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**Official Report
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Wednesday 28 January 2004

**Journal
des débats
(Hansard)**

Mercredi 28 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
Clerk: Tonia Grannum

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LEGISLATIVE ASSEMBLY OF ONTARIO

ASSEMBLÉE LÉGISLATIVE DE L'ONTARIO

**STANDING COMMITTEE ON
GENERAL GOVERNMENT**

**COMITÉ PERMANENT DES
AFFAIRES GOUVERNEMENTALES**

Wednesday 28 January 2004

Mercredi 28 janvier 2004

The committee met at 1001 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): Good morning, everybody. Welcome to the standing committee on general government for the hearings on Bill 31. Our first presenter—

Ms Shelley Martel (Nickel Belt): Chair, may I raise a point of order? I would like to raise something, and I apologize to the first presenters, from the auditor's office, whom I know very well. I wonder if I can deal with a matter with respect to the schedule for next week. There was a subcommittee meeting about this yesterday, but decisions were essentially not made, and I think they should be made, with respect to determining what the schedule is going to be and making the presenters aware of that.

I don't know how many committee members saw the final list last night for presenters, but the Soo has six in total, Kingston has four in total with one of those people who would go to London as well, and London has a full number. In the subcommittee meeting yesterday, there was a discussion—I'm not implying there was any consent, but there was a discussion about what we should do with those numbers and if it made sense to actually travel with the whole committee to some of these locations if the numbers were low or if it would make more sense cost-wise to actually invite people to participate via teleconference in two of the sites. I am asking the committee to think about in essence doing that in the case of Sault Ste Marie and Kingston.

I asked the clerk yesterday if he might prepare some costing so we would know what we were dealing with, specifically the cost for the charters to take us to the Soo and to Kingston, the hotel rooms; there are of course per diems for food for people; there of course would be costs associated with having the equipment that we would have to rent in the Soo and in Kingston to do the Hansard. So

he's got some of those, which I'd like him to share with the committee, and then I'd ask for some discussion among committee members about what to do.

Obviously, I don't have the full idea of the costs, but I think they're significant enough that it would make some sense for us to consider doing it by teleconferencing. In the Soo, for example, the most we would have hearings for is two hours. In the case of Kingston, the most we would have a hearing for would be one hour and 20 minutes. So, Trevor, if you wouldn't mind giving the committee an idea of the costs, I'd appreciate it.

Clerk of the Committee (Mr Trevor Day): For the charter for all three cities, rooms for 16 people—that's 10 committee members and six staff—and the meeting rooms in all three cities, the total was \$18,301.98. That doesn't take into account catering or some of the broadcast requirements as far as moving equipment.

If we were to do just London on an overnight, where the numbers seem large enough, had we gone the night before, Air Canada return, rooms for 16 people and the meeting room costs us \$10,002.08. If we did the same trip going VIA 1, for 16 people and the meeting room, it's \$5,532. If we did it as a day trip—London is fairly close—then we're looking at just the air travel and the meeting room, \$8,258.

Mr Peter Kormos (Niagara Centre): And by bus?

Clerk of the Committee: We haven't looked into the charter costs yet. We were unable to get them last night.

Interjection: Not a whole lot, though.

Mr Kormos: Speaking to this point of order, that's an incredible amount of money.

I'm told that when the subcommittee met yesterday, there were but two parties who wanted to make submissions in Sault Ste Marie, which suggests to me that there wasn't an overwhelming enthusiasm about participating in the committee process around this particular bill in Sault Ste Marie.

In Kingston, there was a total of five, one of whom was prepared to go to London, which leaves you with effectively four people. At 20 minutes a pop, that's 80 minutes or one hour and 20 minutes. Lord love a duck, Chair, travelling all the way to Kingston, with the associated cost, for what will amount to one hour and 20 minutes of hearings?

Let's talk about Sault Ste Marie. When there were but two participants, that would have meant 40 minutes—less than an hour of submissions. Far be it from me to

suggest that anybody scrambled, from the government caucus, the whip's office or the House leader's office, to beat the bushes to find some more participants for the Sault Ste Marie hearings. I wouldn't in any way suggest that that happened yesterday, although I've seen it happen on previous occasions, because it would be embarrassing to go all the way to Sault Ste Marie for but two people.

Sometimes the government and its members have an interest in travelling to a given community, especially with such a benign piece of legislation as this one appears to be. Notice I've been here a couple of times during the committee hearings and I haven't seen any outrage. I've heard submissions but I haven't seen anybody waving picket signs or any angry murmurings in the audience.

The reason why you travel about and go out with committees is to accommodate people. Also, let's understand that the participants in this process are all what I call professional participants. There are no Jane Doe/John Doe participants, no plain folk kind of participants. What that means, and why I raise that, is that these organizations like the Sault Area Hospital or the Children's Aid Society of Algoma up in Sault Ste Marie would not be overly discomfited by using, let's say, teleconferencing. The technology wouldn't be overwhelming to these people.

I'm saying to you, with respect to this point of order by Ms Martel, that it is pretty foolish on the part of a committee to incur those types of incredible expenses, to be spending taxpayers' money in such a way for, as I say in one instance, one hour and 20 minutes of hearings; even in Sault Ste Marie, now that the list has been expanded from two to, oh, my goodness, six, for but two hours, for 120 minutes. Good grief. You wait that long at the airport to get on your plane. Right? You understand what I'm saying? That's how long it takes you to get your plane, and boom, it's over. So you're talking about a whole lot of bucks here. We're talking in the context, at least so far as where I come from, of social assistance recipients and ODSP recipients who are still not seeing a penny increase in their allowances.

1010

I listened to Mr Sorbara on Monday morning talking about the formidable deficit that was going to force some considerable restraint on the part of the government and its expenditures. I would say to you, Chair, and to this committee, that it would be delinquent and out of order for this committee to be dropping 10 grand, 15 grand, 20 grand a pop to travel about when the interests of the parties who want to make presentations can be served by teleconferencing.

When we're in this climate of fiscal restraint, of tightening our belts, of telling public sector workers that they might have to wait for their fair share, for what's due them in terms of wage and salary increases, what an affront to people on ODSP, to people on social assistance, to our public sector workers who are going to be told that the cupboards are bare, for this committee to be

blowing money like drunken sailors—and I've got nothing against drunks or sailors; I don't want to hear from the SIU about that comment; it was made in the context of the historical reference—in a time of fiscal restraint, when the interests of these parties can be met with teleconferencing, with the technology that's available. Good grief. Are they a bunch of Luddites here? Let's use that technology and save the taxpayer some money, especially when the taxpayer is going to be told he's going to be faced with bigger user fees because there is no money in the till, because the government coffers are empty.

Ms Martel says, "Wrap up," and indeed I do.

Mrs Elizabeth Witmer (Kitchener-Waterloo): I don't often find myself agreeing with Mr Kormos, but on this occasion I think he has made some excellent points. In a time of fiscal restraint, and having seen yesterday that there was really limited interest in speaking to this bill, I think it would be quite irresponsible for us to travel when we have the opportunity to do it by videoconferencing.

Mr Lorenzo Berardinetti (Scarborough Southwest): I had the opportunity to sit and listen to the deputations that the people who came yesterday and on Monday made to this committee. They made excellent presentations. I think one of the purposes of this committee—I am new, and I always like to preface my first few months in this job by saying I'm new, that I don't have the experience of Mr Kormos or Mrs Witmer.

Mr Kormos: You're lucky you're not as old as I am either.

Mr Berardinetti: Well, yes. I'm going to have to ask where you get those boots, because I think I'd like to get a pair myself one day. But, anyway, that's a different story.

One thing I've learned very quickly in being elected to provincial government is that the interests of the province are different than the interests of simply the city of Toronto. Whether we be in caucus, in the Legislature or in a committee meeting like today, we can't be always Toronto-centred.

The minister came on Monday and spoke and indicated the importance of this bill and of having wide public consultation. He made that very clear. When I saw the agenda on Monday morning, it was made clear that this committee would travel to Kingston, London and Sault Ste Marie.

Yesterday, the issue arose that there weren't enough deputants in Sault Ste Marie and/or Kingston and that perhaps it could all be done in London. We're all for saving money, but one cannot talk out of both sides of one's mouth. If we want to be democratic, if we want to be an open and fair government, a government that listens, then we must be committed to going beyond the borders of Toronto, beyond north of Steeles or west of Highway 427 or east of the Pickering town line or the Scarborough border.

As a city of Toronto MPP, I would think the world gravitates around Toronto, but it does not. Clearly there

are people here who are from other parts of Ontario who want to be heard, and I think it is incumbent upon this committee to go and listen to these individuals and to also commit ourselves to hearing from individuals across this province.

With all due respect to the concerns raised by the previous two speakers, I will be supporting or at least, if it does come down to a vote, putting forward the schedule in front of us and requesting that this committee continue with its schedule to go to Kingston, to London and to Sault Ste Marie. I think the costs are justified. Some of the speakers listed here are from the Sault Ste Marie area, some are from the London area and some are from the Kingston area. One could argue we could put them on teleconferencing, but then once again more reason to hate Toronto. Why is everything done in Toronto? Why are we always centralized in Toronto? This is an opportunity for this government to show that we want to go beyond the borders of the city and to hear from people beyond Toronto. So I will be supporting the travel and the locations listed in front of us today.

Ms Martel: If I just might make a few points, because I was part of the subcommittee meeting and no one at the subcommittee meeting yesterday suggested that we do everything out of London. That's the first point. And no one suggested that we limit the public hearings in any way by accepting fewer deputants or making them travel to places that they didn't want to travel to in order to accommodate them. Rather, we are suggesting that we can certainly accommodate the participants, we can listen to the participants by videoconferencing and teleconferencing here on Tuesday in the case of the deputants from Sault Ste Marie and from Kingston. That was part of the proposal that was put forward, that we would use Tuesday, use this room, link into the group from the Soo in the morning, link into the group from Kingston in the afternoon, and then make the trip to London, because clearly there was going to be quite a large number, or perhaps a full house, in London.

I just think that it makes absolutely no sense, at a time when the government is telling everybody else to tighten their belts, that we would refuse to look at some alternative ways to have people participate. We're not talking about limiting their participation. We are talking about accommodating their participation in a different way, because frankly there hasn't been an enthusiastic response from people in the Soo and people in Kingston.

It's interesting to note that at noon yesterday we had two participants in Sault Ste Marie and by 5 o'clock the government House leader's office had managed to rustle up four more. I'm not saying they're not legitimate but it seems bizarre that, if people really wanted to participate, by 12 noon on the same day that we were supposed to have that list in we only had two. So it's clear somebody got on the phone in response to that and found some more people. But I think the way we can accommodate those people is a much cheaper way for the taxpayers. I see no benefit in spending the kind of money that we are proposing to spend to actually physically be in Sault Ste

Marie and in Kingston. I point out we can save even more costs by actually using some of the government buildings. For example, in Sault Ste Marie at Roberta Bondar Place there's probably a board room at the Ministry of Northern Development and Mines which would accommodate the two hours of hearings that we're going to have, and I suspect we could do the same in Kingston so that we wouldn't even have the costs of the meeting room that we're now going to incur.

I don't understand what the problem is with this. It is not a controversial bill. It is a bill that we're going to have unanimity on and probably have a very good bill by the time it's over, and that's probably why we haven't had people banging down the door to participate and to make their views known, although I've appreciated the points that have been raised because they've clearly signalled the need for amendments. But I think it makes absolutely no sense at all to spend the kind of money that we're going to spend when we can hear from people just as appropriately through a different technical mechanism.

Mr John Yakabuski (Renfrew-Nipissing-Pembroke): I certainly agree with the members on the opposition side here, the third party. The government has made it clear, and the finance minister has made it clear, that given the circumstances they've been articulating over and over again we'd have to find creative ways of being more efficient in the way we spend our money. The teleconferencing option is a way that is not even that creative, but certainly will be more efficient in the way we spend our money. It will in no way affect the opportunity of persons or organizations who want to make submissions to the committee—it will in no way hamper them in doing so. Without repeating the points of others, I certainly think we should explore and go ahead with the option of teleconferencing in the way Ms Martel articulated could be done in one day. That would certainly serve the purpose of the submissions on the bill but would also save the taxpayers money, which is something we're all trying to do.

1020

Mr Kormos: Very briefly, let's also consider some of the practicalities of the season. Over the last two days we saw real pressure on Pearson airport in terms of flights cancelled and so on. Quite frankly, once again, the prospect of travel out of Toronto in the months of January and February has inherent problems. The best laid plans of mice and men—you could end up making all these wonderful plans and having them kiboshed and incurring yet more expense and more inconvenience.

I put to the government members and Mr Berardinetti that I read in the *Globe and Mail* earlier this week about the triumvirate of communications gurus, the high-priced help—I know you're not one of them; they're paid more than you are—in the Premier's office who are controlling the messaging. Far be it for me to give advice to government members, but the government members may want to ask for a brief adjournment to go and talk to the communications gurus, to ask them to reflect. As Mr Justice Osborne noted the other day downtown, how is it

going to look in tomorrow's paper when the National Post—as they have been wont to do about the flagrant, gross overspending and the expenditure on luxuries here at Queen's Park—runs a story about the committee blowing tens of thousands of taxpayers' bucks for an hour and 20 minutes of hearings in one community and two hours of hearings in another? That's gratuitous advice, which is probably worth exactly what you're paying for it, for your consideration, because I like you guys.

Mr Lou Rinaldi (Northumberland): I certainly support the fact that we need to save money. Anybody in their right mind who would want to waste money certainly is on the wrong side of the page. Once again, I am new here, the same as some of my cohorts—all of us, I guess—and I made a strong commitment when we formed the government, which we did, that we were going to bring the government to the people of Ontario, and I guess I'm referring mostly to rural Ontario. One of the things under the previous member from my riding was that the people in a 20-story building at Queen's Park could not see Northumberland county or any other part of rural Ontario.

If we truly wanted to use technology and save money, I think we could have done the whole thing through teleconferencing. Those people, especially yesterday, are to be congratulated for braving the weather. Some of them were late, but they made it here because this was very important to them. Why is something from people in Sault Ste Marie or Kingston—and we promoted that we were going to listen to those people—any less important than something from those who came here the other day? If we truly want to use technology and if we, as a government, believe that technology works and we want to use teleconferencing, then we should scrap this whole hearing process and we could all do it from the comfort of our living rooms. I would have loved to stay in my living room in Brighton yesterday instead of taking two and a half hours to come to Toronto to listen to the very important submissions we had yesterday. They were very good.

When I hear about spending thousands of dollars, when we think of the importance of this bill and the fact that it's been on the books for God knows how many years, way before my time here—and we do have some consensus of all-party support—I think it's very important that we listen to those people. I'm not suggesting that teleconferencing is not as good, but it certainly makes a big difference when I can sit across the table, one to one, and address those issues. I don't believe in double standards. Considering the amount of time and money that former governments have spent to come up with what we think—from what I've heard in the last couple of days—is a good compromise, with fine tweaking, I think a little bit of expenditure is the least we can do, as elected officials, to really prove to Ontario that we as a government and all members are listening to what they're saying. I don't think it's a waste of money.

Mrs Witmer: One final comment: This bill—and I guess the government members probably don't know

this—has been with us for a long time. I was Minister of Health when we drafted the first version. There has been ample opportunity for people to give input. I think we can see by the input we're receiving that this no longer is a controversial bill; it's a bill that really does reflect the best advice of people throughout Ontario. What we're dealing with now are requests for some very minor amendments.

Certainly we need to operate and be seen to be operating within a democracy, but whether you travel or whether you do it here, at this point in time everyone is going to have the opportunity to make a presentation. I know the government has been given their marching orders, but do you know what, folks? At a time when we see there is a problem with the finances of this province, I don't know how we can justify traveling when we have the opportunity for everyone to make their presentation and do it in a way that to me is much more fiscally responsible. I think we, as a government, need to lead; we need to demonstrate. Mr Sorbara is telling us we have a problem. Well, do you know what? We need to fix that problem, and it needs to start with us.

Ms Kathleen O. Wynne (Don Valley West): I'm going to hold off on my remarks. I'm going to suggest that we hear the deputants now, and if we need to continue this conversation—and we do need to continue this—we do it at lunchtime. Can I ask for consent from the committee to hear the deputants now?

The Vice-Chair: Is there consent?

Ms Martel: I probably won't be speaking to it any more. I was going to move a motion so we could actually have it on the floor and vote on it.

Ms Wynne: I just don't want to go into any more discussion. I think there are a couple more of us who have something to say, so I'd like consent to hear the deputants now. That's what I'm asking for.

Ms Martel: As long as I can get consent that when we go back to it, the discussion will be on Hansard. I don't want to move in camera.

Ms Wynne: That's fine. I don't have a problem with that at all. We'll continue this discussion on the record once we've heard from the morning deputants. Is that all right?

Ms Martel: Yes.

Ms Wynne: OK. Thank you.

OFFICE OF THE PROVINCIAL AUDITOR

The Vice-Chair: Our first presenters are from the Office of the Provincial Auditor. Good morning. You have 20 minutes to present. You may begin now.

Mr Gary Peall: My name is Gary Peall. I'm a member of the senior management of the Office of the Provincial Auditor. Seated beside me is John Sciarra, our executive assistant. Jim McCarter, the assistant Provincial Auditor, who is currently acting as Provincial Auditor while that position is vacant, is attending a financial statement symposium with the other Auditors General across the country and is unable to attend today.

In Jim's absence, I have been delegated the responsibility to act in his place.

We certainly appreciate the opportunity to comment on the proposals contained in Bill 31. I'd like to assure the committee from the outset that we won't be expressing outrage or carrying picket signs either. We're quite supportive of the bill.

We have reviewed the proposed legislation from the perspective of its potential impact on our office's ability to access information and records that we require to perform our audit duties under the Audit Act. We are particularly concerned about the possible impact of Bill 31 should the proposed amendments to the Audit Act contained in Bill 18, which was tabled by the Minister of Finance on December 9, 2003, be passed.

We respect the principles upon which the proposals contained in Bill 31 have been drafted. However, I also want to emphasize the needs of our office vis-à-vis the Ministry of Health and Long-Term Care's proposals. There are times when our staff need access to personal health information in the custody of the ministry in order for the Provincial Auditor to fulfill his or her duties under the current Audit Act, and from other health information custodians under the expanded mandate of the office as proposed in Bill 18. In this regard, we are pleased to note that schedule A of Bill 31, entitled the Health Information Protection Act, 2003, recognizes the need for the disclosure of personal health information for our audit purposes.

However, we do have a significant concern with a proposal contained in schedule B of Bill 31, entitled the Quality of Care Information Protection Act, 2003.

1030

While members here are no doubt familiar with the role and responsibilities of the Provincial Auditor, it might be useful just to provide you with a little background before I get into specific concerns we have. We are appointed as an officer of the Legislative Assembly and are responsible for the administration of the Audit Act. Under subsection 9(1) of that act, the Provincial Auditor is required to audit the accounts and records of the receipt and disbursement of public money forming part of the consolidated revenue fund, whether the money is held in trust or otherwise. To this end, the office of the Provincial Auditor audits the administration of government programs and activities, as carried out by ministries under government policies, and performs attest audits of the financial statements of the province and those of various crown agencies.

I want to emphasize that the work of our office is carried out in strict confidence and our employees are bound by the confidentiality restrictions imposed by sections 21 and 27 of the Audit Act. As well, according to section 19 of the Audit Act, our working papers cannot be laid before the assembly or any of its committees. As well, audit files and working papers, which include all information obtained from an audit entity during the course of an audit, cannot be accessed from our office under the provisions of the Freedom of Information and

Protection of Privacy Act because, by necessity, our office is not subject to its provisions, thus further ensuring the confidentiality of any information we collect.

Under section 10 of the Audit Act, every ministry, agency of the crown and crown-controlled corporation is required to provide the Provincial Auditor with such information regarding its powers, duties, activities, organization, financial transactions and methods of business as the Provincial Auditor requires. Also, the Provincial Auditor is to be given access to all books, accounts, financial records, reports, files and all other papers, things or property belonging to a ministry, agency of the crown or crown-controlled corporation necessary to the performance of the duties of the Provincial Auditor. For instance, in our audits of the Ministry of Health and Long-Term Care, we have needed from time to time to access information and records relating to personal health information. The ministry has always provided us with full access to that information and the records we've needed in its custody, as required by the Audit Act, including access to files such as OHIP claim files.

However, the ministry also provides grants to a variety of health care providers and institutions for the delivery of health care services to Ontario's citizens. Under subsection 13(1) of the Audit Act, we may perform an inspection audit of a payment in the form of a grant from the consolidated revenue fund or from an agency of the crown. However, an inspection audit provision in the Audit Act allows us to determine only whether the recipient of the grant has spent the funds provided for the intended purposes, but restricts us from performing any value-for-money-related audit work of grant recipient organizations. For many years, to allow us to better serve the Legislative Assembly, we have asked the government to amend the Audit Act to enable us to perform full-scope, value-for-money audits of grant recipient organizations.

Recently, the government responded to our request when the Minister of Finance introduced Bill 18, An Act respecting the Provincial Auditor, which, if passed by the Legislature, will give the auditor the discretionary authority to perform value-for-money audits of grant recipient organizations. I should point out that in drafting the amendments contained in Bill 18, advice was obtained from the Office of the Information and Privacy Commissioner to ensure that subsection 27.2(1) of that bill, regarding the confidentiality of personal information, meets current privacy requirements. In particular, subsection 27.2(3) of Bill 18 refers specifically to medical, psychiatric and physiological information because we recognized that, as with our audit work at the Ministry of Health and Long-Term Care, under the proposals of Bill 18 we could from time to time require access to personal health information in the custody of a grant recipient organization.

Turning to the specific concern with the provision of schedule B, this schedule protects from disclosure information that is provided to a quality-of-care committee of

a health facility or a health care entity or oversight body that is prescribed in the regulations. From our reading of this proposed legislation, there is a potential conflict between its provisions and the intended full access to information and records provisions contained in Bill 18.

Here is an illustration of the potential conflict we see. Under the proposed expanded audit mandate of Bill 18, if we were to perform a value-for-money audit of a hospital, it would be logical for us to examine the systems and procedures that the hospital has in place to monitor and improve quality of care so that the auditor can provide the board of trustees, the Legislature and the public with assurance that the hospital's systems and procedures are adequate. One such procedure might be the establishment of internal quality-of-care committees. However, the provisions of schedule B would prevent our office from reviewing quality-of-care information or assessments and evaluations done by a quality-of-care committee, including its recommendations to the management of the health facility itself.

The proposed legislation would also seem to prevent us from having access to any information disclosed to a quality-of-care committee. We are concerned that the restrictive provisions contained in schedule B could severely limit the possible scope of value-for-money audit work at a health facility, as defined in the act, and could prevent us from concluding on the adequacy of the procedures in place at such a facility. This, in my opinion, would contradict the intention of Bill 18 regarding the auditor's proposed expanded audit mandate.

To address this concern, our suggestion would be to amend the bill by providing a specific reference in subsection 4(3) of the act that would permit a quality-of-care committee to disclose quality-of-care information to the Office of the Provincial Auditor for the purpose of enabling the auditor to carry out his or her responsibilities under the proposed expanded audit mandate contained in Bill 18.

That concludes my remarks. Thank you very much again for the opportunity to present our concern. I would be pleased to answer any questions that the members of the committee might have.

The Vice-Chair: Thank you very much.

Mr Peter Fonseca (Mississauga East): I'd like to thank the Provincial Auditor for your presentation and for being here with us today. In regard to some of your last comments, the Provincial Auditor does have access to personal health records. Do those not give you enough information to do your work? What kind of information would you be looking for, exactly, within those personal records?

Mr Peall: The personal records that we would examine would be the ones supporting the actual procedures that a hospital would put in place to ensure the quality of care. If we were trying to conclude whether or not the policies they had established or were required to follow by regulation or legislation were actually being followed, the only evidence we could secure to determine that and conclude on that would be to examine the individual patient records.

Mr Fonseca: Would that not be sufficient?

Mr Peall: We'd also need to see what is done with the process from there on in. If they've established a whole set of procedures to make sure that their quality of care is maintained or improved, we would want to examine each of the steps along the way and the evidence that is there to prove that that is taking place. If, for example, they identify concerns, there should be a process in place to follow up on those concerns, to make certain recommendations for changes and that there is some follow-up process so that the institution and the board of trustees of that institution, if there is one, are assured that those things have been addressed. It's really having access to all the information to allow us to confirm whether those systems and procedures work as they were intended to.

Mr Jeff Leal (Peterborough): Just to follow up from Mr Fonseca, there were recent revelations, a long, in-depth series of articles in the Toronto Star about care in long-term-care facilities, indeed what you're suggesting here, the ones that are operated under provincial government regulation. So you're suggesting in your previous answer that you need those powers to look at those kinds of problems when you do money-for-value audits in the broader public sector?

Mr Peall: In the broader public sector, yes, that's our main concern and that's what Bill 18 introduces: the new powers for us. My understanding is—and I could be corrected—under long-term-care facilities, in the relationship we have now we already have access to that information and have had it in the past. So I believe we can access what we need to deal with those facilities. It is the broader public sector that we need access to.

Mr Leal: Thank you very much.

Mr Yakabuski: I think you've already addressed it, but it seems to me that your concern is that the Office of the Provincial Auditor would itself be handcuffed in the carrying on of its own investigations should the provisions in this bill not be amended in some way to allow you to have more access to those records, particularly in the case of auditing a health facility like a hospital.

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Mr Peall: That's correct; certainly something as important as the quality of care, which everyone would agree is fundamental.

Mr Yakabuski: You've indicated the section that you would like to be amended in your submission. Very good. Thank you very much. Sorry about the delay.

Mr Peall: Don't apologize. Any discussion of value for money is time well spent as far as we're concerned.

Mr Yakabuski: We staged that because you guys were coming.

Ms Martel: I just want to get confirmation. Right now, in long-term-care facilities you can, and have been able to, access what essentially would be quality assurance matters—not just matters with respect to quality of care, but matters involving personnel. Is that correct?

Mr Peall: I'm not absolutely certain of that.

Ms Martel: I'll tell you where I'm going, because normally I'm supportive of what the auditor moves

forward with, but I'll tell you what concerns me about schedule B in your request.

My understanding is, and my understanding may be wrong, that essentially the information we're talking about, coming from a quality-of-care committee, would be information that would impact on an employee's conduct versus systems and procedures to improve quality of care in a hospital. Maybe sometimes there's a very fine distinction between those, but that's my understanding.

I have no problem with your looking at concerns that would come to a committee involving procedures and standards and how to improve those. I'm a little more concerned about information that relates solely to an employee's conduct and how the institution or facility dealt with that in terms of their human relations. That's why I'm asking the question about what you do in long-term-care facilities now. If you do that already, then I could understand this would be an extension of something that you do. But I'm not clear that that's what you do and that's why I'm nervous about what you're requesting.

Mr Peall: Certainly in the kinds of audits we do, we don't take it to a level of personal cases in terms of what action was taken. However, we do have to confirm whether or not there is a process to take corrective action. It's not up to us to judge what corrective action ought to have been taken, and in this particular case there'd be professional matters associated with that which we're not in a position to judge and wouldn't attempt to, but we do have to be satisfied that there is a process in place to take care of those.

I can't think, off the top of my head, of a time when we've actually got into one of those circumstances in a long-term-care facility, but again, it would just be strictly process. I can certainly check with my office to see if there are any other kinds of situations we've been in, but certainly we wouldn't be looking at any individual case from the point of view of, "What did you do in this particular instance?"

Mr John Sciarra: If I can just add something. I don't believe the definition of "health facility" in schedule B includes long-term-care facilities.

Ms Martel: It was a recommendation that was made yesterday in one of the hearings, so you wouldn't have been party to that.

Mr Sciarra: Oh, OK.

Ms Martel: I'd appreciate it if you could get back to us. Thanks.

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

PSYCHIATRIC PATIENT
ADVOCATE OFFICE

The Vice-Chair: Good morning. You can begin your presentation.

Mr David Simpson: Thank you, Mr Chair and members of the committee. Good morning. My name is

David Simpson. I'm the program manager with the Psychiatric Patient Advocate Office. With me today is Lora Patton, our legal counsel at the patient advocate office.

We would like to thank the committee for its invitation to further consult on the proposed bill. We are here today to share our perspective as a rights protection organization and to let you know from our two decades of experience where we think this legislation can be strengthened to provide maximum rights protection for our clients and others with respect to the privacy of their personal health information. We are also pleased to inform the committee that the Mental Health Legal Committee, a group of more than 50 lawyers who represent our clients, has also supported our submission. You will notice too in our written submission before you that we also support a number of the recommendations made by the Canadian Mental Health Association, Ontario division.

Let me begin this morning by telling you who we are and what we do. The Psychiatric Patient Advocate Office was established in 1983 as an arm's-length organization of the Ministry of Health and Long-Term Care to protect the civil and legal rights of in-patients in the current and divested provincial psychiatric hospitals. Since our inception we have been partisan advocates for our clients.

We provide a range of services, including instructed and non-instructed advocacy, systemic advocacy, rights advice and public education. Since the changes to the Mental Health Act in 2000 we have also been designated by more than 95% of the schedule 1 hospitals in Ontario as rights adviser, now providing more than 20,000 rights advice visits, working on more than 4,500 advocacy issues and 140 systemic advocacy issues per year. Last year we also had more than 250,000 hits on our Web site, which has become an important tool in our public education efforts.

While our submission will focus on areas of this act that we feel are not adequate, we would like to acknowledge that the bill is a marked improvement over previous drafts. Specifically, the patient advocate office is pleased that PHIPA strengthens the privacy protection afforded to individuals through a very broad definition of personal health information; an obligation to obtain explicit consent for fundraising and marketing, which should not include provisions for opting out; and an expanded oversight role for the Information and Privacy Commissioner. Further, this bill restricts access by the Minister of Health and Long-Term Care and balances that access with a number of safeguards. PHIPA as well incorporates whistle-blower protections and ensures public consultation for most regulations. In general, the legislation is based on the fundamental value that individuals own their information and consequently should control its collection, use and disclosure.

However, as with any significant piece of legislation, PHIPA has certain limitations. While we are going to focus on two primary areas in a moment, we would like to draw your attention to a number of key issues that we

will not have time to discuss in detail. These include our status as a health information custodian; disclosures without consent or notification; the use of “informed” consent rather than “knowledgeable”; clarification of substitute decision-makers, a default substitute decision-maker, and the authority of a board-appointed representative; and more stringent rules around disclosures relating to risk.

PHIPA attempts to govern all personal health information across a number of sectors. While consistent rules are necessary throughout the health care system, both institutionally and in the community, some personal health information has a greater sensitivity attached to it due to its very nature. Mental health information is one of these special types of information that in fact may require special rules.

As a rights protection organization, let us be clear that PHIPA significantly erodes the rights that patients in psychiatric facilities currently enjoy. We will highlight some of these this morning.

The two broad issues that we are going to highlight from our written material are PPAO’s access to client information and areas of PHIPA that fail to recognize the special quality of personal mental health information.

As I stated, the PPAO has been providing advocacy in Ontario’s 10 provincial psychiatric facilities since 1983. Advocacy takes many forms: assisting in self-advocacy; individual instructed and non-instructed advocacy; regional and provincial systemic advocacy; and public education. In every case of individual advocacy, it is our preference to receive a client’s instruction. Unfortunately, our clients are sometimes unable to communicate their needs and to instruct patient advocates due to their illness, including perhaps having dementia, a dual diagnosis, schizophrenia, an acquired brain injury, or their medication may interfere or other factors. In cases where such clients are unable to instruct patient advocates, we ensure that their basic quality of life and care concerns are met through non-instructed advocacy.

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Our approach is to begin advocacy at the level of least contest: approaching the decision-maker closest to the issue. Such advocacy requires a great deal of communication with front-line staff and administration. Often issues are resolved very quickly with an inquiry from the patient advocate.

The authority to perform a patient advocate’s duties presently comes from the Mental Health Act, section 9. You’ll see that located at page 2 of our written submission.

The Minister of Health and Long-Term Care designates patient advocates under section 9. Authority in divested hospitals is derived from a standard memorandum of understanding signed by the facilities, the Ministry of Health and Long-Term Care and our office. The wording is described in our written submission.

There has been a lack of clarity respecting the patient advocate’s ability to access patient records for a period of time, given the tension between section 9 of the Mental

Health Act, which appears to provide authority for a patient advocate to access “books, records and other documents relating to patients” and section 35, which requires all disclosures to occur according to the rules in that section.

While the PPAO has largely been able to provide services despite the lack of clarity to this point, PHIPA will further complicate this process as that legislation and its disclosure rules appear to supersede any authority granted through section 9 of the Mental Health Act.

PHIPA does not presently provide any access to patient records for patient advocates. While patient advocates could obtain formal consent from the person or their substitute decision-maker, as would any other person wishing to access records, such a process would be impractical and unwieldy and would fail to ensure the protection of the most vulnerable clients—those who could not consent.

This process would be impractical because patient advocates would be unable to discuss client issues with staff on an ad hoc basis and would therefore be unable to resolve matters quickly, without further escalation.

It would be unwieldy to regularly obtain updated consents for each client that patient advocates speak to and to have staff acknowledge the same by reviewing the record before each discussion. Also, patient advocates may not wish to alert staff immediately to an issue; they would want to review the information in the clinical record first in some situations.

It would also fail to protect our most vulnerable clients, those who are unable to consent to release their own records or to instruct patient advocates. Patient advocates must be able to protect these persons without the step of obtaining consent from a third party who in fact is not their client. You will note that our recommendation is for PHIPA to provide our office with clear authority to carry out our mandate.

The second broad matter we are going to discuss relates to specific issues of mental health information. There are a number of areas in the legislation that presently fail to address matters specific to our clients.

The first issue is regarding disclosure of information without consent. Personal health information relating to mental illness is perhaps one of the most sensitive of the various types of information. Rules around disclosing that information cannot be dealt with in the same manner as general health information, yet PHIPA makes no distinctions. The continuing discrimination against persons with mental illness makes disclosure of information without consent a serious matter. A person who has been admitted to a psychiatric unit in crisis is much less likely to want that information shared than a person admitted to cardiac care.

Consequently, section 37 is not appropriate in the mental health context. The provision allowing a facility to contact a relative or friend if the person himself or herself is unable to consent where they are “injured, incapacitated or ill” is far too broad a statement. Many persons with mental illness entering hospital may be in

crisis and unable to immediately communicate their wishes regarding contact. That same person may feel very strongly that he or she does not wish to have family involved due to embarrassment or other factors.

Further, the ability to share information with those inquiring if the person is a patient, their general health status and location in the hospital is inappropriate. If the facility is a psychiatric hospital, informing someone that the person is a patient also discloses that the person is likely to have a mental illness. The person's general status could mean disclosing that the person is acutely ill and in four-point restraints. Location in a facility, when it is a general hospital, could mean stating the person is being held on the psychiatric ward. Many persons with mental illness would not want this information shared, particularly if the inquirer were an employer, probation officer or a separated spouse involved in a custody dispute. This would be a significant departure from current practice under the Mental Health Act.

We recommend that PHIPA not permit such disclosures without the explicit consent of the individual. Section 37 should be amended to permit the disclosure of information regarding a person's status, location in the facility or their condition only in circumstances where such disclosures would not disclose a diagnosis or mental health information. This would make it consistent with Manitoba privacy legislation. Also, appropriate emergency provisions could be created to permit disclosures in limited circumstances.

The Psychiatric Patient Advocate Office is also concerned about the provisions related to "implied consent." Implied consent to disclose information is inappropriate as it relates to mental health records or information, even where such information is being disclosed to another health practitioner for the purposes of providing health care. The increased sensitivity of such information and the continuing stigma encountered by our clients dictates that such disclosures only be made on the express consent of the individual or their substitute decision-maker.

The PPAO submits that subsection 20(3), a provision allowing a disclosing health information custodian to advise a receiving health information custodian that full disclosure was not provided due to limited consent, is inappropriate in the mental health context. One of the criticisms of privacy legislation in the past has been that health care practitioners will share information about patients without consent. While this provision improves on such open disclosures, a real concern exists that persons with a mental health history will be required to share that information with unrelated health care practitioners, which may result in actual or perceived reduction in service.

For example, clients have advised our office that their complaints of physical symptoms are not taken as seriously by health practitioners when the practitioners are aware of their mental health history. Inquests have also raised this concern. As such, persons with a mental health history are perhaps justified in not sharing that

information with health care practitioners they are seeing for unrelated purposes. Allowing the disclosing health information custodian to advise of the undisclosed information will undermine that ability.

Information belongs to the individual, and he or she must be permitted to disclose it as wished. If non-disclosure places them at risk, that is a risk that the individual may assume with appropriate informed consent. If non-disclosure of significant information is an issue, it may become part of the determination of capacity.

We are also concerned that the harm provisions might be over utilized by health information custodians who want to provide full information, without consent, citing risk and liability issues. That would undermine the intent of the lockbox. The PPAO has addressed the harm provision in the written submission, and we would encourage more stringent rules around the release of information for this purpose.

The last issue involves access to information. PHIPA will repeal the provisions of section 36 of the Mental Health Act and replace the section with access to one's own personal health information provisions under PHIPA. The Psychiatric Patient Advocate Office believes that section 36 of the Mental Health Act should not be repealed but should remain and be exempt from PHIPA.

Section 36 of the Mental Health Act in its present form provides significantly increased protections to persons in mental health facilities. Under the Mental Health Act, the facility must provide access to a record within seven days as opposed to the 30 days with indefinite extensions found in PHIPA.

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The Mental Health Act places the burden of withholding a portion of the record on the Consent and Capacity Board; that is, if the facility wishes to withhold the record, it must apply for permission to do so. PHIPA places the burden of the application on the individual. Instead of providing clear and responsive access to one's own record, PHIPA significantly erodes the protection of our clients.

The PPAO recommends that the present provisions under section 36 of the Mental Health Act be retained in the context of mental health facilities and, further, that the present provision for rights advice in section 38 of the Mental Health Act be retained.

In conclusion, the Psychiatric Patient Advocate Office is pleased that the government has taken this step to create legislation that will enshrine privacy protection both institutionally and in the community. We would, however, like to encourage this committee to strongly consider the recommendations relating to the protection of information specific to mental health.

We look forward to working with the government in finalizing, implementing and educating stakeholders on this new law.

Mr Yakabuski: Thank you very much for joining us this morning and thank you for your submission.

It seems you have a bit of a conflict. You feel one portion of the bill is too restrictive in your access as an advocate and another portion of the bill is not restrictive enough when coming to the disclosure of patient information to other health care providers. Am I reading that correctly?

Mr Simpson: Yes.

Mr Yakabuski: So what you're looking for is amendments to allow you, as an advocate, more access to those patient records in the case where people may or may not be able to make that informed consent themselves, but you want to see the exchange of information tightened up, particularly with people with mental health difficulties, when it comes to their cases being disclosed to other health care providers.

In your case, where you can't get that access, you're saying you're afraid you won't be able to get that access under section 35?

Ms Lora Patton: Our understanding of the new bill is that at present we won't have any access to any information, including conversations with staff on the floor of the facility. The day-to-day practice of patient advocates is to obtain an issue from a client: They've come to us; they've asked us for assistance. We then proceed with assisting them. Quite often they will give us some form of consent or certainly their agreement to pursue the issue. We're not simply going into someone's record. To be able to resolve those issues in some sort of reasonably efficient way, we would have to have those conversations on the floor with the staff, rather than escalating it to higher levels of administration. If we're required to get a form 14 or whatever the equivalent would be under the new legislation, the informal processes couldn't happen day to day on an ad hoc basis.

As well, Mr Simpson commented on the fact that we have clients who are unable to instruct us. These are clients who are most ill and, just to provide an example, one case that we had was a client who was in a locked seclusion room. They were left for a considerable period of time without access to washroom facilities, without access to walking around. In one case it was a client who had artificial limbs and they were removed, so she was unable to even walk on her own. If that client is unable to provide consent to us to access the record, it would be incumbent on us to find their substitute decision-maker. Under this legislation, we wouldn't even have the authority to find out who the substitute decision-maker is to get that consent. As a result, our advocacy activities are really handcuffed.

While I appreciate the conflict between on the one hand asking for increased access for our services—we are one of the safeguards that are built into the Mental Health Act to provide safety, to increase the quality of care and service to clients with severe mental illness. That's not the same situation that another health information custodian would be in.

Ms Martel: If I just might follow up with respect to the comments on access to records, what you stated was that you needed clarity or some clear authority to carry

out your mandate, and you made that reference particularly with respect to access to records. What would be the changes, then, that you propose in the bill that would more clearly point out that authority?

Ms Patton: One of the things that Mr Simpson mentioned was that section 9 of the Mental Health Act is our present authority in the non-divested psychiatric facilities across the province. While we may suggest something similar to that, in recent years it has become clear that there is some disagreement that that even provides us with effective authority. So we would ask for a clear exemption in the disclosure rules for access to patient advocates.

Ms Martel: I understand what you're saying. Thank you.

Mrs Maria Van Bommel (Lambton-Kent-Middlesex): I'd like to draw your attention to page 7 of your presentation. In the area of ability and right to appeal, you're saying that under the current Mental Health Act a person has the right to view findings in their files as they impact upon their legal rights and that the current legislation we're discussing is going to jeopardize those protections. Could you elaborate on that and possibly give an example?

Ms Patton: Under the Mental Health Act currently, someone who is found incapable for accessing his or her records has the absolute ability to apply to the Consent and Capacity Board to review that finding. Under the present draft of PHIPA, a person only has the ability to review that finding if they don't already have a substitute decision-maker in place, and that limit, we would submit, is inappropriate. If that finding is made, a person should have absolute authority to have that reviewed by an independent body.

Mr Simpson: You'll also see in our submission that we make a recommendation with respect to fees for accessing records. For many of the clients we work with, their sole income is government assistance, whether it be ODSP or Canada pension, disability benefits or something like that. There is no standard right now across the province, so hospitals charge different amounts. We're concerned that the fees charged shouldn't bar your access to getting access to your information and also shouldn't cause you financial hardship. It's your information; you should be able to access it if you'd like to see it. So you'll see in our submission that we talk directly to that and make a recommendation that if the fees are going to bar access or cause financial hardship, then the person shouldn't have to pay those. We're concerned that a great way to keep people from seeing their information is to escalate a fee schedule.

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

NATIONAL ASSOCIATION
FOR INFORMATION DESTRUCTION

The Vice-Chair: The next group is the National Association for Information Destruction. Good morning.

Mr Dan Steward: Good morning. My name is Dan Steward. I'm a member of the executive of the National Association for Information Destruction, or NAID. With me today is Sheldon Greenspan, the chair of NAID Canada. Sheldon and I are affiliated with companies involved in the provision of records and information management and document destruction services. On behalf of NAID, we would like to thank the committee for allowing us to appear here today to discuss Bill 31.

We believe this bill is a positive step in helping safeguard the protection of personal health information and ultimately the privacy of Ontarians. For this, the government should be commended.

We hope the government will take the opportunity of eventually introducing complementary legislation for the private sector which would supersede or replace the privacy provisions that are currently in force under the recently implemented federal PIPEDA legislation.

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Bill 31 does an excellent job of dealing with the collection, maintenance and disclosure of information. However, we are concerned that the legislation in its present form, like PIPEDA and other pieces of privacy legislation in this country, does not effectively address a critical part of the information life cycle—namely, the destruction and disposal of information—with the result that it jeopardizes and weakens the very privacy protection it seeks to provide. Information, be it documents or records of any kind, is only as secure as the weakest link in the life cycle. This legislation does not currently provide adequate measures to ensure the proper destruction and disposal of potentially sensitive information.

We also have some concerns and questions about the relationship between health information custodians and their agents, as currently outlined in the bill. We will address these issues here today.

First of all, I would like to start by telling you a little bit about NAID. NAID Canada, which was formed last spring, is a national association that represents companies that specialize in secure information and destruction of documents. We are a chapter of the National Association for Information Destruction, which was founded in 1993 in the United States. There are currently over 375 NAID members throughout North America.

Our mission is to raise awareness and understanding of the importance of secure information and document destruction. In doing so, we want to ensure that private personal and business information is not used for purposes other than that for which it was originally intended. NAID plays an active role in the development and implementation of industry standards, advocacy and professional development. NAID has also developed an industry certification standard for its member companies.

NAID is also active at the legislative level, not only here in Canada but in the United States and other jurisdictions around the world. We are actively working to promote common standards and approaches to the disposal and destruction of information and privacy protection.

Here in Canada, we have met with federal officials from Industry Canada and the office of the privacy commissioner. We have also met with and made submissions to various officials from both British Columbia and Alberta regarding the development, implementation and enforcement of their privacy legislation. Here in Ontario, we have met with and made submissions to officials from both the previous and current administrations to share our views on the development of made-in-Ontario privacy legislation. We intend to continue working with all levels of government to ensure the best possible protection of personal information and individual privacy.

Sheldon and I could easily spend all day discussing with you the best ways to destroy and dispose of information, be that crosscutting, continuous shredding, pulping and incineration or a variety of other methods, depending on the nature of the information, how and where it is stored, the volume of information and a range of other considerations, as well as why every organization should use one of these methods to ensure the proper protection of such information.

However, today we would prefer to focus on a few specific measures that we believe must be part of this legislation in order to ensure the effective protection of health information and privacy of individuals and, in doing so, provide some clear definition and direction for those who will be subject to the legislation regarding what constitutes proper destruction and disposal of information.

With these points in mind, we offer the following recommendations regarding Bill 31:

First, we believe that this legislation will be strengthened significantly if specific references to and definitions of the terms “destroy” and “dispose” are adopted and incorporated in the legislation, as appropriate. Similarly, we want to bring to the committee's attention regulations that we believe are necessary to support the implementation and enforcement of this legislation in order to ensure that information is properly destroyed and disposed of.

In several sections of the legislation—in particular 10(3), 13 and 17—the bill refers to the term “dispose.” However, the legislation does not define what is meant by the term “dispose” nor does the legislation mention any prescribed requirements regarding what constitutes effective disposal.

We raise this point because the word “dispose” and the notion that the disposal of health information implies, means or guarantees the destruction of this same health information is not assured.

It is also very important to note at this juncture that recycling is not an acceptable alternative to information destruction, nor is it good enough to assume that information put in a garbage bag or some other receptacle will effectively be destroyed.

To guarantee the secure protection of personal health information, this information must be destroyed before it can be either disposed of or recycled. And to effectively

protect privacy, any standards for the proper collection, management, use and disclosure of information must also include specific requirements for proper destruction and disposal of this same information.

An important consideration when developing and implementing provisions respecting protection of personal information is that identity theft and other information-based crimes are among the fastest growing in Canada and indeed in Ontario. They are growing, in no small part, because of inadequate destruction and disposal requirements. Failure to adequately address the destruction and disposal of health information will only contribute to the continued growth in these activities, be they criminal or otherwise, and further jeopardize the privacy of Ontarians.

Let me be clear. We understand that protection from identity theft and other crimes is not the only or even the main reason that Bill 31 needs to be strengthened.

If I may, I would like to quickly share with the committee an illustration of how the lack of appropriate provision and definition can lead to significant problems. This particular story was shared with us on many occasions by officials in British Columbia recently.

A British Columbian health administrator was asked to dispose of some health records. In the interest of saving some money, he decided late one evening to take these records to a beach and burn them in a bonfire. He thought no one would be the wiser and see him, and he also thought he would be fulfilling his duty of document destruction and disposal. He made the fire, but did so unaware that high tide was moving in. The tide not only washed out the fire but carried with it and scattered hundreds of personal health care records for miles down the shore line, making personal health information available to anyone walking along the beach. A true story.

An extreme example, yes, but there was no criminal intent on the part of the individual. He was asked to get rid of some information. He did so in the most efficient way he thought possible. There were no clear procedures to instruct him on how to do so and, unfortunately, the approach taken came at the expense of a number of unassuming individuals.

Stories like this are plentiful. Many of them originate here in Ontario. Recall the recent case of a big bank's computer hard drives that were not properly cleaned before being resold; or, more relevant to our discussion today, the case of the Ottawa woman whose medical records ended up as part of a real estate flyer.

It is for these reasons of personal protection and privacy that Bill 31 and ultimately the regulations developed in support of this legislation must include appropriate definitions and provisions prescribing requirements to ensure proper destruction and disposal of health records.

Some definitions: Specifically, NAID Canada would recommend that the following two definitions be included and added to sections 10(3), 13, 17 and elsewhere as appropriate in Bill 31: “‘destroy (destruction),’ the

physical obliteration of records when they are no longer required in order to render them useless or ineffective and ensure reconstruction of the information (or parts thereof) is not possible.” For “‘disposal,’ the casting aside or getting rid of destroyed information.”

We'd like to turn our attention to some principles supporting the development of regulations that we believe should be enacted respecting Bill 31. NAID Canada believes that development in support of this legislation must outline the conditions under which records containing personal and private health-related information may be discarded by organizations, and these include but are not limited to: requiring shredding of patient/individual records before they are disposed of; requiring that personal information contained in patient/individual records is erased before they are disposed of; requiring that personal information contained in patient/individual records be made unreadable before they are disposed of; and taking reasonable actions to ensure that no unauthorized person will gain access to personal information contained in the patient records between the time they are discarded and the time they are destroyed.

Specific mention should also be made that organizations are required to take reasonable steps to effectively discard information that requires destruction consistent with the definitions to be included in this act.

In order to comply with this legislation and its regulations, it should be recognized that recycling is not an adequate alternative to information destruction. Only after it has been properly destroyed can, and should, the information be recycled.

Sanctions and penalties should be highlighted so individuals and organizations are clear about the penalties if there is a failure to demonstrate due diligence in their attempts to destroy records containing personal health information.

We believe regulations should also outline specific requirements regarding where and how the information should be destroyed and disposed of, be this in-house, mobile or plant-based shredding, continuous shred, cross-cut/pierce and tear, pulverize, pulping, incineration.

Upon completion of the destruction process, a signed certificate of destruction should be provided by the vendor, termed an “agent” under the current legislation, to the health information custodian confirming that the records transferred from the custodian to the vendor have in fact been destroyed.

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NAID also believes there should be regulations specifying the period of time that records are stored, which should be determined by a retention schedule taking into consideration their useful value and the governing legal requirements, of which we know there are unique considerations when it comes to health-related records.

Finally, ensuring the documentation of the exact date that the record is destroyed is also a prudent and recommended precaution.

Why regulations? As we noted previously, identity theft is one of the fastest-growing crimes. Heightened interest and concerns about these crimes, together with the introduction of various pieces of privacy-related legislation throughout North America, has resulted in rapid expansion of our industry. Many mature, established and well-run document destruction and information management companies have benefited from this, resulting in annual growth of 15% to 20% over the last few years.

This growth has also led to a sharp increase in the number of participants in our industry. This is both good and bad for consumers. On one hand, more service providers allow for more choice, both in quality and cost, for the consumer. On the other hand, in the absence of appropriate regulation, less reputable players are allowed to exist at the expense of both the industry and the people whom such legislation is meant to protect.

NAID Canada believes that the use of regulations in support of Bill 31 will provide the government with enough flexibility to adapt and change them as methods of destruction and disposal evolve over time. At the same time, they provide thorough legislative authority and oversight to ensure proper care is taken, both by the health information custodians and their agents, to ensure that the information is properly destroyed and disposed of.

As a final issue, we'd like to raise with you a concern we have about the use of agents. The legislation mentions, under subsection 17(1), how a health information custodian may permit a custodian's agent to collect, use, disclose, retain or dispose of personal health information on the custodian's behalf.

As we currently understand the legislation, our members would be considered agents for health information custodians. As such, the custodian would define the agent's duties and impose limits on what is expected of the agent, in accordance with the requirements of the bill.

Our question to you, and an area of potential concern, is the relationship between custodians and agents and the need for consent to destroy and dispose of information on the custodian's behalf. We assume and expect the onus to be on the custodian to obtain consent from individuals to allow their information to be destroyed and disposed of. If this is not the case, it would be a major concern to us, as our members would face an unreasonable burden and liability. Accordingly, we would like the provisions respecting the relationship between custodian and agent and the issue of consent to be clarified.

We'd like to thank you for your time, and hope you found this presentation useful. NAID Canada believes that by taking the necessary steps to ensure that the complete life cycle of information protection is properly addressed under the terms of the bill, Ontario will be taking steps to ensure that it is a leader in terms of privacy protection, not only in Canada, but also in North America and the world. We'd be pleased to answer any of your questions.

Ms Martel: Thank you for coming here today and raising these issues with us. This has been a much different presentation from the others we've had.

Let me deal with the recommendations you made with respect to subsection 10(3) and sections 13 and 17, where you were talking very specifically about definitions. I just flipped through those sections and wonder if what you were trying to achieve would actually be served by having specific definitions in the first part of the bill where those are listed and then the reference can be back to the definitions themselves, because these talk about individual rights to modify, collect, use and disclose, and a lot of those terms are found in the definitions section. Would it essentially deal with the concerns you have, that somewhere it be very precisely defined what that means so people can understand their obligations?

Mr Sheldon Greenspan: Clearly we want to have "destruction" defined, as opposed to "disposal." If it was set up in the definitions section, that would be appreciated.

Mr Steward: The ultimate goal is to avoid the BC case, so there's clarity about what those words mean.

Ms Martel: What it means and what your obligations are.

Mr Greenspan: Absolutely.

Ms Martel: With respect to the regulations, I haven't had a chance to look through, but I suspect we're going to need some new ones to deal with some of those provisions as well, rather than add on to the ones that are currently there.

Mr Steward: Most of the legislation, in terms of gathering consent for how information is used—we've kind of gone 90% of the way. This is the last 10% of the way, about how we finally take care of these records once they've served their useful life. Because the chain of security and protection is only as strong as its weakest link, we're really looking for strengthening on that last 10 yards, to use that analogy.

Mr Berardinetti: Thank you for coming today and presenting a very interesting presentation. Just a couple of very quick, short questions here. Do you represent all the groups that destroy records? I'm just trying to understand who you actually represent.

Mr Greenspan: Our association represents companies in the document destruction industry. I get all facets of the industry, including equipment manufacturers—

Mr Berardinetti: Private companies, for example, that are out there that provide shredding services?

Mr Greenspan: Yes, sir.

Mr Berardinetti: The second point is, what about electronic and/or computer records and microfiche-type records? How would you deal with that?

Mr Greenspan: Our position would be the same, the key point being that the information needs to be obliterated, irrespective of the media it's on. So the responsibility would be on the organization to ensure that that information on that media is physically destroyed.

Mr Berardinetti: Do you have a system or a recommendation of how those records would be destroyed if,

let's say, a doctor passes away and leaves behind a hard drive full of information?

Mr Greenspan: We're thinking that, in terms of the evolution of our industry, the technologies are changing so quickly on the media on which information is being stored, but also in terms of methods of destroying that information, that in the regulations it would allow for some additional flexibility to take into account future changes.

Mr Berardinetti: So you'd be willing to work with staff on that?

Mr Greenspan: Absolutely, but really the key point is that the information needs to be destroyed before the media on which that information was on is either disposed of or recycled or reused.

Mr Berardinetti: I understand. Presently, there is no professional standard for all the different groups—let's say doctors and hospitals and all the other groups that would be collecting this information. There is, I take it, no standard or procedure used for all these different caregivers or providers.

Mr Greenspan: That's really our hope: to establish a clear baseline in terms of the definition, and clarifying what the obligations are on the organizations and the people who have custody of that information.

Mr Steward: There are records going into places like landfill or sitting in you-store-it places where somebody doesn't want to incur the cost because the doctor has passed away or ceased practising or moved.

Mr Berardinetti: So your point is, again, destroy it at the point before that happens.

Mr Steward: If you say they're no longer required by all of the legislation that pertains to health records, then there's a clear way of now getting rid of them.

Mr Berardinetti: Because the definition of "records" is pretty broad in the act, I think, but your point goes beyond that.

Mr Steward: It doesn't matter what the media is. The technology does exist to destroy all of it now.

Mr Yakubuski: Thank you for joining us this morning. I think you've raised some very interesting points that we haven't heard before because of the nature of the other submissions. If we bring in legislation that takes privacy protection to a whole new level, which is the intention of this act, we then also assume the responsibility of protecting that information until such point as that information no longer exists, which includes its destruction. I think you've raised a very good argument for defining that in specific ways. The definition can certainly include any currently existing method of storage or anything that happens to come about because of improved technology. I think you've touched on some very good points with regard to the responsibility to protect that information until it no longer exists.

Mr Steward: Thank you.

The Vice-Chair: We're just going back to Mr Leal for one quick question.

Mr Leal: Mr Chairman, I'll be quick.

Thanks very much. It was a very interesting presentation. The fact of the matter is, so much information now moves internationally, I'm curious why the ISO hasn't developed a standard for document destruction that's consistent all over the world.

Mr Greenspan: NAID is actually working with a number of organizations worldwide on setting up, ultimately, worldwide standards. The Europeans have some very stringent legislation on the books. The Americans, of course, have some very stringent legislation, and, of course, there are various pieces within Canada. Clearly, the situation of being left behind is very scary, because in the jurisdictions that have the weakest privacy legislation, the ability for identity theft to transpire over borders is pretty scary. The thinking is that if a jurisdiction is the last to the party, so to speak, that's where a lot of criminals are going to end up committing their identity theft crimes because they realize that the penalties are the lowest or are non-existent. It's very easy to commit one of these criminal activities in a cross-border situation, so NAID is responding in terms of being on the cutting edge of lobbying with a variety of different governments, particularly in North America but also on a worldwide basis.

The Vice-Chair: Thank you for your presentation.

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CANADIAN INSTITUTE FOR HEALTH INFORMATION

The Vice-Chair: The next group is the Canadian Institute for Health Information. Good morning.

Mr Richard Alvarez: Good morning, Mr Chairman, and thank you, members of the committee. My name is Richard Alvarez. I'm the president and CEO of the Canadian Institute for Health Information. Some of you might know us as CIHI. I wish to thank the committee today for giving us the opportunity to appear in front of you. I have with me Ms Joan Roch, who is CIHI's chief privacy officer.

In my presentation, I will begin with my key message to you. I will then describe CIHI's unique role in health information in Canada, and I will end with some specific comments on the bill.

My key message to you is that CIHI supports this bill. It provides a framework of rules for the collection, use and disclosure of health information. It provides individuals with options regarding the disclosure of their information. It also recognizes that some information must flow for the purposes of accountability, management of the health care system and research.

That being said, we would also like to request two things: first, that consideration be given to establishing a special designation for CIHI that would reflect CIHI's multi-faceted role in health information; and second, that consideration be given to an amendment that would facilitate the services CIHI provides to health ministries in other jurisdictions.

By way of background, the Canadian Institute for Health Information was incorporated in December 1993 as a federally chartered, independent, not-for-profit organization, as agreed to by the federal, provincial and territorial Ministers of Health. The ministers also set CIHI's mandate, which is, briefly stated, to serve as a national mechanism to coordinate an integrated approach to Canada's health information system and to improve the health system and the health of Canadians by essentially doing three things: coordinating and promoting the development and maintenance of national health information standards; developing and managing health databases and registries; and providing objective and accurate analyses of health data, which are widely disseminated.

I should tell you that the flow of this data to support this mandate is complex. Let me give you some concrete examples of the data CIHI collects and how the data are used.

At CIHI, we manage some 21 data holdings. Nine of the holdings are related to health human resources and health expenditures and do not contain personal health information. The balance are related to health services and include holdings such as the discharge abstract database. This is in fact our largest data holding. It predates the formation of CIHI. It is collected from hospitals and is comprised of basic data on the causes of the hospitalization, procedures performed and length of stay. It is used to produce national comparative hospital stay reports. These reports allow hospitals to compare their activity to similar sized hospitals across the country. Because of its historical base and comprehensiveness, it is valuable for studying trends in hospital utilization.

Another good example is the national ambulatory care reporting system. This data holding captures data from emergency rooms and outpatient departments, where, as you know, more procedures are now being performed. You may recall that in the summer of 2003 there was a debate that erupted as to the dangers of body checking in minor hockey. Data from this holding provided some important facts as to the number of people who visit emergency rooms each year in Ontario due to hockey injuries. The data showed that the main cause of injury was body checking and that it particularly affected players under the age of 17.

My last example is the Canadian organ replacement registry. The registry tracks trends in renal dialysis and organ transplantation, including patient survival rates of individuals with organ transplants and dialysis. For example, our 2003 report showed that over time, outcomes for lung transplants are improving.

These holdings and the reliability of the associated analyses depend on the continued flow of defined sets of health information from many sources, primarily health facilities, to CIHI. The holdings include data elements determined by advisory groups to be necessary for health services utilization and outcome analysis.

Once we receive the data, it's processed, data quality measures are applied and it's stored for reporting and

analytical use at CIHI. Only a limited number of analysts have access to data holdings, and access authorizations are reviewed regularly. We also have developed programs in place that mask personal health numbers and specific sensitive data elements from the analysts.

CIHI also discloses data to external researchers, many of whom are associated with academic institutions or organizations, such as the Institute for Clinical Evaluative Sciences, ICES. In these cases, consistent with CIHI policy, the data are de-identified before the disclosure and research agreements are signed that address use, retention, publication and confidentiality of the data.

CIHI also discloses identifiable information when it is permitted to under an act. For example, identifiable information is disclosed to Cancer Care Ontario for the purpose of the Ontario Cancer Registry under the Cancer Act. A data-sharing agreement guides this disclosure.

CIHI takes privacy and data protection extremely seriously. The institute recognized at the outset that to be successful it not only had to provide objective, valuable and reliable information but also that it was critical to address privacy, confidentiality and security matters. As such, shortly after its establishment, CIHI put in place privacy principles based on the CSA model code to guide its operations. It also included in its bilateral agreements with Ministries of Health a commitment to abide by relevant health and privacy legislation in respective jurisdictions. Attention to these principles has produced a privacy program that is considered to be one of the best in the field and has led to a culture of privacy at CIHI. We are pleased to be able to say that in our years of operation we have not had a single privacy breach.

As I turn my attention to comments on the bill, first, CIHI is pleased with many parts of the bill. Two which I should mention are research and oversight. We are pleased that the bill includes a definition of research, as well as a list of permitted uses of data outlined in section 36 of the act. This will assist us in determining what activities are subject to the research requirements as set out in section 43. CIHI also supports the requirements set out in section 43, for example, that researchers who wish to use identifiable personal health information must submit a research plan and obtain the approval of a research ethics board. These requirements are similar to those CIHI has in place for access to de-identified data.

As well, CIHI welcomes the designation of the Ontario Information and Privacy Commissioner's office as an experienced entity to perform the oversight function with respect to the personal health information of Ontarians.

At the same time, there are two aspects of the bill on which we would like to make some recommendations.

The first aspect is in relation to CIHI's designation under the bill. Subsection 36(1) lists the permitted uses for personal health information by a health information custodian. This list encompasses most of CIHI's functions, but CIHI is not included in the list of health information custodians set out in subsection 3(1). Although subsection 3(1), paragraph 7, makes allowance

for other persons to be prescribed as custodians, because CIHI has no direct relationship with a patient, it is unlikely CIHI could comply with the obligations of the custodian designation. As such, for CIHI to carry out its functions, it must be under a designation other than custodian.

To this end, we reviewed the health data institute designation. However, it appears to be intended for the minister to undertake specific research projects as opposed to the wide program of work under CIHI's mandate, and it clearly indicates in clause 45(15)(f) that the minister can control the release of research findings. Such a limitation would be contrary to CIHI's role of an objective and independent provider of health information.

Subsection 36(2) permits a custodian to provide information to an agent, who may use it in the same manner as would the custodian. "Agent" is defined in section 2 as "a person that, with the authorization of the custodian, acts for or on behalf of the custodian." Under this arrangement, CIHI would need to establish an agent relationship with each facility in order to access the data. Given the many facilities that we deal with, this is potentially an unmanageable situation.

You should know that today CIHI receives the vast majority of its data under regulation 23 of the Public Hospitals Act. That regulation states that when a hospital is requested to do so by the minister, it shall provide information "to a person for purposes of information and data collection, organization and analysis." This would suggest to us that one possible solution would be to establish CIHI as a specially designated agent or organization of the ministry, possibly in regulation.

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Based on our review, a type of agent could be established in Bill 31 similar to the "information manager" designation in Alberta and Manitoba. Based on our experience in both of these provinces, such a designation with a limited number of parties is workable.

CIHI has discussed this as a possible solution with representatives of the Ministry of Health and Long-Term Care, and we look forward to continuing working with them to this end.

My second concern is in relation to disclosures related to out-of-province patients. As you may be aware, patients from other provinces and territories come to Ontario for health procedures. It is important for the home jurisdictions to receive information on the services their residents are receiving elsewhere. This helps the home jurisdiction make health policy and service decisions and is particularly important to smaller jurisdictions such as Nunavut, where residents may receive many health services from other jurisdictions.

The authority for CIHI to be able to disclose this information back to the home jurisdiction is not abundantly clear in the bill. Currently section 48 permits disclosures outside of Ontario for the administration of payments only, as we understand it. CIHI would request that the section be revisited and consideration given to an amendment that would clearly permit this limited type of

disclosure to be made regarding out-of-province patients for the purpose of health services utilization analysis.

In closing, I would like to reiterate that CIHI supports the intent of Bill 31. We look forward to legislation in Ontario that provides a framework for the protection and oversight of personal health information in Ontario. I believe this bill provides such a framework.

We also believe the comments we have made are necessary to facilitate the smooth functioning of the health information system. We look forward to working with representatives from the ministry to address our concerns.

In the meantime, I'd like to assure you that until personal health information legislation or some other form of legislation is in place, CIHI will continue to apply its robust privacy protection program.

Once again, I'd like to thank this standing committee for the opportunity to make this oral presentation. We will be making a written submission outlining our suggestions in more detail. Thank you.

Mr Fonseca: The Ministry of Health and Long-Term Care thanks you very much for the great work you've done for this province, and we're taking into account the recommendations you've brought forward.

One recommendation was around the designation of CIHI. If you were designated as a data institute, would this address the concerns you have brought out?

Mr Alvarez: I don't think so. I'm going to leave it to my chief privacy officer to explain why it's restrictive.

Ms Joan Roch: I understand from the way the health data institute is structured right now that a lot of powers rest with the minister and that it is for specific research programs only. He does have the power to restrict disclosure of the outcomes of that research, even if they are de-identified. It says, "even in de-identified form." One of CIHI's basic roles is to disseminate de-identified information for purposes of health utilization information. So that would be contrary to what we do, and it doesn't satisfy our need to provide a larger program of work. We do more than just specific research projects. Is that helpful?

Mr Fonseca: That does help.

Mrs Witmer: Thank you very much for your presentation. I've always appreciated the work CIHI has undertaken.

You are suggesting, then, that you would like to be given a designation that would be similar to what we have in Alberta and Manitoba, and that would be "information manager"?

Mr Alvarez: An information manager, and it could be accommodated, I suspect, in the regulations.

Mrs Witmer: That has solved the problem in those two provinces?

Mr Alvarez: It certainly has for us. In the agreements we have with them, it seems to have solved the problems. It takes into account the variety of work we have and does not interfere with our objectivity and independence, which is really important.

Mrs Witmer: Yes, for sure. That's the basis of everything that you do.

You talk about the disclosures that are going to be required for out-of-province patients. For the purposes of health services utilization analysis, what type of information do you want to be able to communicate to other jurisdictions, such as Nunavut?

Mr Alvarez: It would basically be the information we collect under the discharge abstract from hospitals. Nunavut, for example, needs to know how many of their patients got services in Ontario, for what types of conditions, what were the diagnoses. It's that type of information. They're less concerned about who it was; they're more concerned about the numbers and what actually happened to them. A similar thing would apply to Ontario as well if Ontario patients travel outside the province.

Mrs Witmer: And so at the present time that's not possible?

Mr Alvarez: At the present time, the way this bill is structured, it's not possible.

Mrs Witmer: Thank you very much.

Ms Martel: Thank you for being here this morning. I want to follow up on the request for a designation of information manager and be clear about something. If we were to define "information manager" in the definition section, would that solve the problem, or would there be other parts in the bill that then have to be amended around mandate and role?

Ms Roch: I think that would go part way to solving the problem. One of the key elements in the manager arrangement would be the need to establish an agreement which would specifically outline the kinds of roles we undertake on behalf of the ministry and would include our national reporting responsibility, which we don't think is possible with the existing agent designation. However, I'm not a legal draftsman, so perhaps some work could be done to the "agent" definition as well; I'll leave that up to the drafters.

Ms Martel: You said you were going to be sending us another brief.

Mr Alvarez: A written one.

Ms Martel: Is it possible—because I'm not clear either on the best way to do it. There are certainly any number of definitions that could be added in. There was a request yesterday from another presentation for a similar designation and the reference to Alberta was made. I don't know what their legislation says. If it's not too much of a problem and if that's something you were going to look at anyway before you provided us the written brief, I'd appreciate that.

Mr Alvarez: We will do.

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

ONTARIO DENTAL ASSOCIATION

The Vice-Chair: The next presenters are the Ontario Dental Association.

Dr Blake Clemes: Good morning and thank you for this opportunity to address the standing committee on general government. I am Dr Blake Clemes, president of the Ontario Dental Association. With me today are the ODA director of government relations, Frank Bevilacqua, and Linda Samek, director of professional affairs.

The Ontario Dental Association, the ODA, is a voluntary professional organization which represents over 80% and over 6,000 of the dentists of Ontario. The ODA supports its members, is dedicated to the provision of exemplary oral health care and promotes the attainment of optimal health for the people of Ontario. The patient-practitioner relationship is based on trust, and patient confidentiality is central to the trust between regulated health care practitioners and patients. Patients expect that their health information is private and that regulated health providers will respect that confidentiality.

The ODA supports the development of provincial legislation intended to protect personal health information. Recent experiences with the application of the federal Personal Information Protection and Electronic Documents Act, PIPEDA, to the health care sector demonstrate that the federal legislation is not sensitive to the nuances of existing privacy practices within the regulated health environment in Ontario. It is the view of the ODA that the public, health care providers and others will benefit from a made-in-Ontario solution to some of the issues and confusions raised by PIPEDA.

While the ODA generally supports this provincial approach to the protection of personal health information, it is our view that the legislation is complex. Consequently, there are areas of the legislative draft that require greater clarification and other sections that require revisions to ensure that disclosures of personal health information serve the interests of the patient while balancing the responsibilities and accountabilities of the regulated health care provider.

Let me start with a question about the clarity of the definition of "health care." The definition outlined in Bill 31 does not include the term "assess." It is not clear that the use of the word "assessment" in the preamble to the listed health-related purposes is sufficient to ensure consistency between Bill 31 and the existing Regulated Health Professions Act. Under the RHPA, the provision of a health care diagnosis is limited to a small number of regulated health care professions and the omission of the word "assess" may be significant to the interpretation and application of the definition under the Health Information and Protection Act.

Accordingly, the ODA recommends that clause (a) of the definition be amended to read:

"Is carried out or provided to assess, diagnose, treat or maintain an individual's physical or mental condition."

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Subsection 7(2) sets out that the proposed act will prevail in the event of a conflict between the legislative provisions of this act and the provisions of any other act or its regulations. This blanket attempt to protect against

future problems may not always serve the true interest of the public. Indeed, it is our view that there are instances where the Regulated Health Professions Act, related profession-specific acts and regulations may apply more stringent privacy protection measures. For instance, the regulations drawn under the Dentistry Act make the following an act of professional misconduct for the purposes of clause 51(1)(c) of the Health Professions Procedural Code:

“(17) Giving information about a patient to a person other than the patient or his or her authorized representative except with the consent of the patient or his or her authorized representative or as required or allowed by law.”

Considering the intent of this bill and the existing legislated framework of the RHPA, the ODA recommends that the Health Information Protection Act not be permitted to prevail over the RHPA, the related profession-specific acts and regulations. To accomplish this, an amendment should be made to Bill 31 under subsection 9(2), entitled “Non-application of the act and other rights and acts.”

Section 14 proposes that a health information custodian may keep a record of personal health information about an individual in the individual’s home in any reasonable manner to which the individual consents. The ODA supports this approach, to ensure that home care is able to be provided on an ongoing basis with the use of the individual’s current health information. Nonetheless, the ODA recommends that other locations, such as nursing stations and other designated centres, also be able to be used to store records of dentists who frequently provide care in this type of setting, especially in northern and remote communities. As dentistry often is provided by individual practitioners on a locum basis in these communities, it is essential that the patient records be housed in a centralized location for continuity of care by subsequent providers. This is preferable to having the health information custodian removing the records to their traditional office location for filing and safety.

The ODA understands that the definition of “health information custodian” may already capture delivery in such settings under subclause 3(1)(3)(vii): “A centre, program or service for community health or mental health whose primary purpose is the provision of health care.” The ODA raises the issue for greater clarity and certainty of the application of this section and/or to confirm the need to expand this section to capture such facilities.

The ODA supports the elements of consent outlined in section 18. The association is pleased to see that consent may be express or implied. Further, the ODA supports the provisions requiring express consent where a health information custodian makes the disclosure to a person who is not a health information custodian; or a health information custodian makes the disclosure to another health information custodian and the disclosure is not for the purposes of providing health care or assisting in providing health care.

The ODA believes that payment issues are significant and that it is important for the individual to understand what personal information is being shared with third party payers. With this in mind, the ODA recommends that the patient be required to provide express consent for the release of personal health information to insurers. This takes into consideration the practice of some insurers and claims administrators of requesting personal health information that is unnecessary for the purpose of claims processing. This recommendation is consistent with some of the key sections of the bill that refer to having the knowledge that is reasonable in the circumstances. However, given the significance of the matter, the ODA recommends that this be spelled out in the legislation.

Section 37 makes provisions for a health information custodian to disclose personal health information about an individual who is deceased or is believed to be deceased. Traditionally, provisions to release information to identify the individual are made through the use of a coroner’s warrant. The ODA does not support a blanket removal of existing requirements and questions the changes introduced in subsection 37(4). However, the ODA recognizes that there are related compassionate and practical reasons or to expedite the identification process in the case of official missing persons.

While the ODA recommends using the shortest possible list of exceptions, the ODA proposes the inclusion of a specific disclosure. The ODA believes that dentists could be more active in assisting in the identification of deceased individuals who may be listed as missing persons. There is a national police computer system, CPIC—the Canadian Police Information Centre—that can be used in the identification of bodies through the odontograms of an individual. If dentists were permitted to release to police a simple pictorial drawing indicating by tooth position missing, decayed and filled teeth of an individual who has been officially declared to be missing, we believe that more deceased individuals could be identified more quickly.

We recommend that the legislation be amended to allow dentists to release the odontogram of an individual who has been reported to the police as being missing for 30 days, where the spouse, partner or relative, within the meaning of an appropriate substitute decision-maker, approves the release of the odontogram of the missing person to the police solely to be placed on CPIC computer files. In the past, the ODA met with Dr James Young on this matter on a number of occasions. This new legislation provides an important opportunity to address this outstanding issue of identification of deceased individuals, who are presumed missing, through odontograms.

Section 43 proposes to permit disclosures for research purposes, where, in part, there is a decision of a research ethics board that approves the research plan. While admirable, this section does not appear to go far enough to adequately protect personal health information.

As noted in earlier consultations, the ODA supports consent-based research. The current proposal relies on a

research ethics board, and the ODA agrees that the use of such a board is a fundamental requirement to bring balance to the research process. However, the steps to be taken by the research ethics board permit variability in the application of the research process. Indeed, the ODA is not aware of the application of common protocols related to the formation of research ethics boards, and this introduces fundamental variables into the use of personal information for research purposes.

Patients seeking information about agreeing to participate in research have no registry to turn to to see if the board in question meets established criteria. Bill 31 introduces decision-making options for the health information custodian, who may apply additional restrictions and conditions to the release of information. There is no common framework for the custodian to use in making such decisions, and this limitation would introduce variability within a single research project that requires records from multiple custodians. The ODA recommends careful review of this section to ensure consistency through a common research framework.

Section 45 refers to de-identifying personal health information. The ODA believes it is essential to de-identify any information being forwarded to a data institute approved by the ministry. Further, to protect the privacy of individuals, the data must remain separate and distinct, protecting against the relinking of the data with the personal identifiers of an individual. Based on this, personal identifiers should be removed prior to submission to the health institute that may be approved under this section. Without including appropriate privacy protections, the ministry would be condoning unconsented research.

The ODA supports provisions outlined in subsection 53(9) to have professional opinion or observations made in good faith excepted from the proposed correction requirements. This is exactly the type of personal information that might come into dispute but should not be changed simply because the patient does not agree with the professional opinion and observation of the practitioner. Here again, the ODA believes that giving precedence to the Regulated Health Professions Act, the related profession-specific acts and regulations will serve to protect patients and the regulatory process that requires that health records not be altered.

Clause 58(1)(c) provides the commission with the right to conduct a review under sections 55 or 56 and to permit the inspector to enter without a warrant or a court order, even where the inspector does not have reasonable grounds to believe that a person has committed an offence. Further, the inspector is able to copy any books, records or documents. These broad powers are disturbing and serve as another indication of the continual erosion of the role of self-regulatory bodies within the Regulated Health Professions Act.

Indeed, clause 60(3)(d) recognizes that other bodies may be legally entitled to regulate or view the activities of a health information custodian. The ODA believes that this should be recognized at the front end of the process,

rather than after the issuing of an order. Ensuring that the RHPA, the related profession-specific acts and regulations prevail where there is a conflict and acknowledging the role of the regulatory colleges within this bill will serve the public and the professions while providing important privacy protections of personal health information.

To conclude, the ODA will provide the committee with a more detailed submission on the bill in the next few days. To briefly summarize some of our key discussions this morning, the ODA seeks consistency with the RHPA in the definition of health care; recommends that the Regulated Health Professions Act, the related profession-specific acts and regulations take primacy over the Health Information Protection Act; seeks clarification that dental records can be retained at a nursing station or other designated centres, especially in northern and remote communities, to ensure continuity of care; recommends the need for a framework for the establishment and operation of research ethics boards; and recommends that the legislation permit the release of odontograms in an effort to identify deceased individuals who are presumed missing.

Thank you again for the opportunity to speak on the important issue of protecting personal health information.

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Mrs Witmer: Thank you very much, Dr Clemes, for a very thorough and good presentation. You've raised a few issues that are similar to what some of the other health professionals have brought to our attention, but at the same time you've actually identified some other areas where we need to look at making amendments.

I guess where there is unilateral agreement is in the need for the Regulated Health Professions Act to take primacy. Again, you have pointed out some of the shortcomings if this doesn't happen.

I guess one of the new points that you brought to our attention today is the fact that dental records need to be retained at a nursing station or other designated centres. How widespread is that need? You referred to northern and remote communities.

Dr Clemes: I'll have Frank Bevilacqua answer that.

Mr Frank Bevilacqua: It's fairly common. We, on behalf of the federal government, run a remote areas program where we fly dentists into remote communities throughout northwestern Ontario. There is a similar program that operates out of Moose Factory. Dentists go into the communities all the way up the coast there. Generally speaking, there is some sort of a facility on the reserves. Some of them are buildings, essentially, and often dentistry is even done in an empty room with portable equipment that's set up. Records are retained on-site usually at these nursing stations. In terms of those communities, there are a fair number of them across the north. We certainly would want to make sure that the records could be safely kept in that environment so that when a locum dentist does come up, the previous treatment history for that community is there and readily available.

Mrs Witmer: Thank you very much. I look forward to getting your more detailed submission.

Ms Martel: I just wanted to ask a question with respect to missing persons and your recommendation for an amendment that would allow the release of odontograms. I know we have another brief coming in from you that might be more specific, but can you give me a sense of where in the legislation that change would have to come into effect in order for that to happen?

Ms Linda Samek: We certainly need to look at that in more detail. I think we had two concerns here. One was that there seemed to be a general change in direction to simply allow records to be released. We think that may be a bit too broad. So in that section, we were looking at trying to make a specific area where you look at something like the release of these odontograms for CPIC only. We think that would be very helpful. We can certainly give you a little more look at that, but it's kind of that balance. I think the approach tried to look at this type of thing, but it was too broad. What we're saying is that we need to be very specific about when you're going to do things without having the proper warrants and protections behind it.

Mr Fonseca: I thank the ODA for your presentation and recommendations. One of your concerns was around the word "assess." In the definitions, we have health care defined as "means any observation, examination, assessment, care, service or procedure that is done for a health-related purpose." Does that not suffice?

Ms Samek: We weren't clear that it was, because you turn around and say it's done for these things, and it doesn't say it's done to assess something. We see it in a preamble, but then it gives a list of specifics, and it's not clear for us that it's captured. We just needed to have some conversation and clarity around it.

The Vice-Chair: Thank you for your presentation.

ST MICHAEL'S HOSPITAL

The Vice-Chair: The next group is St Michael's Hospital.

The Acting Chair (Mr Lorenzo Berardinetti): Good afternoon. Please go ahead.

Mr Peter Lambert: I appreciate the opportunity to speak with you today on this important matter, the Health Information Protection Act. By way of introduction, as manager of information security at St Michael's Hospital in Toronto, I am the privacy point person at that hospital. With me today are Patricia McKernan, the chair of our privacy and security committee, and Naomi Margo, our general counsel. Pat and Naomi will assist me in addressing any questions you may have.

In speaking with you today, I have three goals: to tell you a bit about St Michael's so that you'll understand our perspective on the act, to outline in summary fashion our views to date on the bill, and to identify key changes we believe are needed and the reasons for these.

First, a little bit about St Michael's: We are a major teaching and research hospital located in downtown

Toronto. Human dignity is one of our core values. We value each person as a unique individual with the right to be accepted and respected. We therefore have a natural and compelling interest in protecting the privacy of patient information as an important part of showing respect for individuals. At St Michael's, protecting privacy is an integral part of patient care.

St Michael's provides primary and secondary care to an immediate catchment area in downtown Toronto and is a major tertiary and quaternary referral centre for patients from Toronto and across Ontario. The local community is ethnically, culturally and economically diverse and is home to Canada's largest lesbian and gay community. Our governance structure includes community advisory panels on the homeless and underhoused, women at risk, people with HIV/AIDS and those who are severely mentally ill.

Every day, we deal with privacy issues of the most sensitive kind. In 2001, based on the fair information principles that underlie most privacy legislation, St Michael's developed comprehensive policies and procedures for the protection of personal health information. In this work, we strove to adapt the fair information principles to a hospital setting, an adaptation not unlike that pursued in Bill 31. The framework of protection thus created is similar to that apparent in the bill, so we feel our experience to date may represent a valuable preview of applying the proposed legislation, and our observations and suggestions flow in part from that experience.

A summary of our views on the bill: We strongly support the intent of this legislation. Such law can and must play a crucial role in protecting the privacy of personal health information for the people of Ontario by creating a legal framework within which patients and health care providers alike can be assured that individual privacy will be respected. Because this law is the first law in Ontario that substantially addresses privacy of health information in a modern setting, it addresses an important and pressing need.

St Michael's recognizes the sustained and difficult work by a wide range of stakeholders that has gone into the development of this bill and strongly supports the result of that work and its broad outline: designated health information custodians being accountable for protecting patient information; open with patients about how their information is used and protected; and operating largely on the basis of implied consent with notice. This is essentially the framework that we have adopted at St Michael's and it strikes us as one that is both effective and practical.

However, we do have concerns about the bill as drafted. Though the framework is strong, we believe that in a few key areas, changes are needed in order to prevent the bill's effectiveness from being seriously undermined. The areas I will highlight today are express consent for fundraising and the lockbox provisions. We do have other concerns as well, such as permissible disclosures in certain cases where the patient may be incapable or unconscious at the time, the general impact

of the bill on our own day-to-day dealings with the police, concerns about certain research provisions and about the proposed pace of implementation. Our written submission will expand upon those points.

As written, the bill's requirement for express consent for fundraising threatens the capacity of hospitals to raise money needed to support patient care. Hospital foundations play an integral role in raising funds for equipment and facilities essential to care. At St Michael's alone, over the past three years, the foundation has raised close to \$40 million for vital projects. Foundations find the money not only for equipment and facilities but also for renovations, scholarships, education research chairs and fellowships. Such renewal and modernization are important to enabling hospitals to attract and retain high-calibre staff.

1210

Today hospital capital projects are typically funded on a matching-funds basis, with local foundations raising half the cost of major projects and the government requiring this local fundraising as a prerequisite for its own contribution. In this arrangement, government correctly recognizes the vital contribution of foundations, without which the full burden of funding would fall to government. Foundations are the main vehicle by which the communities themselves, whether a geographic community or a community of interest, may contribute to, participate in and support local hospital development.

Foundations not only play an integral role in local health care delivery, but also in province-wide health care delivery. For example, the funding of research chairs helps create in Ontario a pool of expert health care knowledge that is globally competitive—a reverse brain drain, if you will. For example, with the University of Toronto, St Michael's created in the year 2003 the first ever nursing chair in women's health.

Foundations share values and goals with their hospitals. They typically manage professionally with established codes of ethics and excellent track records in terms of demonstrating respect for patient privacy. Respecting patient privacy is not only good for the foundations from an ethical perspective, it is necessary for building long-term relationships upon which effective hospital fundraising depends.

A requirement for express consent will put hospital fundraising at a distinct disadvantage relative to fundraisers outside of health care who would not be subject to a similar requirement, and where an express consent model has been tried it has curtailed fundraising effectiveness drastically.

Finally, I would point out that in the bill disclosure of some personal health information to government is justified, and reasonably so, on the basis that the disclosure is needed to support the business of health care; for example, by preventing billing fraud. A similar justification can, and should, be extended to foundations. An opt-out model for fundraising, on the other hand, can substantially preserve for the individual his or her opportunity to control the use of personal information,

that is, preserve his or her privacy, while at the same time allowing effective fundraising to continue. Moreover, with an opt-out model there is the opportunity to eliminate the possibility of coercion in fundraising and to reduce the potential for nuisance contacts with individuals.

A second area of serious concern to St Michael's is found in the lockbox provisions that enable a patient to specify that some or all of their personal health information is to be excluded from the normal flow of patient data among health information custodians. In the current health care environment, implementing these provisions as drafted will be very unpractical and on occasion may place patient care at risk. If a patient specifies certain items are to be placed in the lockbox, a gap is immediately created in the completeness of the patient record that is readily available to caregivers. This is at variance with best practice in health care today, where a major goal is to ensure that as complete a record as possible is readily available to a caregiver at the point of care and at the time of care.

The health care system in Ontario and elsewhere strives in this direction for a very good reason. Optimal diagnosis, care and treatment rely directly on having as much relevant clinical information as possible available at the point of care. The quality of care delivered depends directly on this, as does the cost of care. For example, unless a physician has full access to test results previously obtained, he or she is likely to order the tests again, incurring unnecessary costs and possibly creating risk to the patient.

As another example, in an emergency or urgent care situation the inability of caregivers to access all relevant information may seriously affect outcomes. Is that patient taking certain medications which may interact with drugs about to be administered? Does the patient have a pre-existing condition that would dictate or preclude the use of certain treatments? In a pregnancy, should a Caesarean section be ordered because the patient has predisposing risk factors, such as hypertension or a psychiatric illness?

Lockbox provisions potentially shift the onus on to the patient to determine the relevance to their future care and treatment of the information locked up. Unfortunately, most patients are not in a position to judge that relevance. For example, whether one has had a previous pregnancy may determine the correct course of treatment for an apparently unrelated illness years later. Even honouring patient requests to place information in a lockbox would be problematic. For example, if a patient asked to have the fact that he or she has AIDS suppressed, multiple changes would potentially need to be made to multiple records, extensive narrative notes might have to be reread in order to do the relevant necessary editing.

It may be intended in the bill that in a medical emergency or an urgent care situation or a situation where the patient is incapable of authorizing disclosure of the locked information that a caregiver might override the lockbox provision. However, the mechanisms for making sure this works in a timely way have not been spelled out

and would be difficult, if not impossible, to operationalize if, for example, non-digital records were involved, as they often are.

To make lockbox provisions into law is to create an unrealistic expectation on the part of the public and an unrealistic demand on health care providers. Individual providers would potentially be put in the position of having a conflict of interest between honouring a lockbox provision and ensuring proper care for the patient.

In short, a lockbox provision in the current Ontario health care environment is just not practical when it comes to implementation. At some future time, perhaps when and as Ontario moves to a fully digital patient record, the lockbox idea could be revisited. It is really something that can only be operationalized in a fully computerized setting, and even then, all the real-life scenarios would need to be carefully accounted for and tested out before implementation. Until then, a lockbox provision is impractical and inadvisable. The bill already includes many other provisions to ensure that custodians properly control access to patient data.

In conclusion, the time has come for a modern Ontario law to protect personal health information, and Bill 31, with some key changes as suggested here and outlined in our written submission to follow, will serve custodians, Ontarians and their government well. Thank you.

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

Ms Martel: Thank you very much for your presentation. As you will appreciate, we've heard from a number of presenters from the hospital sector about these two similar concerns. For clarification purposes on this second provision, which is the lockbox, if you look at section 39 of the bill, which would be a disclosure related to risk, does that give you any comfort that in the areas you've identified there would be disclosure when it's necessary, or is it just too uncertain, especially for health care providers, to work with a section like that?

Mr Lambert: I think the number and variety of situations that will come up in the context of trying to make a lockbox work are too many to try to consider within the framework of the current legislation. I think section 39 does help in a specific set of situations but not all of them.

Ms Martel: Then, your concern would be that people making decisions about whether or not to comply and how would put patient care at risk in any number of circumstances?

Mr Lambert: And in addition, it may put the actual care provider in a very difficult situation where, for example, the care provider who participates with the patient in collecting the information then possesses that information for a long time and in a way is perpetually faced with the prospect that the information they hold may be relevant to subsequent care and yet be constrained from doing much about it.

Ms Martel: OK. Thank you.

Mr Fonseca: Thank you, St Michael's, for your presentation. In regard to the fundraising issue that you

brought up, have you experimented with or ever tried different models in terms of asking for consent?

Mr Lambert: In the past few years, the model that we have largely used at the hospital has been a different model, which involves a two-step process: A letter goes from the hospital and basically presents the benefits to the patient and then gives them the opportunity to connect with the foundation. That is the basis of what we do to date. It has worked very well in terms of having, to my knowledge, no complaints associated with it at all. However, we do know that in fundraising in the future, the opportunity to offer people more opportunities to contribute is a real prospect that we ought to be pursuing.

1220

Mr Fonseca: So the model that you're using is one where you send out a letter to a former patient, and that patient then—what would the letter entail?

Mr Lambert: It essentially makes them acquainted with the existence of the foundation. So it goes from the hospital, and it describes in general terms what the foundation is about. It gives them the opportunity to mail in to the foundation if they want to deal with them further.

Mr Fonseca: Are they being solicited right away with that first letter?

Mr Lambert: I think that is a matter of interpretation. It is not a solicitation by the foundation.

Mr Fonseca: Are you asking for funds in that letter?

Mr Lambert: Not directly. We give the patient the opportunity to fill out a form if they wish to talk to the foundation or make a contribution to the foundation. But the contribution itself flows separately to the foundation.

Mr Fonseca: Is this a model that is being used pretty much across Ontario at the different hospitals or is everybody using a different model?

Mr Lambert: I think there is a variety of models. Many of the hospitals, as I understand it, do have their foundation contact people directly and ask for donations but provide opt-out opportunities.

Ms Naomi Margo: I think we've also seen on the original consent form, when you attend at a hospital, an implied consent to share identity and address with the foundation; so doing it upfront upon admission.

Mr Fonseca: How has that worked?

Ms Margo: I can't speak on behalf of other hospitals. I don't know if they've encountered anything. You asked about what other hospitals are doing.

Mr Fonseca: You're not doing that?

Ms Margo: We're not doing that. Other hospitals sometimes go that route.

The Vice-Chair: Ms Wynne, just very quickly.

Ms Wynne: In the absence of Bill 31 and this lockbox provision, what happens now when a patient doesn't want information disclosed? What's the St Michael's practice?

Mr Lambert: I think it's fair to say we make best efforts to comply with their request. Those efforts are not always successful. They're frustrated by practical realities, the fact that we cannot and do not control, for

example, every conceivable use of each piece of data piece by piece, patient by patient, through their subsequent cycles of care. We don't essentially have the systems to be able to do that yet—someday we may—and I don't believe many hospitals really have the systems to do that.

Ms Wynne: But I guess that's what the bill envisions, a time when we can. That's what's desirable, that's what could happen.

Mr Lambert: I believe the bill does envision that. What concerns us is the immediate casting into implementation of it.

Ms Wynne: OK. Thank you.

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

Mrs Van Bommel: John didn't get—there's one more.

The Vice-Chair: My apologies, Mr Yakabuski.

Mrs Van Bommel: The third party. Oh, no.

Mr Yakabuski: The fourth party, maybe. Let's party.

Thank you very much for your presentation. I certainly share your concerns on the fundraising front. I think a lot has changed over the years. I think there's still a large segment of the population out there that does not realize how much money is generated for hospitals through private fundraising. We've become a little more aware of it by getting the Princess Margaret and CHEO and things like that in the mail for the house and the cars, which is good. But I think a lot of people still think that everything associated with health care is paid for by the government and don't realize that the institutions they use do rely on personal donations as well. So I certainly share your concerns in that regard, and I hope that some amendments can be made and that without hamstringing your ability to function as foundations, we can still protect the privacy rights of individuals. I think the opting-out clause is certainly something worth looking at.

I'm looking at section 39 with regard to the lockbox. Maybe you have looked at it a little more closely, but in the case of someone who has changed physicians for whatever reason, hypothetically has changed physicians three or four times, if they locked the box at physician number one and they're now a patient of physician number four and they need some specialized treatment or whatever, I'm not sure what kind of continuity is involved there. You people in the health care field would be able to enlighten me more. If you're only going one step back, that box couldn't be opened because it wouldn't be realized it was locked. Is that a realistic question?

Mr Lambert: I'd think very realistic in this way, that the whole notion of continuity of care, which of course is very important to patients and their care providers, is premised on the idea that the information is readily and consistently available across all those providers. In fact, as we move more and more to the delivery of health care in teams, whether it be teams of nurses or teams of physicians, it becomes very complex to even understand how one would operate the lockbox in those cases.

The Vice-Chair: Thank you very much, Mr Lambert.

Ms Wynne: I don't know if I need to make a motion, but I'd like to move back into the discussion of the travel. I wanted to speak to that. Can I speak to that?

The Vice-Chair: That's fine.

Ms Wynne: I wanted to make a couple of points. First of all, I am new to this side of the table in these committee hearings, but I'm not new to the other side of the table. I just wanted to make the point that I have spent a lot of time in committee meetings as a presenter, as somebody following committee hearings. I travelled around the province during the last government's regime and you really hear different things outside of Toronto than one hears in Toronto.

The other point I wanted to make is that my understanding is that if we are in either the Soo or Kingston, if there are people who didn't know about the committee hearings and want to speak, with the consent of the committee they would be able to do that. I believe that's the case.

The Vice-Chair: That is the case.

Ms Wynne: So I think we need to be aware that it's not always the centre of everyone's mind that these hearings are going on outside of Toronto, and my expectation would be that there will be stakeholders, there will be interested parties who will want to speak to us and that we may be able to consider that. I think it's very important that we're trying to change the culture of how we do business in this province, and in terms of hearing from urban, rural, other voices, we're not going to do that if we don't have face-to-face interactions with them.

As far as the issue of finding different places to meet and cutting costs that way, that's a conversation that we should have, and certainly I personally would support looking at other kinds of meeting places than expensive hotel rooms. But I think that's another conversation. The issue of whether we travel or not is what we need to determine now. So we're trying to change the culture, and I can imagine that we could be having a conversation here today, if we weren't going to travel, accusing us of not travelling and not reaching out to people outside of Toronto. Because this is a bill that—obviously there are lots of amendments that we need to consider. We've heard some of them. We will hear more and different ones when we travel outside.

I am completely supportive of doing that and having the conversation about saving costs in other ways at a different point.

Ms Martel: Mr Chair, I'd like to move the motion and then speak briefly to it if I might. I have copies that Trevor was good enough to have typed up for me.

I move that given the limited number of presenters on Bill 31 in both Sault Ste Marie and Kingston, that the committee not incur substantial travel, hotel and meeting-room costs but instead ensure the participation of presenters in these two communities via teleconferencing and videoconferencing.

I think members are receiving copies of the motion now. May I speak to that, Mr Chair?

The Vice-Chair: Yes, go ahead.

Ms Martel: A couple of things: We've had an earlier discussion and we're continuing it, and I feel compelled to make some comments in response to the comments that were just made. There's no doubt that you do hear different things outside of Toronto, and nothing in the way of videoconferencing or teleconferencing is going to stop that. We are going to hear via a different mechanism the same presentation, the same comments, the same concerns, the same questions as we would if we were physically present on-site. I really do fail to see how operating by videoconferencing or teleconferencing in order—

Mr Rinaldi: On a point of order, Mr Chair: Shouldn't the motion be seconded before we speak to the motion?

1230

Clerk of the Committee: There's no need.

The Vice-Chair: Go ahead.

Ms Martel: There's nothing that precludes us from hearing anything—different things, good things, bad things—from presenters in either Sault Ste Marie or Kingston. We are going to hear from the presenters. The motion has nothing to do with shutting down hearings and not hearing from people. So there is every opportunity, every possibility to hear different things from people in Sault Ste Marie and Kingston via teleconferencing or audioconferencing without physically being on-site.

The second point: On rare occasions, people do come to committee who are not on the list and ask to be heard. Again, there is nothing in the process that I propose that would preclude them from doing that. If people know where the hearings are going to be, then they can come to listen and, if they want to, present, and we will certainly have time for that because we don't have a full schedule. They can certainly make the request at the time to participate.

Obviously, if we do it by teleconferencing or videoconferencing, there is going to have to be someone at the other end just coordinating that. The government's own member, who might have sat with this committee on Tuesday, may well want to do that if he was going to be there, and I suspect he would be because it was going to be in his community. But there is nothing in terms of the mechanism I propose we utilize that cuts out or dismisses or undermines an individual who wasn't on the list from coming to participate—nothing.

Third, I've been here 17 years. I've been on both sides of governments being accused about public hearings. I think what's different in this case—and I don't want to undermine my friends in the opposition now. The previous government had a very bad tradition of having very limited hearings with no opportunity for travel in the first place, so that the government motion that was put forward was very restrictive in terms of two days' hearings, very short notice, only in Toronto.

That is not what happened here. I applaud the government for ensuring that that is not what happened in this case. In this case, it was very clear that an oppor-

tunity was given, and all members of all parties accepted that there would be travel and ample time for people to participate.

The reality, and I think we have to face this, is there hasn't been overwhelming public response for people to participate. I'm not drawing any kind of inference from that, but that is the reality. At 12:30 yesterday afternoon, we had two people who wanted to present in the Soo and four in Kingston. As I said earlier, some efforts were obviously made by the government House leader's office to boost those numbers in Sault Ste Marie. That's their job; I appreciate that. I've been here a long time; I know how this works. But we are nowhere near the same circumstance with respect to public hearings as we have been in the last number of years under the Conservatives, where from the get-go, from the government motion that was passed by the majority, there was no effort for people to travel, there was no effort for people in other communities to participate. That opportunity has been given to people, and my concern is that there hasn't been really broad response from the very presenters we hoped to attract.

As a result of that, I am suggesting that we can just as easily, just as effectively openly allow presenters to have their say, doing it in a fashion that doesn't require us to be on-site. From my perspective, the response here, which has been very limited in those two communities, does not warrant the committee to be physically present in either of those two communities in order to have the give-and-take that we would like. I think that can be adequately accommodated from here. The groups that we have are groups that have made presentations before, that will not feel uncomfortable or worry about having to do it that way, and it would at the end of the day save significant costs that I don't think we should be spending.

London is a completely different matter. We have a full schedule. I think the committee should go there, but I don't think that's the same situation in either Kingston or Sault Ste Marie.

Mr Yakabuski: I certainly support the motion of Ms Martel. I think that it is very clear that the whole point of these committee hearings is that we allow people, organizations and groups to make a submission to the committee if they feel that amendments need to be proposed or the legislation as a whole is simply not acceptable. There is nothing in her motion that limits the ability of those organizations to make those presentations. They are given every opportunity to do so via a different medium: teleconferencing. At the end of the day, the messages will still be received by this committee as to what the intentions or the concerns of those groups are, but we will have done the right thing and saved the taxpayers of Ontario a significant sum of money.

Mr Kormos: At Ms Martel's request, I'm not going to be overly lengthy. I appreciate her cautioning me that I shouldn't consume too much of her brief lunch period.

What did we say earlier? An hour and 20 minutes in Kingston and two hours in Sault Ste Marie, and you're going to drop tens of thousands of dollars of taxpayers'

money to fly 16 people, minimum, to those destinations, accommodate them in hotels at a minimum cost of 100 bucks a night, easy, plus the food allowance, plus whatever little travel arrangements in town. You're dropping a whole whack of taxpayers' money here for literally minutes worth of so-called consultation.

Let's put it this way, because nobody has looked at this perspective: It would be cheaper to fly all of those participants into Toronto, put them up over there at the Courtyard Marriott—it's a unionized hotel at the corner of Yonge and Wellesley—give them a food allowance of 30 or 40 bucks, and you're still saving a whole whack of dough. At the very least, it seems to me that if you were prudent managers of the public purse, you'd be interested in demonstrating some fiscal responsibility.

I say teleconferencing is the way to go. Heck, Apple has those little things for 150 bucks where you can communicate back and forth. You can go down to any computer shop—Future Shop—and buy those things. This is not high-tech stuff any more; teleconferencing is now low-tech stuff. It just rots my socks that we're seeing a government that is telling other folks out there that they're not going to see any investment from this government because there's no money, the bank account is empty, yet these guys are willing to blow all sorts of big bucks—it's not change—on travelling around to places for about an hour or two.

If you want to reach out, you've got travel budgets. You do. Go travel to Sault Ste Marie as an MPP if you want to reach out and touch someone in Sault Ste Marie or Kingston and hear what the folks are saying there, by all means, but don't ship 16-plus people on a high-ticket item where there is modest interest being displayed. You're not going to have packed committee rooms with the public clamouring to see what the exchange is going to be between these presenters and members of the committee. I think this is a very suspicious thing going on here. I'm not quite sure what's happening yet, but there's something going on here that causes me great concern and leaves me very suspicious.

I say that Ms Martel's motion demonstrates prudence and responsibility and reflects her many years of experience here at Queen's Park. People should listen. This woman is one of the senior members of this assembly. This young woman is one of the long-time, senior veterans of Queen's Park. She is the sage of the chamber, and we ought to be listening to her and adopting her direction and guidance.

I don't know, but once again I'd refer to Mr Justice Osborne's comments last week: The test is whether you want to read about it on the front page of a major newspaper the next day. You guys want to justify it? God bless. Who am I to interfere with your career goals? But I say that this is a responsible resolution and you folks should be supporting it.

1240

Mr Berardinetti: With the greatest respect to the senior member and her motion and the last speaker who just spoke right now, I am going to reiterate or move

again, if I have to, the motion or the decision of the subcommittee that was brought forward on the 26th.

The Vice-Chair: There is currently a motion on the floor.

Mr Berardinetti: OK, so that's on the floor. I just want to read it again, "That the committee meet for the purpose of public hearings on Bill 31 during the week of January 26, 2004, in Toronto; and during the week of February 2, 2004, in Sault Ste Marie, Kingston and London."

To make it very brief, we want to work. Back in the House in December, accusations were made by members of the third party that we were going on a three-month vacation. I don't think going to Sault Ste Marie is a vacation. I don't think going to Kingston is a vacation.

Mr Kormos: I don't see any sweat stains.

Mr Berardinetti: I haven't taken off my jacket yet.

It's the responsible thing to do. I look at the list in front of us and, again, this list can grow, but in Kingston alone, the Kingston General Hospital is listed. They have an expectation that we're going to appear there. The Ottawa Hospital is going to appear in Kingston. Those two alone are critical, and their cultures in Ottawa and Kingston are going to be somewhat different from Toronto's culture. Even the issue of fundraising, which has been brought up here in this committee with regard to Toronto hospitals, may be different in Kingston and Ottawa, and it may be different in Sault Ste Marie. The Sault Area Hospital may have different points that it wishes to raise.

With the greatest respect to members of the opposition and the third party, this Liberal government is committed to hearing from the public. Driving out to Kingston or London for a day is not that expensive. It doesn't mean you have to stay there overnight in a hotel. You can leave early in the morning and come back late at night. If Hazel McCallion does it in Mississauga, we can do it. We're all young and healthy, at least on this side of the table, and we're willing to go out to these locations.

Ms Martel: I can't wait to drive to the Soo.

Mr Berardinetti: Maybe that's the only one that requires overnight accommodation, but I could just hear the accusations on the other side. I think the third party made these accusations to the Conservatives when they were in power, that broad public consultation did not take place.

Hello. We are now entering a new period of time where we are going to consult. I think it is very important that we do travel to Kingston, Sault Ste Marie and London. We want to work; that's the bottom line. If the others don't want to work, they can moan, they can stay in Toronto and they can—no, I won't say get a job, because you already have a job—either follow us or stay here.

I will not be supporting the motion of Ms Martel, with the greatest respect to her knowledge and experience, but will reiterate subcommittee decision number 1.

The Vice-Chair: Any further debate?

Ms Martel: I'd like a recorded vote.

The Vice-Chair: Ms Martel moves that, given the limited number of presenters on Bill 31 in both Sault Ste Marie and Kingston, that the committee not incur substantial travel, hotel and meeting room costs but instead ensure the participation of presenters in these two communities via teleconferencing and videoconferencing.

Shall the motion carry?

Ayes

Martel, Yakabuski.

Nays

Berardinetti, Fonseca, Leal, Rinaldi, Van Bommel, Wynne.

The Vice-Chair: I declare the motion lost.

Ms Wynne: So then the motion that was moved by Ms Jeffrey on the first day stands, is that right?

The Vice-Chair: The subcommittee report stands.

Ms Wynne: The subcommittee report stands.

I don't know if this needs to be a motion, but I'd like to suggest that we explore ways of reducing costs. Whether it's driving or whatever the travel arrangements are, I'd like to suggest that we explore ways of reducing those costs. I don't have a problem with that at all. Does that need to be a motion or can we just ask the subcommittee to do that? Can I just ask that the subcommittee look at that?

Interjection.

Ms Wynne: Yes, so we can meet in government buildings, basically what Ms Martel was suggesting, without the full motion.

The Vice-Chair: Do we have agreement on that?

Mr Kormos: What about restricting the meal allowance to \$10 a day?

Ms Wynne: I don't need that much. That would be fine with me.

Can we leave this to the subcommittee to talk about? Mr Chair, can we leave this to the subcommittee, please?

The Vice-Chair: OK, the subcommittee will look after that. We'll recess until 1:20.

The committee recessed from 1246 to 1327.

The Vice-Chair: Order. Our next presenter was the Ombudsman of Ontario. They're not here yet. We'll have a recess for 20 minutes.

The committee recessed from 1327 to 1346.

OFFICE OF THE OMBUDSMAN ONTARIO

The Vice-Chair: Order, please. Our next presenter is the Ombudsman of Ontario.

Mr Clare Lewis: Good day.

The Vice-Chair: You have 20 minutes. Start any time.

Mr Lewis: Thank you, Mr Chair, members of the committee and of the Legislature. It's a great pleasure for me to have the opportunity to be before you—maybe I'll

tell you whether that's the case after we've finished, but it certainly is a privilege. I appreciate the opportunity to address you on what I know to be your very important work.

As I stated to the standing committee considering the Personal Health Information Privacy Act, 2000, in March, 2001, "as a matter of principle I support in general terms jealous guarding of personal health information." However, I do have a specific concern regarding Bill 31 as it relates to my office.

If I can just depart from the text for a second, and the text is before you, in discussing this matter I want to say that in fairness I must make a disclaimer. I believe it is the intent of the act—that's my view as a lawyer—to allow me access for the purposes of investigations under my act, but our experience in dealing with both the health ministry and other agencies, such as the correctional institutions and so on, is that we do get blocked from time to time under the Freedom of Information and Protection of Privacy Act. I feel that we are going to be in the same position today with this act. Even if it's the intent, it may not be sufficiently clear to not impede our investigations when we have need of third party information, and it does occur and I'll try to explain that.

My problem is that if we do get impeded and it becomes serious, I may be compelled to have to go to the courts to advance my position. I think that's an unfortunate way to have to go. I have yet to have to litigate with respect to my jurisdiction and I would not like to have to do it before my end of term, which is in one year by reason of my advanced age. So I only have a year to make the rest of what I can of my office.

Under Bill 31, a health information custodian is prohibited from disclosing personal health information about an individual without that individual's consent or unless disclosure is permitted or required under the act. Non-health information custodians are also prohibited from disclosing information—that's why we get into trouble with institutions like corrections—that they have obtained from health information custodians for any purpose other than that for which the custodians disclosed it. Section 7 of the bill provides that in the event of a conflict between this act and another act, this act, Bill 31, prevails.

I have the authority to conduct investigations—and I do—relating to a broad range of provincial government organizations, many of which routinely have in their possession personal health information. These organizations include the Ministry of Health and Long-Term Care and agencies such as the Health Professions Appeal and Review Board, the Health Services Review and Appeal Board and health care units of provincial correctional facilities. It is often necessary to obtain relevant personal health information, including third party information, in the course of my investigations of provincial government organizations. Obtaining individual consent in these circumstances can be impractical and, at times, impossible.

In the past, I have conducted investigations on my own motion in order to investigate situations involving

vulnerable persons and systemic issues impacting a large group of individuals. In these circumstances, it is critical that I have full access to relevant personal health information without the need to obtain individual consent. In some contexts, for instance within the correctional system, systemic investigations relating to access to health care cannot effectively be conducted if it is necessary to obtain individual consent. I want to give you an instance Mrs Witmer may recall—it was after you were minister—the issue of Cancer Care Ontario. There was a motion investigation on the northern health travel grant, and that was a perfect case in which it could have been important for me to have obtained third party information. As it was, I was able to finesse it, but that was good luck, rather than good management. As you may know, that came to a head before a committee and ultimately some changes were made.

Bill 31 does provide in clause 42(1)(g) that a health information custodian may disclose personal health information about an individual subject to the requirements and restrictions, if any, that are prescribed, to a person carrying out an inspection, investigation or similar procedure that is authorized by a warrant or under an act of Ontario or Canada for the purpose of complying with the warrant or that act.

At first glance, this provision would appear to support the view that the act, as drafted, would permit disclosure to my office for the purpose of conducting investigations without the need for individual consent. Frankly, I do believe—this is what I referred to in my opening—that is what is intended by the section, that the Ombudsman should not be precluded from having access in appropriate circumstances. However, my office's past experience with FIPPA suggests that further clarification would certainly be useful if not required, and may be required.

FIPPA was amended in January of 1991 to delete reference to the Ombudsman's office in a section permitting disclosure of personal information for certain purposes. The reference to my office was considered redundant, in light of the general exemption in the legislation authorizing disclosure for the purpose of complying with an act of the Legislature. That has had serious impacts on our capacity to do our investigations despite a memorandum from the director of the freedom of information and privacy branch of Management Board of Cabinet in November of 1991, which confirmed that the Ombudsman continued to be authorized to require access to personal information. Further, in June of 1992, the Information and Privacy Commissioner, then an assistant commissioner, responded to a complaint concerning disclosure of personal information to my office by finding that the disclosure was permitted under FIPPA.

Despite the information from Management Board of Cabinet and from the Information and Privacy Commissioner's office, I continue to experience resistance when attempting to obtain access to information, particularly personal health information, without formal written consent from the individuals to whom it relates. It is a credit to those individuals who resist my requests that

they are attempting to follow the rules and exercise due caution, but I think they do so incorrectly and based on a misconception of the law.

Unless this act clearly refers to disclosure to the Ombudsman being permitted and there is no room for ambiguity, I foresee, based on my office's past experience since 1991, that I will face resistance in my investigations, and delay, when attempting to obtain personal health information.

Bill 31 recognizes that to ensure compliance with the legislation, the Information and Privacy Commissioner must have inspection powers. However, I echo her submissions to this committee yesterday, that for effective oversight the commissioner must be able to compel testimony and access personal health information without the procedural requirement of obtaining a warrant. It's not for me to argue her case. She did so quite well. But in order to fulfill my mandate properly, I have been given broad statutory powers of investigation. I suggest, respectfully, that it is fundamental that I continue to have full access to such information in order to fulfil my role and ensure that government is accountable in its administration. I am concerned that my authority will be restricted as a practical result of the implementation of this act.

I would like to assure the committee that I appreciate the sensitivity relating to personal health information. If I can get personal, my wife is vice-president of the Trillium Health Centre and she doesn't think anybody should have access to anything at any time, including me, but I don't think that's quite true. I have my own jurisdictions.

It's important to realize that the Ombudsman Act and its regulations contain strong confidentiality provisions to ensure that information obtained in my investigation is not unnecessarily disclosed. I took an oath of confidentiality when assuming office in accordance with subsection 12(1) of the Ombudsman Act. Every member of my staff is bound by my obligations of confidentiality. My act requires that my investigations are conducted in private, and section 2 of the regulation provides that neither my staff nor I can disclose information to third parties except when permitted by the act.

My office—and this is important—is also not an institution subject to FIPPA. Accordingly, members of the public cannot obtain disclosure of information within my custody and control through an access request to my office under FIPPA.

In our complex and changing society, it is important to have clear rules respecting the privacy of personal health information. It is also important to ensure that government administration is held accountable both for its use of such information and for its conduct generally. My concern is that the proposed legislation may have the unintended effect of impairing my ability to conduct investigations of provincial government organizations in some circumstances.

I believe it is necessary that PHIPA expressly provide that a health information custodian or non-health infor-

mation custodian who has obtained personal health information may disclose personal health information without consent to the Ombudsman for the purpose of allowing me to carry out the investigations under the act. The best way to accomplish this, in my view, is to add a separate section to the legislation in part I, under the application of the act, stating, “Nothing in this act shall apply to prevent or restrict disclosure of personal health information to the Ombudsman of Ontario.”

Alternatively, the standing committee may wish to consider recommending a consequential amendment to the Ombudsman Act clarifying that FIPPA and PHIPA—this act—do not prevent me from obtaining personal information and personal health information during the course of my investigations.

Subsection 19(3) of the Ombudsman Act could be amended by deleting it and replacing it with the following, and I set out what I propose:

“Subject to subsection (4), no person who is bound by the provisions of any act, other than the Public Service Act, Freedom of Information and Protection of Privacy Act or the Personal Health Information Privacy Act, 2003, to maintain secrecy in relation to, or not to disclose, any matter shall be required to supply any information to or answer any question put by the Ombudsman in relation to that matter, or to produce to the Ombudsman any document or thing relating to it, if compliance with that requirement would be in breach of the obligation of secrecy or non-disclosure.”

I believe the confidentiality provisions in the Ombudsman Act and the integrity of my investigative process strike a balance between the public interest in having an Ombudsman with the right to access personal health information and the private interests of individuals in having their personal health information protected. I believe PHIPA intends to preserve that balance.

However, as I pointed out, my experience has shown that in the very sensitive area of personal health information—and as recently as this week, the coroner’s office’s hesitation to provide me with information of a proper investigation, and understandably so—any legislative uncertainty will inevitably lead to challenges to my investigative authority.

I thank you for your consideration of the matters I have raised. I would be pleased to answer any questions, and I’d like to introduce Ms Laura Pettigrew, my senior counsel, who has been of great assistance to me on this issue for several years.

I would just like to explain one reason why I think I do have the right under the act. I think the section that proposes that it could be disclosed for purposes of an investigation under an act of Ontario provides me with that right. The problem is that the section in my act, under subsection 19(3), which appears to give persons who are bound by a secrecy provision the right not to respond to me—I don’t think a health custodian under this act is bound to a secrecy provision, but I know it’s going to be argued that they are, and I don’t want to have to go to court if I don’t have to. That’s not a threat. I think it’s unnecessary.

There’s one thing I wanted to mention. Like the Information and Privacy Commissioner, our office works very quickly and informally on most of our work; 75% of our matters are disposed of within three weeks. We’ve got some very terrible tales, like any other office, but we really do move quickly, and we informally resolve, mediate and get rid of matters quickly and effectively. That doesn’t happen when people dig in and say, “We don’t think this is going to work; we haven’t got the right,” and so on and so forth.

I apologize that it’s a little long, but thank you for hearing me.

1400

The Vice-Chair: Thank you for your presentation.

Mr Leal: Mr Lewis, thank you very much. A question as a new member, just for my own clarification: On page 2 you talked about a decision that was made to amend FIPPA back on January 1, 1991, and that your interest was declared redundant at that time. Why was that put in there back then?

Mr Lewis: Why was subsection 19(3) put in?

Mr Leal: Yes.

Mr Lewis: It was already there but they thought under PHIPA that I had a right, so they didn’t think I needed this section in there. It was not me, it was my predecessor.

Mr Leal: That was going to be my follow-up question.

Mr Lewis: It was long before my time. I think there was resistance to it by my office at that time, but it was simply seen as redundant as between my act and the Freedom of Information and Protection of Privacy Act. It has unleashed difficulties for us.

I understand the position at that time was that there shouldn’t be a surplus of legislation, but the concern of the office was that we really needed the section because we didn’t think we could always rely on another act to support us.

Mr Leal: Sometimes these things are like a boomerang.

Mr Lewis: Yes. I think the fears at the time have been realized. It’s not constant, but it’s sufficient and it’s quite an impediment.

Mr Fonseca: I’d like to thank the Ombudsman for presenting. Sir, would a consequential amendment to the Ombudsman Act address your concerns about the information being disclosed to you in appropriate circumstances?

Mr Lewis: The appropriate circumstances wouldn’t, in my respectful view, be set out in Bill 31; they already are set out in my act. I have a broad right of inquiry but I have to operate within quite a distinct set of rules. Yes, I think a consequent amendment to my act, such as we have suggested, would in fact do what I have suggested, or clarify it.

People have a great fear—and that’s what this bill’s all about—that if information is released it will be abused. But I’m bound by confidentiality and my staff are bound by it, and we can’t be accessed by FIPPA. So, yes, a

consequent amendment, such as I have stated or something close to it, would probably address the issue, and you wouldn't have to do it in PHIPA, or in whatever.

Mrs Witmer: I guess, basically, it does come down to the fact that there's a need for either a separate section or the consequential amendment. Do you have a preference, or do you think that either one of these—

Mr Lewis: I guess it would be easier from my point of view if it were in this Bill 31, because then the custodian and those receiving information from the custodian would have it right there. They'd see it; they wouldn't be surprised if all of a sudden I showed up on the horizon. So that would be preferable, but I think the other would work, yes.

Ms Martel: Thank you very much for being here today. Just to follow up on that point, I want to ask you about another way to do it, and maybe legal counsel can tell me why you've chosen the route that you have. You referenced subsection 42(1) already when you referenced (g) saying that you felt it probably covered you because it talked about investigation etc. But if you look further up in (g), we're going to give information—

Mr Lewis: Where is that?

Ms Martel: Subsection 42(1).

Mr Lewis: Yes, I've got it.

Ms Martel: If you look above—those ideas would come really in regulation—there are other people who are actually named. We say that we will disclose information to all of the regulated colleges, the board of regents, the Ontario College of Social Workers and Social Service Workers, the public guardian and trustee. What happens if we just reference you in there, as your office? Would that solve the problem—and having to do another amendment to the Ombudsman Act?

Mr Lewis: I'm told that would work.

Ms Martel: Does it matter? Do you have a preference?

Mr Lewis: But I thought there was a—I'm sorry, I don't mean to have a private discussion, but I thought the reason—

Ms Martel: That's OK. That's why I wondered, because it looked a little bit easier, but maybe there's a reason why you don't want to do it that way.

Interjection: I don't see why it wouldn't work, but I'm not—

Ms Laura Pettigrew: It would depend on the wording that you put in, in terms of the exclusion, if it was similar to what was suggested.

The Vice-Chair: Can I get you to introduce yourself for Hansard?

Ms Pettigrew: Yes, sorry. I'm Laura Pettigrew, senior counsel.

Ms Martel: If you were to say to the Ombudsman, "for the purpose of administration or enforcement of the Ombudsman Act," for example.

Mr Lewis: I'm sure that we can work out a section that would. We've had access to your counsel, the Ministry of Health's counsel, and so on, and we could talk.

Ms Martel: OK. I'm just looking for the easiest way to do this.

Mr Lewis: We're very grateful for that access, by the way. I must say that when I raised this matter with the ministry they were very quick to respond and see that we got here. So we're grateful for that. *[Inaudible]*.

The Vice-Chair: Thank you very much.

Mr Lewis: Thank you. I wish you well in your important endeavours.

RICHARD SPEERS

The Vice-Chair: There's been a cancellation with our next presenter, so it'll be the presenter after that. That's Dr Richard Speers. Good afternoon, Dr Speers. You'll have 15 minutes, not 20 minutes like the other groups. You may start any time.

Dr Richard Speers: Thank you very much. I'd like to thank the committee Chair and staff for allowing me to speak today. At the indulgence of the committee, I doubt I'll be as efficient as the last speaker, but I will try.

I'm sure, since the hearings began, this committee has heard all of the platitudes on why Bill 31 is important in protecting health information, but I wonder if the focus we're having now is more on how we can enhance sharing and using health information for secondary purposes, or whether we can actually find it within ourselves to offer health information the protection it should have.

Just as a quick review, when patients seek care, they often do so at a huge disadvantage. They disclose some of the most intimate details of their lives in exchange for health care. They do so under the assumption that that information will be protected and is necessary to look after their problem.

All too often, though, personal health information is used or disclosed by secondary users without the knowledge or consent of the patient and much to the detriment of the individual. That harm may range from simple embarrassment to loss of social status and may ultimately escalate to discrimination in hiring, housing or insurance coverage, in spite of protective legislation, or sometimes because of it. The Canadian Medical Association struck a poll in 1991, the Harris poll, which pointed out that 7% of respondents avoided seeking health care so as not to affect their employment or insurance status.

Within a health care setting, disclosure without consent may result in prejudicial care or an inability on the part of the patient to access reasonable choices in health care. There are protocols that exist for the protection of patient information, but they appear to be eroded by secondary users intent on elevating their status in the delivery, administration and study of health care, and ultimately financial gain. It may often be to the detriment of care itself.

I think protections in health care information and human rights—if I can go that far—are well defined nationally and internationally. Article 12 of the United Nations Declaration on Human Rights, to which Canada has signed on, clearly defines privacy as a human right.

The European Union similarly accepts privacy as a human right and enacted the standards for personal information sharing that have been a catalyst for both PIPEDA and the bill before us today.

1410

Although Canada has not formally enshrined privacy as a right, sections 7 and 8 of the charter are being interpreted by our courts as bestowing privacy rights for Canadians. With respect to ownership and control of health records, the 1992 Supreme Court decision *McInerney v MacDonald* went so far as to claim patients had a proprietary interest in their health files and described the concept of patient ownership of a file, a medium which is owned by the physician. It also went on to declare the patient had an expectation of control, once disclosed in the health setting.

With respect to human research, this became an issue after the Second World War when medical studies were undertaken on prisoners, resulting in discomfort and often death. In response to that, the Nuremberg accord was drafted and was developed to facilitate prosecution and execution of physicians at the Nuremberg medical trials. Interestingly enough, this human subject protection was never applied to the studies in Canada and in the United States, specifically, the Tuskegee syphilis study and the Montreal LSD studies of the 1960s. Since Nuremberg, it has been replaced by the Declaration of Helsinki, with its last amendment in 2000. Helsinki has been for years the standard for human subject protection in research.

Among other things, the protections from Helsinki apply to interventions, human tissue use and the use of identifiable data. It defines the need to seek the informed consent and voluntary participation of research subjects. It allows for withdrawal from the study without penalty and promotes the interests of the individual over those of society.

The question must be, how does Canada shape up? If one accepts the position that privacy and protection of personal health information, along with control of and disclosure of one's information—we call it personal autonomy—are true human rights, we might not be doing that well. European rules appear to be very clear in the rights conferred to patients in terms of autonomy, consent and control of information sharing and disclosure, even within the therapeutic context. By following Helsinki more rigidly, Europeans recognize the right to voluntary participation in human research.

I have been given 15 minutes to talk about three fairly important points, and I'm going to focus on these. In section 20, Bill 31 gives a caregiver the right to alert another to the incomplete disclosure of a patient record or the unwillingness of the patient to share information that is necessary for the purpose. I would argue that this clause is in conflict with the basic concept of self-determination. In the old days, when physicians did what was best for the patient, it was referred to as "ethical paternalism." Our court rulings have consistently upheld the right to self-determination and, if we can believe the

Supreme Court on the expectation of control of records once disclosed, it's not outrageous to think a patient should have control of what's shared within a health setting. I'm not suggesting that we seek consent every time, but I think we have to respect the patient who wants to hide certain information.

There are cases where unwanted disclosure by one's physician may prejudice a second opinion or even care itself by offering observations the patient is a whiner, a malingerer or other critical personal assessments. As well, a referring physician may offer information such that a proper secondary investigation is not undertaken. Often a fresh look at a medical situation is required to arrive at a proper diagnosis. Roscam Abbing from the Netherlands argued that forced disclosure relegates patients to being mere information packages.

Section 45 gives the minister the right to share personal health information with a health data institute. This is already happening without the knowledge or consent of patients. Perhaps agencies such as the Canadian Institute for Health Information will produce good evidence of care and outcomes and allow us to better predict utilizations—perhaps. Most people, though, are not aware that Stats Canada has a data-sharing arrangement with CIHI and, further, that the Statistics Act, subsection 17(2) mandates Stats Canada to arrange in such a manner "that it is possible to relate the particulars to any individual." Unless I can't read very well, StatsCan appears to have a clear mandate to uncloak the identifiers.

Although StatsCan releases information in an aggregate manner, there are private interests who are dedicated to reassembling anonymous data. For those who receive the cold calls from stockbrokers at night, they may be the recipient of a printout from a computer program known as Mosaic. In my own case, my income had been published within 5% of my declared income. This was garnered through Mosaic and sold to stockbrokers. On that basis, I was targeted to no end.

The privacy commissioner responded to me and said, "You were not identified specifically in the released census material, but that did not save you from being identified by association ... potentially making you a target for aggressive marketing of everything from financial services to sailboats."

Given the scope of information that will be delivered via CIHI to Statistics Canada, one can only project the impact on one's privacy. This is especially the case for those among us who have suffered from HIV, STDs, or sought therapeutic abortions or psychotherapy. Unless the data sharing arrangements with agencies such as CIHI are modified, I'm curious to see how the minister would be able to protect Ontarians from predatory commercial behaviour.

The last area I'd like to deal with is human research without consent. By adopting the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans, Canada may have lessened the protections to which Canadians are entitled. The Tri-Council statement

allows for research with modified consent or no consent where there is “minimal harm” or there is a non-therapeutic intervention. My first thought was that I’m not very brave. I don’t want anyone deciding what “minimal harm” is. I’m in for no harm, but minimal harm may vary based on whose perspective we’re looking at.

Secondly, this paper minimizes the requirement that the research team seek consent for the use of human tissue or identifiable data. Essentially this act—it’s not exclusive to Bill 31. It appears in PIPEDA; it appears in the Saskatchewan health bill and the Alberta health bill. Essentially Canadians are being conscripted as human research subjects.

Bill 31 outlines the conditions where non-consented research can take place. It requires the review of a research ethics board, but there is no issue with respect to membership requirement or that the provision might include a member with privacy expertise. I suggest the participants on these boards will vary markedly between regions and perhaps even within institutions. As it’s written without controls, uneven applications of research protocols and consent provisions will likely be unpredictable.

In Margaret Somerville’s book *The Ethical Canary*, she alluded to two cases involving REBs. In one case, the principal researcher chaired his own REB, and in another the ethicist identified as being on the REB never sat on it once. This should raise alarm bells, at the very least.

When research is privately funded and conducted, we have no assurance what research code will be followed by the team. Will it be the Tri-Council statement, or will it be a more private research code that tends to be more user-friendly? Nevertheless, for-profit research will be entitled to access identifiable information without consent.

It should be recognized that health research is becoming a big business and interests are not always benevolent. In an article, Roscam Abbing wrote that research rarely benefits the research subject.

“Concerns about third party interests have increased with modern medical research activities. The grip commerce gets on research, the increased dependence on researchers on funding by private entities, the financial aspects of patenting, the increased partnerships between academia and industry, the worldwide competition in science and the measurement of research performance in output terms of numbers of scientific publications and patents granted, rather than in terms of their contribution to public health are some of the underlying causes.”

I believe governments are defaulting on their obligation to protect those who cannot protect themselves. European standards do allow for research without consent; however, consent is the default position.

Perhaps Bruce Phillips stated it the best in 1998-99 in his annual report to Parliament, where he stated, “Allowing health bureaucrats and researchers to represent the patients’ interests risks putting Colonel Saunders in charge of the chicken coop.”

The Australians, in developing their electronic health record HealthConnect, recognized and discussed a

hierarchy of information, with the highest level being personally identifiable, degrading down to de-identified but relinkable and, finally, aggregate. They argued that the burden of consent should go up as does the hierarchy, as the identifiability does. We don’t see that in our legislation; we’re defaulting this entirely to the courts or to the research boards.

1420

Alberta Hansard may have captured the essence of the debate when the health minister, commenting on Bill 10, recognized consent for what it actually may be: an administrative burden. Nevertheless, the ability to conduct research on human beings or their personally identifiable information should be regarded as a privilege and not a right. International law, Canadian law, international human rights legislation and the Supreme Court of Canada recognize the ability of the patient to control that information.

As an aside, the Australian HealthConnect also recognized a need and requirement to allow people to mask their identities for certain actions of work or for those among us here today who are public figures. They argued that victims of child or sexual abuse, domestic abuse, sex trade workers and those with very highly sensitive illnesses should have the right to seek care in total anonymity. I would submit those are goals to try to reach.

With respect to the three areas of Bill 31 I have described, I would submit to the committee and to the members that the bill offers insufficient protection of the privacy and dignity of Ontarians. I believe a balance can be struck, but these three areas remain tough to balance.

The Vice-Chair: Thank you, Dr Speers. Unfortunately there’s no time for questions. We’ll have to move on to the next presenters.

Dr Speers: I shortened that a lot.

The Vice-Chair: It was 15 minutes right on.

ONTARIO ASSOCIATION OF COMMUNITY CARE ACCESS CENTRES

The Vice-Chair: The next presenters are from the Ontario Association of Community Care Access Centres. Good afternoon. You may begin.

Dr James Armstrong: My name is Jim Armstrong, chief executive officer of the Ontario Association of Community Care Access Centres. Accompanying me is our policy adviser, Georgina White. On behalf of the association and our members, I would like to express my appreciation for the opportunity to appear before the committee today.

The Ontario association is a voluntary organization that represents Ontario’s 42 CCACs. As the provincial voice for CCACs, our mission is to support and represent the interests of our members, to provide leadership in shaping health policy and to promote best practices on behalf of the people we serve.

As background information, CCACs are statutory corporations under the Community Care Access Corporations Act, 2001, and provide services under the Long-

Term Care Act and the Health Insurance Act. CCAC board members and the executive directors are appointed through the Lieutenant Governor in Council. The centres receive 100% of their operating funds from the Ministry of Health and Long-Term Care, with total annual provincial budgets of approximately \$1.2 billion.

It's the nature of the CCAC services that is central to our perspective on Bill 31; in particular, that many of our services are provided in people's homes and that the services are provided through contracts with many service providers to a large number of people across the province each year. The vast majority of CCAC funding is used to provide home care services with three key objectives: hospital substitution to prevent the need for hospital admission or to enable people to return home from hospital sooner; maintenance to enable people with long-term health care problems and functional disabilities to live as independently as possible in their own homes and prevent or delay the need for long-term-care placement; and prevention services to promote wellness and prevent deterioration of health to higher levels of care, and also to support family caregivers.

Almost 60% of referrals to CCACs come directly from hospitals, with the remainder coming from individuals, family members, physicians, schools and other community agencies. As an indication of the scale of the service activity, last year CCACs arranged 6.5 million nursing visits, 15 million hours of personal support and homemaking and over 1.3 million therapy visits. CCACs manage over 1,000 contracts with nursing, personal support and therapy service providers for the delivery of these services. Managing these contracts requires the timely and effective sharing of information to ensure that the services are responsive to the changing needs of our clients, to meet consistent standards and preserve clients' rights.

CCACs interact with all other parts of the health care system: physicians, hospitals, long-term-care facilities, school boards, community service agencies and health service providers. CCACs have major responsibilities in assisting individuals to navigate the health care system and in facilitating service coordination and information sharing with multiple health care providers. Therefore, we are keenly interested in this Health Information Protection Act, Bill 31. I am pleased to express our support for this legislation and to commend the government for bringing forward an act that deals specifically with the protection of health information. It's evident from the contributions you've had over the last couple of days that there is broad support for this legislation, and we look forward to its successful passage.

In the absence of provincial legislation to date governing the protection of health information, there has been considerable confusion around the scope of application of the federal PIPEDA in relation to CCACs, their contracted service providers and other health care organizations. In addition to bringing clarity in relation to the protection of personal health information, we believe that this proposed act provides a flexible balance between

the protection of personal privacy and the effective delivery of health care. This is of major interest to us because of the sheer scale of services and the number of people that CCACs serve each year.

As well, the permitted uses under section 36 of the act also recognize the importance of using health information for service planning, monitoring and evaluation, education, risk management and quality improvement, all of which are also key parts of CCAC activities.

Section 14 of the act is especially important to CCACs since it permits a health information custodian to keep a record of personal health information in an individual's home with the individual's consent. This provision acknowledges the special challenge of providing coordinated, consistent care, sometimes by multiple health care workers, in the home environment.

The committee has heard concerns from a number of organizations about the requirement for express consent in relation to the use of personal information for fundraising purposes. While CCACs do not carry out fundraising, many of the non-profit service providers with which we have contracts do rely on fundraising to support the provision of other community services. We recognize the importance of these fundraising activities to maintaining a broad range of community services. At the same time, CCACs have been concerned in the past about the use of personal information for these purposes and the confusion it can sometimes lead to when consumers do not fully understand the relationship or lack of relationship between fundraising activities and the fully funded services they receive through CCACs. We would support an amendment that would allow consumers to opt out of fundraising activities while preserving their right to be informed and have the choice about how their personal information is being used.

Like other presenters, we have concerns about the limited consent or so-called lockbox provisions. We are concerned that an individual's choice to withhold consent for the disclosure of information that may be crucial to the delivery of appropriate health care could jeopardize their health and place health care workers at risk. Both as receivers of health information from hospitals and other providers and as providers of information to long-term-care facilities and in-home service providers, we believe the disclosure of all medically necessary information to ensure appropriate treatment and placement is essential.

We very much appreciate the open consultation process undertaken in relation to this act, and in particular the provisions related to consultation around regulations. We believe that consultation will be particularly important in relation to the specification of information practices or procedural processes that health information custodians will be required to comply with when collecting, using or disclosing health information to ensure that they can be successfully implemented.

Briefly, I'd like to also just speak to the time frame and cost of implementation. Education on the act and the regulations will be key to successful implementation. The OACCAC is in the process of arranging an in-service

education program for CCACs on health privacy. In collaboration with the continuing care e-health council and other long-term-care associations, we provided our members with a privacy tool kit based on the Canadian Standards Association principles, in anticipation of the requirements of PIPEDA. That tool kit will now need to be modified to ensure compliance with HIPA.

In addition to ensuring that CCACs have the tools and knowledge to successfully implement the legislation, education of our many contracted service providers will also be necessary. Given the education and preparatory work that will be required for implementation, as well as the time needed for consultation and regulations, our association is concerned that July 1 is an unrealistic implementation date. We would recommend an implementation date that provides a reasonable interval after the passage of regulations to ensure that appropriate standards and practices are in place.

Finally, there is the issue of costs related to implementation, not only for CCACs but also for our contracted service providers. In the absence of specific funding to support the implementation of the act, the result would be that service provider costs are likely to be included in the service rate bids under our managed competition process. Higher rates would then mean that we can provide less service to the public within our overall funding envelope. We will be working with the provincial associations that represent our providers to develop a cost estimate and we will provide this information to the committee.

In conclusion, let me express again my appreciation for the opportunity to appear before you and to reiterate our support for this legislation.

1430

The Vice-Chair: We'll start with Mrs Witmer.

Mrs Witmer: Thank you very much for your presentation. I do appreciate it, Dr Armstrong. You've certainly pointed out some recommendations that need to be made that are very similar to those of other groups—the opting out, the lockbox provisions and the need for consultation on the regulations.

I just want to focus on implementation costs. I would really appreciate it if your association would work with your providers in order that we could have a cost estimate. CCACs at the present time receive just enough funding, and maybe not enough, to do the job that they're required to do, so I think it is important when you take into consideration that there are going to be some tools, education, and certainly other things that are going to need to happen before you could successfully implement this new legislation. It would be helpful if you could give that to us.

The other one is the implementation date. As you and others have correctly pointed out, July 1 just isn't reasonable, because the regulations are not going to be drafted today or tomorrow and they're going to follow what we're doing, and until you have the standards and the practices, it's going to be difficult to embark on education. When you say “a reasonable interval after the

passage of regulations,” what do you mean by “reasonable”? If this were passed by, say, July 1, would you say January 1, 2005? What's reasonable?

Dr Armstrong: At the same time, of course, we need to acknowledge that there is an urgency about proceeding on this. We envisage that a lot of preparatory work could happen in parallel. It's going to be known, once the legislation is passed, what is likely to be a lot of the content that's coming in the regulations. A lot of that can happen in parallel and we're gearing up for that, so I would say that would be the outside date that we would envisage.

Mrs Witmer: Is there any cost saving to implementing this bill at the start of the year, January 1?

Dr Armstrong: I don't think that the time of the year would make that big a difference to us.

Mrs Witmer: Or for any other service provider?

Dr Armstrong: I don't think so.

Mrs Witmer: Changes they might have to make to their system?

Dr Armstrong: Not given the nature of the kinds of changes we're talking about here. We will look more closely at that question as part of the next few days of looking at what the implications are for planning for implementation, but I don't at this point foresee that that would be a big factor.

Ms Martel: Thank you for coming today. Actually, my question did concern the implementation, because we've heard a number of the other arguments already. Certainly a number of people have come forward expressing the same concern. You're saying that six months is the outside limit, obviously, because there's an urgency to be in compliance with privacy legislation. I guess the issue will be whether the regulations can be developed in tandem as the bill moves forward, and we need to know more about that process. So you answered my question effectively with respect to how long you think it would take for you to have it implemented successfully across the system.

Mr Fonseca: Today, when some of the patients under a CCAC refuse to give up information, what happens in that circumstance? What do you do? What do the CCACs do, like a lockbox effect, if they refuse to give out or allow that information to be disclosed?

Dr Armstrong: I'll ask Georgina White to speak to that.

Ms Georgina White: Generally, the client would be counselled around the risks associated with not providing that information, with the hope that at some point they will agree, particularly if it's crucial to their medical care, but if the client refuses to provide the information [*Inaudible*].

Mr Fonseca: And how much information do you need for an appropriate placement? Do you look at everything? Do you only need some? What are you asking for?

Ms White: What would really relate to the client's specific needs, what kind of programming would be necessary for an appropriate placement, whether there were issues related to dementia, with wandering, poten-

tially violent behaviours, those kinds of things that could place not only the individual at risk, but other residents and health care workers as well.

Mr Fonseca: So do the CCACs have policies and procedures in terms of how much information you would actually look for with a specific client?

Ms White: They do a comprehensive assessment on every client who requires long-term care and then basically develop a profile that they provide to the facility that identifies issues and risks related to the person.

Mr Fonseca: And in terms of the fundraising, is all that information in regard to the client—because they can have a wide variety of different ailments—used for fundraising purposes?

Ms White: Sorry?

Mr Fonseca: So if they've got different diseases, are all the different agencies made aware of—

Ms White: No, it would be in relation to some of the non-profit community agencies, nursing providers, personal support providers who also provide other community programs. They may provide volunteer visiting services or other kinds of activities that they rely on fundraising to support. So they often will use their CCAC client lists as potential donors.

Mr Fonseca: My worry, I guess, was around that a CCAC client may be bombarded by different marketing efforts rather than just a cancer patient that may be only targeted in terms of different cancer foundations or organizations.

Ms White: No, I don't think that's been a particular issue. It'd really just relate to the providers that were dealing with it.

Ms Wynne: Just a question around the implementation: Are there changes that you have already made—I'm talking about the timeline here—in order to be compliant with the federal legislation?

Dr Armstrong: There has been quite a bit of activity in terms of further change or development in policies and practices over the past few months in preparation for PIPEDA. So if you're thinking that that takes us somewhat along the path, the answer is yes. Designation of privacy officers, privacy impact assessments on

information systems, establishing policies and procedures related to consent and so on: A lot of activity has been underway, which I think will help in terms of implementing the provincial legislation.

Ms Wynne: Right. So we're part way down the road, but you still think that there's more time needed than what's provided for in the bill.

Dr Armstrong: Right, because there are a number of specific provisions that relate to this. In our case, having so many service providers around the province with so many different kinds of roles, and their own staff over and above our own CCAC personnel and practices, it's just a very extensive process to adapt.

Ms Wynne: It's interesting to me that a lot of those small agencies haven't come to speak to this bill, and that may be just my lack of experience. Maybe they came during the first rounds, but they haven't come this time. Can you explain that at all? They're more happy that this is happening than not, or do you have any explanation for that from your provider agencies? So they haven't been calling you and they're not worried? You're not here representing them particularly. You're talking about the CCACs.

Dr Armstrong: I don't know whether they're relying upon what will be coming to them through the CCACs. They have their own responsibilities. This is one of the reasons why we partnered with four other associations in developing this tool kit, so that for, example, the Community Support Association members were assisted through the development of this joint tool kit, which I want to note was funded by the Ministry of Health and Long-Term Care. So it may well be that they for various reasons did not feel the need to appear this week or were not following the process to this point.

Ms Wynne: OK. Thank you very much.

Dr Armstrong: Thank you.

The Vice-Chair: Thank you for your presentation. Thank you, everybody else, for presenting. Now I'd like to ask that the room be cleared because there is a meeting of the subcommittee. Thank you once again.

The committee adjourned at 1440.

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Also taking part / Autres participants et participantes

Mr Peter Kormos (Niagara Centre / -Centre ND)

Clerk pro tem / Greffier par intérim

Mr Trevor Day

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Ms Margaret Drent, research officer,
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