without consent, disclose the personal information if permitted by law, treaty, arrangement or agreement made under the act or an act of Canada. The use of the words "could" or "may" is not reassuring to health information custodians potentially caught in a conflict between the custodial and access parents.

Significantly, access parents do have the right to information about their children's personal health information subject to the Freedom of Information and Protection of Privacy Act and the companion municipal legislation. Indeed, the privacy commissioner's office has confirmed to us that they have issued orders to that effect under those two pieces of legislation.

The access parent does, of course, have the option of seeking a court order to obtain access to the child's personal health information, but this option is often not feasible; for example, due to a lack of financial resources.

The bottom line is that under stressful conditions where clarity is most required, there appear to be conflicting provisions in different legislation. This places the physician in a difficult position with the custodial and access parents and may not permit the physician to place the child's best interests first. The CMPA believes that this situation can best be resolved by amending PHIPA to expressly permit an access parent to have access to his or her child's personal health information. We encourage you to make this recommendation.

Switching topics, the CMPA believes that the current provisions of the act that guarantee the protection of quality-of-care information and of personal health information collected for the purposes of quality assurance programs are sound. By protecting quality assurance information from disclosure, these provisions, together with the Quality of Care Information Protection Act, encourage health care providers to report adverse events so they can be thoroughly investigated and reviewed. By identifying what contributed or what might have contributed to an adverse event, effective quality assurance programs make a very valuable contribution to patient safety.

The objective of these activities is to reduce the number of adverse events so that health care is safer for all patients. Ensuring quality assurance operates in a protected environment is recognized as being vital to the success of quality assurance programs. PHIPA's provisions achieve a very good balance in this area and they support patient safety efforts. We recommend that you leave these provisions unchanged.

1120

The final topic I wish to address relates to an area which is not effectively addressed by the act or by other legislation, namely the protection of the personal information of health care providers. As Ontario adopts various forms of electronic records, be they electronic medical records or electronic health records, this issue is becoming increasingly important. The act provides reasonable guidance with respect to the collection, use and disclosure of personal health information, including that found in electronic records. However, in addition to patient information, those same records contain an increasing amount of information about individual health care providers—patient volumes, prescription practices, infection rates and so on. The act does not impose any limits on how such information might be used.

The CMPA recognizes there are legitimate uses for such information, as these uses relate to the role of the health care provider within the health care system. At the same time, a degree of reasonableness must apply, particularly as it relates to the access to and use of such information. The association believes this is one of several areas where the implementation of electronic records technology has outpaced the development of a supporting policy framework. I will leave it to the committee to judge whether PHIPA should include provisions related to this issue or whether the necessary limits should be included in other legislation. Either way, this is an issue that should be addressed in the near term and I would urge the committee to address it in your report to the Legislature.

Before Dr. Tucker and I address any questions you may have, let me close by stating that PHIPA continues to serve Ontario well. In the CMPA's engagements with other provincial and territorial governments, we often hold it up as a useful model for others to emulate. However, the issue related to access to a child's personal health information is one that demands attention. We encourage you to amend the act to expressly permit the health information custodian to disclose to an access parent the personal health information of his or her child.

We'd be pleased to answer any questions.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Dr. Gray. We'll begin with the government side, Ms. Jaczek—about a minute or so each.

Ms. Helena Jaczek: Thank you for your deputation. As a physician myself, along with my colleague Dr. Kular, we clearly have had experience with this particular piece of legislation. At one point in my life, I believe I was a health information custodian under five different provisions of this act.

I am extremely pleased to see that you have communicated with the privacy commissioner as it relates to your first point, the access parent. Clearly, from what you've told us today, you would prefer a specific amendment. You have received some reassurance, but from the point of physicians, to rely on the response you got from the privacy commissioner is not sufficient in your opinion. Am I correct that you would prefer a specific amendment?

Dr. John Gray: That is correct. The legislation, in our view, is a bit of an anomaly, because it's inconsistent with similar legislation—FIPPA and the municipal act. So we're not sure how this inconsistency arose, but it's not, in our view, in the best interests of either the children or the physicians or other health care providers who have to maybe disclose.

Ms. Helena Jaczek: In addition, on your second point—

The Vice-Chair (Mr. Vic Dhillon): Just very quickly, Ms. Jaczek.

Ms. Helena Jaczek: Okay, very quickly. We have heard from the Ministry of Health regarding a potential recommendation as it relates to quality-of-care issues. Again, do I understand that you would prefer that PHIPA remain as it is and that there be no amendment in that respect? In other words, consent would be required to transfer personal health information from one health information custodian to another health information custodian?

Dr. John Gray: Mr. Crolla might be in a better position specifically with QCIPA.

Mr. Domenic Crolla: Yes. The provisions—

The Vice-Chair (Mr. Vic Dhillon): Just very quickly, sir.

Mr. Domenic Crolla: Yes, sir. The provisions of both QCIPA and PHIPA regarding quality assurance have worked very well in the experience of the CMPA.

Ms. Helena Jaczek: Thank you.

Mr. Peter Shurman: I'm sympathetic to your point regarding access parents. I wonder if you would put any proviso on with regard to how much information or under what circumstances, or do you want complete equality?

Dr. John Gray: We're only suggesting it's limited to personal health information. As I say, that's already recognized in the common law and other legislation. It just seems this particular piece of legislation is out of step with others. So we're looking for consistency.

Mr. Peter Shurman: Thank you.

Mr. Rosario Marchese: I appreciate the support you're giving to some of the parents, some of whom are here deputing today. I'm also concerned that giving information to some parents may not be healthy. It could be deleterious; it could be a problem. Some parents are a problem, and so access to the information may not be a wise thing. That's why I think the point of what kind of access should be reviewed—and I'm not quite sure what they're doing in British Columbia. But are there circumstances under which information should not be shared, do you think? Or should we just give complete access to parents?

Mr. Domenic Crolla: There are overriding provisions in both the Divorce Act and the Children's Law Reform Act to prevent access when it's deleterious to the child.

Mr. Rosario Marchese: So you would be recommending some line that says—

Mr. Domenic Crolla: And this issue was raised with regard to FIPPA and the municipal companion legislation, so their access to both custodial and access parents is the same, with the overriding provision applying to both equally.

The Vice-Chair (Mr. Vic Dhillon): Thank you, gentlemen.

SOUND TIMES SUPPORT SERVICES

The Vice-Chair (Mr. Vic Dhillon): Next, we have Sound Times, Ms. Frado. Good morning. You have 15 minutes. You can state your name unless it was different from what I stated. Actually, it would be good to state your full name. I just had the last name.

Ms. Lana Frado: Yes, thanks. My name is Lana Frado, and I'm the executive director of Sound Times Support Services. I'd like to thank the committee for the opportunity for us to speak here today.

Sound Times is funded by the Toronto Central LHIN to provide community supports to mental health consumers and psychiatric survivors. Located at Dundas and Parliament in Toronto, we serviced over 600 individuals who made just over 19,000 visits to our facility in the last year. Sound Times is a distinctive agency in that we are staffed entirely by individuals who themselves are mental health consumers or psychiatric survivors. We are the largest initiative of this kind in the country.

Among the services we are funded to provide are services for individuals with significant mental health problems who are involved in the criminal justice system, a prevention or pre-charge diversion project for individuals at risk of offending or reoffending, and planning and support for individuals being released from custody. While my colleagues in the broader disability community will be presenting submissions that I'm certain will address numerous issues with the Personal Health Information Protection Act that impact individuals with disabilities, I come on behalf of Sound Times in an advocacy capacity to provide the committee with a specific and pragmatic exemplification of how the spirit of the legislation as we understand it is not being upheld within the context of mental health service delivery. Hopefully, this will result in further investigation into the practical applications of PHIPA in other sectors.

Like many disability groups, individuals with psychiatric disabilities depend on or are required to depend on service providers to mediate many aspects of their lives. These services include not only clinical services, but also encompass entitlements, such as housing, employment and education. I would like to speak to you today specifically about access to supportive housing, individuals with criminal records and psychiatric histories, and the impact of PHIPA on that access. These individuals are not only marginalized within the broader community, but are also marginalized within the health care system. I use this particular situation to illustrate the problematic of two concepts defined within the legislation, that of the health care record and the notion of consent.

About three years ago, as a result of an interministerial agreement including six ministries, the Ministry of Health and Long-Term Care flowed funding to agencies in Ontario to specifically address the increasing number of consumers and survivors in contact with the criminal justice system. This was a significant amount of funding for our system—$55 million, in fact. Among the services funded were case management, prevention services, specialized services for individuals with co-occurring substance use or intellectual disabilities, court supports, mobile crisis intervention teams, safe beds and housing. The criteria for accessing these services were a diagnosis of a mental illness and involvement with the criminal justice system. Each service may have had additional criteria more specific to the type of service.

1130

I provide you with this background so that the committee can give some thoughtful analysis to the parameters of what constitutes the health care record in circumstances such as these, where the health care system intersects with the criminal justice system. The nature of our criminal justice system work at Sound

Times results in our having access to information that we would not normally have as a community mental health service—and in some cases should not have—including synopses, disclosures, CPIC reports, criminal reference check results etc. Some of these documents, such as CPIC reports, should never have fallen into our hands in the first place, but were sent to us by an ill-informed service provider either in the criminal justice or mental health system.

The question that emerges is, how far do the boundaries of the health care record extend, and furthermore, how does this impact on an already marginalized individual's attempt to access services? In our experience in referring individuals to housing, for example, the answer is: significantly. We have noted in our dealings with some service providers a preoccupation with gathering what they term "collateral information" that correlates, coincidentally, with the passing of this act.

When the provider of that service is accountable under other acts, such as the Residential Tenancies Act, access to health information in the broad sense, as it is designed in PHIPA, creates a legal quagmire from which the service user is sure to emerge having had their rights violated. Specifically, we have had some housing providers deny housing to individuals with convictions that were several years old on the basis of the nature of the offences, while their current charges are relatively minor. When pressed, managers of these programs default to a risk management argument. However, it is our understanding that once an individual has been found guilty and has served their sentence, they have paid their debt to society, as it were. We do not understand how it falls within the mandate of some parts of the mental health system to continue to essentially punish these individuals by denying them access to such a fundamental right as housing.

Ironically, these individuals have been referred to non-health-funded housing, such as Toronto Community Housing, where disclosure of the health care record is not required. But they will not receive the ongoing support that they have requested from the mental health system.

This conflation of the roles of support service provider and landlord has always been problematic in many respects and for numerous disability groups. The advent of PHIPA appears to have complicated matters. We offer a mandated de-linking of the landlord function from the support function as a potential solution to reduce the possibility of discrimination on the basis of information obtained through PHIPA.

I would like to return to this notion of collateral information for a moment. It has been explained to us by numerous service providers that "the more information we have, the better we can service someone." However, we have witnessed numerous acts of presumptuous and discriminating treatment of our clients based on inaccurate and/or incomplete information. We have experienced service providers collecting third party information of dubious accuracy which falls more within the realm of impression than fact or actual assessment results. Individuals who use Sound Times have been denied access to services based on collateral information that is so far-reaching as to be irrelevant to the situation at hand.

Finally, we would like to address how all of this carrying-on takes place—with the consent of the client, of course. We believe that the committee has to think about what "consent" means for individuals who are desperate for services, individuals who are so marginalized as to not only be excluded from meaningful participation in the community, but who are denied many of the entitlements of citizenship that most of us enjoy. If you are a mental health consumer and you are desperate for housing before winter hits, if you need stable housing in order to battle a substance use problem, if you are trying to regain custody of your children by proving your stability, if you have the potential of having your charges diverted if you agree to access services, if you feel that you have no hope of accessing employment but through funded employment programs, would you consent to have people share information about you? If it was your health care provider who was sharing the information, would you assume that information would include anything and everything, from a five-year-old probation order to a note from a log in a shelter you stayed at last month? Out of literally hundreds of consent forms we receive at Sound Times, we have yet to see one that is not a blanket consent to any and all information we possess.

We understand the spirit of PHIPA is to offer Ontarians protection as to how their health care information is used. However, the government of Ontario has neglected to provide vulnerable individuals whose lives intertwine with numerous services and jurisdictions with effective information about their rights. Thus far, education efforts have not reached these individuals and have not been resourced to nearly the extent that education activities for service providers have. As we are all aware, rights can only be exercised if you know you have them.

The Vice-Chair (Mr. Vic Dhillon): We'll begin with Mr. Shurman—a couple of minutes each. Nothing? Mr. Marchese.

Mr. Rosario Marchese: I'll leave the questions to the Liberal members.

The Vice-Chair (Mr. Vic Dhillon): Any questions from the government side?

Mr. Khalil Ramal: Thank you very much for your presentation. I think you said what other people mentioned earlier.

ONTARIO HOSPITAL ASSOCIATION

The Vice-Chair (Mr. Vic Dhillon): Next, we have the Ontario Hospital Association. Good morning, Mr. Closson; good morning, Mr. Jonker, I believe.

Mr. Tom Closson: That's right: Anthony Jonker and Tom Closson.

The Vice-Chair (Mr. Vic Dhillon): You have 15 minutes. You may begin.

Mr. Tom Closson: Thank you very much for letting us present. I'm the president and CEO of the Ontario Hospital Association, which represents 157 hospitals throughout Ontario. I'll go through this fairly quickly. We do have a submission that we've given you, which contains more detail.

Overall, we are quite supportive of the fact that there is a review going on of the PHIPA, and we think this review will help ensure that the legislation is well positioned for the changing e-health environment that we have in health care, specifically as it relates to emerging technology, security and widespread integration that's occurring throughout the health care system and the opportunities that creates for better health care.

Over the last four years, the OHA has not heard many criticisms from hospitals regarding PHIPA, and in our opinion, based on our membership, the legislation is working. Nonetheless, we think there are challenges that will continue to emerge as we go forward, as technology changes, and we expect that those challenges will accelerate as the technology becomes more widespread.

The OHA's key recommendation for this review is that PHIPA needs to be an enabler of e-health. E-health is a major priority to improve the health care system in Ontario, and PHIPA needs to enable it. It should not be rigid; it should not impose a barrier to achieving a more integrated health care system for the people who live in this province.

To get a sense of the opinion of our members, we canvassed them in July. We received 88 responses from our members, and in this short presentation I'll just give you a sense of what we heard from them. We had 15 open-ended questions based on a multiplicity of issues, including new technologies and privacy and security standards, integration and use of emerging technologies, privacy impact assessments, managing privacy breaches, accessing correction of records, transparency of research ethics boards, lockbox implementation, the adequacy of education tools and support. There was an overarching consensus from the survey respondents on a number of issues, and I'll speak to those shortly. In contrast, there were a number of topics or questions in which the view of the respondent hospitals was quite divergent; in other words, there wasn't a lot of consensus in terms of how people feel. We're going to just highlight those now.

I'll just give you a couple of examples of where there was quite a bit of divergence. For example, with respect to the question of who should be responsible for notifying a patient when there has been a privacy breach, 41% of respondents suggested that the health information custodian where the breach occurred should be responsible, 20% suggested that the health information custodian where the personal health information originated should be responsible, and 21% suggested alternative means or a mixed joint effort. So it wasn't very clear, in their view. As you know, as we get electronic health records, information comes from many sources into the record, and there are many custodians involved.

Another example of divergent views is related to access and correction rules in the context of the electronic health record. The question was posed as to whether access and corrections should occur in a more centralized fashion, given that an EHR would be accessed and created by multiple health information custodians. While 50% of the respondents suggested that only the health information custodian who created the record should deal with the access correction, 25% indicated that any health information custodian should be authorized to access and correct a patient's record, and 15% of the respondents suggested that access and correction should be handled in a centralized fashion. So in fact, the view of centralization seemed to be less than the others, but there was quite a mixed view.

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Our conclusion from this—and there are other areas where there's mixed response, as you'll see in our submission, but both of these are examples of how the legislation does not address issues emerging from greater data sharing. No one disagrees with the principles in the legislation, only on how to best comply to an increasingly integrated health care environment in terms of sharing of information. Providers, managers of shared repositories and other health information custodians would benefit from thoughtful consideration of these issues, followed by clear, precise practice standards. So there's work that needs to be done in these areas for sure, and obviously the OHA is quite keen to participate in the development of what those standards should be.

There was a general consensus among the survey respondents on a number of issues, which we would like to take a couple of minutes to speak to. These include the use of privacy impact assessments, the need for privacy and security standards to address new technologies and the electronic health record, challenges with respect to the lockbox in the context of the HR, and clarification respecting the circle of care.

The summary indicates that a streamlined approach to privacy impact assessments is necessary to ensure that they're conducted in a manner that's consistent and based on defined principles. More than 85% of survey respondents suggest that mandatory privacy impact assessments may be appropriate in limited and prescribed circumstances, such as where there's a significant change in technology or addition of a new pool of users, or when multiple organizations are involved.

More than 75% of respondents suggested that as emerging technology constantly changed the health information landscape, the legislation and regulations need to keep pace. Privacy and security standards for electronic health records should be set out in regulation to ensure flexibility to evolve. I think there's an important point there about how this is going to change, so whatever you do now isn't the end, it's just the beginning. And the use of regulations so that it can evolve as e-health systems evolve is very important.

Broad standards are important, given that hospitals and other health information custodians are at varying stages of implementation of the HR technologies and information systems. We have hospitals in this province that have almost no electronic records and we have hospitals in this province where everything is electronic, and they're able to share with multiple providers in a totally electronic manner. So we're dealing with a piece of legislation that's covering a wide range of situations—again, the need for some flexibility and enablement through the legislation and through the design of this, primarily through regulation.

I wanted to speak briefly to the lockbox. Despite the logistical challenges, hospitals have been successful in implementing policies and procedures to ensure compliance with the lockbox requirement in paper-based records. However, hospitals continue to face numerous barriers in implementing lockbox requirements in electronic health records. The problem is that most of the systems that hospitals use are developed in the United States and they're not easily changed. It's not easy to get the vendors to change them and they're not designed in a way that's capable of facilitating a lockbox on electronic health records.

For example, while some hospitals can lock an entire health record electronically or flag a record to indicate that a patient has locked specific personal health information, health information custodians are generally unable to lock portions of electronic health records when requested to do so. So what some hospitals have done is to actually create a paper record separate from their electronic record for that patient, which, you can imagine, is extremely cumbersome and probably dangerous in some situations in terms of ease of access. Having said that, there are very few people who request to have information locked, so this is a fairly minor issue in terms of its frequency. Until software is developed with the lockbox functionality built in, hospitals will continue to face implementation challenges.

We've left what is perhaps the most important issue for the end, the one that's creating the biggest challenge for us. It's the concept of circle of care. As you all know, PHIPA was built around the concept of implied consent within the circle of care. But hospitals—and as I've said, we have 157 of them—have varying interpretations and opinions in determining whom and which organization fit within a patient's circle of care. I just heard yesterday from my own personal family physician that a number of family physicians are having difficulties getting information from hospitals because the hospitals aren't sure whether the family physicians are part of the circle of care. Additional clarity as to the types of situations which constitute a patient's circle of care, either through legislative or regulatory amendments or through additional policy direction and tools, would be of assistance to health information custodians. Some people are just so nervous about doing the wrong thing that they are doing the wrong thing by not ensuring that the clinical people in the circle of care actually have access to information they need to provide good care.

The survey also asked respondents to identify what additional templates and resources would be of assistance to implement the legislation. Respondents were generally satisfied with the current resources that are available, including fact sheets and resources provided by the Information and Privacy Commissioner, and there's a hospital privacy tool kit.

With regard to additional resources, they requested a second video produced by the Information and Privacy Commissioner for training and education purposes, templates for privacy impact assessments and breach notification, and fact sheets and resources related to circle of care.

Health information transformation in the form of integrated care is gaining momentum in this province. You may know that the Ministry of Health has budgeted over $2.5 billion over the next few years for the implementation of electronic health records. PHIPA must keep pace in order to facilitate the information integration effort. Shared repositories and an EHR provide the infrastructure of communication access in a centralized fashion, and effective information governance to clarify responsibility and liability within provincial and regional data repositories is required to ensure that health information custodians can participate with confidence.

Thank you for letting us present today. We'd be quite happy to take any questions that you might have.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Mr. Closson. Government side, about a minute each.

Mr. Khalil Ramal: Thank you, Doctor, for your presentation. We listened to many different—

Mr. Tom Closson: I'm not a doctor. I want to correct that just in case anybody gets sick.

Mr. Khalil Ramal: Okay. Thank you anyway for your presentation.

Interjection.

Mr. Khalil Ramal: You spoke like a doctor. You have a lot of knowledge about hospitals.

Mr. Tom Closson: I'll take that as a compliment.

Mr. Rosario Marchese: Okay, your minute is up.

Mr. Khalil Ramal: We listened to many different families speak about sharing of information. We talked about the health care custodian—who's in charge and not in charge. You mentioned specifically that some doctors have a problem to be included or not included in the sharing of information. I'm not sure if you were here earlier or not, but Mr. Elson mentioned in his presentation that as a parent with a son with some kind of schizophrenia problem, he's not able to share information in order to care better for his son. It's not just him alone in the province of Ontario; there are many others. What do you think about expanding the sharing of information in order to make sure that the patient gets the best service possible?

The Vice-Chair (Mr. Vic Dhillon): That's a long minute. If we can just get a quick response on that.

Mr. Tom Closson: I would think that that would have to be handled very carefully because the caregivers might be concerned about certain family members having access to information that may be actually used in an inappropriate way with a vulnerable patient who had psychiatric problems. I'm not saying it shouldn't be considered, but I think—if a person was a substitute-decision-maker, I think that's quite clear: They should be. But if they're not, how do you determine which members of the family—for example, maybe it's somebody who wants to contest a will; who knows? Who knows the reason that they would ask?

The Vice-Chair (Mr. Vic Dhillon): Thank you. Mr. Shurman.

Mr. Peter Shurman: Interesting presentation. I'll be brief because I know I have to be. I'm interested in the report card on e-health implementation because I infer from what you said that you're not as happy as you could be $650 million in. From my information, we're losing about 8,000 people a year because of inefficiencies in the transmission of information, absent universal e-health care, and that's what PHIPA is about—yes or no?

Mr. Tom Closson: We think e-health is a major priority. We're very pleased that the government has decided to invest this much in it. We've got to catch up, though. Ontario is behind many other provinces in Canada.

The Vice-Chair (Mr. Vic Dhillon): Mr. Marchese.

Mr. Rosario Marchese: Thank you, Mr. Closson, for raising a number of questions, including the one that says some doctors can't even get information from hospitals because they don't know where they fit into that circle of care. I'm assuming the ministry is familiar with this and is dealing with it. And thank you for the information about how good the government has been in devoting $650 million in electronic health care records. A lot of that money was spent by the previous government as well, and we still have hospitals where there are no electronic records, so you raised some good questions.

On the issue of centralization of information, you talked about how many of your members are divided in terms of how to deal with that information, and I'm assuming you have no opinion of your own—that's why you want to be part of some group that attempts to solve that?

Mr. Tom Closson: You're talking about who deals with changes, corrections to information. Yes, we think this needs to be thought through. We need an efficient process, whether it should be centralized or it should be the custodian where the information resides, but we think it needs a bit more work, because there seems to be quite a mixed view from our membership as to what the solution is.

Mr. Rosario Marchese: I'm assuming the minister is just working on that right away, to get all of these people involved. I'm assuming.

Mr. Tom Closson: I don't know.

The Vice-Chair (Mr. Vic Dhillon): Thank you, Mr. Closson.

That ends the morning session for the committee. We'll break for lunch and resume in the same room at 1 p.m.

The committee recessed from 1151 to 1301.

ONTARIO PSYCHOLOGICAL ASSOCIATION

The Vice-Chair (Mr. Vic Dhillon): Good afternoon, everybody. The committee is back in session for the last four presenters. We should be done around 2 o'clock.

Our first presentation is from the Ontario Psychological Association. Good afternoon. If you could state your names for Hansard, and then you may begin. You have 15 minutes.

Dr. Ian Nicholson: I am Dr. Ian Nicholson, chair of the Ontario Psychological Association's ethics and policy committee. I'm joined by committee member Dr. Carole Sinclair and by Dr. Ruth Berman, our executive director.

Mr. Chairman and committee members, thank you for giving us this opportunity to share with you our thoughts on the Personal Health Information Protection Act as part of your review of this important piece of legislation. My colleagues and I are here representing the Ontario Psychological Association, which is a voluntary organization that represents psychologists in Ontario.

Ontario psychologists work in a variety of settings, including health facilities, social services, schools, industry and corrections. In our work, we often collect and use the results of psychological assessments of the social, emotional, behavioural, personality, intellectual, and neuropsychological functioning of children, adults and families. We provide psychotherapy, counselling and diagnostic services, including the collection and exploration of an individual's most private and sensitive feelings, thoughts and personal history, and we research the causes and patterns of health problems in the interest of knowing how to prevent and continuously improve treatment of those problems.

As with other health care providers in Ontario, members of the Ontario Psychological Association participated in the consultative processes in the development of PHIPA, and have now had four years' experience with this act.

In our current presentation, we would like to outline seven aspects of this important legislation that we strongly support, believe have been particularly effective and would be very concerned if they were changed. This will be followed by an outline of four aspects that our members have found to be problematic.

With respect to aspects that we strongly support, in the interests of time I will only refer to specific topics.

(1) The movement toward an emphasis on privacy and autonomy—collection and use—rather than only on confidentiality or disclosure: We believe this to be an important move forward in the protection of the privacy of personal health information.

(2) The emphasis on collecting, using and disclosing only information that is needed for the current purpose; and the prohibition of the collection of information for purposes not consented to by the individual, such as research, or disclosure, for instance, of an entire record of

personal health information simply because the entire record has been requested.

(3) Wording, such as in subsection 18(2), that allows the health information custodian to make the determination that express consent may be more appropriate than implied consent in a specific situation, even though express consent is not required by the act: Our association believes this is an important protection of the autonomy of persons, insofar as general privacy information, postings and information booklets may be insufficient to assume knowledgeable consent in a particular set of circumstances.

(4) What we call the "lockbox" provision of PHIPA in part III, which allows individuals to control which aspects of their information can be disclosed to others—we also support, however, the freedom allowed in subsection 20(3) for disclosing custodians to notify receiving health information custodians if the disclosing custodian believes that information is reasonably needed for the receiving custodian's services to the individual. The Ontario Psychological Association believes this to be an important safeguard that balances professional judgment with the rights of the client.

(5) The exceptions under subsection 40(1) that allow health information custodians to share information for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons: Our association believes this exemption to be in the public interest.

(6) Clause 51(1)(c), which restricts an individual, when accessing their information, from accessing the raw data from standardized psychological tests or assessments: We believe this protection of the tests supports the continued efficacy and utility of these tests. Our association believes that if this exemption were not there, the continued utility of these measures would be substantially negatively affected, as their being in the public domain would seriously undermine their validity.

(7) Subsection 52(5), which allows the health information custodian to consult with either a member of the College of Physicians and Surgeons of Ontario or a member of the College of Psychologists of Ontario before deciding whether to refuse to grant an individual access to his or her personal health information, where it is feared that granting access might be reasonably expected to result in the risk of serious harm to the treatment or recovery of an individual or a risk of serious bodily harm to the individual or another person.

I want to move on to the four areas that we found problematic.

(1) In section 3, insurance companies are not included in the list of health information custodians. Although we understand that information privacy practices of insurance companies come under federal privacy legislation, OPA members frequently report that insurance companies sometimes do not fully adhere to basic privacy principles. They report receiving requests for disclosure of complete records, including information that goes well beyond the legitimate need of an insurance company for information about assessment results, diagnosis, or treatment plan or progress. Complete records often include very sensitive information such as personal history or therapy notes, the details of which could not reasonably be considered necessary by the insurance company to fulfill their functions. Such requests usually are accompanied by consent forms signed by the clients concerned. However, our members report that clients frequently seem to be under the impression that they had no choice, that to refuse to sign would mean that they would no longer be eligible for their insurance benefits. We have been informed of numerous instances in which clients were very distressed by such requests from insurance companies. Our association would strongly support insurance companies being subject to the personal health information protections of PHIPA, possibly by including them as health information custodians in section 3.

(2) Another aspect of PHIPA with which our members have reported experiencing difficulty is the interpretation of the concept of "circle of care," a phrase that does not appear in the act, but which has become a common language term applied to the situation in which several health care practitioners providing services to the same individual share information about that individual, based on the individual's knowledgeable consent. Our members report that a common misunderstanding of this concept in the broader health care community has been that we no longer need to get the individual's permission to share information about them, that we're all part of the same system, working in the best interests of the client, and that all we need to do is inform the client of which health care providers or organizations are part of their circle of care. We realize this is not what the legislation intended or says, and we're not sure that wording changes to the act would help to correct this misunderstanding. However, there would appear to be a need for clarification and further education regarding the consent provisions of PHIPA as related to the concept of "circle of care."

1310

(3) Another difficulty our members report is a strict interpretation by administrators in some health care settings of the need for consent to collect or use unsolicited information that is relayed, for example, through an e-mail or voice mail message. A strict interpretation can result in organizational policy that the information cannot be recorded or used in any way, regardless of its relevance to the services being provided. For example, an adolescent under 16 who was deemed competent to consent to substance abuse treatment may not want the health care practitioner to know about his or her recent return to non-prescription drug use, but a parent, concerned about the adolescent, leaves a phone message to let the practitioner know of the adolescent's recent return to using drugs. When a strict interpretation of the act becomes organizational policy that forbids the recording or use of this information, we are put into an impossible position. The Ontario Psychological Association suggests that the legislation could clarify that such

unsolicited information could be recorded and used by the practitioner when needed for the provision of adequate health care services.

(4) Our members also report concerns relating to subclause 44(1)(a)(iii), which requires a research ethics board to approve research that involves access to existing personal health information. Regulation 329/04, section 15, prescribes the requirements for such research ethics boards, which exist almost exclusively in large academic settings such as universities and health science centres. Many members of our association, who have been trained on a scientist-practitioner model, work in relatively small centres such as correctional facilities, school boards or private practices. We have encountered instances where such psychologists would like to engage in personal health information research projects to better understand client needs and help establish the evidence base for effective treatments. However, because they're not linked to an academic setting, they are unable to move forward on such initiatives because no alternative bodies exist outside of large academic institutions. Indeed, it would be expensive and difficult, if not impossible in some small communities, to establish alternative ethics review bodies that would meet the prescribed requirements with respect to numbers and areas of expertise, such as, for example, in a school board. The Ontario Psychological Association would like to see the prescribed requirements for research ethics boards be modified to allow for alternative processes or structures for ethics review of personal health information research by qualified persons based in non-academic settings.

These are only a few highlights of our thoughts in relation to this very important piece of legislation. By and large, although there have been difficulties, it's our opinion that this legislation has been a very important move forward for the protection of the rights of the citizens of Ontario.

We want to thank you very much for your time. We look forward to any further opportunities for consultation as your review of PHIPA unfolds.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. We'll begin with the official opposition. No questions? Mr. Marchese.

Mr. Rosario Marchese: I'm assuming that you communicated these concerns to the ministry before you came here. Did you get any feedback yet from them?

Dr. Ruth Berman: Not in terms of any specific legislative or statutory or regulatory amendments. Yes, we had a meeting with the ministry. We were pleased that they invited us to consult with them. We did voice some of our concerns.

Mr. Rosario Marchese: There's usually some dialogue between you and ministry staff in terms of, "Yes, this would work," or, "No, we have some concerns about that." Was there any kind of dialogue in that regard?

Dr. Ruth Berman: I think there's a certain sensitivity to the concerns that we raised.

The Vice-Chair (Mr. Vic Dhillon): Government side, any questions? Mr. Naqvi.

Mr. Yasir Naqvi: You mentioned a proposal to include insurance companies in section 3. Do you have any examples from any other legislation in Canada where insurance companies have been included?

Dr. Ruth Berman: I don't have any examples. As Dr. Nicholson mentioned, we were involved in discussions with government when PHIPA was being developed, in a very early stage. The early draft of the legislation did include insurance companies. When the legislation was finally enacted, they were not included as health care custodians, though they clearly are recipients. They argued that because many of them are federally incorporated, they're subject to federal legislation. But it has created significant problems.

For example, everyone who drives a car is required to have auto insurance. The moment that you enter into a contract of insurance with an auto insurance company, if you read the fine print, you have, in essence, consented to have all of your health information available to them in case of a claim for injury. So you have, in fact, waived your right to informed consent. You've consented to have information released before you even know what the nature of the information might be. This is at a time when you're healthy and assuming that you're never going to be in an accident. They have the right to have all of that information. If it's not released, then you don't get any benefits. As Dr. Nicholson says, typically, when you get a request as a practitioner, it's for all the information, including any health information that predates the accident, because what they're looking for is a pre-existing condition to enable them to disqualify you from your benefits. So it is a big problem.

Mr. Yasir Naqvi: In your opinion, then, could the solution also lie in more strict enforcement of the federal privacy legislation, as opposed to making changes in the provincial legislation?

Dr. Ruth Berman: Again, I have less knowledge of the provincial legislation, so I don't know what teeth it has in terms of enforcement with respect to insurance companies. All I do know is that they were included originally in PHIPA, but they lobbied to be excluded so that they would have, I believe, greater freedom to access the information they felt they needed in order to adjudicate claims.

The Vice-Chair (Mr. Vic Dhillon): Thank you for your presentation.

HIV AND AIDS LEGAL CLINIC (ONTARIO)

The Vice-Chair (Mr. Vic Dhillon): The next group is the HIV and AIDS Legal Clinic of Ontario. Welcome. You have 15 minutes. Please state your name for the record.

Ms. Renée Lang: My name is Renée Lang. I'm a staff lawyer at the HIV and AIDS Legal Clinic of Ontario. We're also called HALCO.

On behalf of HALCO, thank you very much for giving us this opportunity to speak with you today about PHIPA.

HALCO is a charitable, not-for-profit community-based legal clinic serving low-income people living with HIV and AIDS. It is the only such legal clinic in the country and has extensive front-line experience in addressing the day-to-day legal issues faced by people living with HIV. HALCO provides legal advice and representation and engages in law reform endeavours, public legal education initiatives and community development work.

The legal issues that we encounter the most are about tenancies, social assistance, human rights, health law, employment law, insurance and prison issues. We receive over 2,500 client inquiries a year. Our client base is the over 27,000 people living with HIV and AIDS in Ontario. That's a 2006 figure; it's probably a little higher now.

I'm going to limit my submissions today to the lockbox provisions in PHIPA. These are sections 20, 37(1)(a), 38(1)(a) and 50(1)(e). As the previous presenter has stated, these provisions allow someone providing health care to withhold or withdraw consent to disclose or use his personal health information in whole or in part. We ask that this committee not delete the lockbox provisions in your review of PHIPA. We fully support these provisions. We believe that they provide essential protections to our clients.

People with HIV face discrimination in every facet of their lives. Some of our clients have been abandoned by their family and their friends. Some have lost their housing and their jobs. Some have been refused medical or dental care. Our clients must be very careful about to whom they disclose their HIV status, so one of our most common questions from clients is whether they must disclose in this or that situation. This question arises in a number of contexts, but especially in health care, criminal law and employment matters. At least half of our public legal education presentations are on disclosure issues.

1320

Some of our clients are even shy about accessing our services because our letterhead has "HIV" and "AIDS" emblazoned on top of it, so that whenever we communicate with outside persons on their behalf, their HIV status is automatically disclosed. We have had clients who have refused our services because they did not want their HIV status to be disclosed to their landlord or employer, for example.

So this is an access-to-justice issue, but to our clients, the lockbox provisions present an access-to-health-care issue as well. We have had clients express concern about disclosing their HIV status to health care providers, even with the existing provisions in place. A person with HIV who is reluctant to reveal his or her HIV status to health care providers may not receive adequate medical care. They may not pursue medical care at all. The lockbox provisions help to balance our clients' disclosure concerns with their need for medical care.

Another thing I would like you to consider is that there is a rather large gap in legislative protections for privacy in Ontario. The federal legislation, the Personal Information Protection and Electronic Documents Act, PIPEDA, along with PHIPA doesn't cover the field. PIPEDA only applies to commercial endeavours; PHIPA only applies to health information custodians, who are generally health care workers. So this leaves an enormous gap. For example, there is no privacy legislation that applies to most AIDS service organizations in Ontario unless they happen to provide health care, which most don't.

The courts are not very much help in this area. The tort of breach of privacy is an emerging tort. It's very young, it's in its infancy; not a lot has been done in this area and it's going to take a while to develop. We can't rely on the courts. I have a very hard time advising clients when they want to know whether or not to sue in breach of privacy because of the unpredictability of the courts in this area.

We should be expanding the law's capacity to protect privacy, not limiting it. Please don't erode one of the few privacy protections that exist now for our vulnerable clients. Thank you.

The Vice-Chair (Mr. Vic Dhillon): About three minutes each. The NDP?

Mr. Rosario Marchese: Thank you, Ms. Lang. Some of the information is consistent with what the ministry representative was talking about earlier. Ms. Appathurai made the point that 1.2 million withhold information out of fear and 750,000 did not see health care providers, again out of fear, and I think you're expressing that. You said you want to keep the lockbox provision. Are you somehow concerned that there's a desire by some to change that?

Ms. Renée Lang: We've been given that indication in meetings. We've heard there may have been some concern on the part of health information custodians that it's administratively inconvenient to continue the lockbox provisions and continue adhering to them.

Mr. Rosario Marchese: Perhaps the others might have heard something that I don't know about. I think there's no move to do that, so if others have other information, it would be helpful to hear it.

Mr. Khalil Ramal: Thank you very much for your presentation. We listened to the privacy commissioner in the morning, we listened to the ministry speaking. I don't know why you have those concerns and who's speaking about it. In her presentation—I think it will be an official document—she mentioned the system is working and no need for changes or eliminating the lockbox. For many different reasons there was mention made of it during the presentations today. I don't have any information more than that, and since the system is working, why would we have to change it? We're trying as much as possible to advance it and to do something better to enhance communication and to better the life of the people of Ontario.

The Vice-Chair (Mr. Vic Dhillon): Mr. Shurman?

Mr. Peter Shurman: I have no questions but I'll simply make a comment on behalf of the official opposition. We've never discussed any such changes and I certainly would not entertain them. Thank you for your presentation.

Ms. Renée Lang: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

JO-ELLEN WORDEN

The Vice-Chair (Mr. Vic Dhillon): Next we have Jo-Ellen Worden. Good afternoon. You have 15 minutes, and you may begin.

Ms. Jo-Ellen Worden: Ladies and gentlemen of the Standing Committee on Social Policy, honourable ministers, members of the opposition, third party members, and other honoured guests and speakers: I thank you for your collective efforts in conducting the mandated review of our province's Personal Health Information Protection Act.

One of the purposes of this act is to establish rules for the collection, use and disclosure of personal health information about individuals that protect the confidentiality of that information and the privacy of individuals with respect to that information, while facilitating the effective provision of health care. In layman's terms, I understand the Personal Health Information Protection Act is one of our province's most significant pieces of legislation, essential for ensuring the right of each individual to access their own personal health information as well as each individual's right to decide to whom, when and if that information shall be disclosed.

My submission will speak to a methodology used for obtaining informed or knowledgeable consent for disclosure of personal health information. I will speak to the provisions made under part III, subsection 18(1), which outline that the elements of consent must be a consent of the individual, they must be knowledgeable, they must relate to the information and, of greatest importance, they must not be obtained through deception or coercion.

I will speak to the provisions made for collection, use and disclosure of personal health information under part IV, clause 43(1)(e), which reads:

"A health information custodian may disclose personal health information about an individual ...

"(e) to the Public Guardian and Trustee, the Children's Lawyer, a children's aid society, a Residential Placement Advisory Committee established under subsection 34(2) of the Child and Family Services Act or a designated custodian under section 162.1 of that act so that they can carry out their statutory functions...."

Under the above-quoted portions of the act, there are two contradictory yet seemingly justifiable mechanisms in place by which personal health information, albeit allegedly, is being unlawfully and coercively obtained by individuals with less than honourable intentions during certain investigative proceedings, especially during investigations involving police-perpetrated domestic violence, when the accused officer is involved in an intimate personal relationship with children's aid society personnel.

For those of you members of the Standing Committee on Social Policy who may not be familiar with the term "police-perpetrated domestic violence," it is a syndrome referred to in a document sent to me by the Ministry of the Attorney General's office to describe domestic violence that occurs at the hands of men and women who have been trained in the tactical manoeuvres of intimidation, interrogation, manipulation, deception, power and control. It is the term used to describe the workplace harassment and the domestic violence that occurs at the hands of the very officers bound by oath to serve, protect and uphold the law.

On January 31, 2007, I provided a deputation before the Standing Committee on Justice Policy. I made recommendations to the standing committee with regard to Bill 103, the bill introduced to amend the Ontario Police Services Act pursuant to the inquiries and recommendations outlined in the LeSage report. I am pleased to see some of my recommendations were indeed incorporated in a form into the legislation that received royal assent. For the convenience of the respected members of the Standing Committee on Social Policy, I refer the members to the Hansard transcript of my deputation dated January 31, 2007.

I also provided a copy of the victims' handbook on police-perpetrated domestic violence sent to me by the Ministry of the Attorney General's staff.

As the Standing Committee on Social Policy is no doubt aware, local children's aid societies have come under great scrutiny as a result of atrocities committed against children, and for good reason. It is widely believed by Ontario residents, members of the government and the Ombudsman that Ontario children's aid societies lack effective oversight and may abuse their powers under certain statutes that were designed for the protection of children. These laws were not designed to protect CAS personnel who abuse the provisions afforded by these statutes to harass members of the public, nor where they designed to allow children's aid society staff to engage in criminally negligent behaviours. In respect of the act under review by this committee, I submit:

Parts III and IV of the Personal Health Information Protection Act outline criteria for providing and obtaining valid and binding consents for the collection and disclosure of an individual's personal health information. As a result of the often-intentional re-victimization, which occurs in many cases of police-perpetrated domestic violence, post-traumatic stress disorder can result. Many responsible parents, who recognize the impact of PTSD on themselves and their families, voluntarily seek the services of counsellors or other medical personnel involved in the practice of clinical psychiatry. In cases of police-perpetrated domestic violence, this responsible action made in good faith by a well-intentioned parent has been manipulated into an assault weapon through misuse and abuse of certain provisions afforded under the current provisions of parts III and IV of this act when they are executed in conjunction with other acts designed to protect vulnerable members of the population, acts like the Child and Family Services Act, the Health Care Consent Act, 1996, the Freedom of Information and Protection of Privacy Act, the Municipal Freedom of Information and Protection of Privacy Act and the Mental Health Act.

1330

When the child of a police officer discloses abuse, the ensuing CAS investigation involves the utilization of a special 04 case classification. This special designation is used due to the sensitive nature of CAS investigations into allegations of domestic violence perpetrated by law enforcement personnel. Many of the investigative and diagnostic techniques utilized during the course of an investigation of this nature are tailored in order to extend unofficial professional courtesy to individuals who do not wish to be identified as clients of the involved children's aid society. This special status conferred upon the involved officer serves to protect the reputation of the involved officer but not the child.

Part IV of this act outlines criteria for the collection, use and disclosure of personal health information within limitations and in compliance with mandated requirements. When child protection issues arise, Ontario children's aid societies have been permitted, under the guise of "in the best interest of the child," to utilize coercion and deception as a tactic to obtain consent for the disclosure of personal health information. In the province of Ontario, local children's aid societies can either restrict or completely deny access between a mother and her child should they feel so inclined. In a case of domestic violence where a police officer is the assailant and this assailant is involved in an intimate or personal relationship with CAS personnel, the above-mentioned clauses serve to empower assailants to blackmail victimized mothers into signing consents for disclosure of their personal health information, uninformed, under the pretence of allowing access to occur only if the mother would cooperate with the society and just sign the consents.

Members of this committee may find it interesting that local children's aid societies are manipulating a provision that was intended to protect children and are equating the signing of consents, uninformed and via coercive methods, with cooperating with the society. This information has been used to remove their children from their care and custody. The unofficial professional courtesy that is extended to the abusive officers endangers the lives of their children and other medically vulnerable individuals affected by the officers' abusive behaviours.

Recommendations to the assembly:

Section 43 of the act must be repealed and replaced with a mechanism of law that ensures the protection of the privacy of individuals who have been repeatedly victimized by spousal abuse involving police and CAS personnel. Our Victims' Bill of Rights is designed to help guarantee victims of crime are not re-victimized by their assailants or by our highly respected justice system. I respectfully submit, in light of the fact that members of the public at large, including the Ombudsman of Ontario, have lost confidence in local CAS personnel who have been remiss in their prescribed duties and the fact Bill 93 has passed first reading in the Legislative Assembly, Bill 103 has received royal assent and a petition has been introduced before the House of Commons to immediately conduct research into police-perpetrated domestic violence and amend the Criminal Code in order to identify police-perpetrated domestic violence as an indictable offence with mandatory minimum sentencing guidelines for individuals found guilty of said offence, that there also be a bill introduced before the Legislature that amends the Personal Health Information Protection Act to safely and expeditiously address matters where personal health information is being sought coercively or for malicious intent in order to obstruct justice in cases where allegations of domestic violence at the hands of law enforcement personnel have been made. The amendment must protect us from abusive collection methods and subsequent utilization of obtained personal health information for malicious purposes in cases where allegations of police-perpetrated domestic violence and/or CAS negligence have been made. Because there are far-reaching consequences, and at times repeated re-victimization in cases of domestic violence involving law enforcement personnel, I believe this abuse of the justice system via child protection law loopholes warrants added layers of protection incorporated into our provincial statutes.

I also respectfully suggest an immediate repeal and reworking of part IV, subclause 36(1)(c)(i) of the act. This section of the act addresses the indirect collection of personal health information.

The manner in which these statutes are worded leave victims of police-perpetrated domestic violence fodder for revictimizations. Institutions such as child and adolescent mental health assessment and treatment centres are being misused by children's aid societies under the guise of child protection, but in reality this misuse of provincially funded institutions facilitates police-perpetrated domestic violence.

Review of this piece of legislation, the Personal Health Information Protection Act, must be afforded diligent consideration, with the highest degree of deference for an individual's right to choose, as decisions made during the course of these deliberations will likely affect the outcome of processes which arise during the most vulnerable times in one's life, those times when one is required to access resources imperative for one's physical or mental health.

Finally, I challenge the honourable members of the Standing Committee on Social Policy with the commission to ensure that there be legislated and severe sanctions for all breaches of a newly amended Personal Health Information Protection Act.

Police-perpetrated domestic violence is a carcinogenic violation of the trust of some of the most vulnerable citizens of our province that desire only to encourage and support our honourable, noble and truly courageous men and women in uniform. The utilization of the provisions of the Personal Health Information Protection Act, in conjunction with the other relevant acts noted above, for dishonorable purposes must not be tolerated in any form by any individual, regardless of any professional designation.

Thank you for your time and attention to this matter.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. A minute each. The government side—no questions? The opposition?

Mr. Peter Shurman: One question: At the outset of your—

Interjection.

The Vice-Chair (Mr. Vic Dhillon): Mr. Shurman—

Ms. Laurel C. Broten: It's okay—

The Vice-Chair (Mr. Vic Dhillon): We'll come back to the government side. Go ahead, Mr. Shurman.

Mr. Peter Shurman: Sure. At the outset of your presentation, you talked about and highlighted the issue of obtaining information through deception. In the prior presentation by the Ontario Psychological Association, they talked about clarification of a section which dealt with—the example they gave was a parent who found out that a child was back on drugs after having gone through rehabilitation, maybe failed, and calling a psychologist and giving that information to the psychologist. Is that information obtained through deception?

Ms. Jo-Ellen Worden: That is not the information that I am referring to. In regards to my—

Mr. Peter Shurman: No, I know it's not, but it's an example. You're talking about obtaining information through deception. There's a question here; they're asking the question because they want clarification. I want your opinion on whether that is an example of information obtained through deception.

The Vice-Chair (Mr. Vic Dhillon): Very quickly, please.

Ms. Jo-Ellen Worden: That is not something that I can speak to right now because I do not know the provisions of that act. I am not a lawyer. That I can't speak to at this point. I am willing to research that, come back and answer your question more formally when I'm more informed.

Mr. Peter Shurman: Thank you.

The Vice-Chair (Mr. Vic Dhillon): Mr. Marchese.

Mr. Rosario Marchese: Jo-Ellen, thank you very much for coming. You obviously put a lot of emotion into your presentation and you feel strongly about it. There are probably many reasons.

I'm not the health critic, so it's hard for me to get as involved in some of these issues as the health critic might, but it would be wonderful under these circumstances to be able to get an opinion from the ministry, because presumably they would have a lot of background to be able to say what the experiences are with that, what the problems are, what's good about it. But it's hard under the way we structure committees to get that kind of feedback.

I just want to say you raised some good points. It would be wonderful at some point to be able to get answers to such situations. Maybe the Liberal members might have some information that they could provide for me. If so, that would be helpful. If not, I just want to thank you for your presentation.

Ms. Jo-Ellen Worden: May I speak to that issue?

The Vice-Chair (Mr. Vic Dhillon): Very quickly.

Ms. Jo-Ellen Worden: When the petition was introduced into the House of Commons, the federal government did conduct research into this area. We have found that in the country of Canada, there is not a lot of research at all—and I'm speaking specifically to police-perpetrated domestic violence in the general sense. One of the statistics that had come back was that in the research that the federal government did conduct, they found that only 10% of individuals—

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Ms. Jo-Ellen Worden: Stop?

1340

Mr. Rosario Marchese: Let her finish the sentence.

Ms. Jo-Ellen Worden: Okay. Only 10% of the individuals who had made allegations of domestic violence of this type actually received appropriate attention and investigation. Because the statistics are so small and it's such a challenge to be able to deal with issues of this type of domestic violence because of the inherent conflict of interest that comes into play, there aren't a lot of statistics on it simply because many individuals do not disclose—

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Ms. Jo-Ellen Worden:—and when they do disclose, they cannot get help, so the statistics don't exist.

The Vice-Chair (Mr. Vic Dhillon): Thank you. Government side?

Ms. Laurel C. Broten: Thank you. I just wanted to thank you, Jo-Ellen, for your presentation. These are certainly some very large-scale issues that you raise before the committee today, some of which may well fit within the examination that we're doing and some that you've opened our eyes to for us to be aware of as we look to other roles and responsibilities that all of us might have. So thank you very much.

Ms. Jo-Ellen Worden: You're welcome.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much.

Ms. Jo-Ellen Worden: Thank you.

SCHIZOPHRENIA SOCIETY OF ONTARIO, EAST YORK CHAPTER

The Vice-Chair (Mr. Vic Dhillon): The next presentation is from the Schizophrenia Society of Ontario, East York chapter. Good afternoon, Ma'am. If you can state your name for the record, you have 15 minutes. You may begin.

Ms. Vicky Voukelatos: Good afternoon, everybody. Thanks for giving me the opportunity to voice my concerns in front of you. I am here as a member of the East York chapter of the Schizophrenia Society of Ontario. Mainly, I'm here because I am a mother and family member of someone who is very severely ill from a severe form of paranoid schizophrenia and that is my son.

He became ill 20 years ago, while in university, fourth year. He was studying law. He was very talented, on scholarships. He was very smart and, above all, he was a very loving son and brother. He became ill while he also had a business hiring students on summer jobs. At that time, he had over 150 people working for him. At that time, everything became a rollercoaster for the past 20 years. For a number of years, doctors, nursing staff and hospitals were very hesitant to communicate information regarding his condition. In many cases, it was difficult for me to give or take information. I could see that they wanted to help, but they had difficulty doing it.

I found out from other family members at the support group I attended that part of this problem was form 14 regarding confidentiality. In his many hospitalizations, he would sign form 14 one minute and revoke it the next, before I had the chance to see the doctor or even as soon as I left the ward while in hospital. I would go to the doctor or treating team, only to find out that it was revoked. This became an habitual practice for him, to go back and forth, signing and revoking form 14. Then, in 2004, certain changes were made to the privacy act.

I thought that these changes would make it easier for parents and caregivers to communicate any information with doctors, treating teams and acting members. After all, I thought, we all care for the treatment and well-being of the patient. Well, I was wrong. I was stunned to find out that these changes made it extremely difficult and unbelievably hard to communicate with doctors and treating teams any information regarding my son's illness and treatment. It became next to impossible to talk to anyone, or even find out if my son was in hospital or had been released, or where he had been released. As a result of that, I often walked the streets up and down for days, to find him homeless, hungry, dirty and very ill.

I'm his mother and his caregiver. I love and care for my son for all these years and all the treatment he had in and out of hospitals on many, many occasions. He still has no insight at all, and he doesn't think he's ill and he doesn't think he needs any help.

Through those 20 years he's been homeless, hungry, and abused on the streets. I could write a book on the hardships of my family and myself all those years. The illness makes him suspicious of anybody who loves and cares for him. This act makes it even worse. Instead of trying to work together and build bridges with the families, who are the caregivers, this act makes us, the family members and myself—I feel like an enemy, and in my son's eyes, I am an enemy because he doesn't think he's ill, he has no insight.

I realize that doctors, nursing staff, and treating teams are hesitant to communicate any information, and are confused with this act, these changes. They don't know how to interpret it and, most of all, they are afraid to say anything for fear of being sued. They ask my son's permission even to say "hello" to me. On one occasion I drove my son to his doctor's appointment—I had not met with his doctor for two years, although I was trying. A person appeared at the door of the waiting room, and I asked the staff person, "Is this the doctor of my son?" I got a "yes" answer, so I said, "Hello, I'm so-and-so's mother. Nice meeting you." I extended my hand to shake hands with the doctor, but the doctor turned to my son and said, "Can I speak to your mum?" And my son, although he had agreed before, said, "No." So the doctor turned their back to me and left the room while I was standing there waiting to say, "Hi, nice meeting you." All I wanted at that time was a "hi." You can imagine my frustration and you can only put yourselves in my shoes as a mother. The doctor was afraid to even say hello to me. That made me very angry.

For the past 12 years, my son has been in a city almost 300 kilometres away, one way. I visit him two or three times a month—or more, if needed. I spend money helping him, supporting him, buying him food, clothes and other necessities. I have paid bills for rent, phone bills, utility bills, and out of all this I have no right to any information or communication. I am good enough to pay bills and support him, but I'm not good enough to have any information or relate any information to the treating teams or doctors or hospitals.

I leave Toronto knowing that the consent has been given, but I never know if that consent is still valid when I get there or that I will be able to speak to the doctor. Sometimes he even asks me to visit, and when I get there, he refuses to see me. That's the nature of his illness. He is paranoid of me, because I try to help when he doesn't think he needs help.

In closing, I want to emphasize strongly that good communication between caregivers, caregiving families and doctors, treating teams and nursing staff is absolutely necessary. Communication without the fear of breaching confidentiality will only make sure that our loved ones will get better care and treatment overall.

Finally, I firmly believe that the privacy act should be amended, should leave room and should include in its decision-making a caring support network, especially with caregiving families, the way, as I heard the previous speaker saying, it's done in BC.

That's all I had to say. Thank you very much for listening.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much. A couple of minutes each—Mr. Shurman.

Mr. Peter Shurman: Thank you very much for an interesting presentation. My heart is with you for what you've endured for these many years.

As I understand it, at the beginning of your presentation, you mentioned that your son had gone through an education, had a business, so he had obviously attained the age of majority by the time he got sick, which means his legal status was adult at that time.

1350

Ms. Vicky Voukelatos: Yes.

Mr. Peter Shurman: Have you at any time since then ever been in a position to be considered legal guardian or have you had power of attorney over his affairs?

Ms. Vicky Voukelatos: Not until his last hospitalization, which was a year and a half. The doctor at that time in the hospital was very good, a very caring doctor who communicated with me all along. We exchanged information. It took a long time to stabilize him, because every time he relapses, he relapses more than before, and every time he gets better, he's stabilized less than before. So every hospitalization is longer than before. The previous was nine months; this was a year and a half.

Mr. Peter Shurman: But your son's legal status has always been, since this started, self-dependent. In other words, he's independent. No court, no body has ever—

Ms. Vicky Voukelatos: This last time, I was named as a substitute decision-maker, but only for the period of the community treatment order, which expires in a month. He refuses to sign it, so he's going to fight me at the review board to take me off as a substitute decision-maker. It has been very difficult, when I cannot get any information or cannot relay any information and he keeps on relapsing, based on this privacy and confidentiality that allows him to—and he manipulates me, also, because when he needs something, he signs, and when he gets it—and I cannot do anything.

Mr. Rosario Marchese: I just want to thank you, Vicky, for the sacrifices that you're making, including Madame Aubert, who obviously you know, and the family Elson who are at the back. There's got to be a better way to find solutions to these problems, and I'm hoping, because of this review, that we will do that.

Ms. Vicky Voukelatos: I hope, and I count on all of you, that you will make the necessary changes so that we can better care for our loved ones. We didn't bring them into the world to be hungry and homeless in a society like Canada.

Mr. Kuldip Kular: I really want to thank you for presenting here. I am a family physician and I understand the dilemma. It is sometimes very difficult for physicians as well as parents, especially in cases of schizophrenic patients, because, as you know, schizophrenic patients have very poor insight and that makes it very hard for the person's health care providers and parents to communicate. Definitely, during this review, some of these issues will be looked after.

The Vice-Chair (Mr. Vic Dhillon): Thank you very much for your presentation.

That concludes our meeting for today and we're going to have a two-minute recess. I'm going to ask the members to remain in the room and if everybody can please clear out as soon as you can so we can have a closed-session meeting. Thank you very much to all the presenters.

The committee continued in closed session at 1356.

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CONTENTS

Thursday 28 August 2008