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Tuesday 27 January 2004

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des débats
(Hansard)**

Mardi 27 janvier 2004

**Standing committee on
general government**

Health Information
Protection Act, 2003

**Comité permanent des
affaires gouvernementales**

Loi de 2003 sur la protection
des renseignements sur la santé

Chair: Jean-Marc Lalonde
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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**STANDING COMMITTEE ON
GENERAL GOVERNMENT**

**COMITÉ PERMANENT DES
AFFAIRES GOUVERNEMENTALES**

Tuesday 27 January 2004

Mardi 27 janvier 2004

The committee met at 1000 in room 151.

**HEALTH INFORMATION
PROTECTION ACT, 2003**

**LOI DE 2003 SUR LA PROTECTION
DES RENSEIGNEMENTS SUR LA SANTÉ**

Consideration of Bill 31, An Act to enact and amend various Acts with respect to the protection of health information / Projet de loi 31, Loi édictant et modifiant diverses lois en ce qui a trait à la protection des renseignements sur la santé.

The Vice-Chair (Mr Vic Dhillon): Order. Good morning and welcome to the standing committee on general government on Bill 31.

**INFORMATION AND PRIVACY
COMMISSIONER OF ONTARIO**

The Vice-Chair: The first presenter is the Information and Privacy Commissioner of Ontario. You will have 20 minutes. Any time that is not used will be divided among the three parties for questions. You may start.

Ms Ann Cavoukian: Good morning, members of the committee, ladies and gentlemen. I'm very pleased to have this opportunity today to address the committee. Since I have not yet had the pleasure of meeting most of the committee members, I'll just take a moment to introduce myself and my office very briefly. I'm Ann Cavoukian. I'm the Information and Privacy Commissioner. I'm joined here today by my assistant commissioner of privacy, Ken Anderson. My office was created in 1987 to oversee Ontario's public sector access and privacy legislation, the Freedom of Information and Protection of Privacy Act and, three years later, its municipal counterpart, the Municipal Freedom of Information and Protection of Privacy Act. I've been with the office since it was created in 1987 and was appointed Information and Privacy Commissioner in 1997.

Let me start by saying how very pleased I am that the new government has moved forward so quickly with the introduction of this much-needed health information privacy legislation. My office has been advocating the need for health information privacy legislation since its inception in 1987, but we are not alone in this regard. Members of the public, health care providers and other stakeholders have been waiting for the introduction of

this legislation since Justice Horace Krever's report of the royal commission on the confidentiality of health information in 1980. This is 24 years ago—a long time coming.

There have been numerous commendable attempts over the years to get a bill introduced and passed, but for one reason or another they have not been successful. This is largely due to the unique characteristic of personal health information and the enormity of the task of balancing all of the competing interests. On the one hand, you have the need to protect the privacy of individuals with respect to their most sensitive personal information. On the other hand, you have the legitimate needs of the health care sector to collect, use and disclose this information for a wide range of purposes that not only benefit the individual but the public as a whole. Personal health information is not only used to provide health care to the individual but also to help manage and plan our publicly funded health care system, to improve the quality of health care and for medical research purposes—uses that benefit us all.

In my view, this proposed health sector legislation strikes an appropriate balance between these competing interests—no small task, I assure you. I want to acknowledge the efforts of the Ministry of Health and Long-Term Care for listening carefully to stakeholder concerns and developing what I see as a very workable framework.

Let me take a few minutes to highlight some of the improvements in this bill over previous attempts to introduce legislation. All previously proposed legislation has relied heavily on the use of broad regulation-making power to specify operational details. Bill 31 is no different in this respect. However, what is different about this bill is that it incorporates an open and transparent regulation-making process. While the bill includes the ability to alter the established rules through regulations, my office and the public and any other interested parties will now have the opportunity to comment before any regulation is adopted. This is a very significant breakthrough, increasing openness and transparency. I'm very pleased to see this.

Another significant improvement is the establishment of a health data institute to receive and de-identify personal health information that the government needs for analysis of the health care system. The issue is the de-identification of personal health information. That's at

the heart of the problem. Once the identifiers are removed, things are far improved. This, too, is a unique feature in this bill.

You may recall from hearings on previous legislation that there was strong opposition to the government giving itself the authority to direct any health information custodian to submit personal health information that it needed for this purpose. Under Bill 31, these directed disclosures of identifiable data to the government without any oversight by my office are a thing of the past. We are also pleased that Bill 31 will apply to all types of personal health information. There are no carve-outs for certain types of information, such as mental health records, for example.

Another positive feature of the legislation is the use of an implied consent model for the collection, use and disclosure of personal health information for the purpose of providing health care. In my view, this model more accurately reflects the existing status quo, the existing patient-provider interactions, than the previous no-consent model and should not in any way hinder that relationship.

This implied consent model comes with the so-called lockbox, which allows individuals to instruct their health care providers not to disclose their personal health information to other health care providers. Now, I know that there may be some opposition to this lockbox, particularly from health care providers, but it is important to note that an instruction not to disclose does not preclude disclosure. It just means that you have to obtain express consent from the patient before the disclosure can be made.

Also, in the event that an individual does exercise the right to have certain personal health information withheld from disclosure, there are safeguards built into the legislation to ensure that health care providers inform any recipients that not all of the personal health information they may require has in fact been disclosed. This places them on notice. This will ensure that recipients know that they should be approaching the individual regarding withheld personal health information to explore the possibility of obtaining consent for that information. These are all very significant improvements over previous drafts of health information privacy bills.

Now for my concerns. I'm going to talk primarily about one major concern. While this legislation is clearly better than anything we've seen to date, I have one enormous concern, and that relates to my office's powers, or lack thereof, in conducting reviews and investigations. I'm particularly concerned about my inability to compel production or inquire into records of personal information without consent unless I apply for a warrant and a justice of the peace agrees to this. Such a limitation on a privacy oversight body is simply unheard of. No other jurisdiction in Canada or elsewhere, no other commissioner, is subject to this limitation, and I am quite frankly baffled by this requirement in the bill. It's an insult. It makes no sense to me. It would cripple us in terms of our ability to conduct effective reviews and investigations.

Since the conditions under which a warrant may be issued are very limited and do not include circumstances in which I merely need access to personal health information, conducting effective reviews and investigations will be virtually impossible in many cases. How can I conduct a review without access to the very information that is the subject of that review? It's perplexing.

It's important to point out that this type of restriction on access to personal health information does not apply across the board but only to my office. The legislation permits the use and disclosure of personal health information without consent and without a warrant for a wide range of purposes to an individual, such as the following: an individual conducting an audit, the chief medical officer of health, a health professional regulatory college, the board of regents under the Drugless Practitioners Act, the Ontario College of Social Workers, the public guardian and trustee, the children's lawyer and the Children's Aid Society, among other things. I'm not objecting to this, but they can all access personal health information without consent and without a warrant and we can't.

So I simply can't fathom why there would be greater restrictions on access to personal health information for the oversight body administering and enforcing the Health Information Protection Act than there are for other organizations administering and enforcing other legislation. My office has an excellent reputation, and we have earned the trust of the public, who routinely turn to us when they encounter difficulties with personal information. What justification is there for requiring a warrant before personal health information may be disclosed for a proceeding before the commissioner?

1010

It's also important to note that unlike other potential recipients of personal health information, my office would be bound by strict confidentiality provisions set out in section 66 of the Health Information Protection Act, as we should be. So we could never use the information for any other purpose nor could we disclose it to anyone, nor would we. Just look at our track record. In virtually all jurisdictions with privacy legislation, including jurisdictions with legislation specifically governing the health sector, the commissioner is permitted to access any necessary information, including personal health information.

This legislation must be amended to ensure that my office has access to whatever information is necessary to conduct an effective review. Only then will we be able to assure the public that health information custodians are indeed living up to their obligations under this legislation.

I'm also concerned that the commissioner's inability to compel testimony presents a problem. You may recall an investigation that my office conducted into the disclosure of personal information by the Province of Ontario Savings Office, POSO for short. In that case, we were unable to conduct a thorough investigation into the

disclosure of very sensitive financial data. It was very frustrating. The primary reason we couldn't do this was because a number of key individuals simply refused to be interviewed; they would not co-operate with our investigation and I did not have the power to compel them to do so. The result was a report that could not satisfy the public's right to know the full details of a government institution's non-compliance and unauthorized use of personal information. That, to me, was untenable.

In virtually every other jurisdiction with some type of comparable legislation, including Canada federally, British Columbia, Alberta, Saskatchewan, Manitoba, Quebec, Australia and New Zealand, the privacy oversight bodies have the power to require the testimony of individuals without a warrant. I see no reason why Ontario should fall short in this critical area.

It is also important to note that without this power, the proposed legislation may run a serious risk of not being considered substantially similar to the federal legislation, the Personal Information Protection and Electronic Documents Act, and it is essential that it be deemed to be substantially similar. This would be a most unfortunate and unnecessary outcome.

Privacy oversight bodies operate primarily as privacy advocates, advisers and educators, ensuring compliance with legislation through establishing co-operative relationships with trusted keepers. When an issue of non-compliance arises, the vast majority of cases can be resolved through mediation, education and persuasion. That's the first route that we always pursue, as opposed to imposing penalties or sanctions. For example, under the existing public sector legislation in Ontario, over 80% of privacy-related complaints and appeals are resolved informally through mediation and other alternative dispute resolution methods. We take pride in this. Rarely do we have to resort to issuing a formal investigation report or ordering an institution to take some remedial action to ensure compliance.

In the proposed legislation, the powers of the commissioner to compel testimony and to demand the production of records only exist within the context of an inspection with a warrant. This would force my office to resort to obtaining a warrant on a much more frequent basis instead of pursuing the more desirable informal route of mediation. Since a search warrant is almost always associated with criminal or quasi-criminal activity and issued in order to force individuals to take some action that they would not otherwise take, in my view, conducting investigations with a warrant would be embarrassing and humiliating to health information custodians, who are generally viewed as the trusted keepers of personal health information by the public. They are usually very willing to co-operate in resolving any issues of non-compliance.

So the routine use of warranted powers would be very counter-productive because it would change the nature of the relationship between the oversight body—in this case, my office—and the health information custodian from a co-operative one to an adversarial relationship.

This is the last thing I want. We've worked very hard over the years to develop very strong positive relationships with numerous organizations, and I think this would truly set us back.

It would also make the entire complaint resolution process far more costly, more formal and more adversarial in nature. As a result of this, it will be less accessible to the general public.

For all of these reasons, we strongly urge the deletion of sections 57, 58 and 59 of the proposed legislation and a complete redrafting of the provisions relating to the powers of the commissioner in conducting a review. I ask that you please refer to our submission for specific proposed language, which we've drafted for these purposes.

In summary, our recommendations would eliminate the concept of investigations with warrants and they would provide my office with the much-needed power necessary to compel testimony from witnesses and to access personal health information during a review.

In our written submission, you'll find a number of other recommended amendments, which I'm not going to review for the sake of time and to allow you some time for questions. I think these amendments would further enhance the privacy protections provided by the legislation in order to promote harmonization with legislation in other jurisdictions, particularly the federal Personal Information Protection and Electronic Documents Act, and to facilitate implementation of the legislation. I invite you to read our submission for greater details on all of our recommendations.

Thank you very much for your kind attention. I am, of course, here to answer any questions that you have, and I urge you to feel free to call upon me in my office at any time if we can assist in this bill progressing through the legislative process. Let me end by telling you how delighted I am that the bill is moving forward and that we actually may see it enacted.

The Vice-Chair: Thank you very much, Ms Cavoukian. We'll start with the third party, with two minutes each.

Ms Shelley Martel (Nickel Belt): Thank you very much for being here today. We are on round three or four at least of privacy legislation. I don't pretend to know what the requirements were in the others. But with respect to your own powers and with respect to the issue of warrants and the compelling of evidence, which you have stressed to us needs to be changed, what did the previous legislation say, and is this a new version, is this a limitation of powers that was not seen before, or are the sections completely new?

Ms Cavoukian: The previous draft of Bill 31?

Ms Martel: This is the third draft, I think, of privacy legislation. You would have looked at some of them before. Are these new restrictions?

Ms Cavoukian: It's not entirely new, regrettably. We have suffered from this encumbrance for a while—I'll ask Ken to expand on that—but for some reason these powers, which do routinely appear in other statutes and

for other commissioners, appear to be consistently lacking in bills of this nature here.

Mr Ken Anderson: I think there's been a particular question as to whether a major case called the Inco case would in fact have some negative impact on the powers of our office, and there was a subsequent case called the Jarvis case, which came along after the Inco case, which we feel completely vindicates our legal position and is a major Canadian case.

When you view this whole issue about powers, about compelling testimony, about requiring production of documents and so on, and you look at what is the state of the law in Canada, we believe that constitutionally the recommendations that the commissioner is proposing are totally appropriate and they don't offend the charter.

Ms Cavoukian: When I discussed this bill in that one area with my colleagues in Canada, my fellow commissioners, they were astounded. They simply can't believe that those restrictions exist here.

Ms Martel: That was going to be my next question, because I gather there are three other provincial jurisdictions that have privacy legislation in some form or another. I don't know who their oversight body is, if it's the commissioners in those provinces. Do you know if that's the case?

Ms Cavoukian: They have the powers. There's Quebec, British Columbia and Alberta. I've spoken to all my commissioner colleagues there, and they have the powers.

Ms Martel: Specifically related to health information and privacy for health information?

Ms Cavoukian: Saskatchewan, Alberta and Manitoba have specific health information legislation. British Columbia has broad legislation which is private sector legislation but includes health information, so it's not specifically a health information statute but includes the protection of that. And Quebec, of course.

The Vice-Chair: Thank you. Any questions from the government side?

Mr Peter Fonseca (Mississauga East): Commissioner, thank you very much for being here today and presenting to us. It's always nice to see you.

I wanted to ask, in regard to the consent that you would get from the individual to investigate, would that not give you the right to access their records?

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Ms Cavoukian: In a number of cases you simply don't have the luxury of going to all the individuals involved to obtain their consent to review their records. So if we have a complaint relating to disclosure—an unauthorized use, for example, of a number of records in a hospital—to attempt to obtain consent from each of those individuals, which could number into the hundreds, often makes it extremely difficult, and it ties your hands in terms of proceeding with the investigation.

Again, I remind you that no other investigatory body is subjected to that restriction, and in this very bill, all these other people I named can do it without consent and without a warrant. So why can they do it and I can't? It's

truly perplexing. I think it's just a flaw in the bill that was not carefully reviewed.

Mr Fonseca: In terms of an individual case, you do get consent by that individual, if an individual patient asks you to look into something within their own records?

Ms Cavoukian: Of course, and if an individual patient is initiating a complaint, by virtue of them bringing the matter to our attention, we are obtaining their consent, and clearly we're not going to review any records that they would not wish us to review. But then you point out that that may impose certain restrictions on the nature of the investigation. The complainant is rarely the problem.

The Vice-Chair: Thank you very much. We'll move to the opposition.

Mrs Elizabeth Witmer (Kitchener-Waterloo): Thank you very much, Commissioner, for being here. I'm sorry that I didn't have a chance to listen to your presentation, but I guess what we were hearing yesterday from the colleges was their concern about the lack of supremacy of the RHPA and the fact that they had concerns about their ability to deal with their members. Could you speak to that issue, please?

Ms Cavoukian: Certainly. Of course we value the work of the colleges and in no way wish to interfere with their ability to engage in disciplinary practices or whatever duties they're engaged in. Our reading of the bill does not suggest that there is a conflict. Our reading of the bill—and I'll ask Ken to expand on that—suggests that Bill 31 does not override the authority of the regulated health professionals to collect and use personal information. We think the current wording is sufficient and we don't think there should be a general carve-out from Bill 31.

Having said that, I would defer to the Ministry of Health and Long-Term Care in reviewing this, because certainly our intention is not to create any obstacles for the colleges. They must engage in their duties. We don't want to interfere in that. Our reading of the bill, though, suggests that there is in fact no conflict. I'll ask Ken to expand on that.

Mr Anderson: What I'll do is expand by giving you the reference, because I'm sure you don't want to go through sort of a technical line by line, although if you do, I would do that.

Section 6 concerns interpretation of the bill, of the draft legislation. In subsection 6(3) there's a section for permissive disclosure. Under 6(3)(b) it indicates that a provision of the act "does not relieve the custodian"—the health information custodian—"from a legal requirement to disclose the information." So there's a permission there.

Then, if you go over to 42, "Disclosures related to this or other acts," 42(1)(b) specifically indicates that "A health information custodian may disclose personal health information about an individual," and there's a series of different groups that are listed; one of them is "to a college within the meaning of the Regulated Health

Professions Act, 1991 for the purpose of the administration or enforcement of” various other legislation as well.

So it’s our reading of this that we think they’re already OK. We don’t object, in any event, to them doing the work they need to do—good and useful work. If the staff and the Ministry of Health and Long-Term Care find a need to make some different provision, that’s fine by us.

Mrs Witmer: That’s fine by you, you’re saying? OK. So I guess the concern is their ability to discipline their members to make sure that nobody could hide behind this act.

Mr Anderson: That’s right. We think the act is currently sufficient as we read it, but if it’s not, I’m sure the ministry can address it.

Mrs Witmer: You would support clarification?

Ms Cavoukian: Yes, because clearly this bill is not intended to, nor should it, serve as a shield in any way in the context of a disciplinary action.

Mrs Witmer: That’s right; that’s the question. OK, great. Thank you very much.

The Vice-Chair: Thank you for your presentation.

ONTARIO DENTAL HYGIENISTS’ ASSOCIATION

The Vice-Chair: The next group is the Ontario Dental Hygienists’ Association. Good morning and welcome. We’d appreciate it if you could identify yourself before speaking, for the record.

Ms Sandra Lawlor: Good morning. My name is Sandra Lawlor. I am here today presenting on behalf of the Ontario Dental Hygienists’ Association, known as the ODHA. I’m a practising dental hygienist from Hamilton and serve as past president of the association. Joining me today is Margaret Carter, the executive director of the ODHA.

Dental hygienists are a self-governing profession regulated by the College of Dental Hygienists of Ontario under the Regulated Health Professions Act, the RHPA. The Ontario Dental Hygienists’ Association represents approximately 6,000 dental hygienists across the province, accounting for approximately 85% of the total number of dental hygienists registered to practise in the province. We are one of the largest health associations in this province.

Dental hygienists do more than just remove plaque and floss teeth. We contribute in large part to our patients’ overall health through the prevention of oral disease and the promotion of oral health care. Dental hygienists provide a process of care that involves assessing the oral condition, planning the treatment, implementing that plan and evaluating the results.

Access to and exchange of health information are critical to the practice of dental hygiene. In many instances, dental hygienists are the first health care practitioner a client sees in a dental clinic. As part of our oral health assessment and evaluation, the first visit to a dental clinic will usually involve an interview with the

patient. At this time, information is gathered relating to the client’s medical history and a comprehensive health record is established and completed. This health record will form the basis for subsequent examinations and diagnoses by other practitioners such as dentists.

Such a comprehensive medical history is required in order to provide the safest and most appropriate care. For example, if a patient has recently undergone joint replacement surgery, the possibility of infection from teeth cleaning rises due to the bacteria in the mouth being released into the bloodstream as the plaque and tartar, the hardened deposits, are broken up and removed. The dental hygienist would need to ensure that these patients are appropriately pre-medicated with antibiotics.

The protection of personal health information is something that our association and its members take very seriously. It is for this reason that the ODHA unequivocally supports the principles behind Bill 31. We are pleased that this bill has been introduced and look forward to its successful passage and subsequent implementation. We congratulate the government for treating this matter as a priority and bringing this bill forward so quickly. Dental hygienists, like other health care professions, were increasingly concerned at the uncertainty and the vacuum created in Ontario by the previous government that led to the application of PIPEDA on January 1. We have all had to go to the time and expense of implementing PIPEDA for what now appears to be an interim period of a few months.

Ms Margaret Carter: The ODHA had a number of reservations concerning the previous legislation that was introduced in 2000. We are delighted that many of our concerns have been addressed with this bill.

For example, the previous legislation allowed for a number of instances whereby personal information could be disclosed without a person’s consent. One such instance was for fundraising purposes. The ODHA was fundamentally opposed to allowing the health care custodian to release personal health information for fundraising purposes without the patient’s consent. We are pleased that Bill 31 addressed that concern and now requires the explicit consent of the patient before any information can be disclosed for such purposes. As well, the ODHA is satisfied that directed disclosures by the Minister of Health and Long-Term Care are no longer permitted as they were in the previous legislation.

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We are especially pleased that the appointment of a designated contact person is no longer mandatory for sole practitioners. Instead, health information custodians who operate an independent facility with only a small staff—if they have any staff at all—like some dental hygienists throughout the province, are now given the option of performing the functions of the contact person themselves.

Dental hygienists who operate independent clinics already follow stringent health record management policies and procedures defined and enforced by the College of Dental Hygienists of Ontario. We are pleased

that there will not be the extra burden of hiring a separate contact person to ensure compliance with this bill.

While we support Bill 31, the ODHA still has a few minor concerns that we feel, if addressed, will further enhance the principles behind the protection of personal health information.

The ODHA is of the firm belief that explicit and informed consent should be at the heart of any privacy legislation, as it is with any treatment and as it is with the federal legislation. We like the formulation of the federal legislation, the PIPEDA—namely, that information cannot be collected, used or disclosed without consent, and information can only be collected, used or disclosed for the purposes for which the consent was given. Bill 31, as was the case with the previous legislation, still allows for the collection, use and disclosure of personal health information without consent in a variety of circumstances. For example, clause 35(e) allows the collection of personal health information from a third party without patient consent or knowledge.

The ODHA recognizes that the requirement to obtain case-by-case, informed consent before disclosing a patient's health information could be a costly and time-consuming endeavour. Many businesses that have been working to comply with the federal privacy legislation have expressed this very concern. The ODHA suggests the creation of a standardized consent form specifically for research purposes. Patients receiving treatment, regardless if they are visiting a dental hygienist or any other health care professional, would be asked to provide consent in advance, thereby eliminating the time and cost involved in contacting individual patients. It would then be up to the patients to determine whether their information may be divulged for research purposes. The form would explicitly state that confidentiality would always be protected and a time limit would be imposed on disclosure.

Section 50 of the bill gives the patient the right to access their own personal health information, as well as the right to request correction, which is in section 53. However, there are certain exemptions whereby the health information custodian is not required to comply. We believe that the right of access and the request to correct one's own personal health information are an essential part of privacy protection and should be unrestricted. Therefore, any exclusions should be avoided.

We understand that a dental hygienist providing care in a municipally-owned long-term-care facility, for example, would be governed by the provisions of the Municipal Freedom of Information and Protection of Privacy Act. To avoid confusion, to ensure equal treatment and to minimize implementation and enforcement costs, we suggest that this legislation clearly and concisely outline the proper procedures and guidelines that all health care custodians must follow, regardless of the type of facility or practice setting.

In this vein, we are also concerned that Bill 8, Commitment to the Future of Medicare Act, 2003, currently before the Legislature, would authorize another

stream for access to and disclosure of health information—that is, section 13—that would operate quite independently of the bill before us today. In fact, as currently written, section 15 of Bill 8 would prevail over this bill and would require personal information to be disclosed without consent in the situations listed there.

Lastly, once Bill 31 has been passed, we hope there will be an extensive consultation process prior to the drafting of any regulations. The ODHA will be happy to participate in these consultations.

Ms Lawlor: In conclusion, the ODHA supports Bill 31. We recognize that it will go a long way to protecting personal health information while at the same time ensuring that the information required for treatment by the health care team will continue to be available.

That concludes our formal comments today. We would be happy to take any questions you might have.

Mr Fonseca: Thank you very much, Margaret and Sandra, for coming out on this quite Canadian winter day. It's great to have you here.

I'm so glad that you support Bill 31 pretty much in most of its entirety. I wanted to ask you, in regard to the balance of the bill: Does it bring enough balance between the individual and the health information custodians?

Ms Lawlor: I think, having read through the bill, yes, it does. It's a good balance. It's not so terribly restrictive that you can't, in that dialogue with your clients, get the information you want. There are only those few points that we were a little bit concerned about.

Mr Fonseca: I'll take those under advisement. Thank you.

Mrs Witmer: Thank you very much for your presentation. As you've pointed out, we've been at this for a long time. Governments have been able to take your previous advice and now you have some final areas where you'd like to provide your input.

You mention here that you'd like to be involved in the drafting of the regulations. I guess I would just ask you, are there any regulations that are to be drafted that would give you reason for concern, that you think in particular are going to require considerable input from yourself and perhaps some of the other health stakeholders as well? What do you think are going to be the key ones?

Ms Lawlor: I think initially the very fact that this government has established such an open dialogue has been a very major plus for us as a health care profession. As part of that, we see that the continuation of that would be to have dialogue and input during the creation of regulations.

Mrs Witmer: So there aren't any regulations in particular that you think you want to be involved in? There is none that you think is more important than any others that are going to be drafted?

Ms Carter: I would say that our major concern would be ensuring that it's a process that's easy to implement at the health care professional level. That would be what we would be looking at through the development of those regulations.

Ms Witmer: When you talk about consultations and you think about the number of groups that obviously want to give additional input, what do you think the best way would be to hold these consultations? Is there a vehicle or mechanism that you think the government should be using?

Ms Carter: Certainly the health care professionals as a group often meet as a coalition of health care professionals and often approach such bills in a joint manner, to ensure that we're looking at the same issues, and if we identify the same issues, we often bring forward the one voice as opposed to tying up everybody, saying the same thing.

Mr Jerry J. Ouellette (Oshawa): I know the dental hygienists are trying to gain independence from the practice and profession of dentistry. What do you think the cost and impact will be of maintaining and controlling the records of individuals? I've met with hygienists in my riding, as other members have, and they want to go into seniors' homes and have those abilities. Who do you think the responsibility for maintaining and controlling the information in these records should fall upon, and how is it going to impact your profession?

Ms Lawlor: First of all, I would like to point out that dental hygienists are separately regulated from dentistry, so that, in and of itself, is an independence that didn't exist before in oral health that does presently exist.

The situation is that if dental hygienists were able to practise independently, the same implications of the bill apply to them as they would to a dentist who owns his own clinic, to a dental hygienist who owns her own clinic, and to a dental hygienist who perhaps does long-term care. We believe the regulations cover very clearly the role of the health information custodian.

Mr Ouellette: Do you think it would be very onerous on them to maintain these records and control them?

Ms Lawlor: No more onerous than it is on us in a dental practice, where we work with dentists.

Mr Ouellette: I can just see a cost adding in to the factors as this comes forward, because the control of the records has been expressed by other groups as being rather expensive, maintaining and controlling them over periods of time.

Ms Lawlor: It's always one of the costs of doing business.

Ms Martel: Thank you for being here today. I have two questions. The first relates to fundraising, because you were quite explicit that you were opposed to fundraising being permitted without express consent.

We heard quite a compelling case yesterday from one of the hospitals in terms of the money raised through the foundation and where those funds would come from for research and equipment if this were not allowed. One of the suggestions to come forward—and while she didn't focus on it, the Information and Privacy Commissioner also has this in her brief—is that one way perhaps that you could get around this would be to have an initial contact of the patient by the health care organization and the patient at that point being offered an opt-out oppor-

tunity, and every time a fundraising letter was sent that same opportunity being provided. Would that be a mechanism that could be used that would make you more comfortable?

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Ms Lawlor: I would think so. You just don't want to provide information about a client without their permission. So if there is a mechanism by which they can approve that, I would be comfortable.

Ms Carter: I think it still comes down to consent, and so if there is an opt-out option, then that's addressing that issue.

Ms Martel: She also said that in cases where there was a very specific health care facility that could be construed as being sensitive in terms of treatment provided, you might request express consent. So she has allowed for a provision where clearly people may want more protection than others. I think we do need to do something about that, because I think the money that we're looking at in terms of what could be potentially be lost is going to be difficult to come up with.

The other question I had had to do with municipal freedom of information. If I'm understanding you correctly, it would be your view that what should prevail would be the provisions of this bill, regardless of the workplace or the health care setting, and regardless of whether that health care setting normally would be regulated under municipal freedom of information. Am I understanding you correctly?

Ms Carter: We're certainly prepared to address that further in our written submission, but our point is that we want to know that it's clear to our members which bill will prevail and what the rules and process will be. That is our issue, because right now there is some question.

Ms Martel: Thank you.

The Vice-Chair: Thank you for your presentation.

ONTARIO HOSPITAL ASSOCIATION

The Vice-Chair: The next group is the Ontario Hospital Association. Welcome. You will have 20 minutes. If you could please identify yourself for the record before you speak, you may begin.

Ms Hilary Short: Good morning. My name is Hilary Short and I'm president and CEO of the Ontario Hospital Association. With me this morning is Brian Keith, our external legal counsel, and Elizabeth Carlton, OHA senior adviser of legislation and policy. I would like to begin by expressing our appreciation to the committee in allowing us to make this submission today on behalf of OHA and its members, the public hospitals of Ontario.

The OHA has consistently taken the position that the privacy of health care information is a highly sensitive issue, the complexities of which cannot be adequately addressed as part of a general privacy law designed primarily for the treatment of commercial information. We are therefore very pleased to see that the government has heard this message and has introduced privacy legislation devoted exclusively to health information

legislation that is clear and understandable, yet affords individuals the necessary protections in respect to their health information.

I should say that this really is the culmination of many years of work by successive governments, all of which have struggled with this very difficult legislation, and we're pleased to see this finally come to fruition. We would like to thank the ministry staff in particular, who have clearly worked very hard to develop this legislation on such a complicated issue.

The OHA appreciates what a challenge it is to draft this legislation—legislation that protects the privacy of individuals, while at the same time ensures that health care practitioners and facilities have the information they need to provide care to patients in a timely way. We believe that to a great extent Bill 31 achieves this delicate balance, and wish to congratulate the government on taking this step.

We're also particularly pleased with a number of the key features of the bill, such as provisions that provide patients greater rights in respect to their own health information, a workable consent framework for the health care system, and the creation of the position of assistant commissioner for personal health information.

We are also very supportive of including the Quality of Care Information Protection Act as part of Bill 31. Again, this is a goal that the association has been working toward for many, many years. As patient safety experts have universally acknowledged, one of the most important ways we can enhance patient safety is to ensure that information respecting the quality of care provided to a patient is not admissible in legal proceedings. As you can well appreciate, it's very important for hospitals who are endeavouring to promote a culture of openness and one that fosters a full and frank discussion inside hospitals in terms of the discussion of adverse events and near misses. I think you can appreciate that in terms of the recent discussion over infection control.

What our members tell us, however, is that this cannot be achieved unless there are safeguards for information disclosed in such discussions. We therefore believe that these legislative protections are critical in enhancing patient safety and that ultimately these changes will save lives.

Overall, the OHA endorses this legislation. However, in reviewing the specific provisions of Bill 31, we have at the same time noted several areas where we believe the legislation could be improved or strengthened. We will be providing a very detailed written submission to the committee next week, but I'd like to give you an overview of those recommendations today.

Our two chief concerns are, number one, with the type of consent required for fundraising and, second, the so-called lockbox provision allowing patients to withhold or block critical information from health care providers.

With respect to fundraising, we are concerned that the requirement that hospitals seek express consent from individuals will pose considerable challenges. You've

heard much about that already. OHA recognizes that it is fundamentally important to ensure that the privacy rights of individuals are respected, and that patients who do not wish to be contacted for fundraising do not receive unwelcome solicitations from hospital foundations.

However, we believe there are other means to accomplish this, such as providing patients with an opportunity not to be contacted, as Ms Martel mentioned to the last speakers. We would support what is commonly known as the opt-out consent. In our submission, we have provided some indication as to specifically how this might operate in the hospital context.

We must ensure that we protect hospitals' ability to undertake fundraising, because without these donations, which total some \$500 million annually across the province, hospitals would not be able to undertake critical research or renew their capital infrastructure. While it is impossible to quantify with any precision at this time, if passed, these new provisions could severely jeopardize the ability of hospitals to raise the funds they need. At a time when hospitals are already facing severe funding shortages, this could be a serious blow to the bottom line.

You will be hearing more about the fundraising issue in detail, as well as its impact on the research that hospitals are able to conduct. You will shortly hear a presentation from the Ontario Council of Teaching Hospitals, as well as the Association for Healthcare Philanthropy.

Secondly, the issue of the lockbox: While we appreciate the need to ensure patients have an opportunity to control their personal health information, we do feel it's important to alert government as to how this may impact the quality of patient care in Ontario. For many health care practitioners working within hospitals, the right of individuals to effectively block access to what may be very pertinent personal health information could pose real challenges. Hospitals have told us that such a provision may, in some instances, seriously impair the ability of a health care provider to disclose information for purposes that may be essential to the effective delivery of health care, and may thus inadvertently undermine the quality and safety of care to that individual. We would therefore ask that, in the interests of patient care, the government give serious consideration to removing these provisions.

On the substantive matters, we are proposing several specific amendments to the legislation in our written submission. In addition, we are also suggesting a number of technical amendments in the interest of providing clarity and certainty for health care providers in implementing the legislation. Again, these are set out in some detail in our written submission.

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Having identified some of the ways in which we believe the bill could be improved, we wish to emphasize again that the OHA fundamentally endorses Bill 31. We are confident that these issues we have raised here today, and in our submission, can be addressed through the

legislative process. We look forward to working collaboratively with the government to find workable and practical solutions so that we may finally move forward with enacting health privacy legislation for Ontario.

In conclusion, we would just like to comment on the matter of implementation. While the OHA acknowledges the need for privacy legislation and commends the government for undertaking the initiative, we do have some very serious concerns about the implementation date of July 1. We believe it will pose very considerable challenges for hospitals. Although many hospitals have done much to develop comprehensive privacy programs, the new legislation sets out very detailed standards for which they will have to develop new policies and practices. We thus believe that some consideration should be given to extending the date.

We need to accelerate immediately the development of guidelines, templates and audit tools for stakeholders and organizations affected by the legislation, as well as information pamphlets and posters for dissemination by providers to the public, because they will be affected by the legislation.

We have already done a great deal of work on this front with our Ontario Hospital e-Health Council privacy and security working group. We have circulated the document that they recently produced, entitled *Managing Privacy, Data Protection and Security for Ontario Hospitals*. As you will see, that document offers detailed templates and guidelines in an effort to create standardization throughout the sector. While that is an excellent resource, it is but one tool, and because it was created last summer, does not provide any specific guidance on how to implement Bill 31.

Although the OHA is committed to working with the government to ensure that such tools are tailored to the needs of hospitals, we certainly would appreciate assistance in this regard and would welcome a commitment from the government to help organizations such as OHA in educating their members and preparing for eventual implementation.

Not surprisingly, we would suggest that the costs of implementing Bill 31 may be significant. New requirements, such as those relating to information practices, consent, the rights of patients to access and correct their health records and standards for electronic health records, will all have financial implications for hospitals. Moreover, as we mentioned previously, the potential loss of revenue resulting from restrictions on hospital fundraising will have an enormous impact on the ability of hospitals to finance capital projects not currently funded by government.

The OHA has consistently supported efforts to introduce privacy legislation. To date, however, legislation has not passed, in large part because it had not been drafted to meet the explicit needs of both patients and the health care community.

We believe that in Bill 31 we have, finally, a piece of legislation that does achieve that balance, and we would urge the government to enact Bill 31 as soon as possible

with the amendments that we are proposing, but within an implementation time that is manageable for the hospitals.

Thank you for the opportunity to present. We would be pleased to answer any questions that any of you may have with respect to our presentation.

Mrs Witmer: Thank you very much for your presentation. I would agree with you that I think we are at a point where the legislation certainly is one that achieves the balance that people have been seeking now for a number of years. There remain, however, a few amendments that should be incorporated to make it the best it can be to provide the protection that people need and deserve.

But I guess you spoke here about cost. We have been hearing from various presenters that they believe there are going to be some costs associated with the implementation of this bill. Have you taken any look at what it may cost hospitals in the province of Ontario?

Ms Short: We have, yes.

Ms Elizabeth Carlton: Actually, we did some of that work when we published the document last summer, and although we didn't provide actual cost estimates, you'll see in the appendices that it does give an estimate of the number of hours just to establish a privacy program, develop guidelines etc.

I think for a medium hospital it was 1,000 hours. So we're looking at, I think, costs in terms of not only staff time, but development of tools and templates, whether it be brochures, pamphlets, notices. All of that needs to be done. Then there's the whole issue of educating staff in a very large organization, because without that education, none of this is implemented appropriately.

Ms Short: So we would have to make that assessment, maybe survey our members in terms of what we think the actual dollar cost will be, but it will certainly be—I don't want to hazard a guess, because we haven't done that work, but it will be substantial.

Mrs Witmer: That's right. That's why, I guess, for some of the people who are independent practitioners, there's not as huge a cost as there is for an organization such as a hospital. I appreciate that.

As well, you talked to the implementation. I would certainly agree, having been in government myself, we're always very optimistic and we think that maybe we can get this all done by July 1, but the reality is, government moves more slowly when we get there than we realize.

The other thing is, this bill has not even passed yet. Do you have a date that you could see that would be a little more realistic than July 1 as to the introduction of this legislation? What amount of time are hospitals going to need to feel totally comfortable that patients and staff understand the changed environment?

Ms Short: What we're suggesting is that first of all, the regulations are going to be quite complex and key to this. So we would suggest that six months following the development of the regulations would be a reasonable date.

Mrs Witmer: Thank you very much.

Ms Martel: Can I just return to the issue of costs? I don't pretend to understand a dollar value for 1,000 hours. Is it possible—without having surveyed your members, obviously—to put that in a more concrete context for the committee?

Ms Carlton: I think we could certainly undertake to provide that in a submission, if that's something that would be helpful to the committee. As Hilary suggested, we haven't surveyed our members on implementation of this, and obviously a lot of it will rest on what the regulations say, how detailed and prescriptive the standards will be to determine what the costs will be. But we will undertake to get you that information in some precise term.

Ms Martel: That would be useful.

My second question then is, because a great deal of work went into this, and I assume hospitals were moving forward in response to this, are you going to be starting from scratch, then, with the passage of this bill? Can you give us a sense of how far along you might be, looking at the bill that's before us? I suspect there won't be many changes to it, so that's effectively what we're going to be working with.

Ms Short: We will not be starting entirely from scratch, but that was developed under the understanding that there was no provincial legislation that was developed for PIPEDA.

We can expect that it's not just the one-time cost. It would be ongoing costs. As any new development in a hospital, it always adds cost to the bottom line. I would say, certainly, I don't think I'd be far off if I said \$100 million or something like that; I don't think I'd be wildly exaggerating, but we would have to do that detailed work.

Ms Carlton: I should add that the document we produced in the summer really sets out best practices in terms of privacy, but it doesn't drill down to specifics as to what you need to do in terms of this particular situation, whether you're dealing with mental health information, if you're dealing with fundraising information, if you're dealing with research. In this bill it's set out in a very detailed manner. We will have to then turn that information into guidelines, templates, so that each hospital knows how to implement it from A to Z.

The Vice-Chair: Thank you.

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Mr Fonseca: I'd like to thank the OHA, Hilary Short, your colleagues. That was an excellent presentation—very detailed and thorough.

If we could just go back to fundraising, what percentage of fundraising do you feel would come through this direct mail for your own—because you brought up fundraising and how it would affect the hospital, the percentage that would come.

Ms Short: I'm not an expert. My understanding is that direct mail has always been the most effective method of fundraising for hospitals overall. While they get some very large donations, they really depend on the direct mail.

Mr Fonseca: Couldn't you just do it through mailers in your catchment area for each hospital?

Ms Short: Again, I think you'll hear from the Association for Healthcare Philanthropy and others that the targeted fundraising to people who have recently received the service of a hospital has been very effective, because despite all of the sometimes negative publicity you hear, generally speaking people are very satisfied with the care they receive in hospitals, and if they have had successful cataract surgery or successful surgery of any kind, they are likely to be quite appreciative of that and are likely to donate after a good experience in a hospital.

Mr Fonseca: In regard to the lockbox, if you can give a specific example of how it would interfere.

Ms Short: The example we might use—and it's sort of an extreme example—say you were HIV-positive, for example, and you wished to block that information or any kind of other diseases of that nature from other care providers, that could have pretty negative consequences.

Are there any other examples we could give?

Ms Carlton: Also the example of there being potential drug interactions and adverse events occurring from that. If one physician is prescribing certain drugs and they don't know what other drugs this individual is on, there's a great potential there for some adverse incident occurring.

Mr Fonseca: So then, under this bill, you would let the patient know that this could happen and try to then get consent to open up that box.

Mr Brian Keith: Can I just explain one thing? We're talking about information for which you either already have a consent from the patient or you're entitled to collect it indirectly without the patient's consent. So what we're talking about is adding on top of that a provision that in effect allows the patient to go back and censor their own records and allows them to make a decision about what is or is not relevant. That can lead to enormous problems when the patient may not appreciate what the significance of the information is, and it's an enormous investment of time to have to sit down with them and say, "Well, we really do need that, so we'd really rather you didn't cross that out."

Ms Short: Again, this has been a long-standing issue of how you protect yourself from your personal health information against what is needed for optimal care.

The Vice-Chair: Thank you very much for your presentation.

ONTARIO COUNCIL OF TEACHING HOSPITALS

The Vice-Chair: The next presenters are the Ontario Council of Teaching Hospitals.

Ms Mary Catherine Lindberg: Good morning and thank you, Mr Chairman and members of the committee. My name is Mary Catherine Lindberg, and I'm the executive director of the Ontario Council of Teaching Hospitals. With me today is Martin Campbell, our legal

counsel, and Ken Bednarek, who's working as a consultant with the Ontario Council of Teaching Hospitals.

We thank you for giving us the opportunity to speak to you today about Bill 31. We will also be filing a written submission for February 6. We join the Ontario Hospital Association in commending the government for bringing this legislation forward. There has been a long consultation process, and we are pleased that there has been useful dialogue on this important issue. We are particularly pleased that the government has chosen to introduce legislation specifically dedicated to privacy and confidentiality issues in the health sector, rather than combining health care sector issues with the general legislation covering many sectors. We're also pleased that the government has adopted the concept of both implied and express consent as ways in which patients can give consent to health care providers. The Ontario Council of Teaching Hospitals also commends the government for including the Quality of Care Information Protection Act as part of Bill 31, which we consider to be essential to ensuring full and frank discussion of medical care and treatment without the chilling effect of possible litigation or regulatory scrutiny.

Before I raise OCTH's specific concerns, which are about fundraising and research, I'd like to tell you a little bit about the Ontario Council of Teaching Hospitals and its members. Our members are the 22 academic health science centre hospitals in Ontario. Our members are also members of the Ontario Hospital Association. These hospitals provide highly complex care. They are health care institutions of the last resort. They train the next generation of physicians. They conduct world-class research. They provide over 40% of the patient care in the public hospital sector. They are able to provide this complex care precisely because they have access to research. The wide diversity of care received in our institutions provides the best opportunity to train our students in leading-edge techniques.

Clinical care, health care education and health care research are interrelated. We cannot do one without the other two. The funding that our hospitals receive from the province goes to clinical care. This covers approximately 85% to 95% of the cost of operating a hospital. Hospitals must fundraise for capital, capital equipment and to conduct medical research. Research is funded by the government through peer review research grants, which include some money for overhead. However, for research to happen, there need to be support structures and a place to do their research. The academic hospitals' research foundations raise money to provide the infrastructure for research, namely the construction and renovation of facilities, the maintenance of laboratories and equipment. This is why our fundraising efforts through our members' affiliated foundations are so important. Many patients and their families contribute because they are concerned that research is being done and about the importance of research to their health care.

One of our concerns about the Personal Health Information Protection Act, schedule A of Bill 31, is the

section on fundraising, section 31, which requires health care institutions to get the express consent of an individual before the individual can be approached for fundraising purposes. We think there's a better way to accomplish the policy objective of making sure that fundraisers are not imposing upon individuals and making sure that the fact that an individual has received health care from a health care institution is kept confidential. A better way could be to provide for an opting-out mechanism. That is, at some point during a person's stay in a health care institution, they can sign a form that specifically says they do not want to be approached by health care institutions for fundraising purposes. We think this is a better way to protect confidentiality of information without restricting our members and their foundations from encouraging donations. We recommend that section 31 provide for opting out, as we have set out above.

I would also like to talk to you about section 43 on research. First, we endorse codification of the role of the review ethics boards into personal health information legislation. Given the vital role played by the review ethics boards in approving research and the importance of the public in the integrity of the research approval process, we recommend that the drafting of the regulations outlining the role, composition and procedures of the review ethics boards be given the highest priority. We would be willing to work with the drafters in crafting these regulations.

Section 43 goes a long way toward protecting the privacy of health care information. However, the section does not fully take into account the way health care research is now being conducted. Research takes place all over the world. Clinical trials take place all over the world. Data from many jurisdictions is pooled and shared. In fact, it is a requirement of licensing some products of research that there be large, randomized studies across as many population characteristics as possible. If we need data from many jurisdictions, not all jurisdictions have the same rules protecting privacy. Most jurisdictions respect the confidentiality of health information, but rules vary. We need to have greater flexibility in section 43 to allow us to share information with researchers in other jurisdictions. We cannot restrict the flow of data in and out of Ontario to other jurisdictions. We recommend that section 43 be amended to permit the flow of data in and out of Ontario to jurisdictions that have privacy protections that are substantially similar to Ontario's.

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The second problem is that research agreements and clinical trials may run for many years. Longitudinal studies are one of the best ways to measure health outcomes. Section 43 provides a one-year transition phase. We recommend that the transition provision be extended to five years so that research projects and clinical trials which are now underway will not have to be stopped or will not have to undergo extensive revision.

Finally, if any other health care institution has collected personal health care data before the act comes into force and if the data was collected according to the law which existed at the time it was collected, additional consent to the further use of the data should not be needed. We recommend that section 43 be amended to provide for a longer transition period of five years to provide for use of data which has been validly collected in the past without further consent.

We fully support and endorse Bill 31, subject to our recommended amendments. We think it is a great step forward and will codify and improve the way in which health care institutions deal with personal health information. We look forward to the early enactment of the bill.

My colleagues and I would be pleased to answer any questions you might have.

Ms Martel: Thank you very much for being here this morning. With respect to fundraising, in two submissions now the sum of about \$500 million has generally been used to describe what foundations are raising. Given your position in terms of the hospitals you're working with, can you tell us what the impact would be, at least to the 22 you deal with? I appreciate that wouldn't represent all of the fundraising going on in the sector, but you've got some of the biggest ones.

Mr Ken Bednarek: Yes, we definitely have the bulk of them, and it would definitely have a substantial impact on their ability to raise funds. I think the number they were quoting me was that up to 80% of the funding goes directly to the research initiatives.

Ms Martel: So 80% of the money raised goes to research initiatives?

Mr Bednarek: Yes.

Ms Martel: Do you have a more complete total in terms of what the value of that is? Is that possibly something you could get for us?

Ms Lindberg: Yes, we can get that for you.

Mr Bednarek: We can try to get that.

Ms Lindberg: We actually have it; I just didn't bring it.

Ms Martel: That would be great. My second question has to do with research and disclosure to other jurisdictions that you said had similar privacy legislation to Ontario's. We've heard about some of those, at least in Canada; I don't know about anywhere else. Do you have particular wording for an amendment that would deal with what you'd like to do?

Ms Lindberg: In our written submission, we actually have some amendments. The issue is, especially in Canada, where we don't have a large population, we do need to share studies, at least across provincial boundaries, to be able to carry out some of the studies that we're currently doing.

Ms Martel: Just generally in terms of the length of studies, because the bill talks about the transition period being one year, is most of the research that's being done much longer than that, then?

Ms Lindberg: Most of it is done longer. The issue, especially in some of the clinical trial research on drugs, is that you really do need to have an extended period, because everyone knows that we always come up later with the side effects of drugs. Out comes this effective new drug, and then we find out about the side effects. So we need to do longitudinal studies. You have to keep the same patients on those drugs for the same length of time. We've now started some of them; we need to be able to continue them.

Ms Martel: Just so I'm clear, the proposed amendment would reference five years after the day the section comes into force?

Ms Lindberg: There are a few longitudinal studies that we do in health promotion and those kinds of areas where we go 20 and 25 years. The Ontario health study itself follows the same people, but they've already given explicit consent, so I don't think we'd have to worry about those.

Mr Fonseca: I'd like to thank the Ontario Council of Teaching Hospitals, Mary and your colleagues, for a great presentation and for the recommendations you have brought forth. I want to ask something around fundraising: Do you have information about the impact of the opt-out process as opposed to the consent process in the health care fundraising field, and is it used anywhere else in the country that you know of?

Ms Lindberg: No, I don't know whether it's used, but I do know we've had some experience with people having to ask for explicit consent and not getting the kinds of results we would have got when you solicit from the patients or the patients' families who have been in the hospital. You do not get the same kind of results in your fundraising. I think Mr Closson mentioned the Mount Sinai experience yesterday.

Mr Fonseca: Thank you.

Mr Ouellette: Thank you very much for your presentation. A couple of questions. First of all, the drug testing process: Do you see this as initially inhibiting advancing new drugs forward because of the limitations with information?

Ms Lindberg: No, I don't think so. The issue would be if they've already started a clinical trial and they have to get the consent in the next year. We're saying, give us five years for us to be able to transfer this routine over.

Mr Ouellette: That should cover most of the current ones that are ongoing?

Ms Lindberg: Five years should.

Mr Ouellette: One of the other things already mentioned by the OHA as well as yourselves is about the \$500 million. The legislation isn't covering out-of-province information, which means you can bring in information regarding residents from Ontario from other jurisdictions. Do you envision yourself as having to buy lists from other provinces or jurisdictions in order to proceed with fundraising as well?

Ms Lindberg: No, I don't think we would go to that extent. We would probably try to find another way of soliciting for research.

Mr Ouellette: Yeah, \$500 million is a lot of funds.

Ms Lindberg: It's a lot of money, but hopefully we can at least get the opt-out provision in.

Mr Ouellette: OK. Mr Yakabuski has a question as well.

Mr John Yakabuski (Renfrew-Nipissing-Pembroke): Thank you for addressing us this morning. Back to the fundraising issue, the University Health Network spoke to us yesterday and they cited figures—correct me if I'm wrong—of somewhere between a 50% and 70% reduction in their ability to raise funds for capital equipment campaigns, for example. That would be the effect of this bill if enacted as currently planned. Would you concur with those figures? Do you believe them to be fairly dependable?

Ms Lindberg: Mr Closson is a member of our association and, yes, we're hearing that from all the hospitals, all our membership.

Mr Yakabuski: So this particular section would be one of the most damaging sections to you.

Ms Lindberg: Yes, considering that major teaching hospitals have to fundraise for an awful lot of their capital equipment and we are trying to be the leading-edge researchers in Canada and the world. We are always trying to replace to make sure that we have the best equipment there to teach the young students and also to give the best care.

Mr Yakabuski: Some others have indicated a concern with the time implementation of this bill. You don't seem to have a concern with that.

Ms Lindberg: We were trying not to reiterate some of the concerns of the OHA. We are members of the OHA, so we are endorsing their submission.

Mr Yakabuski: So when you say "as soon as possible"—

Ms Lindberg: We mean, within reason. Also, we don't want to be under the two acts either, as long as we can get this in. But we need to be able to get the regulations in, and then the approval.

The Vice-Chair: Thank you very much for your presentation.

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COLLEGE OF PHYSICIANS
AND SURGEONS OF ONTARIO

The Vice-Chair: Now we have the College of Physicians and Surgeons of Ontario.

Dr Rocco Gerace: Good morning, Mr Chair and members of the committee. On behalf of the College of Physicians and Surgeons of Ontario, or CPSO, I would like to thank you for the opportunity to participate in today's meeting. My name is Rocco Gerace and I'm the registrar of the college. Prior to assuming this position, I practised emergency medicine for 29 years in London, Ontario. With me is Katya Duvalko, who is the college's policy director. Dr Barry Adams, our president, is unable to be here today.

From the time of Hippocrates over 2,000 years ago, the issue of patient confidentiality or privacy has been one of the pillars of the medical profession. I can tell you that doctors recognize the importance of maintaining patient confidentiality. With that background in mind, I welcome this opportunity on behalf of the college to speak in support of this bill.

As doctors have an ethical obligation to serve their patients' interests, the college has a statutory obligation to serve and protect the public interest. Having said this, we strongly support the need for comprehensive legislation to govern the collection, use and disclosure of personal health information.

As I'm sure you know, the commitment to privacy is a key component of existing legislation, including the Medicine Act and the Health Care Consent Act. Not least is the inclusion of strong privacy provisions in our governing legislation, the Regulated Health Professions Act, or RHPA. Privacy principles are also espoused in the Canadian Medical Association's code of ethics for physicians. We know that our obligation to protect patient confidentiality is clear and without question.

We realize that you have heard or will hear from a number of regulatory colleges, as well as from the Federation of Health Regulatory Colleges of Ontario. We've worked with the federation for some time on the development of health privacy legislation and are strongly supportive of their recommendations.

Finally, there has been extensive consideration of both provincial and federal privacy legislation over the past few years. We know from experience that in moving forward with the current legislation we need to ensure that unintended consequences that may be detrimental to the public interest are avoided at all costs.

There will be others who will speak to the issue of this legislation and its impact on the delivery of care. Our focus this morning is the impact of Bill 31 on the regulation of the medical profession.

With these introductory comments in mind, we have three objectives this morning: first, to describe for you briefly what the college does and how we use personal health information to carry out our statutory responsibility; second, to highlight those provisions of Bill 31 that will allow us to continue to meet these responsibilities; and finally, to illustrate with some examples how the legislation might be improved to ensure its compatibility with our regulatory framework.

First, I'll talk about the college. As the regulatory body for physicians, we are given this responsibility under the statutory provisions of the RHPA. Within this act, our responsibilities include issuing certificates of registration to physicians to allow them to practise; ensuring the quality of physician practice through ongoing assessments and, when necessary, education and remediation; investigating complaints against doctors on behalf of the public; and disciplining doctors who are found guilty of professional misconduct or incompetence. Our college has approximately 26,000 members, and we regulate our members in keeping with the overarching

principle of the RHPA, which is "To serve and protect the public interest."

To fulfill our legislated mandate, the use of medical records is critical. Medical records provide a window into medical practice by doctors. We need to access these medical records to appropriately assess physician performance.

When the college carries out an investigation, we have a number of options to ensure public safety. We can prescribe educational programs to upgrade a physician's practice; we can restrict the clinical activities of a physician; we can suspend a physician from practice or impose terms and conditions; and finally, if necessary, we can revoke a physician's license to practice.

While we rely on health information in our processes, it must be emphasized that section 36 of the RHPA already provides for complete confidentiality of all information. Section 36 states in part that an individual "shall preserve secrecy with respect to all information that comes to his or her knowledge in the course of his or her duties and shall not communicate any information to any other person..." This provision applies to members of the governing council, to council committees, to all employees of the college and to any physician who may be retained as an expert or an inspector.

There are exceptions to the privacy provision. For example, we can convey information about regulatory outcomes of individual physicians to other medical regulators as well as the public. However, these notifications would never include identifiable patient information.

The two main regulatory activities required of us under the RHPA, which are dependent on patient information, are the investigation of physicians and proactive quality assurance programs. I will describe these for you.

First, in respect to investigating doctors: Concerns are brought to the college from a variety of sources. The majority of concerns are brought by patients. The complaints committee considers approximately 1,400 complaints per year. We also received concerns from other individuals such as the coroner, the chief of staff of a hospital or other health professionals. The college and its committees take every concern seriously. In the vast majority, we investigate vigorously. These investigations almost always require a review of patient records. Occasionally, these investigations and outcomes are reported to the profession. In all cases, as mentioned earlier, patient identifiers are removed.

The other major area of regulatory activity revolves around our quality assurance program. We are leaders in this area and are developing new initiatives whereby physicians' practices will be regularly reviewed on a proactive basis. This program is designed to assist physicians to improve the quality of care they deliver to their patients. Again, we rely on patient records to assess physicians and at all times maintain strict confidentiality.

Let me tell you what works best in the legislation. We think that, with few exceptions, the majority of the provisions in Bill 31 will allow us to discharge our regulatory responsibilities in an effective way.

We strongly support the fact that regulatory bodies have not been included in the list of health care custodians. This was an important consideration during earlier discussions, and we are pleased that our collective voice has been heard. There is little doubt that this legislation has come a long way toward reaching an appropriate balance between the competing policy imperatives of protecting individuals' right of confidentiality with the need for disclosure to allow the proper regulation of the profession in the public interest.

The CPSO also applauds the government's recognition that personal health information needs to be addressed through a legislative framework that differs somewhat from personal information collected, used and disclosed for commercial purposes. Separating out the protection of health information into a separate act will go far to ensure that while confidentiality and patient privacy are protected, the delivery of health care in a timely and effective manner is not compromised.

While many substantive components of this bill are left to regulation, the college applauds the provisions in sections 72 and 10 of the HIPA schedules creating an open and consultative regulation-making process. We would endorse this model of consultation for all health legislation.

Finally, some recommendations to improve the legislation: We do have two areas of concern within the legislation. Both concerns could have a negative impact on our ability to regulate physicians.

The first of these concerns is the primacy of the privacy legislation over the RHPA. We are concerned that physicians could use the privacy legislation to avoid regulatory control through the Regulated Health Professions Act. Given that clear considerations for privacy are contained in the RHPA, we feel it is critical that this piece of legislation take primacy over the privacy legislation. Let me give you an example. If a hospital advises us of a suspension of a physician under the provisions of either the RHPA or the Public Hospitals Act when that physician's care has been deficient, given the primacy of the privacy legislation, we may be precluded from investigating using patient records.

Further, as you may know, many dispositions by statutory committees of the college are subject to oversight by the Health Professions Appeal and Review Board, or HPARB. In conducting these reviews it is necessary to forward all information to the board for their consideration. These reviews by HPARB may be conducted at the request of either patients and/or members of the college. The question we have is: Would the primacy of the privacy legislation preclude the sharing of material with the board? We are concerned that the smooth functioning of this established review process not be impaired by the privacy legislation.

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Our second major area of concern is with respect to quality assurance programs. The college applauds the special protections afforded to hospitals and other similar institutions. However, quality assurance programs within

the regulatory environment are equally critical in promoting high quality of care by health professionals. We believe that regulatory quality assurance programs should be explicitly included in the special protection afforded in the legislation.

In summary, we would again like to congratulate the government for clearly codifying principles for the collection, use and disclosure of personal health information. However, we urge you to continue to work with us to ensure that we've adequately addressed the implications of this legislation. The legislation must appropriately balance protection of private information with the ability to effectively regulate the profession in the public interest.

Thank you again for allowing us to make this presentation, and we would be pleased to answer questions.

The Vice-Chair: Thank you very much. Mr Fonseca.

Mr Fonseca: I'd like to thank the College of Physicians and Surgeons of Ontario for presenting here today and for bringing up a number of recommendations. To address one of them, I'd like to know: What would be the risks of giving a blanket precedence to the RHPA over this act?

Dr Gerace: I'm not sure there would be any risk, especially in respect to privacy. I think it's our feeling that privacy is clearly protected in the RHPA and would continue to be.

Mr Fonseca: We looked at clauses 40(d)(i) and (ii) and clause 9(2)(c). The proceedings include college reviews under definitions.

Section 40 says:

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

"(d) for the purpose of complying with,

"(i) a summons, order or similar requirement issued in a proceeding by a person having jurisdiction to compel the production of information, or

"(ii) a procedural rule that relates to the production of information in a proceeding."

Would that not take care of that?

Ms Katya Duvalco: Let me take a stab at answering that. I think our concerns about the ability of health care custodians to disclose to the colleges have been adequately addressed or could be adequately addressed by a number of clarifications in this act.

The concerns we have would centre around issues outside of disclosures; for example, issues about the use of information that a non-health care custodian gets from a health care custodian. Interpreted narrowly, this legislation could be seen to limit the use to which we put information that we receive. So if a health care custodian discloses, to be in keeping with the legislative requirement, can a college then turn around and use that information to launch an investigation? We think the inference is there that we could, but a literal interpretation of this act would not allow that because it's a different use from the use for which the information was disclosed.

Another instance where we might run into trouble if the primacy of the RHPA is not considered is the whole question of the correction of records. The college fully understands the need in the public interest to allow patients to correct information that is not correct in their records. Our concern is that every once in a while we do run into unscrupulous physicians—there are unscrupulous people in every walk of life—and the provisions of correction and severing of the corrected record from the original record could be used to perpetrate fraud or to correct records in a way that is not at the request of the patient but is the physician trying to cover up some kind of incompetence or fraud or other ill intention. If you put the RHPA as paramount to the HIPA, we think those types of concerns could be addressed.

Mrs Witmer: Thank you very much for your presentation. I'd like to focus on the same issue, and that is, the primacy of the RHPA over the privacy legislation. The commissioner was here this morning and I asked her whether or not she thought there was any danger, and she said no, she didn't think so, but she was not averse to amendments being made that would indeed give primacy to the RHPA. So my question to you is, have you or perhaps the federation that is appearing next given consideration to drafting specific amendments that you think would address the concerns that all of the colleges seem to be expressing to us about your ability to deal with your members?

Dr Gerace: We have not drafted specific recommendations for that, although I'm sure we or the federation at large would be more than happy to do so.

Mrs Witmer: It seems to be the biggest concern that we're hearing from the colleges. As I say, she was certainly not averse that amendments would be added that would allow you to do the job you've been asked to do.

Ms Duvalco: That is something the colleges were able to do with previous iterations of health privacy legislation and I'm sure would be very willing to go through a similar process together with the Information and Privacy Commissioner and with government to come to a reasonable solution.

Mrs Witmer: I think it would be helpful for all of us. We're at a point where the bill probably is going to be exactly as it needs to be.

The Vice-Chair: Any other questions?

Ms Martel: As a follow-up to that, I think the second suggestion would be around your second area of concern, which is with respect to the quality assurance programs. There was discussion about this very matter yesterday and some question about whether or not you could do that in schedule B, by an amendment to provisions in schedule B, or whether you leave that to be a regulation, again still under schedule B. My preference would be that we have that clearly articulated in the legislation versus by prescription through regulation. Perhaps you can put forward something to the committee through the federation that would tell us whether or not that needs to be done under the definitions section of quality of care

committee, if that's the most appropriate place, or if there's somewhere else in schedule B that needs to be amended that would more appropriately deal with that particular concern, because I think you're right and we should have that protection. I don't think there's a question among the committee about that. We just need to know the best way to do it.

The Vice-Chair: Thank you for your presentation.

FEDERATION OF HEALTH REGULATORY COLLEGES

The Vice-Chair: Next we have the Federation of Health Regulatory Colleges.

Ms Michelle Kennedy: Good morning, and thank you for this opportunity on behalf of the Federation of Health Regulatory Colleges. My name is Michelle Kennedy and I'm the registrar of the College of Denturists of Ontario. I'm accompanied by my colleagues Irwin Fefergrad, the registrar of the Royal College of Dental Surgeons of Ontario, and Tina Langlois, the director of complaints, hearings and investigations for two other regulatory colleges, namely the College of Medical Radiation Technologists of Ontario and the College of Medical Laboratory Technologists of Ontario.

I should note for the record that none of us are actually members of a regulated health profession. We are strictly administrators who have been delegated authority from the Minister of Health to ensure that the public is protected when they're accessing care from regulated health care providers.

Between the three of us we actually represent a fairly broad spectrum. I'm from one of the much smaller colleges. We have approximately 450 registrants in the province, whereas my colleagues are anywhere from 7,000 to 8,000. In point of fact, if you look at the totality of the regulated health professions, we're talking about a quarter of a million people in the province of Ontario.

We're very enthused to be here today to support the legislation. We appreciate the opportunity for ongoing dialogue and input into your efforts.

Ms Christina Langlois: In order to really understand the federation, I think you also need to understand a bit about who we are not. It confuses our members from time to time, so certainly it's confusing to others. We are not educational institutions, nor are we colleges or universities. We are not associations of professional members or societies of professional members; we are in fact regulators. All 21 members of the federation are regulatory bodies. Those who serve on executive associations in our professions are generally barred from sitting on the council of the regulatory college.

The regulatory college's function is quite clear: Our mandate is public protection. That is what we were created to do and that is in fact what we do on an ongoing basis.

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Mr Irwin Fefergrad: Public safety and public protection are what we're all about. You gave us the

authority under the Regulated Health Professions Act to have that function.

We have three basic functions: (1) We register our members; (2) we deal with issues around discipline and complaints, and we are the only lawful body—and I include courts in that category—who can in fact remove licences or impose terms and conditions and limitations on someone's licence; and (3) we offer to the public, through your legislation, quality assurance. We'll talk a little bit about that in our presentation.

Our council or our boards consist not only of members of the independent or individual professions. Government appoints up to 49% of people who are not members of the particular profession to sit on our council. The notion is that in the self-regulatory environment where we are required to protect the public interest, the public needs to have some say in what goes on not only in policy development but as well in those three categories I spoke of: quality assurance, discipline and complaints, and entry.

Finally, what really distinguishes us: We each report at some level to the Minister of Health and Long-Term Care.

Ms Kennedy: We're here today to support this initiative. We fully appreciate the importance of the privacy of personal and personal health information and, as such, recognizing that we have our own confidentiality provisions within the Regulated Health Professions Act, fully applaud your efforts in this regard, as we recognize that this iteration of the legislation does differentiate between general commercial activities and the very specific situations encountered by health care professionals in the province of Ontario.

We appreciate the intent of the legislation and look forward to the opportunity to give you some advice on how we could perhaps even improve it to further protect individuals, ensuring that they have access to competent and accountable care, which is why we exist.

Ms Langlois: We want to let you know that the federation and its member colleges are not new to the issue of privacy. All the colleges in the federation have in fact been involved in consultations on previous versions of privacy legislation, and each college has taken a leadership role in preparing information up until the end of last month to make their members ready for the application of PIPEDA, the federal legislation. Colleges have been actively involved in this activity, and we would like to share with you our expertise and our understanding of privacy in our own professional environments and things that can be done to improve the legislation in this area.

Mr Fefergrad: We're here actually not to ask you for anything, but to offer our expertise. We've been in business collectively for hundreds of years, affecting thousands of members and affecting thousands, if not millions, of Ontarians. We have a vast amount of experience in the regulated health field, and we welcome any opportunity that we can be of assistance to you in this privacy area and in fact in any area involving the regulated health field.

Ms Langlois: I have the pleasant job of starting to tell you some of the things we truly appreciate about this draft of privacy legislation. The first, and you've heard it before from our colleagues in regulatory bodies, is the fact that this legislation does not designate colleges as health information custodians. We strongly argued in previous consultations that designation of colleges in this fashion would impair our ability to regulate effectively in the public interest, and we commend the government for taking the approach that it has in not including colleges in the definition of health information custodians and would suggest that that's a very important thing to maintain.

Mr Fefergrad: We appreciate the clarity that you've put in the legislation with respect to consent. It was unclear, as you know, under the PIPEDA legislation as to whether the consent provisions in that legislation embodied express consent or implied consent, and we have received, as you know, mixed messaging from the federal privacy commissioner and from the department of industry, whose legislation PIPEDA is. It's very reassuring to the regulators that there is clarity around consent. You've taken the reasonable approach, which we really endorse and welcome and appreciate and thank you for, in suggesting what embodies implied consent and what embodies express consent. We think it'll be rather easy for the members to adapt and in fact to carry out the intention of the legislation with respect to consent.

Ms Kennedy: Further, we applaud you for recognizing or attempting to recognize our ongoing regulatory activities through several references and also through ensuring that steps will be taken for open consultation in the regulation-making process, and we look forward to working with you in that regard.

Mr Fefergrad: However, the act isn't perfect—nothing in life is perfect—but it's good; it's really good. We would like to offer some suggestions for your consideration that might in fact make it as close to perfect as any privacy legislation in this country can come. We think there are some modifications that can be made that will not at all affect the intention of the legislation, that will not at all affect the IPC and will, in fact, make this a model of privacy legislation, not only in this country but internationally.

Ms Langlois: The first recommendation that the federation and its member colleges would have is around the issue of the paramountcy of the Regulated Health Professions Act, which is the act we deal with on an ongoing basis. As my colleague Mr Fefergrad has stated, we were given the authority by the provincial government to license, investigate and discipline members. Even courts don't have this authority. Our concern is that if the RHPA is in fact not made paramount, HIPA may in fact have the effect of somehow eroding that authority or ability to carry out those functions, so we would recommend that it would be appropriate that the RHPA be made paramount to HIPA in order to facilitate our ability to continue to do our very important job.

Ms Kennedy: Secondly, we are relieved and appreciate the efforts you have made with regard to the Quality of Care Information Protection Act for facilities, and we would ask that you consider extending that protection to the quality assurance activities of colleges. Quality assurance could in fact be considered a misnomer. It's more so an assessment and enhancement process to ensure that, through voluntary disclosure in a co-operative and non-penalizing format, members or registrants can actually identify their own shortcomings, both on an individual basis and on a profession-wide basis so that those shortcomings can actually be addressed to ensure that there is continuous quality improvement in the health care sector. But to do that effectively, it does have to be voluntary and there does have to be buy-in, which means that information has to be protected so members do not feel they are in jeopardy should they disclose information to the colleges in that regard.

Mr Fefergrad: Staying with the theme of paramountcy, I know some of you with previous presentations, and indeed yesterday, had asked for some examples as to how the lack of paramountcy—in fact, quite the reverse; the legislation, HIPA, says that HIPA is paramount over the RHPA—would affect the work that we do that you've given us under the Regulated Health Professions Act. We'll try to discuss with you, if we could, a few examples. The HIPA legislation has a notion that the test for record keeping is reasonable. In fact, there is a notion as well in the legislation that in the event that the records are not in good shape, there is an opportunity for our members to correct the notations in the records. Taking it to an extreme, deficient or no records can be corrected through the HIPA legislation, on the one hand.

On the other hand, the Regulated Health Professions Act requires each member to not only have accurate records but to maintain them in a way that is consistent with colleges' guidelines, and every college has guidelines that impose on its members not just reasonable standards, because there's a lot at stake when the health of the public of Ontario is involved, but accurate standards. We're not interested in excuses when it's quite possible and easy for members to keep records which are accurate. It has implications in terms of, for example, the delivery of health care. A record that is inaccurate or does not contain medication lists, contraindicated medications, allergies, a record that is deficient, may in fact create serious harm to a patient when a subsequent treating practitioner takes a look at that record and tries to diagnose and recommend treatment.

Further, from the regulatory perspective of complaints and discipline, it becomes difficult for us to address the regulatory scheme you've given us under the Regulated Health Professions Act when the RHPA says the standard is "accurate" and HIPA says "reasonable." So in the event we determine, through our council and committees—which, as you know, consist of not only members but public appointees—if it's determined that the records are inaccurate and that is an act of professional

misconduct, it might in fact lead to discipline. But you've provided the member with an absolute defence in HIPA, and that defence is that the test under HIPA is reasonable. Therefore, because HIPA is paramount, the RHPA falls to the wayside. And there are other examples.

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Ms Langlois: One of the examples that some colleges certainly have to deal with is situations where practitioners and patients are actually colluding to defraud an insurance company. In those situations it becomes extremely difficult for the college to access accurate records and extremely important for the college to access accurate records. Obviously it would be terrible to think that this piece of legislation could somehow be used to allow a patient and practitioner to carry on that collusion and to block the college from ever being able to discover it or deal appropriately with it through their processes.

Mr Fefergrad: So we're suggesting that what HIPA does is offer in the regulatory process an unintended consequence, and that is, a defence to professional misconduct allegations. Will it succeed in the end? We're not sure, but the cost of that challenge is formidable.

You've given authority to smaller colleges and larger colleges, and regardless of the size, our budgets are very tight, and to spend thousands and thousands of dollars to withstand the affections of some defence that was unintended has several consequences.

One, it impacts very severely on budgets. Two, it allows the practitioner to continue doing the acts that the college, through the Regulated Health Professions Act, has complaints about, while it trots its way through the divisional court and the court of appeal. While at the end of the day it may not be successful or it may be successful, why not have that legislative safety net that each and every college has suggested is really necessary for the integrity of the Regulated Health Professions Act to continue?

For the time left, we're open to any questions.

Interjection.

Mr Fefergrad: I'm sorry—I'm reminded by my colleague that in the exuberance of being here, I left out one important example. I apologize.

Ms Kennedy: He's an expert at this. I know he looks familiar from yesterday.

The other area where we have concerns that there might be erosion of our authority would be in the area of mandatory reports. Right now the RHPA is very cleverly written in that it gives some latitude to colleges with regard to how they can access information. Dealing with that information is still governed by our regulations and requires that there is due process.

Our concerns with regard to HIPA is that it does speak very directly to disclosure but is silent on the concept of use, and in that regard would potentially hamstring colleges from dealing with concerns with regard to boundary issues, professional misconduct, capacity or incompetence.

For example, one potential is that a reporting facility, an employer, or another colleague would make a report—

perhaps it might have to do with drug abuse—and because it would essentially contain some personal health information with regard to the practitioner, we would be limited in that regard. As well, the practitioner could argue that the use was to advise the college first and foremost and that's it, and then we would not be able to use that information to initiate an appropriate investigation and carry out our duties as protectors of the public.

The Vice-Chair: We only have time for one quick question.

Mrs Witmer: Thank you very much. I really appreciate the work done by all of the colleges and the way you do protect the public. My question would be similar to what I asked the medical college. Do you have amendments or are you in a position to draft amendments that would guarantee that RHPA would be paramount to HIPA and would continue to provide that protection to the public that I think we all agree is needed?

Mr Fefergrad: If you look at section 9, Mrs Witmer, it provides exceptions. Subsection 9(2) says, "Nothing in this act"—meaning HIPA—"shall be construed to interfere with"—and there's a list of things. It looks like there's room just after (e) to insert "the Regulated Health Professions Act." If you inserted that, I think that wouldn't need great drafting and would just give that safety net that I think we all want.

Mrs Witmer: Which is pretty simple.

Mr Fefergrad: I think so.

Mrs Witmer: Thank you.

Ms Martel: Except that, if I go to page 5, your request to us was complementary amendments to the RHPA. So which one do you want—whichever's easier?

Ms Kennedy: One of the reasons why I think we broached that is that, again, we compliment you on your efforts and realize that there is a purpose to the introduction of this legislation. That was sort of a compromise position. If you could not open up this legislation to make the amendment, we felt that that would be another way to address the concern.

Ms Martel: So the preference is the addition of a clause (f) to subsection 9(2).

Ms Kennedy: That would be by far the simplest and most effective way to deal with it.

Ms Martel: OK. Then let me deal with schedule B and see if you have a similar thought with respect to inclusion of your quality assurance programs.

Ms Kennedy: I believe it would actually be fairly simple in the same regard, but we can certainly provide you with formal wording later on in the day.

Ms Martel: That would be great. I'm not meaning to put you on the spot. That would be helpful. The easiest way to do it is the one we would, I would assume, move forward with.

Mr Fonseca: Of the colleges that were included under the quality assurance provisions in schedule B, would this be a new tool for the colleges, wouldn't you say, right now? How would you foresee the committees that would be set up? What would your role be in setting up those quality assurance committees?

Ms Kennedy: In point of fact, our legislation already mandates that we do have quality assurance committees that have a very specific task and mandate. It simply extends the provisions that are accorded to the facilities' quality assurance committees to our quality assurance committees. But that framework already exists and is required. So that certainly would not be a major issue.

I should say—I neglected to mention this earlier—that, for the record, the support for our position as the Federation of Health Regulatory Colleges is in fact unanimous in this case. All of the colleges respect the efforts with regard to protecting the privacy.

Mr Fefergrad: She says “for the record” because that’s really unusual. We don’t agree on very many things.

Mr Fonseca: Thank you.

The Vice-Chair: Thank you very much for your presentation.

We’re going to go for a recess. If anyone wants to leave their belongings here, they can. The door will be locked.

If I could ask the members of the subcommittee to leave for a short discussion, or their substitutions.

The committee recessed from 1158 to 1302.

CANCER CARE ONTARIO

The Acting Chair (Mr Berardinetti): Our first presentation is at 1 o’clock: Cancer Care Ontario. Welcome. You have 20 minutes.

Dr Terrence Sullivan: My name is Terry Sullivan. I am the provincial vice president of cancer control and research for Cancer Care Ontario. Joining me here, to my immediate left is Dr Alan Hudson, who is the chief executive officer at Cancer Care Ontario; to his left, Mr Peter Crossgrove, who’s the chair of our board of trustees; and to my right, Pamela Spencer, who is the general counsel and chief privacy officer. I’d also like to recognize Mr Sid Stacey, who’s sitting in the audience, who is the executive director of the Cancer Ethics Review Board for Ontario, which has recently been established overall.

I should start out by saying that we welcome the opportunity to tell you a little bit about Cancer Care Ontario and our interest in this bill. We are very supportive of the initiative of the government of Ontario and the Legislature to introduce an effective health privacy bill for the protection of personal health information.

However, we are not reassured that the bill provides for clear rules on the disclosure of data for Cancer Care Ontario, how we might use it, and how we might use it in working with others. If there is insufficient clarity in the bill, as detailed in our brief, we are concerned that, taken together, a number of core activities that we are now engaged in will be compromised. In particular, because we are host to the Ontario Cancer Registry, a person-specific database about everyone who has been reported to have cancer in Ontario, if our capacity to collect and disclose information is compromised, we are quite

concerned that we will not be able to do a number of important things that we currently do. In particular, if we were interested in trying to identify patterns of cancer associated with certain occupational exposures or certain areas where people live where they may be exposed to toxic exposures, this will be compromised. Likewise, if we are not able to identify outcomes related to patterns of service and care for people with different kinds of cancer, this will be an important problem if we cannot collect and disclose information in a clear and transparent way.

Let me tell you a little bit about who Cancer Care Ontario is and what the burden of cancer is in Ontario. First of all, with respect to the burden, in this year in Ontario, just under 60,000 people will be diagnosed with new cancers and just under half of that number will die during the same period of time. Barring dramatic changes in prevention and screening activity, the number of newly diagnosed cancers will rise dramatically by about two thirds over the course of the next 15 years. We know that half of these cancers can be prevented.

Let me tell you a little bit about Cancer Care Ontario. Cancer Care Ontario is an agency of the government of Ontario and it’s provided for in relation to the Cancer Act and under the Corporations Act. We act as the provincial government’s chief adviser on cancer issues and we’re responsible for planning in the cancer system and for the financing and coordination of a good portion of that system. In this role, we’re responsible for setting direction, providing leadership and funding surveillance, prevention, screening, research, treatment and supportive care. We use data from the registry now to project the changing pattern of cancer, and this helps us advise the government on where new cancer centres should be built as a function of the changing pattern and profile of cancer.

As I mentioned, we’re also responsible for the operation and use of the Ontario Cancer Registry. This registry is a computerized database of information on all Ontario residents who’ve been diagnosed with cancer or who’ve died of cancer. Since the early 1960s, over one million cases of cancer have been registered in the Ontario Cancer Registry. That information comes from multiple sources, including hospitals, pathology laboratories, the registrar general and our own cancer centres.

What are we doing about privacy at Cancer Care Ontario? We take it very seriously. More than a year ago, in advance of any provincial legislation, our board approved a privacy policy based on the 10 principles set forth in the federal legislation. We have in place, as I mentioned, a chief privacy officer who’s also our general counsel and an expert in privacy and health law matters. We have a working group carrying forward privacy matters throughout the organization. In addition, we have done a series of detailed privacy impact assessments with respect to our own operations in advance of any provincial initiative with respect to privacy.

Unlike the previous Bill 159, the current bill makes no specific provisions with respect to the disclosure of personal health information to Cancer Care Ontario. We

recognize that there may be a couple of areas in the bill which would allow for disclosures related to Cancer Care Ontario; however, we do believe that we need to have a clear and explicit recognition in the statute.

Our authority to collect information will not be made easier by this bill unless this authority is set out clearly and straightforwardly in this act. Under the Cancer Act, Cancer Care Ontario is permitted to compile information on cancer patients, and hospital and medical practitioners are saved from harm if they provide information to Cancer Care Ontario.

Let me give you one example about how this act may make more difficult the situation as it currently exists. The government of Ontario currently is supporting Cancer Care Ontario to convert the approximately 100,000 paper registrations of cancer that come from pathology laboratories around Ontario to an electronic database. We are currently having trouble because numbers of hospitals have employed privacy consultants to discern what our explicit authority is to collect and use this information for the purposes of cancer registration and surveillance. We would like to ensure that this act makes that quite explicit and clear. So with that in mind, we have a series of recommendations with respect to amending the legislation as it goes forward.

We recommend first of all that section 1 of the bill be amended to provide that one of the uses and purposes of the act is to enable personal health information to be shared and assessed where appropriate to manage the health care system, as part of our role is in the planning and management of cancer services. We note that there is no particular mention of planning in the preamble to the bill.

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Second, we request that the disclosure rules set out in part IV of the bill be amended so as to provide that CCO may request a health information custodian to disclose to it personal health information for the purposes of compiling statistics and carrying out research—these are enumerated explicitly in the Cancer Act now—for planning and resource allocation, cancer system management and surveillance. In addition, we also want to ensure that a parallel provision exists for the use of this information under the bill.

Third, we would suggest that Bill 31 state the grounds upon which a health information custodian may refuse to disclose personal health information requested by CCO for purposes identified in recommendation 2 above and set out rules for governing this process by an independent review of such a refusal in a fashion comparable to that which has been established in section 47 of the Alberta Health Information Act.

Our fourth recommendation really relates to the use of the information, paralleling our second recommendation.

Our last important recommendation is that, in the absence of such amendments to the legislation, we would suggest that the Cancer Act be amended consequentially to make explicit the basis on which CCO may collect, use and disclose personal health information, and that

accordingly Bill 31 provide that CCO may collect, use and disclose information for the purposes set out in the Cancer Act.

We have a couple of other recommendations that are consequential for greater clarity, but perhaps I'll stop there at the key recommendations.

The Vice-Chair: Thank you very much. We'll start with Ms Martel—three minutes.

Ms Martel: I appreciate all of you coming here today, and also that you've been good enough to be as specific as you can with respect to the release of information.

Can you go through with me, if you don't mind, on your page 5—you were giving examples of ambiguity with respect to the intent of section 7. Can you give us some more concrete examples?

Ms Pamela Spencer: Perhaps it would help just to indicate what is set out in the Cancer Act, and I apologize for not including a copy of the Cancer Act with the materials.

The difficulty with the section that deals with confidential information is that all it says is that any information that's provided to us will be kept confidential and will only be used for certain purposes—compiling statistics or epidemiological or medical research. It doesn't actually say that anyone may disclose information to us.

Related to that, there is a limited indemnity that's provided in subsection 7(2) that just indicates that certain health providers and hospitals who disclose information to us are protected. What's missing here is a statement that hospitals and other entities may disclose information to us for certain purposes. It's implicit; it's not explicit.

The other difficulty is that the Cancer Act, unlike other provincial cancer statutes, does not make cancer a reportable disease. So when you look at the other acts in, for example, Alberta or Manitoba, what it provides is that hospitals and labs must disclose information related to cancer. What we're looking for is that kind of certainty.

The other difficulty with the section is that it refers to "a case of cancer." That's an issue in terms of at what point in time you've actually got a case of cancer. We've had this argument with many lawyers across the province as to at what point you have a discernible case of cancer. That's very important to us because we're interested in collecting information related to prevention and screening etc before the case may actually be crystallized.

Ms Martel: The second question had to do with your recommendation 3, where you referenced section 47 of the Alberta act. What's the review process there? Is it their privacy commissioner?

Ms Spencer: Exactly. Essentially what the act says is that—and it ties back to the Alberta Cancer Programs Act in that, as I mentioned, it's a reportable disease. There are certain very specific restrictions upon which a health information custodian may refuse to provide the information to the Alberta Cancer Board, and that's where the safety of the individual may be compromised. What they provide is that there is a process by which the hospital or the refusing party may apply to the commissioner to basically resolve the dispute. So it sets out a process.

Mr Fonseca: Thank you very much, Cancer Care Ontario, for your presentation. Looking at section 36, would that not allow for the disclosure that you're looking for, and can you provide an example of a scenario of where and how and perhaps why a custodian would refuse you information?

Dr Sullivan: To start with the latter question first, we have a situation now where the Ministry of Health is actually funding a project to convert paper pathology reports to electronic pathology reports. This is obviously a sensible thing to do, because it can be done quickly, routinely and, frankly, with higher levels of security than the transport of paper copies of pathology. So if somebody is diagnosed with cancer, the pathologist sections the tissue, writes a report saying, "Yes, this is cancer of this type, this degree of invasiveness," and that information comes to us.

Right now we are in the process of converting, and we have converted more than one third of all the labs in Ontario, close to half of them now, for electronic pathology reporting. But a number of hospitals have called into question what our authority is to collect this information because, as our counsel has suggested, the language in the Cancer Act is permissive, it's not authoritative, with respect to our ability to collect and use this information.

Ms Spencer: With respect to the first part of the question, section 36 just deals with use by a health information custodian. First of all, we are not named in the act as a health information custodian, although we are recommending that we should be named so that our partners in the health care community know that we are also going to be compliant with the information practice rules that are in the act. Even assuming that we were named as a health information custodian, the information still needs to be able to get to us in the first place, so we have to look to the disclosure rules, and there are only two avenues under the disclosure rules whereby we could get this information. One is to be prescribed as a registry, and the other would be to rely on the Cancer Act under section 42(1)(h). As Dr Sullivan has indicated, the difficulty is that when you tie the Cancer Act to the disclosure to us, the Cancer Act is not sufficiently clear.

Dr Sullivan: The consequence of that will be that our current situation will be made murkier. If I may, I can't stress enough that the business of collecting and compiling and disclosing information related to cancer patients is our core business. We will not be able to proceed unless we're able to remedy this situation and have a clear reference in the bill.

Mrs Witmer: Thank you very much for your presentation. Have you had an opportunity prior to appearing here to have any conversation or dialogue with the ministry regarding, I guess first and foremost, that you would be named a health information custodian, or regarding any of the other recommendations?

Dr Sullivan: We had one preliminary interaction in the run-up to this exchange, and the ministry has presented a very open posture with respect to our submission.

In fact, they are party to this submission; they've seen the material as well as you've seen it. We have no clear picture about what their posture is. We're concerned that they may believe that simply identifying us as a registry and scheduling us in this fashion will solve our problem. It will not, because now hospitals and the small industry of privacy consultants that currently exists will be looking to this act to give clarity, and there won't be any.

Mrs Witmer: That's right. It's absolutely essential, then, for you to continue with what you're doing, that these changes be made as you have recommended.

Dr Sullivan: Yes.

Mrs Witmer: They certainly appear to make sense, and we would certainly be supportive. The ministry and the minister have indicated that they are very open to recommendations of this sort. Thank you very much.

The Vice-Chair: Thank you for your presentation.

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CARDIAC CARE NETWORK OF ONTARIO

The Vice-Chair: Next we have the Cardiac Care Network of Ontario.

Dr Eric Cohen: Thank you very much, Mr Chair. I'd like to thank the committee for the opportunity to present today on behalf of the Cardiac Care Network of Ontario. My name is Eric Cohen. I'm a practising cardiologist at Sunnybrook and Women's, but I'm here today in my capacity as an executive member and chair of the clinical services committee of the Cardiac Care Network. I'm accompanied by Joyce Seto, who is a director of information and information technology at the CCN. We may be joined by our legal counsel and adviser in these matters, who doesn't appear to be here yet.

The network would like to acknowledge the recognition by the Ministry of Health and Long-Term Care of the need for privacy legislation specific to personal health information and its expeditious efforts in the drafting of Bill 31. CCN considers privacy to be of the utmost importance and has ensured and will continue to ensure that it has measures in place to safeguard the privacy, confidentiality and integrity of the personal health information in its possession or control.

CCN's commitment to protecting personal health information led it in May 2003 to retain Mr David Flaherty, a recognized expert in this field, to conduct a privacy impact assessment on CCN's information policies and practices. CCN is working toward 100% compliance with the recommendations that came out of that assessment.

The provisioning of patient consent is also being addressed with a pilot currently underway to inform patients on CCN's information practices.

In addition, CCN's executive committee has approved the privacy policies and procedures aligned with the 10 guiding principles as per schedule 1 of the federal act.

The Cardiac Care Network's primary focus is to facilitate timely and equitable access to advanced cardiac services. Specifically, that involves at this time catheterization, coronary angioplasty and bypass surgery. The

network has been in operation since 1990 and consists of 17 member hospitals that perform these adult cardiac services in Ontario. Patients referred for one of these procedures generate a referral, and the referrals are received and collated by hospital-based regional cardiac care coordinators. Information about these referred patients is entered into the CCN registry. This is for the following purposes:

(1) For the tracking of the number of patients waiting for each type of procedure and where they are waiting. That part of the information can be done on an aggregate basis.

(2) For classifying patients according to an objective urgency score. CCN has been involved in refining and validating urgency rating scores to gauge the severity of need for patients needing bypass surgery or cardiac catheterization. This is a crucial step in triage, matching the timeliness of care to the needs of the individual patient, and this relies on patient-specific information.

(3) For tracking what happens at a clinical level to the patients while waiting. This clinical-level contact with individual patients is done by the regional cardiac care coordinators and by the referring and treating physicians at the member hospitals, but the tool for this practice is the patient-specific information in the CCN registry.

(4) In certain situations, efficient system management and optimal individual patient care involves knowledge of workload and wait lists at other hospitals. In other words, if hospital A has a long wait list for a given procedure and hospital B has a short wait list, it may be in the patient's interest to be referred to hospital B instead. This piece as well requires a central registry with patient-specific health information.

In addition to maintaining and compiling the wait list registry, CCN provides information and advice to member hospitals and to the Ministry of Health and Long-Term Care on matters relating to the quality and efficiency of cardiac services provided in Ontario. We use the registry to provide advice on matters relating to equitable access. CCN prepares monthly and annual reports for the ministry and for its member hospitals which contain statistics, including the number of patients on the waiting list, the cases completed, mortality and other adverse events on the waiting list, cancellations and reasons for cancellation, target rates by region and geography, and so on. This information is used by the recipients—the hospitals, the ministry and district health councils—to identify and monitor trends and to help make informed decisions about the provision of and future investment in cardiac care in Ontario.

In summary, CCN assists in facilitating health care for patients suffering from cardiovascular disease by managing a network that generates data about patient need and the status of cardiac care, by facilitating equitable and timely access to cardiac services and by enabling health practitioners to focus on the delivery of quality cardiovascular care. CCN helps to establish guidelines for best data practices to ensure that the quality of data that it puts forth is highly credible and reliable.

Although these appear to be self-evident and compelling reasons for CCN to continue to maintain this registry, it is unclear to us whether under the current wording of the privacy bill we would be able to do so. To walk us through some of the specific areas of concern, I'm going to turn it over to Joyce Seto.

Ms Joyce Seto: I would actually like to walk you through our attempts to interpret the bill as it related and applied to the Cardiac Care Network's information requirements. Basically, our information requirements are in a three-tiered system.

The top tier is how we've defined our collection. Our current collection practice is that we obtain information from our 17 member hospital sites. We receive that information on a daily basis, and that information is aggregated into our Cardiac Care Network system. With that, we also have collection for one-time requests made for third party research studies or requests made out of the Ministry of Health. We take information from ICES on a one-time basis, from other health organizations—they could be within province or out-of-province—and also we'd like to position ourselves in the future to obtain information from other hospital sites and health organizations.

That information is disseminated into the Cardiac Care Network system. We use personal health information to collect that information because it's required at that level, and then we also aggregate that data.

On the disclosure piece, the third layer of the diagram, we disclose non-patient-identified information to the Ministry of Health. We disclose personal health information to ICES. Information based on patient consent and non-identified information is aggregated back to our third party research. We provide information that is patient-identified and non-patient-identified to our CCN hospital sites. Our other health facilities are our referring facilities. We provide them with information on a request basis also, and that is patient-identified information.

As we interpreted the bill, the application that we foresee is that the foregoing description of CCN's activities suggests that it fits into the bill under more than one category. In relation to many of its activities, including providing advice about cardiac care to the Ministry of Health and Long-Term Care, member and other public hospitals, and other health organizations, CCN views itself as the "agent" of the hospitals as that term is defined in Bill 31. As such, the transfer of personal health information between the Cardiac Care Network and its member hospitals is characterized as a use of information under subsection 6(1) of Bill 31. On this analysis, CCN is authorized under Bill 31 to engage in most, but not all, of the information practices that are necessary to carrying out its objects. For this reason, CCN is requesting to be prescribed by the regulations under two sections of Bill 31 and is requesting clarification of its authority under Bill 31 or, if necessary, to allow it to achieve its objects as an amendment of Bill 31.

CCN meets a description in clause 38(1)(c) of a "person who compiles or maintains a registry of personal

health information that relates to a specific disease or condition.” Accordingly, CCN is requesting that it be prescribed by the regulations that will be made under the act as such a person.

Secondly, CCN meets a description in clause 33(3)(d) of a person who is “collecting or using the health number, as the case may be, for purposes related to health administration or planning or health research or epidemiological studies.” Accordingly, CCN is requesting that it be prescribed by the regulations that will be made under the act as such a person.

CCN also asks for requests for clarification. In order for CCN to continue with its everyday operations and to ensure that it is in a position to assist in the provision of cardiac care as it evolves over time, CCN must be able to indirectly obtain personal health information of cardiac patients. CCN uses the information it obtains, as described, to link to other data sources, produce statistics and provide advice that assists public hospitals in providing cardiac care and the Ministry of Health and Long-Term Care to administer the health care system and plan for its future on the basis of reliable data.

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Accordingly, CCN is requesting clarification as to whether, under Bill 31, it may continue to disclose personal health information, including health numbers, to ICES and like organizations for purposes related to health administration, planning and research. If there is no such authority, CCN respectfully requests the amendment of Bill 31 to permit such disclosure. Although it understands that the mechanics of any amendments are best left to the Ministry of Health, on CCN’s reading of Bill 31, amendments to subsections 38(1) and 33(4) might permit it to disclose personal health information.

CCN is requesting that a mechanism be built into Bill 31 to ensure that CCN can continue to receive the personal health information it requires to provide reliable data and meet the needs of patients suffering from cardiovascular disease in Ontario.

In closing, CCN does congratulate the Ministry of Health for its expeditious introduction of Bill 31, with the anticipation that CCN’s core operations will continue to function under a seamless network of patient care and system planning. We will be committed to continue to monitor our information practices to ensure their adherence to the requirements in Bill 31 and the recommendations made from our internally sponsored privacy impact assessment.

We’d like to thank the standing committee for your time and consideration on the matters raised in this submission. We look forward to working further with you and the ministry to serve the best interests of the people of Ontario.

Mr Fonseca: I’d like to thank CCN for your presentation. That was terrific. We’d like to ask what criteria, in your opinion, would be useful for the ministry to consider in deciding what registry should be designated under clause 38(1)(c) of Bill 31.

Dr Cohen: I guess we would look toward registries that are disease-specific, registries that have a clear role

in the facilitation of care, facilitation of access, I suppose registries with a clearly defined mandate and scope, and we would certainly hope registries with an established track record, at the very least, as a starting point, because in many ways, similar to the points made in the previous presentation from Cancer Care Ontario, if some of these questions that we have are not clarified or resolved, our ability to continue to fulfill our core mandate, which is the running of this registry to facilitate access to these services, would be compromised. I guess one criteria could be those registries which are essential to facilitate this type of access.

Mr Fonseca: Can I also ask about the lockbox effect, how that will affect CCN?

Ms Seto: That will tremendously affect CCN. With regard to the lockbox, we rely upon our data. We currently have a full data set. We have 100% participation of our facilities. We believe that it will gravely affect the recommendations of advice that we provide to the system for further planning if the numbers are definitely compromised with that.

Mrs Witmer: Thank you very much for your submission. Certainly, as a former Minister of Health, I greatly value the planning and direction that you have given to the Ministry of Health over the years. I can appreciate your concern if there isn’t clarification on some of these issues. Have you had an opportunity to discuss this with the ministry at all?

Ms Seto: No, we have not.

Mrs Witmer: So actually, this is the first time, then, that the ministry would be hearing your concerns. Hearing them, we’d have to think they certainly would be open to making sure the appropriate clarification is provided in order that you can do the work. Thank you very much.

Ms Martel: Thank you for coming here today. Can I ask a question about your point number 3, where you’re requesting clarification and, if an amendment is required, to permit to disclose? Were the sections you were referencing for amendment subsections 33(4) and 38(1)?

Ms Bonnie Freedman: Yes.

Ms Martel: So you’d need changes in both respects: You’d need an amendment to the legislation and then also to be included in the regulations under that same section to deal with points 1 and 2. Am I correct?

The Vice-Chair: Before you answer that, can I please ask you to identify yourself for Hansard?

Ms Freedman: Yes, I’m sorry. I’m Bonnie Freedman, and I’m counsel to CCN. The firm is actually Goodman and Carr.

I think a number of amendments would be required. Section 33, of course, is to deal with the health number, and then section 38 is to deal with the disclosure. Some of what will be required will depend on, for example, the characterization of an institute like ICES. Because all of this is a bit unknown at the moment, it’s a little difficult to talk about specifics. I think, at the end of these hearings and perhaps at the next round, we will know better specifically what would be required, because we’ll

have a better idea of where everyone is sitting; that is to say, the institutions and other organizations with which CCN works. It's clear that the member hospitals are custodians; the question is the characterization of some of the other organizations with which information is shared.

Ms Martel: Whom you relate to and work with.

Ms Freedman: That's right.

Ms Martel: Thank you.

The Vice-Chair: Thank you very much for your presentation.

ASSOCIATION OF HEALTHCARE PHILANTHROPY

The Vice-Chair: The next presenters are the Association of Healthcare Philanthropy. You may begin.

Ms Pearl Veenema: Good afternoon. My name is Pearl Veenema, and I'm the chair, government relations, for the Association for Healthcare Philanthropy in Canada. I'd like to begin by expressing my appreciation to the committee in allowing me to make this submission today on behalf of our association, which includes 390 health care charities nationwide, 200 of which are in Ontario. I'd also like to introduce my colleague Susan Mullin, who is the president of the greater Toronto chapter and chair, national privacy task force, for the Association of Fundraising Professionals. Susan and I and other colleagues in the fundraising field have been working together for over two years on a coordinated approach to privacy preparedness and response as appropriate to draft legislation. In the materials that we have provided, AFP has included comment on Bill 31.

The Association for Healthcare Philanthropy, or AHP Canada, is an international organization of health care fundraising executives and health care institutions dedicated to advancing health care through philanthropy. AHP Canada's mission is to be the primary source of philanthropic expertise in Canadian health care, building on partnerships with AHP International.

Last year, Ontario members of AHP Canada and other colleagues raised over \$500 million on behalf of the province's 225 public hospitals. This money was spent on new health care facilities, medical equipment and technologies that reduce waiting times and improve efficiencies in the health care system; health research, which provides tomorrow's life-saving drugs and therapies and is therefore crucial to our future health care system; and finally, new programs in patient safety and infection prevention and control required to support health care workers after the devastating effects of SARS.

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AHP Canada has a long history of privacy protection, having recognized several years ago that privacy is an issue of key importance to many of our donors. This commitment to privacy manifests itself in a number of industry best practice safeguards, which we have adopted voluntarily in the absence of provincial health privacy

legislation. We have included information on these privacy safeguards, such as copies of the donor bill of rights and information in our privacy guide, in the folders in front of you.

The privacy guide is based on the model code for the protection of personal information developed by the Canadian Standards Association and was designed to help our Ontario members respond to privacy requirements under the federal Personal Information Protection and Electronic Documents Act in the absence of provincial health privacy legislation.

We are delighted to see that the government has introduced the Health Information Protection Act. AHP Canada feels that the privacy of health information is a highly sensitive issue, the complexities of which cannot be adequately addressed as part of a general privacy law primarily for the treatment of the commercial sector. We are therefore delighted to see that the government has introduced privacy legislation devoted exclusively to health information.

AHP Canada appreciates what a challenge it is to draft privacy legislation that strikes the right balance between the privacy needs of Ontario patients and the legitimate needs of our health care providers to access personal information for the purpose of delivering patient care. We commend the government for striking the right balance with respect to the delivery of health care and health research.

However, we are extremely concerned about an express consent requirement in Bill 31 for health care fundraising purposes. We feel this requirement is inappropriate for five reasons and, therefore, we are requesting that the government consider an implied consent requirement for health care fundraising, to be achieved through notice and opt-out.

Our first concern: We believe that an express consent requirement is potentially detrimental to patient care. This is because if an express consent requirement were mandated by law, most Ontario hospitals would have to undergo significant process redesign to allow for their clinicians and hospital staff to speak with patients about fundraising. Doctors, nurses and other health care workers have already told us that they are unwilling to take time away from their patient consultations to ask them their express permission to participate in hospital fundraising activities. Instead, health care workers are insisting that they need to maximize the time they spend with patients to provide care. In Alberta, where express consent was required for health care fundraising under the province's Health Information Act, the province's physicians actually refused to talk to patients about fundraising, citing that it would result in a minimum of 780 lost patient consultations on an annual basis.

Secondly, AHP Canada cannot support an express consent requirement for fundraising because this requirement is inconsistent with the privacy expectations of most patients. For example, the average Ontario hospital foundation receives between one and two complaints for every 10,000 to 20,000 mailings on fundraising. More

importantly, however, patients have told us that they do not want to be asked for their consent for health care fundraising, even on a simple registration form.

For example, a pilot study on express consent conducted at Mount Sinai Hospital in Toronto in 2001 generated 75 patient complaints on express consent within the first 90 days of the study. Two common patient quotations from that study are as follows:

“It’s not fair for me to have to think about fundraising while I’m trying to focus on the physician’s instructions for my elderly mother”; and

“I spend five to seven mornings a month here for fertility treatment. The last thing I want to think about is how I’m supposed to give my permission to be solicited, although I will gladly donate to the hospital.”

Thus, an express consent requirement for health care fundraising takes away critical time from patient care, as well as perhaps contributing to unnecessary potential stress in patients.

Third, AHP Canada cannot support an express consent for fundraising because the public health care system requires such enormous reforms over the next decade, reforms which, quite simply, federal and provincial governments are unlikely to finance on their own. The Romanow report estimates that these reforms will cost nearly \$15 billion between now and 2006.

The types of reforms required are programs to increase efficiency and productivity in the system, new programs to reduce waiting times, new strategies for addressing shortages in health care workers, increased partnerships and collaborations between providers and private sector, and the development of national home care standards. Given this long and challenging list of required reforms, our health care system cannot afford to lose one single philanthropic dollar to perhaps a poorly designed consent mechanism which neither the majority of patients nor clinicians in Ontario support.

Fourth, AHP Canada cannot support an express consent for fundraising since health care charities now play an increasingly critical new role in supporting research in communicable diseases and the construction of isolation facilities following the SARS epidemic.

Finally, AHP Canada cannot support an express consent requirement for fundraising since this poses a more restrictive consent requirement on health care foundations than their charitable counterparts in other sectors, such as education or the arts. This does not seem fair when foundations in these sectors are receiving the same type of personal information that hospital foundations receive; for example, names, mailing and e-mail addresses, and telephone numbers, which is all that AHP Canada asks that Ontario health care charities be able to receive with the same implied consent.

Thus, for the five reasons I have described, AHP Canada believes that Ontario hospitals and their foundations should be able to collect, use and disclose personal information for fundraising purposes using implied consent through notice. In our written submission next week, we will outline two options for implementing this.

To summarize, AHP Canada cannot support an express consent requirement for health care fundraising.

Thank you for the time today, and once again thank you for the opportunity to present the concerns of AHP Canada. Susan and I would be pleased to answer any questions that you may have.

Mrs Witmer: Thank you very much for your presentation. Just for clarification—I maybe missed it—you represent who?

Ms Veenema: The Association for Healthcare Philanthropy. That is an association of fundraising professionals—it’s a professional association—across Canada.

Mrs Witmer: So would you represent most of the hospital foundations in the province?

Ms Veenema: That’s correct, across Canada, and my colleague Susan represents the Association of Fundraising Professionals. They represent more than hospitals and health care institutions.

Mrs Witmer: So you have the benefit of knowing what’s going on across the rest of Canada when it comes to the privacy legislation.

You mentioned Alberta and the fact that the doctors obviously had concerns about asking for the express consent, and we’ve certainly heard that. I would agree; I don’t think it’s the role of a doctor to do that. What happened then in Alberta? Did they make changes? Have they made changes?

Ms Veenema: The changes they have made are really in investing significant dollars to acquire new donors through what would normally come through the grateful patient basis. We are collecting statistics for our submission from all of the provinces just so that the government can see the impact analysis. In fact, most organizations, where there was express consent, are finding that they are spending 20% to 30% more on their acquisition programs and indeed are seeing great attrition over the years as a result of not being able to have access to grateful patients, who tend to support within a range. Based on the information that we have, 70% to 90% of the income coming in on an annual basis comes from grateful patients.

Mrs Witmer: We’ve heard different numbers as to how much money is raised in the province, but I guess it approximates something in the neighbourhood of half a billion dollars, perhaps. So there could be a substantial loss. I guess the only way that you could make that up is for the provincial government to invest foreign health care, and it’s unlikely that they’re going to be in a position to do that. So I certainly think and hope that the government—and they’ve said that they’re certainly willing—will consider the impact this is going to have on the ability to fundraise and make some of the appropriate changes without sacrificing the privacy of the information.

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Ms Susan Mullin: I’m going to add that the AFP represents a broader sector, so we have many health organizations that are not hospital foundations and social service organizations that would also be custodians of

personal health information. So when we talk about hospitals, we have a pretty clear picture of the number of dollars raised. Because these other sectors don't have the same sort of organization and are more broadly represented, we don't yet have numbers—we're trying to pull together some stats—but many of our small organizations are very grassroots-based and their only natural donor constituency is in fact the people who access services.

Mrs Witmer: Can you give an example?

Ms Mullin: Sure. The organization I work for is Surrey Place Centre Foundation. We serve people with developmental disabilities across the city of Toronto. It would be difficult for us—we're a tiny foundation—to be able to go out and do any significant acquisition donor mailing programs, telemarketing programs, whatever. Some 80% to 90% of our current donors are patients or clients who have been asked to make a gift. So it would have a tremendous impact on us.

Ms Martel: Thank you for coming today. I know you're going to put this in a written brief to us, but would you mind going through the preferred options you outlined to give us a practical sense of how you see this working if we could get some amendments?

Ms Veenema: I'd be pleased to do so. We have been working with our colleagues and with hospitals—in fact, for the past two years, with the previous draft legislation—to look at some very practical ways in which we could look at implied consent through notice, both through the hospitals and foundations. Again, signage in the hospitals would be one cost-effective way if the hospitals themselves would produce that signage to provide the opportunity for patients and families to be aware of foundations in health care institutions. Therefore, what we're also doing is relying on them to take the next step, which is to want to participate.

Foundations very specifically have been, and have been for more than a year, in particular the larger foundations, investing in donor surveys, both written communications through newsletters, through their tele-fundraising programs and through direct surveys, informing their donor constituency about the nature of their fundraising programs and asking them very specifically about how they would like to continue to support the philanthropic effort.

Also, foundations now are utilizing their Web sites where in fact the general public has a tremendous amount of electronic savvy and are wanting to go to the Web sites to be able to see the kinds of fundraising opportunities that are available at the respective institutions. Those are some of the ways in which we see that there can be significant notice providing the opportunity to opt out.

Also, there are a number of institutions that have actually begun to include in their printed materials receipts and letters that they would return, thanking people for their gifts, providing them with the opportunity to opt out for future. Those are some of the examples.

Mr Fonseca: I thank you very much, the Association for Healthcare Philanthropy. It was a good presentation. I

want to ask, are there a number of processes in place already throughout the province, in terms of opt-out processes? In regard to your fundraising, what percentage of your fundraising—this was asked earlier—of the OHA is done through direct mail, and why could you not use mailers to do a whole catchment area or the lottery type of fundraising that we see going on?

Ms Veenema: The stats vary considerably with respect to what percentage of fundraising programs are from the grateful patients. We certainly would be pleased to provide this information in our written submission. I'll give you a few examples.

The Ottawa Hospital Foundation: 90% of their 20,000 active donors are in fact grateful patients. One of the things they did was they tested the response rate with an address on envelopes and so on, something that's fairly personalized, compared to an unaddressed household drop, as you just recommended or asked questions around. As an example, in that particular foundation, 75% of the donors would renew with an addressed program that came from the hospital. A household drop saw a return response of 0.4% to 0.5%, and that is a large foundation.

I'll give you an example of an organization in the Niagara region where in fact the institution has implemented express consent as if it were law, and they have just now cancelled a telefundraising program that generally would provide \$250,000 and a 30% to 40% rate. So now they're doing an unaddressed household drop and the experience within the first two weeks is that there are fewer than 10 responses back.

So your question related to other options around unaddressed or household drops in comparison: Fundraising is about relationships. The relationships that patients and their families feel and the appreciation for their care provide a very natural opportunity to begin a relationship that is very different from those who simply may not receive care. Second, institutions or foundations are challenged from a cost accountability point of view to in fact have the lowest cost per dollar raised, so those other options are significantly more expensive.

Mr Fonseca: In both cases, was there a policy and a procedure to opt out?

Ms Veenema: In the instance I gave you with respect to the more recent one that I've been called about this week, no; the institution implemented an express consent. So that particular foundation did not receive the 90,000 names that they would have received ordinarily for their telefundraising program.

In the Ottawa program they have implemented the opportunity for grateful patients or for their donors to opt out from receiving further fundraising solicitations, and foundations are not finding that their donor community is in fact asking to opt out. In the London region, with over 80,000 donors, they had fewer than 10 who asked to opt out of future solicitations.

Mr Fonseca: Thank you.

The Vice-Chair: I'd like to go back to Mr Yakabuski, whom I missed and who had a question.

Mr Yakabuski: Thank you for your submission. We're hearing this more and more through these hearings. I can certainly relate a little bit from personal experience. I sit on a capital equipment campaign at a local hospital in my hometown. Also, my wife and I became donors at a particular hospital after our children were patients there many years ago. I certainly understand where you're coming from. The information you're looking for—there's no medical information.

Ms Veenema: That's correct.

Mr Yakabuski: You're simply looking for the ability to contact these former patients to solicit their support in maintaining the programs and the things you need to do to operate those hospitals outside of the funding from the Ministry of Health. Is that correct?

Ms Veenema: That is absolutely correct. We are asking for personal information that relates to name and address.

Mr Yakabuski: Other than knowing they were a patient at that hospital, there would be no other medical information you would need?

Ms Veenema: That's correct. That is consistent through the Association of Fundraising Professionals and the Association for Healthcare Philanthropy. It's the opportunity to invite patients to support our programs. We do not need to know their areas of service or the type of care they have received.

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Mr Yakabuski: If the bill were amended to allow for that, but also included an opting-out clause, would that certainly satisfy you? Could you work with that, and that would accomplish what you need to do?

Ms Veenema: We could work with that, and perhaps when you have an opportunity to look at some of the recommendations in the privacy guide that we have produced for our colleagues, again, it's clearly stated that that's what we're asking for.

Mr Yakabuski: But not having access to those names would severely, critically damage your ability to raise funds?

Ms Veenema: Absolutely, quite significantly.

The Vice-Chair: Thank you very much for your presentation.

SMART SYSTEMS FOR HEALTH AGENCY

The Vice-Chair: Next is the Smart Systems for Health Agency.

Mr Allan Greve: My name is Allan Greve. I'm the chair of the Smart Systems for Health Agency's board of directors. With me this afternoon are Michael Connolly, who is the CEO, and Brendan Seaton, the chief privacy and security officer for Smart Systems for Health Agency.

On behalf of Smart Systems, I would like to thank you for hearing our submission this afternoon on the important subject of the Health Information Protection Act.

The Smart Systems for Health Agency was established by the government of Ontario in the spring of 2002 to support the effective delivery, planning and management of health services in Ontario. We provide a secure, province-wide information infrastructure for the collection, transmission, storage and exchange of information about health matters, including personal information. The objectives of the Smart Systems for Health Agency are defined in the regulations and direct the agency to, first of all, safeguard the confidentiality and integrity of information about health matters and, second, protect the privacy of individuals whose personal information is collected, transmitted, stored or exchanged by and through the information infrastructure.

At Smart Systems we take all the necessary steps to ensure the security of that information. Smart Systems is mandated to provide information management and information technology services to a number of the major health information systems initiatives sponsored by the Ministry of Health and Long-Term Care and other health system stakeholders. These initiatives will result in the implementation of an information infrastructure that will be available to most health care providers in Ontario and includes the physicians, hospitals, public health units, community care access centres, laboratories and pharmacies. Smart Systems is also mandated to provide leadership in the development and deployment of an electronic health record for all Ontarians.

Smart Systems provides comprehensive information infrastructure services, including secure and reliable communication networks, data centre services, e-mail, on-line directories, Web-based information portal services and comprehensive security services. Smart Systems has established a privacy and security division that is focused solely on the protection of personal information within the infrastructure.

It should be noted that Smart Systems has been designated as an institution under the Freedom of Information and Protection of Privacy Act and is subject to oversight by the Information and Privacy Commissioner of Ontario.

I'm now going to ask Brendan Seaton to discuss our comments in regard to the legislation.

Mr Brendan Seaton: In our submission we would like to make three points.

The first is that Smart Systems strongly supports this bill and believes that it is essential to protecting the privacy rights of Ontarians. Furthermore, it ensures the confidentiality, integrity and availability of personal information when it is required for health care purposes.

Second, Smart Systems is uniquely positioned to work with the government and the Information and Privacy Commissioner of Ontario to promote the principles and privacy practices that are articulated in this bill.

Third, Smart Systems would like to offer comments and recommend two amendments to the bill. Our recommended amendments ensure that the services provided by Smart Systems will mesh seamlessly with the information and information systems that are in the custody

and control of health information custodians and their agents, and promote the efficient, secure and private exchange of personal health information.

With respect to the first, it is fair to say that in Ontario we have an uneven patchwork of privacy legislation applying to the health sector. For example, Smart Systems and the Ministry of Health and Long-Term Care are covered by the Freedom of Information and Protection of Privacy Act. Boards of health are covered by the Municipal Freedom of Information and Protection of Privacy Act. Physicians, private labs, pharmacies and other commercially oriented health providers are covered by the federal Personal Information Protection and Electronic Documents Act, or PIPEDA. Many parts of the health system, most notably public hospitals and non-commercial community agencies, are not covered by any privacy legislation at all. This uneven patchwork leads to serious problems of privacy protection in health care. Among these problems are gaps in privacy protection, a risk of conflict between the provincial and federal jurisdictions, and inconsistent application of privacy principles.

The Health Information Protection Act will provide a level playing field and a common set of rules for privacy protection in Ontario. Ontarians will benefit from consistent policies on consent, access to their personal information and the right to challenge compliance with privacy principles. Health care providers, or health information custodians in the language of the bill, will be able to exchange information with others in the circle of care, confident that the information will be appropriately protected. For information technology providers such as Smart Systems, a common set of rules will mean greater acceptance of best practices for privacy and security management and more economical information systems and services.

Smart Systems strongly supports this bill because it will bring order to the current state of confusion in privacy protection, it will increase the confidence of Ontarians that their privacy rights will be respected by all players in the health system, and it will provide technology providers with the framework needed to build strong, private and secure systems.

Our second point is that Smart Systems is uniquely positioned to work with the government and the Information and Privacy Commissioner for Ontario to promote the principles and privacy practices articulated in the bill. Many of the services offered by Smart Systems will assist information custodians and their agents to comply with the requirements of the act, particularly when it involves the secure and private exchange of personal health information.

Health care providers who access the Smart Systems infrastructure can have confidence that personal health information will be protected by state-of-the-art security systems. For example, our secure messaging infrastructure will enable custodians to send encrypted e-mail through the Internet, ensuring confidentiality while in transmission. The same technology allows for strong

authentication, meaning that the receiver of the message can know with certainty the identity of the sender. In addition, the technology can ensure that the message has not been corrupted or tampered with during transmission, assuring the integrity of the message.

In building the information infrastructure, Smart Systems has learned many lessons about how to build information systems and processes that comply with state-of-the-art privacy and security standards. As we implement the infrastructure throughout the Ontario health system, we will be in direct contact with many health information custodians. It has always been part of Smart Systems' plan to promote the privacy and security of information with our customers through service level agreements, policies and training programs. You can be assured that Smart Systems will be an active and aggressive promoter of the principles outlined in this bill and will work collaboratively with the Ministry of Health and Long-Term Care and the office of the Information and Privacy Commissioner to put those principles into effect.

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In our third point, we want to ensure that the information technology and information management services provided by Smart Systems are captured by the bill in a way that clarifies the role of Smart Systems with respect to health information custodians. We would like to recommend two amendments. The first is to introduce the role of information manager into the bill, and the second is to expand the use of the health number from its current restriction to persons eligible for OHIP to all recipients of health care in Ontario.

Bill 31 introduces three key roles: the health information custodian, the agent and the recipient. In considering its present mandate and service offerings, Smart Systems believes that it is neither a health information custodian nor a recipient as defined in the bill. Indeed, an attempt to characterize it as either would be inappropriate because Smart Systems does not collect, use, disclose or retain Ontarians' personal health information. We do not believe that Ontarians would want an agency such as Smart Systems to have any custody or control of their personal health information or to use that information in any way.

Turning to the definition of "agent" in the bill, the health information custodian retains full accountability and liability for the agent's actions. Because the information infrastructure is provided through an agency of the government of Ontario, custodians will not have the requisite control necessary for them to fully exercise their obligations under the act. Through its regulations, Smart Systems has been specifically established to provide a province-wide secure communications infrastructure—a mandate quite separate from health information custodians. As such, the agency acts independently to develop and implement its products and services. This is in marked contrast to the agent concept and related obligations defined in Bill 31.

We are concerned that defining Smart Systems as an agent, as contemplated in the bill, will discourage health

care providers from accessing our services, because they will not want to be liable for the actions of an agency of the government of Ontario. Where Smart Systems will be acting for tens of thousands of health information custodians, it will be impossible for any one custodian to fully exercise their obligations under the act with respect to agents.

In our analysis of the bill, we have come to the conclusion that the Smart Systems for Health Agency does not fall into any of the currently defined roles. Because most personal health information about Ontarians will eventually flow through or be stored in the Smart Systems infrastructure, it is critical that Ontarians see that their privacy rights, as expressed in the bill, are protected while in the Smart Systems infrastructure.

We believe there is tremendous value in introducing a fourth role to the bill, that of the information manager. The information manager concept is not new. In fact, health information privacy legislation in Manitoba, Saskatchewan and Alberta all define roles for the information manager. The role of information manager was defined in Bill 159, the Personal Health Information Privacy Act, 2000, which wasn't passed by the Ontario Legislature.

Our proposed definition of "information manager" means a person other than an agent with whom a health information custodian contracts for services that include the processing, storage and disposal of records that contain personal health information, or information management, information technology or networking services to the custodian with respect to the custodian's records that contain personal health information.

The information manager will have an agreement with the health information custodian that imposes certain obligations on the information manager by the custodian, but can also be subject to regulations established by the government that govern the manner in which the information manager must handle personal health information. This would relieve the custodian of the sole burden of having to monitor and control the actions of the information manager, while at the same time ensuring that the information manager behaves appropriately. We would suggest that the Information and Privacy Commissioner have direct oversight of the activities of an information manager such as Smart Systems.

We believe the role of information manager provides a home for information management and technology services providers like Smart Systems. It ensures that the privacy rights of Ontarians are adequately protected while personal information is collected, transmitted, stored or exchanged through an information infrastructure.

For the committee's convenience, we have taken the liberty of drafting some language, adapted from Bill 159, which covers our proposed amendment to Bill 31. You will find that language in appendix A to our written submission.

Moving on to our second proposed amendment, we note that the bill imports much of the language of the

Health Cards and Numbers Control Act, 1991, into section 33. The proposed legislation links the health number directly to an insured person within the meaning of the Health Insurance Act. This essentially limits the use of the health number to only those people who are insured by OHIP. This has been recognized by the Ministry of Health and Long-Term Care and the broader health sector, including the OMA and OHA, as an impediment to the automation of the health care system, since non-OHIP-eligible users of the system are not covered. For example, foreign visitors, members of the military and RCMP and inmates of federal penitentiaries cannot be given a health number. They must be given alternate numbers issued by each health care provider.

We strongly recommend that the proposed legislation be amended to allow the use of the health number by non-OHIP-eligible health care recipients. If this is not done now, it will be raised again in the near future, because this has been a continuous problem for the health care system. We'd be happy to work with the committee and the Ministry of Health and Long-Term Care to draft appropriate amendments to section 33.

In closing, we compliment the government for bringing this important bill forward and thank the committee for taking the time to listen to our remarks. We'd be happy to take any questions.

The Vice-Chair: Thank you very much. We'll start with Ms Martel.

Ms Martel: Thank you for being here today. I want to move directly to the amendment. I gather that it's not exactly as it appeared in Bill 159. You've made some additions or revisions to it, is that correct?

Mr Seaton: Some minor revisions, yes.

Ms Martel: Do you have any idea why this was taken out in this round?

Mr Seaton: No, we don't have any direct knowledge.

Ms Martel: Have you had any discussions with ministry staff about this? It's just kind of bizarre, in my opinion, that a provision that was in before has now been taken out.

Mr Seaton: We have had discussions with the ministry staff over the last couple of weeks, mentioning to them that we were interested in seeing this provision brought back in and also that we would be bringing it forward to the committee in our submission.

Ms Martel: And their reaction was?

Mr Seaton: They seemed prepared to listen.

Ms Martel: So it may just have been an oversight in terms of the drafting of this one.

The second one I'm not as clear on, in terms of use of OHIP numbers. Would that be something that's common in the privacy legislation in Manitoba, Saskatchewan and Alberta? Is that where you're drawing that from, or is it more to try to resolve an ongoing problem?

Mr Seaton: It's more to resolve an ongoing problem. It has been a problem with the Health Cards and Numbers Control Act. I suspect—and I can't recall directly how these are applied in the western legislation, but certainly this piece of legislation—that the Health

Cards and Numbers Control Act was imported directly into the act.

Ms Martel: You're just not sure whether or not there are some sort of provisions in the other privacy acts in the other provinces.

Mr Seaton: That's correct.

Mr Jeff Leal (Peterborough): As a new MPP, I wonder if you could just explain to me the Smart Systems for Health Agency—what you do, what your role is and how you're vitally connected to the delivery of health service in the province.

Mr Greve: The Smart Systems for Health Agency, as was indicated, is an agency of the government of Ontario. In essence, it is the infrastructure. If you think about the cables that connect hospitals, pharmacies, all of the health care providers, we are the infrastructure so that all of that information can be shared among the health care people who, in actual fact, need that information.

Think about it this way: If you were a patient in your hometown and you happened to be sick wherever it is in this province, your information should be available to that particular emergency department or that hospital without their having to do your tests all over again.

Smart Systems is the infrastructure that connects all of this patient information across the province in a secure fashion and makes it available to somebody who, first, has the ability to use it and, second, has the codes and is a physician or has a particular way of getting into the system to find that information—all the emergency departments, hospitals and things of this nature—so as to make that information available across Ontario and reduce duplication.

Mrs Maria Van Bommel (Lambton-Kent-Middlesex): Are all hospitals, pharmacies and doctors across the province connected to you, rural and northern as well?

Mr Greve: I'll let Michael answer the specifics of that.

Mr Michael Connolly: My name is Mike Connolly. We are in the process of connecting all of the hospitals. About 85% of the hospitals in the province are connected at the moment, all of the CCACs, all of the public health units. We are in the process of connecting laboratories, pharmacies and doctors, and that will happen over the next couple of years. We have been connecting people on an as-required basis. If they're capable of using the system, then we've been connecting them at that time. Many places can't use it yet. Effectively, the result will be in two to three years that all health care providers will be on one common secure network, and there will be an electronic health record for an individual—voluntary; they can sign up for this if they want—and then that would follow them around as they move from health care provider to health care provider in the province.

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Mrs Van Bommel: Do you deal only in health care records, or do you have things such as PACS and tele-radiology and those types of endeavours?

Mr Connolly: Yes, PACS, tele-radiology, tele-homecare, all that stuff is involved in it, so anything to do

with health care in the province. For instance, we have in Ontario now the largest tele-health application in North America. It's all connected on our network. So if you're in Timmins, you can have a consult with a doctor in Sunnybrook, for instance.

Mrs Witmer: Thank you very much for your presentation. I guess the first thing is that I'd go back to where Ms Martel started. I'm just a little perplexed that the role of the information manager, which was defined in Bill 159, has been removed. Seeing that it's also being used in Manitoba, Saskatchewan and Alberta, others obviously have recognized the need for that role. You have no further explanation, I guess, other than what you've already provided as to why it would have been removed.

Mr Seaton: That's correct.

Mrs Witmer: Those that have that definition in the other jurisdictions, would they have roles that are very similar to yours?

Mr Seaton: As a matter of fact, yes. Alberta and Saskatchewan both have smart systems like Agency. In Alberta, it's called Wellnet; in Saskatchewan, it's called the Saskatchewan Health Information Network. They very clearly have made use of that particular role definition in their legislation.

Mrs Witmer: Hopefully, then, it is an oversight and that can be corrected.

I'm not quite clear as to why you think it's so important that everybody have a number.

Mr Connolly: In order to electronically track a patient so that they can move from one part of the health sector to another and be treated, we have to be able to identify them. To identify them, we need a number. From a purely administrative point of view, they can't be typing in their name and address and all that sort of stuff over and over again. For most of the patients in the province, we've used a health number. However, between 2% and 5% of health services are received by people who do not have a health number, because the current health numbers act links health number with OHIP eligibility. So there are quite a few people—I mean, we're talking hundreds of thousands of people—who do not have a number. As a result, we've developed literally dozens and dozens of numbering systems across the province. It's very difficult to connect these.

Just so you know, there's an e-health council in Ontario that's made up of the major players, the OHA, the OMA and the OACCAC. Their number one e-health priority is to get the current health number used as a unique personal identifier for health care in the province. That's basically what we're recommending here. We're bringing that recommendation forward from those health care providers.

Mrs Witmer: So how would those people who don't have a health number now get access to one—the foreign visitors and the federal penitentiaries?

Mr Connolly: Let's say that I'm from the States and I end up in the hospital at the University Health Network. They would ask, "Do you have an OHIP number?"

They'd say, "No." As they registered that person, they would then have a set of unused OHIP numbers, or health numbers, and they'd allocate one of those numbers to that person. Then that number could follow them as they move through the health system while they are in Ontario.

The Vice-Chair: Thank you very much for your presentation.

JUSTICE FOR CHILDREN AND YOUTH

The Vice-Chair: Next we have Justice for Children and Youth. They were slotted for 2:40, but they kindly agreed to move up.

Interjection.

The Vice-Chair: They're not here, actually; they are running late.

Ms Martha Mackinnon: I'm Martha Mackinnon, executive director of Justice for Children and Youth. The first thing I would like to say is a tentative apology. I haven't actually looked at my written document in the last two and a half hours because the power was out for many blocks surrounding my office. It was only at the very last second that the power came back on, and I just pushed "Print" and ran. If there are any typos or ambiguities, please ask me about them, and I apologize in advance.

Secondly, I'd like to thank you for the opportunity to be here today. Similar to the speakers who spoke to you immediately before me, I would like to praise the Legislature for this legislation, even its name. The fact that Ontario has acknowledged the importance of the privacy of health information, to tackle what appears to be a daunting task by both the length and the complexity of the legislation, is enormously laudable.

My organization represents young people under 18, so, as opposed to the administrator and health care provider perspective which you just listened to, the perspective of Justice for Children and Youth is: What does it feel like to be an underage consumer of the health care system and what does it feel like to have your privacy rights determined by legislation and external or other people? That's the perspective that I hope to bring to you today.

From that perspective, again, the first thing I would like to say is that I laud this legislation for reinforcing the notion that in Ontario people can access health care when they have the capacity to do so. We don't have a magic age. We have sort of presumptions. We have ways in which we question whether a person might be capable or not capable. But at the end of the day, if a kid—I think back to when measles immunization was a large Ontario program and these needles were given to every grade 7 kid in the province. The consent forms for this particular piece of health care were delivered home through kids to their parents. I don't know whether some of them got lost on the way home, in the home, or on the way back, but you can imagine that not every piece of paper was returned one way or another. Public health officials

thought long and hard about that and decided that basically, most kids actually do know—school-age kids at any rate—what a needle is, what it's for, what it does, that it will hurt to a certain extent. They felt at that time that they could presume that a child of 10 had the capacity to consent. So that was a working age that public health officials in Ontario worked with on that particular program.

Again, I'm not suggesting that any arbitrary age is right. I'm only praising the government for acknowledging that it's a capacity test. If any young person is able to understand what it is that they are being asked about, or understand what it would mean to have a particular health treatment, and they are able to be voluntary about their choice as to whether to have it or not, Ontario recognizes the right of that young person to access health care. So we do have underage persons—ie, under 16 years old—who are able to consent to having stitches when they've been injured in a playground and there isn't a parent around.

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As I said, I would praise the fact that this legislation reinforces and confirms those existing rights elsewhere and suggests that young people also can determine how their health information will be handled, if they have the capacity to make that decision. For example, if they have been found to be capable of deciding whether or not to get stitches, then they also can be capable of deciding who should find out about it and can, in appropriate circumstances, decide that they don't want their parents or their substitute decision-maker to know. That's consistent with the fact that they can have the stitches without their parents knowing.

Given that I believe this legislation intends to work with and not create a totally different set of rights from the young person's ability to access health care itself, there are one or two concerns with gaps in that ability to make both the information side and the health care side itself mesh. I'm going to address, in that area, particularly section 23 of the legislation.

Section 23 points out that young people are allowed to veto the rights of some other substitute decision-maker to get access to information if they have already been found capable of accessing the health care treatment itself or they've been found capable of and have already participated in counselling under the Child and Family Services Act. Our concern with that is that it leaves a gap. What if the young person hasn't yet had counselling but has sought information about counselling? The example in my written submission, of course, is the contentious one. What if the young person arrives at the doctor's door and says, "I'm pregnant. What are my options?" They may be able to exercise any one of those options independently of their parental or substitute decision-maker's views, but I would be concerned that this legislation does not allow them to control the fact that they asked for the simple information. So our submission would be that section 23 should make it clear that it encompasses everything to do with health care

information, not simply treatment or counselling that's already been participated in.

The second submission relating to section 23 I guess relates to the vulnerability of young people. A right to veto someone else's access to your own information is only a meaningful right if you know about it. What this legislation does not do is impose any duty on the health care provider to say, "Look, you have the right to keep this confidential. Do you want it to be or not?" Young people tend to assume that they have almost no rights unless they're told about them. So if the intent is to make sure that young people feel they can trust the health care system and access health information as well as counselling and treatment, then they need to be informed of any rights to privacy that they have within that system.

A second area of concern for Justice for Children and Youth relates to section 39, and particularly at this point subsection (2). Subsection 39(2) allows the disclosure of health care information to custodial institutions, penal or detention centres. Young people who are in detention are as capable of deciding whether disclosing or having their health information shared is in their best interests, whether they're in custody or not. In fact, sometimes in custody, as you can imagine, they're more vulnerable. I cannot imagine the young person who would think it was in his or her best interests to have the fact that they are taking drug treatment because they believe they are transgendered disclosed to a detention centre, particularly if the young person is in overnight—hasn't got bail, hasn't been found guilty of anything and doesn't need treatment in the facility. Section 39 doesn't limit the disclosure of health information to custodial facilities where it is necessary in order to provide treatment or in order to ensure the safety or health of the young person; it just says it can be disclosed.

There are many examples, and I'm sure you can think of them as well as I can, but information about HIV status can subject young people to particular bullying, stigmatizing and maltreatment in custodial facilities. Information gets out in custodial facilities. You will already know that there is an inquest into the death of a young person at TYAC, the Toronto Youth Assessment Centre, which is ongoing as we speak. With all the best will in the world, detention centres are closed communities, and once information is there, it is extremely hard, if not impossible, to keep it from becoming better known in the community. I can't see the public good that is served by allowing any disclosure, and I can see harm if disclosure is routine. In our submission, the disclosure ought to be limited to where it's necessary or with consent of the young person, because if the young person wants access to, for example, a medication for a mental health problem, they know they want the access. They'll be willing to consent to the disclosure. If they're able to consent, as I said, to the health care itself, then they will also have autonomous views about whether disclosure is helpful to them or not helpful to them.

I'd like, then, to move to a particularly vulnerable class of young people, and that's young people who are

in the care of a children's aid society. There are two sections, really, but section 42 provides that disclosure of health information can be made to a children's aid society so that it can carry out its statutory functions. There are no limits as to why such a disclosure might be made and whether it's necessary. For example, under the Child and Family Services Act, a child of seven has the capacity to consent or to refuse consent to being adopted but can't control the confidentiality of the health information on which that decision might turn. Again, I assume that a young person who wants to be adopted will know that adoption is more likely if disclosure is made. They already have the legal power to say, "No, I don't want to be adopted." Well, if they can say that but can't say they don't want information collected or disclosed, to me that is inconsistent.

Second, children in the care of CAS, in our submission, should not have fewer rights than kids who live with their parents. So just because a child was found to be in need of protection—that is to say, their parents weren't adequately protecting them—it shouldn't mean they lose the ability to say, "No, I don't want this health information shared with my state parent, the children's aid society." They shouldn't have fewer rights just because they've been found to be in need of protection.

Third, as I indicated, the legislation provides disclosure so that a children's aid society can carry out its statutory functions; not its duties, not just when it is required to investigate child abuse, but any statutory function. That, in our submission, is overbroad. A CAS is required to be a corporation. They must have board of directors' meetings. Does that mean you can disclose health information about a child because it would entertain the board of directors? Children's aid societies offer parenting courses. Is it necessary to disclose the health information of an individual child because a CAS wishes to provide a service for a parent?

In our submission and to sum all that up, the powers with respect to a CAS are overbroad, but more importantly, with respect to a children's aid society, they're uncertain.

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It is not clear who is covered. It is clear somehow that members of the college of social work are in some circumstances subject to the act. What about social workers who don't belong to the college, or all the other workers who behave very much like social workers but are not members of the college and who work with a young person or the young person's family and know a great deal about that person's health information?

Though the act goes back and defines several layers of health care information custodians and health care providers, at the end of the day it doesn't define health. So what is protected from the privacy perspective and allowed to be shared from the facilitation of consistent health care perspective is unclear when it applies to a children's aid society. It would be our submission that not only would kids like to be very sure of who's covered by the act but so would CAS workers.

I find the act complex enough in the way it refers to numerous other pieces of legislation that, even if I'm a lawyer and was supposed to be reading it over the last week or so, if I found parts of it confusing, then a worker with a hundred-family caseload is unlikely to be able to take the time to think it out as thoroughly, or not thoroughly, as I have managed to.

Another section that relates to overbreadth that I would like to address the committee's attention to is section 35—it's on page 6 of my written submission. I'm using this section as just an example of potential problems within the bill. Sections 35 and 36 effectively authorize indirect collection and use of information if the organization that's doing the collecting is also subject to either FIPPA or MFIPPA or other privacy legislation.

If, for example, the other privacy legislation says that information can only be collected directly and this legislation says it can be collected indirectly, does the person have to collect it directly or not? Has the standard been lowered or not? As I said, this is an example, but it struck me as I read all the references to other pieces of legislation that it wasn't always clear, where there was an inconsistency, which one wins. What prevails? What are the dominant principles that will govern if there are inconsistencies?

Next—and I've actually talked about this to someone else, because I don't know whether what I'm reading is an error, some type of typographical error, or whether it's accurate. Section 58 of the legislation authorizes an entry and inspection by the commissioner, and it looks a lot like the kinds of standards one would need if one were entering on to somebody else's premises where they would have a warrant; in fact, it requires a warrant if it's a dwelling. So it looks a lot like the inspection provisions in the Human Rights Code or various other places that give compliance provisions. But what it indicates in 58(1)(c) is that the commissioner can come in and inspect when "the inspector does not have reasonable grounds to believe that a person has committed an offence." I would have thought it meant they could come in when they do think someone has committed an offence. Apparently, if they do think there has been an offence, they wouldn't be able to come in. So I'm hoping that's a typo. If not, then I'm puzzled. I'll just leave that one there, because I don't understand it if it means what it says.

There are two other areas of overbreadth, and I'll do these really quickly.

Subsection 39(1) is a section that in my view is overbroad. It allows disclosure if the disclosure is necessary "for the purpose of eliminating or reducing a significant risk of bodily harm to a person or group of persons." Is eliminating or reducing by 1%—if the risk is 99% and it would reduce the risk to 98%—sufficient to violate a privacy right? If it's to reduce a "significant risk," is a risk significant if it's 10%, 20%? These are all quite subjective terms and open to erratic, inconsistent and subjective interpretation. In our submission, it's therefore critical that this be tightened up and made more clear. In fact, I would suggest that disclosure of personal

information should only happen if the threat of harm is imminent and if it is clear that disclosure would eliminate the risk.

One final comment, and it's on section 72, which appears to say that decisions of the minister or cabinet—this is the giving notice and consulting part of the act. Again, I want to say that it's laudable; it's superb that this legislation includes that as a provision. Health care is terribly complex, and I and the speakers before me come at it from such different perspectives, so I think the consultation part is critical. However, what the section says is that the minister's decisions are immune from any review. I, as a lawyer, have never seen such a section in any legislation. I would submit that it ought to say the minister's decision is final and binding, and not go further.

The Vice-Chair: There is no time for questions, but thank you very much for your presentation.

COALITION OF FAMILY PHYSICIANS OF ONTARIO

The Vice-Chair: Next we have the Coalition of Family Physicians of Ontario.

Dr Douglas Mark: Good afternoon. My name is Dr Douglas Mark, and it is my privilege to serve as president of the Coalition of Family Physicians of Ontario. Dr John Tracey and I are grateful to have this opportunity to share our concerns with you.

Before that, I would like to tell you a bit about the Coalition of Family Physicians of Ontario. Founded in July 1996, the Coalition of Family Physicians of Ontario is a voluntary, member-driven grassroots organization representing over 3,600 family physicians, and growing. It is dedicated to protecting the rights and independence of family physicians across the province. We advocate, on behalf of our patients and members, solutions to improve our health care system and health care delivery to the people of Ontario.

Family physicians—all physicians, for that matter—are acutely aware about the protection of health information. We are our patients' health information custodians, and we uphold patient confidentiality. When becoming full-fledged physicians, we take the Hippocratic oath to pledge our commitment to this paramount principle. Consequently, we generally do support protecting health information, but we have serious concerns pertaining to your legislative proposals about how these changes may affect the already challenging health care environment. Our patients and physicians are aging, health care resources are increasingly rationed and the physician pool is dropping.

To present to you our main concerns, I wish to introduce to you the chair of the coalition's political action committee, Dr John Tracey.

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Dr John Tracey: We thank the committee for providing to us the opportunity to speak today. We believe the committee is aware that the health information of our

patients and its privacy are sacrosanct. Physicians diligently follow the policies and procedures currently set out by our regulatory and licensing bodies to protect information, as has been our tradition.

Last year we presented to government our version of a comprehensive care funding model in Ontario, entitled Primary Medical Care Enhancement Initiative: Ensuring the Future, which we believe contributed significantly to the creation of family health groups, a small step in the right direction to restore comprehensive family medicine. We submitted this solution to address the untenable situation that one million Ontario residents do not have a family physician.

This situation is not due solely to a shortage of family physicians; it is also due to the rejection of traditional comprehensive care by medical students and family physicians. Inadequate compensation, administrative costs and inability to access resources make this form of practice ever more burdensome and unrewarding. We believe the increased economic costs, increased administrative duties and severe penalties that await family physicians with the introduction and implementation of Bill 31 will further erode family physician human resources.

Family physicians have assumed the role of keepers and case managers of the master patient record. This now extends to receiving and being responsible for information sent from third parties and other caregivers to whom the family physician has not referred the patient, nor ever did. Vast amounts of information are exchanged daily with specialists and nurses to facilitate ongoing care in the workplace and to the WSIB, or to the legal profession, to insurance companies, to pharmacies and/or to the ministry.

While we can try to put in place policies and procedures within our own offices, we cannot ensure the confidentiality of patient information when it arrives, for example, on a clerk's desk in a patient's workplace. Even with the caution and discretion used by most family physicians, the potential for inadvertent breach of this bill is apparent. The circumstances of breaches will have to be established by case and tort law. While this is taking place, family physicians potentially face \$50,000 fines and massive disruptions to their personal lives and practice, a daunting reality that many will weigh seriously.

The Canadian Medical Protective Association, CMPA, has not commented on whether physicians carry insurance for fines levied for breaches. Instead, they seem to be waiting for Bill 31 to become law and then assessing this on a case-by-case basis. We have written to them asking for their response on this matter. In addition, we have written similar letters to the College of Physicians and Surgeons of Ontario and the OMA and look forward to their replies as well. We're not sure, therefore, whether or not we have insurance, and probably will not be able to get insurance to cover us for these fines that are going to be imposed. For family physicians, this is almost a repeat of the risks inherent in the scenario where we await interpretive law concerning the medical review

committee of the physician governing body called the College of Physicians and Surgeons of Ontario. This measure has in some instances been very disruptive to a lot of physicians.

There may be a liability imposed on physicians for the conduct of their employees, called vicarious liability, that further adds to the onus of compliance, leaving personal assets open to loss should physicians not obtain adequate insurance, if it is available at all.

Many Ontario family physicians are currently contemplating options available under the auspices of primary care reform, which ask that they form networks between their offices in order to share and access patient information. This, in all likelihood, will involve the establishment of a secure intranet, a substantial economic undertaking for participating physicians. The economic incentives to form networks have been inadequate. These physicians, in order to comply with Bill 31, have to be compliant with an additional unfunded expense.

In the same way that large corporations with a large staff complement are asked to comply with this bill, single and group practitioners are required, in a manner that is practical in the circumstances, to make available to the public a written policy and procedure that provides a general description of the custodian's information practices; describes how to contact (1) the contact person described in subsection 15(3), if the custodian has one, or (2) the custodian, if the custodian does not have that contact person; describes how an individual may obtain access to or request correction of a record and personal health information about the individual that is in the custody or control of the custodian and make it available within 30 days; describes how to make a complaint to the custodian and to the commissioner under this act; requires full knowledge of any substitute decision-maker to ensure that information is not disclosed to the wrong person—often physicians are not aware in an emergency situation if such a substitute decision-maker exists; obtains express consent where appropriate; complies with complaints; permits access to the office for the purpose of inspection without warrant or court order; understands that breach of law could result in a \$50,000 fine; requires that the physician continues to be the custodian of the record even after retirement or illness until he can find a suitably qualified custodian to take over the records—good luck in Wawa; imposes, upon the death of the practitioner, a requirement that the trustee of the practitioner's estate or the person administering the estate is deemed to have assumed custodianship of the records—even after death we continue to be the custodian of the records.

Mr Chairman, with all due respect, are these two conditions taking the concept custodianship of the patient records somewhat to the extreme?

We believe that the imposition of this bill, without amendments, will inevitably place impediments in the path of prompt medical care and cause significant expense to family physicians. We believe that this bill will increase economic pressure upon family physicians

to abandon their traditional role as case managers and custodians of the comprehensive medical record. This will lead, inexorably, to fewer medical students choosing family medicine and more family physicians taking up a walk-in style of practice or other alternative methods of practice.

Dr Mark: Thank you, Dr Tracey. In summary, the Coalition of Family Physicians of Ontario believes that the proposed legislation in this act is open to interpretation and leaves our members exposed to potential inadvertent risk. It places yet another burden upon the family physician profession, which is already in crisis, but also is open to interpretation and leaves our members exposed to potential inadvertent risk. This is why we believe it was imperative to appear today and discuss the potential impact Bill 31 could have on family physicians and the people they care for in Ontario.

We anticipate that amendments will be made to this bill as circumstances arise and would recommend the formation of an advisory committee that would also include representation from various bodies of “care custodian,” and specifically representation from the Coalition of Family Physicians of Ontario.

Mr Fonseca: I would like to thank the Coalition of Family Physicians of Ontario for presenting for us today. In regard to education, if we can do something around education efforts done by the Privacy Commissioner or the Ministry of Health and the Ontario Medical Association, would this help alleviate some of the concerns that you brought up?

Dr Tracey: Education is always a good point, but the reality is that we as family physicians, and being the custodian of the master medical record—we will recognize that fact; that’s what we do—receiving information from every which way and pouring that information out, stand as traffic cops in the centre of the busiest junction of patient information. As such, we are taking on the responsibility of this custodianship that has the potential for \$50,000 fines for inadvertent breach.

The question I ask you back is, when physicians now already are faced with tremendous burdens and all sorts of incentives to leave practice, when 40% of family physicians are over the age of 40 and contemplating alternatives, and we just heard today from the Ontario Medical Association that 26% of doctors are intending to leave the province, then, when we look at standing there in the middle of this information highway and looking at transferring the responsibility to a corporation and becoming a crossing guard instead, we think that a lot of physicians will weigh the alternatives to taking on this extra burden unless we find some way around it, a softer approach.

Dr Mark: Perhaps another way you can look at it is: Say, for instance, somebody invented fire before fire insurance were available for your house, your house burns down, and then you don’t have insurance to cover that. We don’t believe those mechanisms are in place to protect us.

To give you another example of what a patient might do, and hope I’m not stepping over anybody’s boundaries

here: If a patient is not happy with something that is written in the file that they said at one of their visits, and they look at the record and say, “You know, I really did have more back pain at that visit after that car accident and you should put that down, because I think the back pain that started three months after, yadda, yadda,” they can go on and on and say, “Really, my file should have that.” I can just tell them, “No, that’s not what happened. This is not what you told me. I didn’t write that down.” But this legislation now puts a whole new spin on things.

Mr Fonseca: Thank you.

Dr Mark: Actually, it’s one in six doctors, John, it said there—

Dr Tracey: I stand corrected.

Dr Mark: —who are on the point of retiring or leaving Ontario.

Mrs Witmer: It’s still too many.

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Mr Yakabuski: Exactly.

Thank you very much for your presentation and your humorous comment about Wawa. I come from rural Ontario and we have the same situation happening, where we’re having a hard time attracting family physicians. When I talk to family physicians in my riding, one of the things they’re saying is, “We become slaves to our practices”; not slaves to the part of the practice they love, which is working with patients, but to the administration of these practices today. That’s why so many of them are trying to get into a multi-physician situation, but it’s not that simple in rural communities to have practices like the Family Health Network and stuff like that. One of the things they’re concerned about is more administration, and it sounds to me, from your point of view, that this act, particularly for family physicians, will do just that.

I guess what I’m asking is, are there some specific amendments you are going to be proposing to mitigate the effect, not only from the legal point but the administration point, and the burden of dealing with this additional legislation, which from what I can understand from your submission is going to take more and more time away from dealing with patients? The real problem in our system is that doctors don’t have enough time to deal with patients because they are dealing with administration, and it sounds like this is going to add to that burden.

Dr Tracey: Thank you for your question. We would be delighted to be invited to sit down with the people who are proposing this legislation, to make amendments to it, to make it a softer approach toward family physicians. We have really serious concerns about the single practitioner in rural Ontario who may be facing extreme expense in trying to implement this and, more so, putting himself or herself in a position whereby an inadvertent breach, either through them or their staff, could result in a \$50,000 fine. If it’s the intention of this legislative committee to put forward a committee for amendments, we would be delighted to serve on that, yes. Today, we wouldn’t be able to present those amendments until such time as you have further discussion.

Dr Mark: May I offer some comments too? As it stands, each particular physician or group practice would have to put in place their own privacy rules or have their own privacy officer or consultant for each practice. That certainly would be a burden and troublesome, and I don't think many would be looking forward to that.

One other point I'd like to make: The Family Health Network is still a group-type practice, and if it is a comprehensive and secure type of model, whichever payment model it is, it still requires all the administrative headaches and paper forms. We're talking about walk-in clinics. You walk in, see the doctor and say to the walk-in clinic doctor, "Oh, by the way, I have a form to show you." "Sorry, we don't do that. Go see your family doctor," that kind of stuff.

Mr Yakabuski: That is certainly one of the concerns I am hearing over and over again from family physicians in my area, that they are just inundated with forms and it's taking them away from what they've been trained to do.

Dr Mark: And taking away from our family's personal time as well.

Ms Martel: Thank you for being here today. I'd like some clarification about what your requirements are now as family physicians under the federal legislation and what the differences are between what you are required to do now under the federal legislation and this bill. You would have had to do some things in anticipation of that legislation in any event, but it's not clear to me what you see as provisions that are more onerous or in addition to that legislation.

Dr Mark: Are you referring to the PIPEDA?

Ms Martel: Yes.

Dr Tracey: The federal legislation per se—I presume you're talking about PIPEDA.

Ms Martel: Yes.

Dr Tracey: PIPEDA is a piece of legislation, as I understand it, that is on the books to make sure that personal information of all types is protected. The Health Information Protection Act, which this is, has probably foreseen that PIPEDA can cause serious problems for us in terms of the transmission of data. For example, we're told that we can send a referral letter over the fax machine across an unsecured line. PIPEDA would not have allowed that. So this legislation, in the "circle of care," is allowing us to be able to conduct our businesses a little more freely but nonetheless has still put into place onerous requirements for us to be able to do our job. It's still not doctor-sensitive, if you see what I'm saying.

Ms Martel: I think so. I guess what is not clear in my head is, what are the additional burdens that you feel you are now facing as family physicians, above and beyond whatever obligations you would have to be meeting or are supposed to be meeting now under the federal legislation? It's not clear to me what those are.

Dr Tracey: The Ontario Medical Association and the CPSO have told us to continue to do what we've always been doing under the traditional role and rules, governed by our governing bodies that issue our licences under

PIPEDA. They haven't changed their decisions there as far as I can see.

Ms Martel: So there has been no change in your practice in terms of compliance with the federal legislation.

Dr Tracey: None whatsoever; not to this point.

Ms Martel: My other question had to do with—your last line said you thought that if this didn't change, you would see more family physicians taking a walk-in style of practice, a walk-in clinic. Is it clear in your review of the legislation that a physician in a walk-in clinic is not subject to the provisions of Bill 31?

Dr Tracey: The physician in the walk-in-clinic-style practice—as we call it, episodic encounter—is responsible for maintaining a record of that particular visit and any record that comes out as a result of that meeting with a patient. However, most walk-in-style practices are owned by corporations and often physicians working in walk-in-style practices are employees of the corporation. So in effect, if you look at the semantics of the situation, the corporation would be the custodian of the patient record. The physician would simply be providing the patient record to the corporation, and that again may lead to other discussion.

Ms Martel: So the obligation falls to the corporation.

Dr Tracey: Yes, in the same way, presumably, as it does in a hospital setting. While we would be responsible for the maintenance of confidentiality with respect to the content of that record, the actual record would be under the custodianship of the corporation in which the physician was providing the service, which is different from what happens in general practice.

Dr Mark: The other scenario we face in comprehensive medicine is that, say, a patient goes to a hospital, has an emergency visit or a consultation or a procedure done, and it's not even our initiative; that information would tend to go to the family physician. We are responsible for that information and have to then maintain that record appropriately. That's another aspect.

The Vice-Chair: Thank you very much for your presentation.

BAYCREST CENTRE FOR GERIATRIC CARE

The Vice-Chair: Next, we have the Baycrest Centre for Geriatric Care.

Ms Paula Schipper: Good afternoon. My name is Paula Schipper. I am the in-house legal counsel for the Baycrest Centre for Geriatric Care.

I'll just give you a little background about what Baycrest does. Baycrest is an academic health centre affiliated with the University of Toronto. We provide a range of services for the elderly. We're a charity. We operate a long-term-care facility, Baycrest Hospital, which provides chronic care, rehab and a host of other things like palliative care and psychiatric care. We have an extensive out-patient clinic for the elderly, with an adult day care centre for seniors, a community centre and

a host of other community programs, including health services provided in a person's home. In addition, Baycrest is home to both pure and applied research centres focused on aging. Baycrest's Rotman Research Institute is one of the top neuroscience research centres in the world and is on the threshold of major advances in the care and treatment of cognitive impairment.

We are a very large organization that provides virtually all our services from one campus. To facilitate the continuum of care that we provide, we have one centralized health records department. We're hoping this legislation won't require Baycrest to fragment into separate health information custodians. As it is, we work very efficiently and it would be very disruptive, needless to say.

Baycrest is committed to protecting the privacy of personal health information and is very pleased that Ontario legislation might finally pass—please. In late 2003, Baycrest adopted a centre-wide privacy code based on the Canadian Standards Association model code fair information practices.

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We'd like to comment that overall, Bill 31 is a great improvement over previous drafts of health privacy legislation. We're ecstatic that it's finally here. We were very upset at the prospect of only having to deal with PIPEDA in Ontario. But we do have some comments on Bill 31 that we hope you'll find constructive.

Mark Gryfe is the president of the Baycrest Centre Foundation. He was supposed to be with me today to present on fundraising, but unfortunately he is ill. I'll be brief and tell you our concerns about the fundraising provision in section 31.

Consistent with the views of the Ontario Hospital Association and the Ontario Council of Teaching Hospitals, Baycrest is concerned that the requirement to obtain express consent for fundraising is unworkable. We think that this will significantly undermine the ability of the Baycrest Centre Foundation to raise much-needed funds. It will have a direct impact on patient care and Baycrest's ability to meet its capital costs.

In anticipation of adopting Baycrest's privacy code, the foundation's fundraising practices were closely reviewed. We're satisfied that putting clients on notice through postings throughout our facility and in all of our communications is effective. Our notices describe our fundraising practices and provide clients with a convenient way to opt out of being solicited. This strikes an appropriate balance between protecting an individual's privacy interests and helping seniors through the funds we raise.

My next comment is going to be about subsections 25(6) and (7), which is the discretion of the public guardian and trustee to act as decision-maker of last resort. Under the bill, the public guardian and trustee may, but is not obliged to, be that decision-maker of last resort. Usually we would call on the public guardian and trustee for health care decisions if there is simply no other substitute available or in existence or if we've got

two substitutes who share responsibility and they can't agree.

Obviously, these provisions in Bill 31 were based on the Health Care Consent Act and it's unclear to us why it is mandatory for the public guardian and trustee to make decisions about treatment when there is no one else to make those decisions, and yet it's discretionary for them to do so under this bill. We ask that if the public guardian and trustee is not able to make those decisions, then could you please pick another person and oblige them to do it, such as the Information and Privacy Commissioner or even a designated officer from the health information custodian.

People are living longer, and many have cognitive impairment. Baycrest often must turn to the public guardian and trustee for health care decisions because an elderly client has no one else. We are concerned that health care will be stalled while we duplicate consultations and tests because there is no one to consent to the disclosure of valuable health information already learned elsewhere but unavailable.

The next issue I'd like to comment on is the lockbox on information disclosure, and I know you've heard quite a bit about it. We support the principle in the bill that health information custodians may disclose information only if it is reasonably necessary for the provision of health care. However, the so-called lockbox provision enabling a person to restrict the flow of necessary health information is a cause for concern.

At Baycrest, we serve a very frail at-risk population, where any lack of crucial information could result in catastrophic clinical outcomes. A person, for example, might direct that a previous history of mental disease such as depression not be communicated. That might lead to preventing the transmission of what would be critical information about their previous tolerance for medications or previously experienced side-effects which could be dangerous if unknown. It's also an issue for placement. Community care access centres collect information to determine whether seniors are eligible for long-term care and they disclose relevant personal health information to a facility if the person will be admitted. Our own staff determines what care level within our facility a person is suited for, and there's quite a range within just one long-term-care facility and within one chronic care hospital. We also determine if a person is eligible for placement in the hospital. Without full information we can't meet the person's needs, and that could lead to placement on a unit without the proper staff supports or physical facilities in place. We need to know, for example, if a person is at risk for wandering or has a history of physically lashing out. Otherwise, we could jeopardize the safety of that client, the safety of our other vulnerable clients and our staff. So there is a lot at stake.

Debt collection: I don't know if you've heard about this issue from anyone else. You may know that the federal privacy legislation, PIPEDA, has an express exception allowing a custodian of information to permit disclosure or to disclose "for the purpose of collecting a

debt owed by the individual to the organization.” Bill 31 does not contain a parallel provision, and general provisions permitting uses and disclosures, as well as provisions on use of information by agents, do not address the issue. Furthermore, there is the danger that people will expressly forbid information to be disclosed for purposes of debt collection, and we’ve had that experience in the past.

Long-term-care facilities in particular are prohibited from requesting financial information to determine if a facility resident can afford accommodation fees unless the resident is applying for a government-regulated rate reduction. Once a person is receiving care in a nursing home or home for the aged, they can’t be discharged for refusing to pay even if they have the financial means through Canada pension and old age security funds. Under the long-term-care legislation, the facility and the Ministry of Health and Long-Term Care—in other words, the Ontario taxpayer—have to foot the bill when a resident does not pay for their accommodation. Chasing down resident payment is time-consuming and costly, but it’s in the government’s interests to enable facilities to do it. We don’t like to do it. In our past, when we had more funds available, we were not that aggressive. Unfortunately, now we’ve had to be because funds are tight. We don’t have the administrative depth to go after it, so sometimes, as a last resort, we might turn to an outside person or a collection agency. Without an exception under Bill 31 for disclosures necessary for debt collection, long-term-care facilities and, I imagine, many hospitals will be out of tools to obtain payment and our operating budgets will be strained further.

The last point I’m going to mention today is about research, just briefly. Baycrest believes that the provisions concerning research in Bill 31 are a step in the right direction. Baycrest also strongly supports the representations made by the Ontario Council of Teaching Hospitals regarding research, and we refer you to their brief. I’m not sure if you’ve heard from them yet, but you will be.

That’s it. On behalf of Baycrest, thank you very much for letting us present today.

Mrs Witmer: Thank you very much for an excellent presentation. You’ve actually brought to our attention some points for consideration and amendment that we had not been made aware of before, so we really do appreciate it. We’ve certainly heard from others about the negative impact this bill could have on fundraising and the need nowadays, whether it’s an independent agency or a hospital, for fundraising to take place in long-term-care facilities. So we hope that when we make some amendments, there will be some changes made.

You took a look at the lockbox and the disclosure of information, and you mention something here that I think needs to be seriously considered, and that is the fact that if people don’t have access to all the medical information and history, unfortunately the health care professional could be and would be held responsible and liable. We’ve just heard from doctors how difficult this is any-

way, and it just makes their lives even more intolerable, and any other health care provider.

Would you speak about the public guardian and trustee? That’s a new point that we have not heard about before.

Ms Schipper: If you look in the section, it says the public guardian and trustee “may” make those decisions, and it’s “may make the decision” of last resort. That is, if there’s not power of attorney, no relative available or living, then the public guardian and trustee may make decisions concerning the transfers of information but they’re not obliged to. If you look at the wording in the Health Care Consent Act, where we’re used to seeing the public guardian and trustee act, they are obliged; it says “shall.” I would really hope that we change that because we can’t be left hanging.

Mrs Witmer: So are you suggesting it would simply need the change of that one word?

Ms Schipper: Yes.

Mrs Witmer: The “may” to “shall”?

Ms Schipper: That’s it.

Mrs Witmer: Thank you very much for, as I say, a really excellent presentation.

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Ms Martel: Two questions: The first is related to your concern raised on the first page, and then I see you do more that you didn’t refer to in your written marks about the ability to become a single health custodian. Are you concerned then, in what you have read, that somehow you would not get approval, or are you looking for a way that would be much easier to be automatically—in the same way as the public hospitals act?

Ms Schipper: Obviously, we would like it to be automatic. We would have to change the bill itself in order to be included because we’re not one entity operating on several campuses, which is the exception under the bill at the moment. We are several entities or several services from one campus, but we’re actually different corporations. We’re all under an umbrella.

We have a centralized service and we would really like to be a single health information custodian, and one of our concerns is the speed at which this bill is passing. I understand the pressure, especially because PIPEDA is now in force, but we’re concerned that the approval process won’t be ready for July 1. We want to have time to apply and know the answer so we can adjust, because if we’re denied, we have to completely upset the apple cart, just reorganize.

Ms Martel: There are a number of provisions, and I suspect that we need to have more of a discussion about how we do that. I thought there were provisions there that would facilitate that, but you’ve got a legitimate concern about the timing and how long the minister’s approval would take.

You also didn’t have a chance to refer to the second one, but we have heard from some of the regulated health professions their desire to be included in schedule B of the bill. Do you want to just—

Ms Schipper: I would love to. First of all, the Quality of Care Information Protection Act is so important, and

we're delighted that it's finally made it to legislation in Ontario. That kind of protection for quality improvement practice is already available in some other provinces. But it's kind of puzzling to us that long-term-care facilities aren't automatically included under the bill within the scope of that legislation, especially because we're required by statute to have quality improvement exercises. I wish I had the section with me, and I didn't quote it. So I don't understand why it wouldn't be automatic. Certainly, unfortunately, there is scope for error in long-term-care facilities, and we like to have an open environment where people feel safe to disclose problems so we can fix them.

Mr Fonseca: I'd like to thank you for being here with us today and presenting on behalf of Baycrest. I wanted to ask: Fundraising has been a hot topic. Many of the stakeholders have brought it up. We've discussed the opt-out process. What would you see as an opt-out process that would work for the stakeholder as well as for the person who's being solicited?

Ms Schipper: I think you've just got to provide notice everywhere and make sure people understand that we are active in fundraising—this is how we do it and what we'll do—and that you can opt out at any time, and then have an obligation to make it very easy for someone to remove their name from a mailing list and just not be approached again. It's sort of ironic, but if you require express consent for fundraising, when are you going to do that if you don't do it at the beginning, when somebody is there to apply for care? That's a little distasteful, because you don't want to make the implication that your care is contingent on the fact that you check off "yes," that we can solicit you for funds.

We like the idea of making it clear, with written material, that we're going to be active in fundraising. We don't want the health information. We're not going to use it. We're going to use just basic demographic information and give them the opportunity every time to say, "No, please don't approach me again."

Mr Fonseca: My colleague Kathleen Wynne has a further question.

Ms Kathleen O. Wynne (Don Valley West): You talked about the debt collection provision, or the lack thereof. Can you talk about what health information is necessary for debt collection?

Ms Schipper: It's not; it's just that when somebody applies for long-term care or chronic care, because that's where we can charge for accommodation fees, that's when we collect their name, address and everything else. But when I looked in the bill, I was concerned that anything related to health information could include that basic demographic information. I wasn't sure we would be free to remove that information in the context of the health record or whatever we've created.

Ms Wynne: You mean just the name of the person and the—

Ms Schipper: Just the name and address and the basic financial information that we've collected in order to allow payment.

Ms Wynne: That sounds like it's a clarification that we need to—

Mr Fonseca: Health information that's collected—

Ms Wynne: You're not talking about health. You're just talking about the information about the person.

Ms Schipper: Yes.

Mr Fonseca: This is only financial information.

Ms Wynne: OK.

Ms Schipper: Right. Obviously they would know it's the Baycrest Centre for Geriatric Care that is owed a debt, so that might be a bit of a tip-off, but nothing about the care they're receiving, just the basic demographic stuff.

The Vice-Chair: Thank you very much.

ONTARIO PHARMACISTS' ASSOCIATION

The Vice-Chair: Our next presenter is the Ontario Pharmacists' Association.

Ms Ruth Mallon: Good afternoon, Mr Chairman and standing committee members. My name is Ruth Mallon and I am the vice-president of pharmacy services at the Ontario Pharmacists' Association. With me today is Christine Ling, pharmacy services coordinator at our association. Thank you for granting us an opportunity to make a submission to you today.

The Ontario Pharmacists' Association is a voluntary, not-for-profit professional association of pharmacists and pharmacy students. We have over 5,300 members across Ontario representing all areas of practice, including community pharmacies, hospitals and industry. Pharmacists are significant stakeholders in the health sector, and as primary care providers pharmacists have a particularly strong interest in Bill 31.

Pharmacists uphold patient confidentiality to the highest degree. In poll after poll, pharmacists are rated the most trusted of professionals. We want to maintain that high level of trust we have earned from our patients.

In this regard, the OPA supports Bill 31 and the establishment of clear rules respecting the privacy of personal health information. We recognize that the rights of patients to protect their health information must be balanced with access to personal health information for the purpose of providing health care, and we see Bill 31 as striking a good balance. We are pleased that Ontario has proposed privacy legislation specific to health information, given the unique information requirements of the health care sector.

The information practices of pharmacists derive from the scope of practice, which is broader than is generally recognized. Pharmacists do much more than simply dispense medications. Pharmacy practice includes interviewing patients; counselling patients about their medication and any recognized side effects, drug interactions or allergies with other prescription drugs, medicines or herbal products; and checking the prescription against the patient's medical history and current medication program for drug interactions, known allergies, appropriateness and correct dosage. In addition, pharmacists provide

primary care, including performing detailed reviews of patients' medication profiles, working with physicians to manage medication regimes, and monitoring patient responses to and the outcomes of their medication.

Given the demographics of our society and other factors, pharmacists are likely to become much more fully integrated into health care provision, including working more closely with physicians and other health care providers within primary care networks. The changing role of pharmacists within the health care system may necessitate changes to the personal health information practices of pharmacists, but what is certain is that accurate information, provided by the patient or by the patient's caregivers or substitute decision-makers, is and will continue to be essential to the provision of quality health care by pharmacists.

Although Bill 31 will facilitate the provision of health care by pharmacists in many ways, there are a small number of provisions in Bill 31 that the OPA is concerned will hamper the ability of pharmacists to provide health care to patients at the accepted standards of practice. Recognizing that the full scope of pharmacy practice may not be widely known, the OPA would like to raise three issues with the standing committee. These issues involve obtaining consent to the disclosure of personal health information to health benefits providers other than OHIP, clarifying the definition of "personal health information" and clarifying the definition of "marketing."

Under Bill 31, pharmacists must obtain express consent to disclose personal health information to health benefits providers. The purpose of the disclosure is to allow the patient to obtain his or her prescription without having to first pay for it and later be reimbursed by the benefits provider. Given the number of interactions that pharmacists have with patients each day, the requirement to obtain express consent will cause significant delays in filling prescriptions. Further, redirecting human resources so as to obtain express consent will severely detract from the time available for patient-pharmacist contact, such as therapeutic discussion and medication counselling.

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In Ontario, approximately 50% of all prescriptions are paid by the Ontario government, 40% by third parties such as private drug plans, and 10% directly out of pocket by patients. All Ontario government prescriptions and approximately 35% of private-payer prescriptions are reimbursed directly to the pharmacy through an electronic claims network. This direct payment model eliminates the need for the patient to pay for his or her prescription medication at the point of delivery, which is particularly important to the elderly and others living on fixed incomes. The OPA fully endorses the need for patients to be given notice of this disclosure of their personal health information to health benefits providers. After such notice is given, the OPA submits that pharmacists should be entitled to imply the consent of the patient to the disclosure of personal health information to the benefits provider. This position is consistent with clause

38(1)(a) of Bill 31, which permits the disclosure of personal health information for the purpose of verifying the eligibility of an individual to receive health care or benefits funded by the government of Ontario.

The second point is under the definition of patient health information. The definition in Bill 31 includes "identifying information about an individual ... if the information identifies a provider of health care to the individual..." Under the law governing the practice of pharmacy, pharmacists are required to identify themselves on the prescription or in the patient's health record. As such, the OPA is requesting clarification of the circumstances under which a pharmacist's personal information in a patient's health record can be said to be identifying information about the patient. Such clarification will assist pharmacists in implementing Bill 31.

Our third and final point is around marketing. Our information that the scope of pharmacy practice is generally believed to be narrower than it is suggests that certain pharmacy programs may be interpreted as marketing activities rather than health care activities. Compliance programs, which involve pharmacists contacting patients who have failed to renew prescriptions, particularly prescriptions required for serious ailments or ongoing conditions, are an example in point. Wellness programs, which involve educating patients about the management of their disease or condition, are also susceptible to being interpreted as promotional activities rather than health care services. Surveys have demonstrated that these programs are effective in improving the health care of patients, particularly those apt to forget or neglect their medication regimes. The OPA respectfully requests the clarification of the definition of marketing in Bill 31 so as to expressly recognize that compliance and wellness programs provide or assist in the provision of health care.

In conclusion, we congratulate Ontario on the introduction of Bill 31 and hope that once it is in force, an order will be sought from the Lieutenant Governor in Council deeming it substantially similar to the Personal Information Protection and Electronic Documents Act.

Ms Martel: Thank you for being here. I would like to go back to your first concern, which has to do with express consent to disclose personal information to health providers. I'm looking at clause 38(1)(a) that you've referenced, which I see could at least cover people who are covered under the drug benefit plan but clearly would not, I suspect, for people who are covered by private insurers.

Ms Mallon: Right.

Ms Martel: How would you see that section being amended to cover that category of people who are dealing directly with private insurers?

Ms Mallon: We were thinking you could make it as we have done for PIPEDA, in the notice to our patients that information would be shared with their health benefits providers or third party payers for the purpose strictly of getting reimbursed for their medication. So once they

have been given notice, that would be sufficient for these purposes.

Ms Martel: That's what you've done under the federal legislation and that has been sufficient under that legislation?

Ms Mallon: It hasn't been challenged.

It's because the definition of a health information custodian is very clear in this legislation, and a pharmacy benefits manager or a third party payer would not be a health information custodian. Therefore, it's asking for express consent, which would mean finding the person, making sure they're knowledgeable and making sure they give consent, rather than putting it in a notice.

Mr Fonseca: Thank you very much for your presentation. I wanted to ask about the serious delays you brought up in terms of the consent issue.

Ms Mallon: The delays in the consent are around a third party payer, which we were just talking about with Ms Martel. You've got a busy pharmacy. People often don't come in with their prescriptions. They often send their next-door neighbour or a friend or somebody and they send the prescription in. It would be impossible to get express consent from that sort of person; we would have to get in contact with the person directly. That may not be possible; they may be sick, they may be unable to talk, all that sort of thing. That would definitely cause a delay. I can imagine somebody coming home from the hospital with a Tylenol 3 prescription and their husband bringing it in, you can't get consent from the husband, so—

Mr Fonseca: Do you know what percentage of your customers would fall into that category?

Ms Mallon: As I said, most of the time it's 50% ODB, 40% third party. Of that 40%, around 35% and growing numbers are electronically adjudicated, so the patient doesn't pay; I'd have to transmit that information. So a significant number, and of course the number of prescriptions is rising every year too.

Mrs Witmer: Thank you very much for your presentation. It certainly is very much appreciated. It's interesting to see how this bill could possibly have some negative consequences for the pharmaceutical providers, the pharmacists. On the whole issue of disclosure, what would you then recommend that the government do with this legislation in order to continue to allow for these prescriptions to be reimbursed through the electronic claims network?

Ms Mallon: For PIPEDA, we have information for the patient that defines that this information will be sent off to their pharmacy benefits provider. That notice should be sufficient to assume implied consent when they actually use the drug card. In that case we would recommend that be part of the information that would be under—I don't know the exact wording—providing the care and the payment for the care. That would be part of

an implied consent, rather than an express consent. I haven't talked to a lawyer about this, but we may want to consider if that information is given to a non-health information custodian that rules around what they do with that information should perhaps be defined.

Mr Yakabuski: I'm just wondering how the Ontario Pharmacists' Association feels this legislation would work with them in regard to—you know, a pharmacy is not the secure kind of environment that a doctor's office is. You don't generally have privacy; it's in a retail business. When people bring in prescriptions, they're often set down over a counter, and if other people are in line, they can see those prescriptions. Certainly when they're filled and handed over another counter to the person receiving it, they're visible to anybody who may be in the vicinity of that exchange counter in the pharmacy, and as they take it up to the checkout as well. I'm just wondering whether under this bill that constitutes any kind of inadvertent disclosure, because many drugs can be clearly identified as drugs for a particular condition, by anybody who has any medical knowledge at all. They are fairly commonly linked with certain illnesses and the fact they're receiving the drug at all—I'm just wondering how that might impact pharmacists with regard to the disclosure provisions in the bill.

Ms Mallon: Personally, I would say that this bill does not change the situation as it is. The fact that PIPEDA came into effect January 1, 2004, obviously raised the level of awareness around privacy to consumers and pharmacists alike.

What the Ontario Pharmacists' Association did for our members was give them an audit checklist of how to go through your pharmacy, from walking in the front door to delivering the prescription to who has access to your records; how do you destroy those records; how do you keep your patient information confidential. That was one of the things we did to try to heighten awareness of that very important thing, keeping that kind of information private and confidential.

I have to say, from experience, it's very difficult to pull a patient away from a cash register and get them to actually go into a counselling room or a private room. Often they're very busy and in a hurry to go.

The other issue around privacy and confidentiality is around standards of practice, and the standards of practice are that we don't disclose that kind of information to anybody else. So this is no change from what our standards of practice have always been.

The Vice-Chair: Thank you for your presentation.

The next group that's on the list, the Empowerment Council, is not here. The clerk has checked; they didn't confirm and they're not here, so I would say the committee stands adjourned until 10 am tomorrow.

The committee adjourned at 1541.

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