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**Official Report  
of Debates  
(Hansard)**

**Thursday 5 February 2004**

**Journal  
des débats  
(Hansard)**

**Jeudi 5 février 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

Président : Jean-Marc Lalonde  
Greffière : 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**

Thursday 5 February 2004

Jeudi 5 février 2004

*The committee met at 1001 in the Hilton, London.*

**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.

**LONDON HEALTH SCIENCES  
FOUNDATION**

**The Chair (Mr Jean-Marc Lalonde):** Good morning, everyone. On behalf of the standing committee on general government, I want to welcome you and thank you for taking the time to come down and give us a presentation of your concerns and comments that you have to make on Bill 31.

You have 20 minutes. If you're taking the whole 20 minutes, then there's no time left for question period. If there's any time left, it will be divided among the three parties, as long as we have more than one minute. If it is only one minute, I'll alternate today: One party gets the one minute once and then next time, it's another one.

We do have instant translation available also. If anyone wants the equipment, they could go to the technician. It's available there.

Chers amis, si vous avez l'intention d'écouter la traduction simultanée, nous avons des écouteurs disponibles que vous pouvez vous procurer ici de notre technicien.

Merci et bienvenue à l'audience publique.

**Mr Frank Kearney:** Good morning; bonjour. My name is Frank Kearney. I'm the chief operating officer of London Health Sciences Foundation.

I'd like to express my appreciation to the committee for hearing this submission. I'm speaking to you on behalf of the four hospital-related foundations here in London. I have with me two colleagues: Dominic Langley, who is the director of information management at London Health Sciences Foundation; and Ellen Flood, who is senior development officer of Parkwood Hospital Foundation.

Let me begin by painting a picture of the amount of support received by the London hospitals from their foundations. As you can see on this slide and in the presentation that you have in front of you, that support last year totalled \$31.4 million, which comes from southwestern Ontario and, significantly, from the greater London area.

That fundraising takes a number of different forms. Children's Health Foundation receives its funding from direct mail, community events and lottery. It does not have, obviously, a patient-calling program. Its patients are children. The other foundations—London Health Sciences Foundation, Parkwood Hospital Foundation and St Joseph's Health Care Foundation—employ a different mix of fundraising methodologies in order to raise the funds that I referred to.

I want to give you an example of the importance of fundraising, specifically to London Health Sciences Centre. The Ministry of Health and Long-Term Care and the hospital have worked on a \$270-million restructuring program for the London hospitals; \$100 million of that is coming from London Health Sciences Foundation. In fact, we will be later on this year announcing that we have raised more than that amount of money. So that's a very significant contribution to the improvement of health care in this region. As you know, the London hospitals are the tertiary care facility for a much broader area than just London.

To give you some idea of the importance of grateful patient programs, the two largest foundations receive between 5% and 10% of their revenue from first-time donations from grateful patients. But this is not the real picture. The grateful patients later become repeat donors. They leave bequests. They grow in affluence and increase their level of philanthropy and become major donors, and they participate in a host of community events, all of which are fundraising events or certainly promote health care and health consciousness in the area.

To give you an example of the acceptance of grateful patient programs, because we're all concerned about whether or not those programs are just a nuisance—they aren't—50% of grateful patient donors in the first year continue their support in subsequent years, and in some years that support can continue at a level of 80%. So it becomes a stream of support that goes on, in theory, forever, but practically certainly for a great number of years.

Another example is that 14% of patient donors indicate that they have established a bequest to a hospital averaging \$15,000. That could amount to an awful lot of money over a long period of time, and that's why the foundations can raise as much money as they do.

Hence, grateful patient programs constitute a large and continuous source of revenue, in effect replenishing the donor base of support for the foundations each year. It is the view of the foundations—and I must be very candid with the committee that I have no basis on which to base this, other than our own personal opinion—that the supply of new donors would be reduced by upwards of 90% if the hospitals had to rely on express consent for fundraising.

On this basis, the foundations and the hospitals will have an immediate cash loss in the first year of \$1.2 million, in terms of cash contributions. By the fifth year, because this is a continuous program, growing on itself, if you like, that would amount to \$2.9 million, and it would continue to rise in terms of the impact. But certainly over the first five years, if we were to go to express consent and if 90% of people chose to opt out, we would amass a loss of \$10.7 million among the four foundations in London, strictly from grateful patients.

Also, based upon historical patterns, this reduced level of contact with former patients would translate into a further \$45 million in bequests that those same former patients might not give in the future. Lack of contact with grateful patients would impact other revenue sources such as those I mentioned: major gifts, community fundraising events and so on.

There are other benefits to our contact program with grateful patients. When SARS was top of mind with the public, our communicators in call centres were contacting about 15,000 former patients a month. They got a lot of feedback from concerned citizens and were able and trained to disseminate information to the public to help answer those questions. Likewise, they were also trained to gather information and provide it to the hospitals so the hospitals could respond to the community's concerns and provide the information they were looking for. So there are by-products of some of the things we do, other than just fundraising.

The foundations support the concept of privacy and have done so in all their dealings over the years. The introduction of the federal legislation, the Personal Information Protection and Electronic Documents Act, perhaps heightened the sensitivity to privacy, as has this bill. But I certainly can tell you, because I was working with all of my colleagues on privacy, that the hospital foundations meet or exceed the requirements of the federal legislation.

Two of the foundations do not have in their databases any personal health information, as I define it—in other words, medical information—with respect to their donors. The two other foundations are in the process of deleting all that information from their files—not only their electronic files but also their physical files—and that's a massive undertaking. By March 31, and probably

much earlier, that will all have happened. So the foundations will not have what I call personal health information in their files.

It's also important to note that none of the foundations sells, rents or trades mailing lists, not even among themselves. The information we have, we keep and safeguard. It's also worthy of note that we follow the best practices established by all the major fundraising and professional organizations on the continent, some of whom I believe you've heard from in Toronto and one of whom you'll be hearing from later in the day. So we follow the best practices of the industry.

#### 1010

Where hospitals provide data to their foundation, that data is first filtered to remove all personal health information. It's also filtered to eliminate all patients who have asked not to be solicited. It's also filtered to eliminate patients whose type of treatment might be sensitive. Hence, we really are trying not to contact someone who doesn't want to be contacted or perhaps shouldn't be contacted. We're very sensitive to that.

The foundations themselves also do a certain amount of filtering. They receive information from patients and from other donors that they don't wish to be approached or solicited. We have separate files for that, and we make sure we don't repeat a call. Likewise, we look for other eliminations, such as patients whose address appears to be a nursing home, which would indicate that would be an inappropriate person to contact.

We do have some concerns about express consent. From the hospital's point of view, express consent will be a costly thing to implement, because you have to overtly deal with it at a time when patients are more concerned with their medical care than anything else. It's worthy of note that the present practice of the hospitals is to provide patients with notice and, at this time, a privacy publication which outlines their options and provides all the contact information one could have, or you can tell the hospital right then and there that you do not wish to be approached for fundraising and a number of other purposes that are outlined in the privacy statement.

All the foundations wait at least two months, and very typically much more than that, before contacting a former patient, and they typically write to that former patient before contacting them by phone, giving them an opportunity to opt out.

Patients accept implied consent; they have for years. But let's take a look at some statistics. In London Health Sciences Centre and St Joseph's Health Care in the month of January, when all the publicity in the media was focused on privacy and privacy legislation, only four patients out of 32,000 asked to opt out of fundraising. I can't even calculate that number as a percentage; it's something like one one-thousandth. Moreover, when our call centre was contacting former patients by phone—those would be patients from the last calendar year—only 15 former patients out of 15,000 indicated that they did not want to be solicited by phone. So former patients

accept the concept of being approached for fundraising and there is not a lot of objection to fundraising.

One of the concerns of the hospital foundations is that they'd like to be operating on a level playing field with other charitable organizations. The dollars available for philanthropy are obviously finite, and requiring express consent for hospital foundations while others do not have to have express consent would disadvantage the hospital foundations relative to other charities and, as a consequence, would only add to the pressures on government to fund health care and health care facilities.

So the four hospital foundations in London ask for some clarity in the bill. The bill provides that demographic information about an individual—such as name, address and telephone number—is identifying information. Then, when defining personal health information, “identifying information” is used as a term: Identifying information about an individual is personal health information if that information relates to the providing of health care to the individual. Later, when talking about fundraising in section 31, the bill states: “A health information custodian shall not collect, use or disclose personal health information about an individual for the purpose of fundraising activities unless the individual expressly consents....” Some would regard this as triggering the need to obtain express consent for fundraising in every instance, even if the hospital foundation only receives the name, address and telephone number relating to a former patient.

The foundations support the comments made by the Information and Privacy Commissioner of Ontario in her submission to you that “a requirement for express consent would have an adverse impact on a health care organization’s ability to raise much-needed funds.” The foundations therefore ask that the wording of Bill 31 be clarified to allow patient fundraising to proceed on the basis of implied consent, provided that the foundations only have access to what I call demographic information; namely, name, address and telephone number.

This is inconsistent with the Ontario Hospital Association’s position. In their Guidelines for Managing Privacy, Data Protection and Security that organization recommends “that hospitals should only be required to provide a notice to patients informing them about the use of their personal information for hospital fundraising activities.” The suggestion is that there is no need for express consent; implied consent will be adequate. Therefore, the foundations and the hospital ask that Bill 31 be clarified such that they can rely on implied consent on the basis previously outlined.

In conclusion, implied consent has been very well received by grateful patients for many years throughout the province, and in the case of London has allowed foundations to raise well over \$100 million—and I mean well over \$100 million—in recent years.

Thank you, Mr Chairman and committee members. I’m open to any questions you have.

**The Chair:** We have seven minutes left, so it’s going to be divided among the three parties. Next it is the official opposition’s turn.

**Mrs Elizabeth Witmer (Kitchener-Waterloo):**

Thank you very much for your presentation. I think the truth is that fundraising has become a much-needed source of revenue for hospitals over the years. With and all of the restructuring that’s taking place in Ontario, whether it’s a new hospital or an addition or expansion, if we hadn’t had the public contributing we certainly wouldn’t be seeing these new, expanded services to meet the growing needs of our population.

I have a question on slide 11—support of privacy. You say that the hospital foundations do not have any personal health information. So at the present time you are now at a point where all you’ll have is really the name and the address.

**Mr Kearney:** In two cases that’s correct. In two cases, because of some systems deficiencies, the fee that came from the hospital to two of the foundations contained some personal health information, such as the discharge department of the patient, which is being removed from all of the files, both hard copy and electronic copy. It wasn’t noted at the time that it really was inappropriate to have that in the foundation.

In the case of London Health Sciences Foundation, and in the case of Children’s, which of course doesn’t have patients in the first place, there is no personal health information in any of the files. We have gone through the steps of reviewing all of our files to eliminate anything that might inadvertently be there, and the other two foundations are actively, as we speak, eliminating all such information.

**Mrs Witmer:** I was pleased to see as well that you were trying to eliminate from your list people in nursing homes, who obviously would be much more vulnerable in that situation; also people with treatment you might term to be sensitive. Would that be province-wide? Would that be what all foundations are endeavouring to do?

**Mr Kearney:** I can’t say that. I don’t have knowledge of that. I would think as a pragmatic matter that would be an appropriate thing to do. For example, a one-day gynaecological experience would not be someone you should call. Hence, for years we’ve excluded anyone who has gone through that kind of a treatment, someone who’s been in mental health, that type of thing. As a pragmatic matter, a reasonable person would eliminate those people, first from a cost point of view of approaching them, but more important from the fact that this would be very distressful to those individuals. I didn’t mention but we also spend every morning looking through the newspapers for people who are deceased so as to eliminate them from the files of the college; for example, so we don’t cause any distress to a family by calling the family—“I’m sorry, but so-and-so died several days ago.” We take steps to eliminate that type of occurrence as well.

**Ms Shelley Martel (Nickel Belt):** Thank you for being here this morning. On your slide 15 you say, “All of the hospitals provide patients with notice and/or a privacy publication.” I’m not sure what that means.

**Mr Kearney:** The Ontario Hospital Association suggests that notice, ie signage in all of the public areas, would be appropriate. As it turns out, the hospitals in London have chosen to actually provide each patient with a privacy policy statement, which outlines the purposes for which the information is being collected. It also provides for an opt-out opportunity, giving the name of the person to contact, the telephone number, fax number, e-mail address and so on, and a Web site address as well.

1020

**Ms Martel:** That's given to them at the point of admission?

**Mr Kearney:** At the point of admission, that's correct.

**Ms Martel:** If they come through emerg, what happens?

**Mr Kearney:** The policy is to give them the documentation. Remembering, if you think through the process they would come through—there might be a traumatic situation and there might be a family member or other person overseeing their care; nonetheless, among the information they receive is the privacy policy statement of the hospital. That is taken as a take-away so it can be looked at at a more appropriate time to determine whether or not they wish to have their information used for a number of purposes, one of which is fundraising.

Also remembering that it would be most typical not to approach that patient for two to six months afterwards, that gives them a great deal of time to actually say, "Do you know what? I'd rather not be phoned."

**Ms Martel:** So the statement itself at some point explicitly references fundraising?

**Mr Kearney:** Yes, it does. I don't have a copy of the hospital's policy statement, but it does very specifically address the question of fundraising. It uses exactly that word, "fundraising."

**Ms Martel:** There's a statement you can sign if you want to opt out. Does it essentially say, "Don't contact me for fundraising"?

**Mr Kearney:** At the present time what is there is a person to whom you could say, "I want to opt out." Also, there are all the contact points to opt out.

**Ms Martel:** Just let me back up. If you do it at admissions, is it the hospital staff person who is providing that at admissions?

**Mr Kearney:** Yes, it is.

**Ms Martel:** So that's happening now.

**Mr Kearney:** That's happening now. That's PIPEDA.

**The Chair:** The government side, Mr Leal.

**Mr Jeff Leal (Peterborough):** Thanks very much for your presentation. My question is, if I was to make an original donation to your foundation, how many times would I give a second and third and fourth time? Do you track that in terms of people who make donations to your foundation?

**Mr Kearney:** We have to track the donations.

**Mr Leal:** Typically, what is the sort of pathway, or how many people would give additional donations?

**Mr Kearney:** If it's a grateful patient program, approximately 50% would repeat in the first year, and in our case 80% continue to give thereafter. The number obviously includes people who might move away, people who might live far away from London and don't have the affinity to the hospital in London that a local person might have and that type of thing.

**Mr Leal:** We've been told earlier in other submissions that as people give additional gifts they get higher in value each time. Is it your experience?

**Mr Kearney:** That is our observation as well. If I were a young person receiving medical treatment and gave a small gift, as I got older and hopefully more prosperous, I would presumably increase my giving as a result of my increased ability to give.

**Mr Leal:** Thank you very much, sir.

**The Chair:** Ms Wynne, quickly.

**Ms Kathleen O. Wynne (Don Valley West):** I just wanted to check—you're talking about implied consent, but in the process that you just described it really sounds like an opt-out alternative.

**Mr Kearney:** The hospitals are not expressly asking the patient or the person taking care of that patient to sign them up for fundraising. Instead, they're providing the means for them to opt out. That's implied consent.

**Ms Wynne:** So the first that you described would be express consent, which is what's in the bill now.

**Mr Kearney:** That's correct.

**Ms Wynne:** What you're suggesting is that an opt-out alternative would be fine by you, because that's what happening now?

**Mr Kearney:** That's what's happening now and that's what has been happening for years.

**Ms Wynne:** So it wouldn't have to be implied consent, which would be that we assume that everything is fine? You're fine with an opt-out process.

**Mr Kearney:** Opt-out and implied consent are almost the same thing, but yes, we're fine with that. We're seeking clarity on the bill. As the bill reads right now, it could be construed that we have to get express consent—

**Ms Wynne:** And you think across the province that demographic information—name, address, phone number—is what foundations should have?

**Mr Kearney:** That's what foundations should have. Foundations typically are separate—certainly the larger ones—from the hospital.

**Ms Wynne:** Right. But you don't see any need for any more information than that?

**Mr Kearney:** We don't see any more need. There were times when we looked at information like what we would call segmented data, so we might approach a patient knowing that they had an interest in a certain field, such as cardiac or something like that. We decided a year or so ago that that type of information—

**The Chair:** Sorry. Our time has expired. Thank you very much for taking the time to bring to our attention your concerns.

HOSPITAL PSYCHOLOGY ASSOCIATION  
OF ONTARIO

**The Chair:** The next group will be the Hospital Psychology Association of Ontario, Ian Nicholson. For our record purposes, if you could state your name and your position.

**Dr Ian Nicholson:** I'm Dr Ian Nicholson. I'm a member and past president of the Hospital Psychology Association of Ontario.

The Hospital Psychology Association of Ontario represents individuals in leadership roles in psychology services across the hospitals in the province.

As the members are likely well aware, psychologists in the province have been regulated as health professionals since 1960 and have been an integral part of hospital service for several decades.

We want to thank you for the opportunity to come and speak with you about this legislation. We have been tracking its various permutations over the years and are quite happy to give our comments on the most recent version.

We first want to point out a handful of things that we see as really exemplary. But before we get to those particular points, we do want to just generally say how very pleased we are that this has been put forward. We see it as much, much improved over both the previous provincial draft, Bill 159, and the federal legislation that is now in force. We see it as being much more a strong balance between the needs of the health care practitioner and the needs of the individual. So we do want to strongly indicate how much we're supporting this piece of legislation.

Some of the key points that we feel are particularly important and want to support are the reasonableness and the limits put forth on the collection of personal health information. We think the wording of that is very strong and we support that: the way the wording is in section 39, allowing the disclosure of personal health information for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons.

We've continued to have ongoing concerns about who is a personal health information custodian and who is not, and we would think that insurance companies and the WSIB could be listed as personal health information custodians. While they're not included, from our reading of this legislation, in that mechanism, we are happy to see a number of the other limits put on the use of the information that is given to other custodians.

In clause 53(9)(b), we strongly support the splitting out of professional opinion or observation from other pieces of health information as important. We also strongly want to support section 72's recognition of the need for public input before making regulations. The devil is often in the details, and we see that as an important piece we want to support.

There are some other things that we do support but would like to see changed somewhat. I guess what I'd like to do in the interests of time is move forward to

some of the areas of concern that we have identified, areas that we support but would like to see a couple of changes included in that.

**1030**

In the definition of "health care practitioner," we're very strongly supportive that it's beyond just regulated health professionals. We are glad for that broad definition. We would like to add, though, that because of the recognition, particularly by HPRAC in its review of the harm clause in RHPA, we would support and like to see the phrase "including emotional counselling" put in clause (d), that says "any ... person whose primary function is to provide health care for payment." A lot of providers of emotional counselling services do not see themselves, often, as health care providers and say, "I'm not providing health care; I'm just giving some support for this person." But they're getting paid for offering that support, and we feel it's important that those individuals be identified as being included in here.

In section 4, we think there's actually likely an error in the drafting of the legislation. Clause 4(1)(a), when it talks about personal health information, including the medical history of the individual's family—it's about the only place in the legislation where there's specific reference to "medical" information, as opposed to "health" information. We'd like to point that out to the committee and hope that could be changed to that all family "health history" is included as part of personal health information.

For example, if you're assessing someone for learning disabilities versus neuropsychological deficits from head injury, it's important to recognize whether that person has a family history of learning disabilities, yet that is not included. That would not be in medical history, but personal family health history.

Section 23: We like the recognition of children under 16 being able to have the capacity to make decisions around disclosures of their own personal health information. We do wonder about the way it is worded and suggest an alternate wording for that, to make it an even clearer point. It is now divided into two sections, and we think that if it's collapsed into one, it would make a clearer and more definite point supporting competent individuals under the age of 16.

We have some concerns with regard to research. I think part of the issue that goes through this—perhaps this will come out through regulation, or perhaps it might be more appropriate to come out through change in some of the wording of the legislation—is basically, what is research? It talks about the health care custodian sharing information with the researcher and the health care custodian doing quality evaluations of the health care that's going on. But what if the health care custodian is doing something that might be termed research if they had given the data over to somebody else? If they're doing it on their own data from their own patients, from patient records they've kept for years, is that considered research? It's unclear in reviewing the material and it would be of benefit if there could be a clearer definition

of the difference between quality assurance evaluations and research. What we have often taken in the past is that if you are collecting data for the purposes of health care and then one is reviewing one's own information that one has collected on patients, that would be considered more quality assurance, quality evaluations, even if it were to be published or presented later to colleagues.

Section 49: We very strongly support the exemption for raw data from standardized and psychological tests and assessments. We see that as very important to support the continued use of those assessments. When those assessment tools go into the public domain, they often lose a lot of their utility. If the answers were known for all the questions on an IQ test and could simply be memorized, it would certainly impact the ability to use those tests in the future. Those tests take years to develop and are tested on tens of thousands of people before they're employed. If they go into the public domain, it seriously damages their validity.

So we would suggest that some of the wording from the American Psychological Association's ethics codes with regard to test data be included to include raw unscaled scores and the individual's responses to test questions or stimuli, and that test materials also be included in that section to include manuals, instruments, protocols and test questions or stimuli.

Section 50: There is similar wording that's used back in 39 about exempting access to that information if it could result in a risk of serious harm to the treatment or recovery of the individual, or risk of serious bodily harm to the individual or another person. Certainly when HPRAC reviewed RHPA, the harm clause had been stated as "serious physical harm," and their review indicated that that was much too narrow. They suggested removing the word "serious" and making it physical and psychological harm.

One example that a staff member shared with me recently is a patient who came in for depression and anxiety at the age of 13. During the course of the assessment, the psychologist was told that the child had been adopted and the child did not know that yet. At the age of 15 the child was curious and wanted to take a look at their health record to see what had been said about them and what the psychologist was saying, and was still not aware that they had been adopted. If the child were to review that information, that would not be considered serious bodily harm, but it certainly could be considered psychological harm. We would like to see that subsection of section 50 changed to, instead of "serious bodily harm," "bodily or psychological harm to the individual or another person."

Lastly, we do have one concern with issues around correction to the record. At the present time, if a patient comes to me and asks me to change their record because an egregious error has been found which I agree with, the legislation indicates that I would send a note about that written correction to individuals to whom I have sent that health information. However, those are not necessarily the only people that could go to. For example, if I send a

report to a family doctor about a patient's psychological condition and wonder about what mediation would be appropriate for that person and they then send a copy of my report off to a psychiatrist for consultation, there is no requirement under the current rules as stated here—at least in our reading of it—that the family doctor, when they receive notice of the correction of the report, has any responsibility to forward that information to any individual or organization that they have since forwarded a copy of my report to. We would see it as important that when someone receives a correction to a report, they have the responsibility of forwarding that correction on to anyone they have already sent a copy of that report to.

I want to reiterate what I said at the beginning. While we see these as important concerns, we don't want that to undermine our strong support for this current legislation as being far better for health care and the individuals receiving health care in Ontario than the current federal legislation and the previous versions of this legislation which have been discussed in Ontario in recent years.

**The Chair:** Very good. Thank you. We have eight minutes left. We'll start with Ms Martel.

**Ms Martel:** Thank you for being here today. I want to deal with your definition of raw data, because this came up in a previous session. When you refer to raw data, if I am correct, the reference there that you want access not permitted to is essentially the questions themselves, the test questions.

1040

**Dr Nicholson:** That's right. Sometimes it's because, given the nature of the test questions, it's very difficult to separate the question from the response.

If a person in part of a neuropsychological test is putting a block design together or trying to work through a maze to see about their ability, due to frontal lobe damage, for forward planning, those have to be recorded in such a way that the response and the question are really together. It's difficult, if not impossible, to separate out the two. So we want to ensure that the response is included as well.

Another example would be if on a general information test one asks, "What is the meaning of" a certain word, and someone's response is, "I believe that this certain word means" whatever. That is recorded in its entirety, as it should be. Then the question and the response are together, and it's impossible to separate the two out.

**Ms Martel:** OK. If we were to move with the amendment that you suggest, which is to increase what would be protected, essentially, from access, at the end of the day, what would an individual be entitled to receive? What would they get then from the psychological assessment?

**Dr Nicholson:** They would be able to receive the results of the assessment as interpreted by the psychologist, and they would also be able to receive general scores about overall performance. But as I say, just the raw individual items are often very confusing for individuals who may not be aware of what exactly all of these mean. Also, as I say, if they were to get out into the

public domain, it would seriously undermine the validity of these tests in the future.

**Ms Martel:** Thank you very much.

**Mr Leal:** Just to follow up from Ms Martel, my colleague Mr Flaherty asked a question in Sault Ste Marie regarding the release of raw data. He has extensive background, being a lawyer, and is used to psychological testing. He thought there wasn't really a serious issue of providing that raw data material. Could you just comment on that?

**Dr Nicholson:** It depends on the raw data. For example, the raw data in a common paper and pencil test of psychopathology might be just a shape where somebody clicks yes, no, yes, no, yes, no, yes, yes, no, no. Releasing that to somebody is not going to damage anything. It's not going to interfere with the test. However, in some of the intellectual and neuropsychological tests, it's very difficult to separate out the raw data from the questions. The two are often one and the same. If you require that the raw data be released, it would also require that the tests themselves, in many ways, be released.

**Mr Leal:** OK. Thank you very much.

**The Chair:** On the official opposition side, Mrs Witmer.

**Mrs Witmer:** Thank you very much for your presentation, Mr Nicholson.

If we take a look at what you're suggesting here, the addition of the phrase "including emotional counselling" in that definition where we talk about the health practitioner, who are we referring to that isn't included without adding that?

**Dr Nicholson:** It would be more, I think, ensuring that there is the recognition that emotional counselling is a form of health care. Unfortunately, what one sees is the individual saying, "I'm not providing health care. I'm just offering emotional counselling." There is in some quarters, unfortunately, the belief that the two are separate, and in many ways there was the view that emotional counselling is not hazardous. HPRAC, when they went through their review a couple of years ago, did support the idea that emotional counselling can be hazardous and should be looked upon as—and, as a result, we interpret it as being recognized as—a health care activity. None of those changes that were recommended by HPRAC, as far as we're aware, have been acted upon yet.

We would hope that by including this sort of phrase within the legislation, it would ensure that those people are captured and that the individuals who see those people, whom we would consider to be health care providers, are given the same protection for their health information.

**Mrs Witmer:** Would these be people who are now covered within the act or outside of the act? Are there other groups of people that you're referring to?

**Dr Nicholson:** That's a good point. One of the reasons we want to have that in there is to make it clear that they would be covered. We would see the current wording of

clause (d) as being dependent upon its interpretation. We would not want it to be dependent on interpretation; we would like it to be much clearer.

**The Chair:** Thank you, Dr Nicholson, for taking the time and informing us about your concerns.

## FALSE MEMORY SYNDROME FOUNDATION, CANADA

**The Chair:** The next group is the Canadian branch of the False Memory Syndrome Foundation. Could you come up and give us your name and position for our record purposes.

**Mr Adriaan Mak:** My name is Adriaan Mak, and the document you have from me is the brief that begins with "Brief respectfully submitted." That's the document.

**Ms Claudette Grieb:** I will speak first. My name is Claudette Grieb. My family suffered an unparalleled tragedy: the death of my daughter, Jackie, and my granddaughter, Dagmar. My medical advisers have stated that my daughter's mental illness was misdiagnosed and consequently maltreated. Prompt, skilled psychiatric care could have saved the lives of my girls.

Unfortunately, my daughter was subjected to unproven therapy by the unlicensed counsellor, Chris Hutchinson, and a government-supported community centre. The Community Justice Initiatives of Waterloo region is run by facilitators who provide this destructive recovered memory therapy. This practice alienated my daughter from her family roots and generated false allegations against myself and others. In effect, it blocked her access to competent medical care and family support that could have saved her life and the life of my little granddaughter.

Records of significant importance have been denied to me on the alleged basis of confidentiality. As executrix, I sought records concerning my daughter from the Community Justice Initiatives but was provided with only limited documentation of Jackie's treatment. Their intake form automatically lists me as a sexual abuser without any investigation or scintilla of proof, based only on their dangerous mindset.

Unlicensed and unregulated therapists are accountable to no one, and they are free to alter and even destroy their files. Animals in Ontario have better protection than our mentally ill. Fortunately, I retrieved evidence in my deceased daughter's ransacked apartment strongly indicating the mental health abuse to which she was subjected. It had been evident that abuse had been manufactured in a cult-like, guru-driven atmosphere where transference of other abuse stories became the ownership of vulnerable clients, who oftentimes suffered from very serious mental disorders. This funded quackery is where millions and millions of our tax dollars are being squandered.

At the treatment centre, my daughter repeatedly told these facilitators and also stated in writing that she was becoming increasingly isolated, depressed and suicidal. Their answer was, "You have to get worse before you become better." In this case, it led to the deaths of my

girls. On June 4, 1998, my daughter was left totally isolated and penniless, which drove her insane and she took her own life. Jackie hanged her own daughter, my little Dagmar, and then Jackie hanged herself.

**1050**

As things stand, there is no prevention, accountability or recovery. A strong mechanism needs to be put in place to immediately investigate a complaint by third parties before another tragedy occurs. Anyone who does harm must be accountable for their actions and investigators must be given the right to obtain properly kept files. Many elderly and grieving parents have lost not only their misguided children but also everything they worked for a lifetime to acquire. Financial retribution should be required of individuals or organizations that have caused havoc and unbearable suffering.

Information in the hands of the police regarding my daughter's treatment by Chris Hutchinson has been totally denied to me by the provincial freedom-of-information sector of the government for the next 30 years. This means the only individual being protected here is the unlicensed counsellor and her filthy lies. Absolute privacy should not be abused at the expense of the safety of the public and as an excuse to prevent the wrongfully accused from obtaining the exoneration they are entitled to. We demand that our names be cleared from false records within any government files and in any mental health facility. How can we cross the border if we have been branded? We know what happened in the Arar case.

Finally, following this tragedy, the counsellor and this community centre tried to distance themselves, citing confidentiality. By the way, there's a serious police cover-up here too. I have been treated horribly by the police. They sided with the therapist.

My daughter was a gifted artist and donated one of her paintings to this centre. After Jackie's death, the Community Justice Initiatives placed this painting up for sale at the Eldon Gallery—I viewed it—thus profiting from my daughter's death. During Jackie's life they took fees from her for therapy, being well aware that she was a single welfare mom.

I want transparency and I want accountability while the Ministry of Community and Social Services is still funding this Community Justice Initiatives centre of Waterloo region. The need to sustain our health care system should terminate foolish funding of dangerous programs that kill people and destroy families. The number of community support groups should be cut back to one or two in a community, and they should be run by competent mental health experts who are accountable professionally and who follow fact-based, scientifically proven health practices. Above all, do no harm.

Now, here we go buck-passing, buck-passing, buck-passing. I want action and I want accountability. If seeing is believing, how do I get through to you people? This is what they destroyed: a beautiful relationship. My daughter was very mentally ill and they drove her over the edge. This is the last memory of my grandbaby. Have I made my point?

**Dr Harold Merskey:** My name is Harold Merskey, and there is a document entitled Privacy and Access to Medical Records in front of you. Those are the comments I have to make, which I'll go over shortly. I will mention that there is a brief curriculum vitae attached indicating my knowledge of this topic or some parts of which indicate my knowledge of this topic.

I should say that I have advised Mrs Grieb. She is not my patient, although she has confided in me and sought advice on the situation, her experiences and the problems she has addressed in her talk.

I am a professor emeritus of psychiatry and have been consulted by a number of other patients with respect to false accusations made against them on the basis of what are called recovered memories, and which are unreliable. With this document, I've also provided a position statement of the Canadian Psychiatric Association, which deals with adult recovered memories of childhood sexual abuse—I'll come to the case of Jacqueline Grieb shortly.

I should say that I'm also a member of the scientific advisory board of the False Memory Syndrome Foundation, which is a not-for-profit organization based in Philadelphia. The organization has many Canadian members. I'm not a member; I'm an adviser. The board of advisers is a very distinguished group to which I have felt honoured to belong, comprised of leading scientists and others who have been very concerned about the misapplication of psychological treatment and its misuse.

The case of Jacqueline Grieb and her daughter Dagmar and the mother and grandmother, Claudette, is an extreme example of the consequences of the common phenomenon of parents being falsely blamed in the treatment of their children for supposed sexual abuse in childhood. The patients who blame parents have ordinarily tended to see psychiatrists or other physicians, psychologists or still less well-qualified therapists for help with problems in living, psychological difficulties and often depression. A few psychiatrists have engaged in this, more psychologists—there are more overall—and many more unlicensed practitioners. All of them, I think we can now see in the light of current knowledge, were conducting malpractice.

The relevance of this to records is that if the records of treatment become available, they serve as an essential foundation for the acquittal of innocent people who have been repeatedly charged with these offences. In my personal experience, between 1994 and 1999, I took part in a dozen criminal cases as an expert witness for the defence, dealing with false accusations of sexual abuse. In all but one case, there was a complete acquittal, and in the single case, there was conviction on a trivial charge, which I still think was wrongful conviction.

The frequency of this phenomenon is great. Probably there are few towns or cities in the country where somebody has not made such an accusation and where there has even been a trial of the matter. We can never know the exact frequency of false accusations, but they are unfortunately much more common than some of those who are particularly concerned about abuse in general

would have you believe. Again, I give some indication of that in this document. The figures may be as high as 1% of the population of the United States, and probably Canada too, who have been affected by a member of the family having such false ideas over a period of, say, three or four years in the 1990s.

The problem is not as bad as it was, but it remains important for innocent people to secure adequate access to medical records. For a psychiatrist to say this is, of course, somewhat in contradiction to what most of my colleagues are telling you. But I think it is necessary in the interests of justice and to prevent almost as bad an offence as the abuse itself. To be convicted or even slandered without conviction for an offence so grievous as sexual abuse is nasty, is horrible, in proportion to the extent of the abuse itself. I think, in all fairness, one should be looking to protect those innocent members of the community, many of them elderly, who have suffered from the alienation of their children's sympathies by extremely bad therapy.

**1100**

I was honoured by Mrs Grieb asking me to advise her. It is my comment that the death of Jacqueline Grieb was probably preventable. She had a severe depression, which came on quite quickly. She was alienated from her family in the course of therapy, very quickly also. Given access to proper medical care, there is no guarantee that she would have survived, but it is much more likely that had she had formal psychiatric treatment, she would have survived.

A few years ago, two of my friends and I published an article, which is also provided for you as an example. I wouldn't expect you to read all of it, but in the summary we make it clear that in comparing a group of people who had, as it happens, a multiple personality disorder diagnosed—a rather fanciful diagnosis, in my view—who were treated by recovered memory treatments, attempts at suicide and also at self-harm continued, without changing much in frequency, whereas a group of patients with depression who were diagnosed and treated in a regular fashion in our local psychiatric hospital here in London actually did far better, and their frequency of suicide attempts after they had treatment and were discharged fell by 90%. Those sorts of comparisons are important to understand that there is value in appropriate treatment. Had Jacqueline Grieb had appropriate treatment, there is probably a better than 80% chance that she would still be with us, and her daughter as well.

The implications of what I have to say are that in passing an act that affects access to records, those of us who have been concerned about this issue would hope that members of the Legislature would make every effort to see that it is not made harder for people to achieve justice and harder for individuals to be protected from slander. Thank you.

**The Chair:** We have a few minutes left. I'll go the government side.

**Mr Mak:** May I make a bit of a presentation myself? All I have to say really is contained in the brief. I want to

draw your attention to a list of case histories. They are not as serious as the one we have heard, although there have been other suicides.

I have been listening for the last 12 years as contact person for people falsely accused of childhood sexual abuse in 200 cases in southwestern Ontario—London and surroundings—where people who have been in therapy had no memory of childhood sexual abuse but were told that their symptoms indicated there was childhood sexual abuse and that they were in deep denial. The scientific word for this deep denial now seems to be “dissociative amnesia.” It used to be “repressed memories.” In the course of highly suggestive treatments, these people came to believe that they were sexually abused, although they were not. When the cases came to court, in some cases there was always clear evidence that the abuse could not have happened because of the inconsistencies and other so-called corroborative evidence that proved it could not have happened in the way the person was certainly remembering it, or re-remembering it.

My own son has gone through this process of therapy. He has recovered from this terrible therapy. He now understands what happened, and his own case is described as the last one in the series I have presented to you. He tells me what strong pressure tactics occur in such therapy. All these people entered therapy with a problem, some of them with a very deep-seated emotional problem that really should require the attention of a qualified psychiatrist or a fully qualified psychologist; not a graduate from a teachers' college, but people who are far better qualified than that.

I would suggest that when in the course of therapy a client—and of course, the person has an emotional problem, and when this emotional problem is found to be childhood sexual abuse, that the counsellor or therapist refer this case to a qualified professional who can make a proper, fully informed judgment and that it not be left to some sexual abuse counsellor or whoever else, qualified or unqualified. There are many unqualified, unregulated counsellors who work in this field.

**Ms Grieb:** Quacks.

**Mr Mak:** Yes, well, OK. I would say these people should certainly get a second opinion from someone who is fully qualified at a psychiatric institution or at least a top-level, trained clinical psychologist. Not everyone who has a PhD in psychology is qualified to do clinical work, and certainly masters of social work who have specialized in clinical work should be bottom-level practitioners who, when they come across a serious case, should say, “Hands off. This is too much for me to handle. I'm going to get a second opinion and refer this person to a psychiatrist.”

That is basically all I have to say. It's all in my brief. I have heard from across Canada close to 2,000 stories; from around London, around 200. Of the close to 2,000 cases that I have recorded in Canada, 240 went to the courts and over 200 of these were acquitted, which shows you that therapy did tremendous damage. Judges were the first to catch on, before some mental health professionals did. That is a very encouraging thing.

The Canadian Psychological Association knows that. I have one appendix here, and they couldn't word it more strongly: "To the extent that some people may have been convicted of offences based solely upon the testimony of people's recovered memories, the Canadian Psychological Association urges the Minister of Justice"—that is, the federal minister; she is now our Deputy Prime Minister—"to conduct a special inquiry into this category of convictions."

This statement was followed up by a letter signed by 100 professionals. The letter was drafted by the president of the Criminal Lawyers' Association, Mr Alan Gold in Toronto. It was sent to the Minister of Justice. The Minister of Justice has not acted on either the request by the Canadian Psychological Association or the request of Mr Alan Gold and the Criminal Lawyers' Association.

**The Chair:** Sorry, Mr Mak. Our time is up at present. There is no time left for questions, but you can rest assured that your comments have been recorded and will appear in the Hansard. Thank you again for taking the time, all of you: Doctor, Mrs Grieb, and yourself, Mr Mak.

#### LONDON HEALTH SCIENCES CENTRE ST JOSEPH'S HEALTH CARE LONDON

**The Chair:** The next group is St Joseph's health centre. As you are aware, you have 20 minutes. You could take the whole 20 minutes for your presentation, or, if there is time left, for a question-and-answer period at the end. If you could tell us your name and your position for our record purposes.

**Ms Diane Beattie:** I'm Diane Beattie. I'm the integrated vice-president of health information and the chief information officer for St Joseph's Health Care London and the London Health Sciences Centre.

**Ms Judy Farrell:** I am Judy Farrell. I'm the integrated leader for health information and privacy for the two London hospitals.

1110

**Ms Beattie:** Thank you for the opportunity to appear before your committee this morning. I think copies of my remarks are before you.

The hospitals applaud and support the government's initiative to introduce Bill 31, The Health Information Protection Act, and its two components, the Personal Health Information Protection Act, 2003, and the Quality of Care Information Protection Act, 2003.

Our London hospitals are committed to a high standard of privacy procedures for personal health information that is under our custody and control. We are proud of our exemplary performance as custodians of health information and we continually monitor our performance.

The hospital leadership has regular briefings on the status and issues we are dealing with.

—A privacy policy for the two hospitals has been approved based on the 10 fair practices accepted nationally and upon which the federal legislation is built.

—We have a privacy office in place.

—We have an active cross-functional steering committee that works in conjunction with our privacy office to implement our full privacy program and to ensure compliance with the privacy policies and procedures within the hospitals.

—The hospitals have retained independent privacy consultants and legal experts to guide the privacy impact assessment and the implementation of our policies.

—A communication and education plan is underway for all staff, physicians, volunteers and contracted workers at the two hospitals.

—A patient information pamphlet is available for patients to inform them about the personal information and personal health information being collected by the hospital and how that information is being used. Information is also provided to them on how they may contact our privacy office if they have questions or concerns.

—A Web site to share further information with patients and members of the public about the hospitals' policies and practices regarding the collection, use and disclosure of personal health information is also now available.

We have within our technology group two positions responsible for ensuring the security of our electronic health records system and the data.

As many of you are aware, we have gone through significant restructuring in the London hospitals. As a result of restructuring and to be able provide the right information about the right patient at the right time and in the right place, the hospitals have implemented a number of shared services. For example, we have a common medical staff and consolidated laboratory services. The personal information on patients is collected, used, disclosed and retained within the shared services. The hospitals recognize that each organization has both independent and joint obligations with respect to fair information practices.

Our privacy policy is the foundation for other policies and procedures, setting the principles upon which the hospitals collect, use and disclose personal information and personal health information.

As we move to more of a "health system" or integrated approach to providing care, we would recommend that "continuum of care" or "circles of care" be defined to allow health information necessary for quality care to be shared with health care providers across various organizations; for example, providing information to a family physician about a recently discharged patient from the hospital, or, if a patient in a community hospital has a CT scan and the attending physician requests an opinion from a consultant at a major teaching centre such as London, the image can be promptly and securely shared.

The hospitals have had policies and procedures around confidentiality, access and release of information for decades. This new legislation will build on our current practices and will help provide more structure and rigor in the processes for: signing confidentiality statements;

user agreements prior to being granted access to hospital systems and records; release of information; auditing of who has had access to information; and educating and communicating with both our staff and the public.

The approach to patient consent in relationship to the provision of care is significant in allowing our hospitals to work in the most effective and efficient manner.

Express consent for fundraising will be addressed by our foundations separately.

As you are aware, hospitals depend on fundraising for many things, not the least of which are capital projects and purchases to support patient care. Under restructuring, the government requires us to raise 30% of our restructuring or redevelopment costs through fundraising.

As teaching hospitals with affiliated clinics and research organizations, we follow the university research ethics board guidelines for gathering research data. A key issue will be having a consistent approach to the consent process for all of our clinical research.

A patient may refuse consent for sharing of their information for a specific purpose at the affiliated research institute and anticipate that, because of the affiliation between the research institute and the hospitals, their wishes will also be understood at the hospital. The confusion for the researchers and clinical staff is which process takes precedence, the hospital or the research ethics board. We are working with our research community to develop processes and procedures with a goal to ensure that the patient's wishes are always met.

The London hospitals also function as a host institution for such entities as the Ontario joint registry and Cancer Care Ontario. The hospitals are the health information custodian of record. We are aware that these organizations have concerns about their ability to meet their mandate if they have not been identified in their own right as health information custodians. We support such registries and the work that they do, but we do not share their concern in this regard, as we believe the intent of the act is not to compromise their ability to collect and share information as required in carrying out their mandate.

In order to achieve clear accountability of the health information custodian around the management of personal and personal health information under their control and responsibility, and for the effective delivery of patient care, this issue needs further clarification before the legislation is finally enacted. We are committed to working together with our partners to ensure their needs are met.

With respect to the Quality of Care Information Protection Act, the hospitals, and in particular the physicians and clinical staff at the hospitals, want to acknowledge this component of the legislation. They feel strongly that the quality-of-care provisions outlined in the draft legislation enhance and support ongoing education that will significantly contribute to improving the quality of patient care and increase patient safety.

In summary, although there are some areas to clarify and review, the intent of this legislation is commended by our health care providers.

**The Chair:** Thank you. We have six minutes left, so we'll be starting with the government side.

**Mr Peter Fonseca (Mississauga East):** Thank you very much for your presentation. I was hoping that you could expand upon your concerns about including the Ontario joint registry and Cancer Care Ontario as a health information custodian.

**Ms Beattie:** We're not concerned with their status. They work within the hospital walls, and so, Peter, there comes confusion as to whose procedures and processes we follow. I think what we as the hospital feel is that if we set up the hospital as the primary custodian, we're collecting the information. There are provisions in the various sections of the act that then allow us to effectively share back and forth, but if you have two primary people responsible, then there's confusion. In a health care environment, when there's confusion, it just causes possible problems down the way. Let's just get it clear.

**The Chair:** The opposition side.

**Mrs Witmer:** Thank you very much for your presentation. I'd just like to follow up on what Peter has just asked. How would you see us treating the Cardiac Care Network, which has also asked for similar recognition? I notice you didn't mention them, although you did mention the joint registry and Cancer Care Ontario.

**1120**

**Ms Beattie:** Again, we need to be able to move the information effectively across those organizations. As we look at it, the information that's gathered and maintained within the hospital is the hospital's responsibility. We have to have a way to effectively share that information, and then they need to be able to share that information moving forward.

If we have two primary institutions responsible for that information, then one group says, "Well, I'm following this set of procedures," another says, "I'm following this." Pretty soon the patient's health record and the key information that we need for care is in two places. We want to make sure that the custodianship is in one place, it's firm, and that the provisions in the bill do allow for—I think it's section 38, Judy?—the effective sharing of the information.

**Mrs Witmer:** So then you're saying, really, the hospitals should be the custodian, and you'll ensure that Cancer Care and the Cardiac Care Network get all the information that they need in order to do their job?

**Ms Beattie:** That's correct.

**Ms Martel:** You talked about a continuum of care, circles of care, in essence recommending, I would think, a definition of that in the definition section of the bill. Is that correct?

**Ms Beattie:** I think we need people to understand us. We've gone through restructuring. You don't go to St Joe's or one of the areas of LHSC for end-to-end care in the future. If you have a heart attack, for example, or a stroke, you would go to London Health Sciences for your acute care treatment and then over to Parkwood Hospital for your rehab.

What we want to make sure is that, as we move the information around, we understand the continuum of care that the patient is in, and that we can move that information effectively to all of the caregivers for that patient's continuum, so that there's not, "Well, we can't pass this here or there"—to be able to pass it, if the stroke happened and the patient was at LHSC for their acute piece, to Parkwood for rehab and then to their family physician, so that their care is looked at on an end-to-end basis.

**Ms Martel:** Can I back up? What in the bill right now, then, would suggest to you that you can't do that? Is there a specific provision that you feel blocks your ability to do that?

**Ms Beattie:** I don't think it said that it blocks it, but it doesn't come out and talk specifically about—we call it the continuum of care. In some of the other documentation we've read, it's circles of care—but just to make sure that there's a clear definition so that we know that that's going to be happening.

**Ms Martel:** So your preference would be circle of care or continuum to be defined at the front of the bill. Would there be other changes that would be required, then, to accomplish what you want to do?

**Ms Farrell:** I don't think so. In this piece of legislation, they talk about multiple facilities and the ability to apply for that multiple facilities status.

Within the federal legislation, the term "circles of care" is used in that legislation, and it steps beyond organizations to incorporate all the health care professionals who are providing care to that patient, to the extent that the necessary information for care to be provided can be shared. It would go even beyond our two separate organizations to include the family physician, a community care access group, perhaps nurses who would be providing care in the home, so that the legislation allows that information to be shared freely to the extent necessary to ensure care for the patient.

**The Chair:** Thank you very much. The time is up. Thank you for taking the time to come over and give us your concerns or comments.

#### LONDON MENTAL HEALTH ALLIANCE

**The Chair:** The next group is the London Mental Health Alliance. As you are aware, we have 20 minutes that could be taken by taking the whole 20 minutes, or the balance of the time could be taken amongst the three parties for question time. If you could state your name and title for record purposes.

**Mr Michael Petrenko:** Thank you, Mr Chair. My name is Michael Petrenko. I'm the executive director of the Canadian Mental Health Association, London-Middlesex branch; however, I'm here today to present on behalf of the London Mental Health Alliance, of which I am a co-chair. I have my two colleagues with me, members of the organization who are here to assist with any specific questions that may be here, Marnie Wedlake and Kristin Kumpf.

Thank you for the opportunity to present to you today. I have distributed, for your information, a package of materials. There are three distinct parts to it. There is a covering letter. We can just set that aside. We have the loose sheets which are notes to our presentation today and we have a set of stapled sheets which are supplementary documentation that I will refer to in the presentation.

The London Mental Health Alliance is a close network of services that promotes integration, efficiencies and effectiveness across the various components of the health system. The London Mental Health Alliance works collaboratively with its 21 member agencies and other community services in this regard. We work to create an environment for a comprehensive, coordinated, seamless system of service, education and research, which facilitates client-centred support and intervention toward recovery and wellness. We work with a consensus model of decision-making expressed through monthly alliance meetings and several regular and ad hoc operational working groups.

One project in particular that we have invested in earnestly over the past four years is the common client record. This is an electronic database of client records that is accessible to three mental health agencies currently—the Canadian Mental Health Association, the Western Ontario Therapeutic Community Hostel (WOTCH), and the London Mental Health Crisis Service. This tool gives clients the opportunity to permit these agencies to share portions of their records so that an alteration or addition made to that record at one agency is made immediately available to any of the other agencies sharing that record.

The benefits here are clear. A case manager who sees the client on a regular basis can keep the file current, indicating changes in medications, changes in address, emergency contact person, and so forth. If the client is in crisis at a time when their regular community supports are unavailable, the crisis service can access the most current information, even though they may not have had contact with the client in a long time or, for that matter, ever. The London Mental Health Crisis Service, while community-based and equipped with a mobile response team, also has a satellite location directly within the hospital emergency department. This accessibility allows for medical staff and physicians to have direct and immediate access to health information that will provide records such as medical history and relevant and sensitive information such as that recorded by the community case manager.

Information of this nature can save lives in an emergency and can also facilitate access to help in less imminent situations. A client may file a crisis plan with the crisis service at a time when they are well. This plan might include information that is personal to the client. For example, they might disclose that, during times of crisis, reminding them of their cat will help to calm and ground them. It is suggested that this kind of simple but important information might not otherwise be available

to an emergency room doctor or a crisis response worker and that access to information that is this personal and specific can provide for effective and individualized assistance to a client who is in crisis.

While some people in the community had the foresight to see the advantages of using the CCR, there were also many who were fearful of possible negative ramifications of having personal and sensitive information this readily accessible to the health agencies involved. Many of these fears were based on very real and painful, even life-threatening experiences, where a piece of information was used in an inappropriate way by a health professional. One possible example might be a case where a patient goes to the hospital with chest pains and the attending doctor sees that the client has a history of panic attacks and dismisses the symptom as trivial; the patient is discharged and subsequently suffers a real heart attack.

It is interesting to note that now, after a few years of experience with the common client record—some four to going on five years for us now—some of the people most reticent about the idea in the beginning are now ardent supporters. We have included in this package a number of letters of support asking the government to invest further in this project, and we draw your attention to the fact that consumer-survivors are among those who are now in support.

We feel strongly that any health information protection act needs to support and allow for the ongoing expansion of projects such as this common client record. In this context, we are pleased with most of what has been outlined in the bill. It appears that a great deal of effort has been put forth to strike a delicate balance between restricting access to information in order to protect privacy and facilitating access to information needed to provide good health care.

### 1130

There are a few issues, however, that we wish to highlight. In the interests of time, we have a number of pieces there. I'll refer to some of them but I will not read all of them so that we have time to discuss some of them.

(1) Number one is a significant one. We expect that some people will be calling for increased regulation and increased rights for a person to restrict access to their health information. We ask that when considering such requests, the committee always balance such statements with a right not to restrict access. For example, it is currently common practice to put an expiry date on a written consent to share information. Some may call for this practice to be legislated. However, this sometimes creates an awkward situation when consent has recently expired and a client currently has questionable capacity to give consent. In the context of shared electronic health records, expiry dates can cause huge problems. We feel it is important that a client's right to opt in to more open communication between health care providers, as may be afforded by electronic health records, be protected.

(2) Subsection 3(7) allows that "Two or more health ... custodians may apply to the minister, in a form approved ... for an order recognizing that they act as a single health

information custodian with respect to all or part of the powers, duties" and so on. Towards the end there I say that currently the situation is that when a client tries to access case management services, the intake worker is not allowed to do a search to see if the person is already on the database. We're not allowed to do that in the current context. What we are hoping is that with this legislation, some attention can be paid to this issue. I look to the very last sentence of this paragraph and a suggestion for your consideration. The use of a health card or health card number as a unique identifier for these purposes would be of tremendous benefit. We are not clear as to whether this legislation allows for the use of the health card number in this way. There are some pieces dealing with the health card number, but not whether it could be used for these kinds of purposes as a unique identifier; in other words, not for billing purposes but as a unique identifier that each one of us holds.

(3) Implied consent, knowledgeable consent and notice of purposes: We are unclear as to whether the conditions for knowledgeable consent apply to this situation. Does a client need the opportunity to see a written notice of purpose or be given a written outline of the purpose if the primary purpose of collection and the only purpose for disclosure is for the provision of health care? It is very important that wherever there are regulations suggesting that information be given or collected in writing, we allow for exceptions where service is provided over the telephone, as is often the case in a crisis service. This is an important piece because more and more we provide services in our communities by way of, for example, crisis services, where the service is done over the phone and there is not an opportunity to give that written disclosure, requesting that consent. So we need to take a look at the ability of a person to give informed, knowledgeable consent via the phone.

(4) Withholding consent to collect, use or disclose information: This is an issue that we are not sure is addressed at all in this legislation. If a client says, "I don't want anything written down about me; I don't give you permission to collect any information about me," does the health information custodian have the right to withhold service, or should they? Can the health care practitioner say, "I have to be able to keep a record for legal purposes to protect myself and in order to give you quality service, so, no, I won't treat you under these circumstances," or would that be seen as gaining consent by way of coercion, which is a violation of 18(1)(d)? We need to take a look at these kinds of issues.

(5) Withdrawal of consent, section 19: This is one area where we recommend a little more regulation or guidance. I'm going to skip right down to (d). Where there is reason to believe that an individual may lack the capacity to give consent subject to sections 21 and 22 of this act, one can also assume that they may lack the capacity to withdraw consent. So we looked at capacity to give consent. We also need to look at capacity to withdraw consent.

I'll skip down to the note at the bottom to illustrate. Note: While some people may be very uncomfortable

with this, it is crucial to find some way to protect the ability of people with mental illness to create statements, such as crisis plans, when they are well, about what sorts of interventions they want to see happen when they are unwell—once again, the capacity to withdraw consent. In the situation where a person is not well and they have already signed and had witnessed a crisis plan which spells out what they want to see happen when they are unwell, does the removal of that consent when they are unwell apply? We need to take a look at that and see that we can have some sort of provision to cover those areas.

I'll skip to number seven.

(7) We strongly support recommendation number (3) of a presentation made to you from the Canadian Mental Health Association, Ontario division, which states, "Ensure that an education and information program is available prior to the implementation of Bill 31, and that it continues on an ongoing basis. Ensure that expert advice is available on a 24-hour-a-day basis to deal with emergency situations." This is critical for crisis and emergency mental health services that operate around the clock. These are complex interpretations and we need the support to be able to call, in the middle of the night if need be, to get clarity and understanding on some of these pieces. We support that recommendation.

(8) Subsection 37(3) causes some concern as it appears to be written with general medical care in mind. First of all, the term "patient" is not identified in the definitions section of this act. This could be a cause for concern as we do not know whether the facility would disclose information related only to in-patients or whether outpatients or day patients are possibly also implicated. The other issue that becomes problematic is the release of information that a patient is in a particular location of the facility which is identified in the community as, for example, a psych ward or a psych wing. The stigma associated with that type of disclosure needs to be thoroughly addressed with respect to an individual's privacy and their express consent for this disclosure. We don't have the answers for that, but please consider that.

(9) The following two case scenarios illustrate potential confusion when other legislation comes into conflict with this Personal Health Information Protection Act. Clarity and training are perhaps solutions. However, we bring these examples forward as a caution for consideration. I won't read the scenarios now. Please do so later.

I'd like to go to the end of this page and note that there is a clear need to understand the specifics of Bill 31 when addressing issues of consent. The above scenarios also suggest a need to be able to access reliable support in those instances when consideration of legislation is complicated by the involvement of more than one act. So back to our recommendation for 24/7 support for interpretations. When you look at these scenarios, you will see that there are instances dealing with the justice system and the penal system, and instances dealing with the children's aid society. We have different pieces of

legislation. Please ensure that there is some coordination and it is made clear to practitioners in the field on how to interpret situations such as these.

In conclusion, although we have identified several areas where the legislation could be improved or clarified for technical reasons, we urge the government to move forward and enact this legislation. It is a tremendous improvement over current circumstances.

As the London Mental Health Alliance, we offer the common client record of which we have spoken, this initiative in our community, as a test site for evaluation and review of practical operational issues with respect to this legislative process. We firmly believe that a fully operational beta test site, if you will, would add great value in identifying practical operational and training issues which could help guide the writing of the rules and regulations that would accompany this legislation.

We would welcome the opportunity to work with the government to apply this legislation toward real-life practice. We have practised in real-life situations for the past five years with this project and we would welcome an effort to work with government to continue in that practice to evolve this piece of legislation.

**The Chair:** We have approximately five minutes left.

1140

**Mr Ted Arnott (Waterloo-Wellington):** Thank you very much for your presentation. I found it very enlightening. You have given us a lot to think about in terms of the delivery of service in the London area but also across the province. I thought you summed it up very well: The purpose of Bill 31 surely is to attempt to strike a balance "between restricting access to information in order to protect privacy and facilitating access to information needed to provide good health care." Obviously those goals are important ones.

I was wondering about your common client record. As a percentage of all the clients you see in this area, how many clients would routinely access services from the three different agencies? Would it be the majority, or a handful? What would it be?

**Ms Kristin Kumpf:** I don't know the answer to that off the top of my head. Do you have a memory of a number?

**Mr Petrenko:** The total number of clients in the system currently is—

**Ms Kumpf:**—somewhere around 4,000.

**Mr Petrenko:** When we took a look at the services between London Health Sciences and St Joseph's regional mental health care and the services that are covered with these three, it would in fact be a majority, a significant majority.

**Mr Arnott:** I would guess that too. Is there anything in Bill 31 that you feel will limit your ability to properly serve your clients through the common client registry that you've set up?

**Mr Petrenko:** At this point in time we see it as an enabling piece of legislation. Currently, our dilemma here in this community is that you notice the hospitals are not a part of the common client record. The hospitals

currently have form 14s that they must use. They also have legal considerations which, at this point in time, they feel preclude them from participating in a common client record, although there is agreement at the alliance table that all members of the community in the mental health system would like to participate in a common client record of one sort or another.

**Ms Martel:** Thank you for being here. I want to just focus on the disclosure section. You talked about a concern that a facility—obviously a wing in a facility—could identify the patient and why they are there. One of the suggestions we had yesterday was that at the point of admission you could declare as a patient whether or not you wanted that information disclosed. The problem is if you come in at an acute stage and are unable to give that consent. I don't know how we work around that, but you're quite right that we have to figure out some ways to deal with a number of clients.

The section that I want to focus on related to the case scenario that you gave. We heard yesterday and we've heard before that there shouldn't be a reason why health information is being released, for example, of HIV patients who end up in jail. We could have mental health patients who are ending up in custody. What would be the reason why you'd have to release health information in order to determine placement? I haven't been able to sort out why we should be releasing any of that information.

**Ms Marnie Wedlake:** I can speak to that. Part of our role is to provide our clients with a needs assessment process whereby we determine things that would facilitate wellness while they are in the community. We might have a client coming from the detention system who is going to be moving back into the community and that client may also have a mental illness that needs to be addressed. We need to get information about that client and that client's health situation, that comes from the penal institution and comes into our system, so we build a profile and we know what services to provide and what services to link that client with. There actually is a fair bit of information. Our assessment process involves about a five-page intake of information that we collect in order to make sure we're going to point the client in the right direction.

**Ms Martel:** That's if they're being released into—I don't want to use "custody"; I'm not sure if that's the exact word—your care. But what if it's the reverse, that they're in an institution and the institution gets information about their health status? Why would they need that unless there is treatment that is immediately required?

**Mr Petrenko:** For the penal institution to have that information?

**Ms Martel:** Yes. Even in the case of youth custody, the detention centre, unless there was an immediate need for treatment—

**Mr Petrenko:** Only for the health treatment records would they need to go in the reverse flow, back to the penal institution.

**Ms Martel:** So they don't need that information to determine a placement, because you're determining the placement.

**Mr Petrenko:** That's right.

**The Chair:** Could we get your name for the record?

**Ms Wedlake:** It's Marnie Wedlake.

**Mr Khalil Ramal (London-Fanshawe):** Thank you, Michael, for your presentation. I just have a question here about releasing the information. We heard many different opinions, some people with and some against, on the invasion of privacy. In your opinion, which group should determine which information has to be released and how important this information is to the mental health issues?

**Mr Petrenko:** The release of information to whom? To the general public or to the community at large?

**Mr Ramal:** No, to other institutions, to share information in order to have security in our community and also to help the patient himself or herself.

**Mr Petrenko:** We strongly believe that once the patient-client has given informed consent for the sharing of their records, then from custodian to custodian there should be free exchange of that information in support of the person's treatment and care; there should be flexibility with respect to that support and treatment. The ability to access that information should be instantaneous and available to any custodian to whom the individual has given consent to release that information.

For example, in the London Mental Health Alliance we have a common consent form where we list all of the providers that are available in this community. Through an information and knowledge process session with the individual, the person identifies those organizations to whom they wish consent to be released of their own personal information. So some organizations may be excluded because they will not be a part of that treatment service, and others will be included. It's up to the consumer, in an informed way, to identify those organizations to which to release information.

**The Chair:** I'm sorry; our time is up. Thank you very much for taking the time to present your comment to the committee.

**Mr Petrenko:** Thank you. We appreciate the opportunity.

#### ONTARIO CHIROPRACTIC ASSOCIATION

**The Chair:** The next group is the Ontario Chiropractic Association, Dr Robert Haig. If you could state your position with the association.

**Dr Bob Haig:** Good morning. It's Dr Bob Haig. I'm the director of government and professional affairs for the Ontario Chiropractic Association. I appreciate this opportunity to come and present to you this morning.

The Ontario Chiropractic Association is pleased to provide comments on this legislation. We believe the government is taking a very significant, positive step forward with the legislation toward protecting personal health information in a manner that supports the delivery of quality care in Ontario.

The Ontario Chiropractic Association represents over 80% of the 3,000 chiropractors practising in Ontario. Regulated by the College of Chiropractors of Ontario under the Chiropractic Act and the Regulated Health Professions Act, chiropractors are the third largest primary contact health profession in Ontario, after physicians and dentists. That means that citizens of Ontario visit a chiropractor directly for care. Chiropractors are one of only five health professions who, because of the training and the legislated ability and the duty to provide a diagnosis, are entitled to use the term “doctor.”

Each year more than a million Ontarians visit a chiropractor for health care. That means that a significant number of citizens entrust their personal health information to their chiropractor. We take this trust very seriously, and we have long placed a priority on protecting patient health information.

We are particularly pleased that the government has introduced Bill 31 because of the uncertainty and confusion surrounding the federal Personal Information and Electronic Documents Act and the inadequacies of that legislation in the health care setting. This legislation came into effect on January 1, 2004, and while it may be appropriate for the business and other sectors, it is really not appropriate for the health care sector. PIPEDA includes measures and requirements that have the potential to significantly impede the delivery of health care. At the very least, PIPEDA imposes unnecessary, time-consuming and costly obstacles on the movement of health care information for health care purposes. Our members, chiropractors in Ontario, tell us that PIPEDA is confusing, and the interpretations offered by some advisers suggest that compliance with the requirements of PIPEDA will be labour-intensive and costly for most health care practitioners.

#### 1150

In reviewing Bill 31, we believe that Ontario’s health-specific legislation will serve equally the protection of health information and the facilitation of quality health care. Not only does Bill 31 provide for robust requirements for the protection of health information, but it also does so in a manner that facilitates compliance. Ultimately, this is in the best interests of everyone—government, health providers, and, most importantly, the public. So we congratulate the government on bringing forward health-specific privacy legislation and we encourage the rapid adoption and implementation of Bill 31. But it’s also true that such important legislation requires extensive review and consultation, so we provide just a few comments at this time.

Section 7 of the act provides that the act shall prevail over all other acts unless specified in the Personal Health Information Protection Act or in the other act. The OCA understands that the Federation of Health Regulatory Colleges of Ontario has expressed concern that the act does not expressly give legislative priority to the RHPA. We fully support the health professions regulatory process in Ontario and we support the efforts to ensure that regulatory colleges are positioned to fulfill their

mandates. So we urge you to give careful consideration to that issue, which was raised primarily by the federation of regulatory colleges.

Section 13 provides for the making of regulations with respect to the handling, transfer and disposal of personal health information records. We believe that specific regulations in that area are better created and handled under the regulatory health colleges and that there should be no regulations under this specific act in order to deal with that. The colleges are well able to—and in many cases already do—have standards for handling these issues. Because there may well be quite reasonable differences between professions, it may be wise to have the colleges actually set that rather than having it under this legislation.

Section 15 provides for the designation of a contact person who is authorized to perform duties on behalf of the health information custodian. Of course, those functions are laid out in section 15. It does not seem clear that the health information custodian is able to designate certain functions, but not all of them, to the contact person. We believe that should be the case. If that’s the intent, perhaps that can be made slightly more clear in the legislation.

Section 34 prohibits a health information custodian from charging a fee for the collection, use or disclosure of personal health information except as permitted by regulation. Then subsection 52(10) provides for the prescription of a fee to be charged to an individual for access to personal health information. There should be constraints on fees, but the constraints on fees charged by health professionals for these services, we believe, should be outlined under regulations and policies, again, of the appropriate health profession regulatory college. Our recommendation is really that those provisions in this legislation be removed and that those be established under the regulations and the policies of the regulatory colleges.

Although section 41 of the act provides for the transfer of records of personal health information to the successor of a health information custodian, the act does not appear to expressly provide for the review of records that would need to occur prior to the sale of a private health care practice. Continuity of health care in Ontario remains heavily dependent on the ability of established chiropractors, physicians and other practitioners to transfer their practices to their successors at an appropriate market value. For many, the equity built into the practice is a key component of their retirement plans. Unless the prospective buyers, who are regulated health professionals, have the ability to review the health records, it will not be possible to establish the size and nature of a private health care practice. We recommend that there be an amendment to make an allowance for that specific situation where there is a practice that is being sold or transferred.

Section 64 sets out the powers of the commissioner, and clause (c) provides for the conducting of public information sessions and the provision of information

concerning the act. We strongly believe that the public would be well served if the commissioner is also responsible for educating health care providers. Unless that's done, there is a strong possibility that differences in interpretation can lead to differences in practices across provider groups and among providers themselves.

The experience with PIPEDA has demonstrated that, in the absence of authoritative advice and information about the requirements of the act, different groups make different interpretations. This will result not just in inefficiencies but in different policies being applied, and it will certainly result in confusion for the public. So we recommend that this section of the act be amended to provide for the power of the commissioner to conduct information sessions and provide education to health information custodians.

Last, the Quality of Care Information Protection Act protects from disclosure information provided to quality care committees. This is obviously an important and overdue piece of legislation for Ontario, and we strongly support this.

We wonder why the quality assurance programs established by the regulatory colleges for individual health professionals have not been captured by this act. Clearly, as with the quality of care initiatives referenced in the act, the potential benefits from the quality assurance programs of colleges are limited if the information used by these programs is not protected.

In summary, the Ontario Chiropractic Association commends the government for acting quickly to address the void created by the absence of health-specific privacy laws in Ontario and the uncertainty created by the implementation of PIPEDA. We've made a few suggestions for amendment or clarification, but we strongly urge the timely passage and implementation of the legislation.

Just as importantly, we urge the government to make it a primary role of the privacy commissioner to educate both the public and health care providers about the new legislation.

We look forward to working with the government on this and on other issues of importance in the future.

**The Chair:** Thank you. We have nine minutes left. We'll start with Ms Martel.

**Ms Martel:** Thank you for being here today. Let me begin on page 3, your section on handling of records, where you suggest that the handling, transfer and disposal of personal health information records might be better handled under the colleges. I might agree with you if only the colleges were involved here, but you're talking about a broad range of custodians: hospitals, doctors' offices, nurse practitioners, community health centres, community care access centres. I would think we'd want very common standards set out in terms of both storage, transfer and disposal.

**Dr Haig:** Yes, and I suppose the issue is that, for individual health professionals, there is a regulatory body that has the ability to do that. I think what you're saying is that, for these other groups, there really isn't another body that has the power to do that for them.

**Ms Martel:** True, but I'm also concerned about differences in all of that being done. I don't know if, college by college, the standards are the same. I suspect not, so there'd be maybe differences there.

**Dr Haig:** No, I suspect not as well.

**Ms Martel:** Then you go into the broader health sector, who are also custodians, where you again could have a different set of rules. I would like us to be in a position where we have the clearest, most similar set of rules on all of these issues that everyone has to abide by.

**Dr Haig:** In the Regulated Health Professions Act and in the administration of that, there are template regulations and template standards that the ministry comes up with and gives to the various colleges. So there is a lot of similarity in a lot of circumstances—on policies on conflict of interest, for example.

For those health information custodians who are regulated health professions, if it was given to the college, I think that there would be appropriate standards—the fear is that there would be standards that were not appropriate and not acceptable, or that there wouldn't be standards. I think, with the maturity of the health professions legislation in Ontario and the colleges, for that group of health information custodians, the regulated health professions, we could rely on colleges.

Having said that, I understand exactly what you're saying, that it does make it more difficult for the government or for anyone else to assure the public that everybody has the same standards. I appreciate that.

**1200**

**Mr Fonseca:** I want to ask how the bill would change the practices that you have in place at the moment to protect patient information. Would it change that much?

**Dr Haig:** I started off by saying that chiropractors understand the need for and work hard to protect private information, but there's no doubt that everybody can do a better job of it. Individual practitioners are going to have to establish policies and guidelines within their offices to make sure that they're compliant.

The reason why we're so supportive of this legislation, as opposed to PIPEDA, is that it was vastly more onerous and complicated and confusing, quite frankly. People would look at that and not know how to do it, whereas we don't think that will be the case here. We think this is implementable and facilitates compliance. So people will have to change some practices; no doubt about that.

**Mrs Maria Van Bommel (Lambton-Kent-Middlesex):** I want to refer to page 4 of your presentation. You talk about transfer of records, and the sale of the private practice is certainly another scenario.

In the practice of chiropractic, what kind of information would you take from your patients? Is it physical health, mental health? Exactly what type of information do you have contained in those records?

**Dr Haig:** Yes, it is largely physical health, generally. I don't know if you're at all familiar with chiropractic, but chiropractors primarily treat musculoskeletal conditions: neck pain, back pain, headaches, extremity injuries, that kind of thing. So the health records that a chiropractor

would have with respect to those patients would be the same health records that a physician might have with respect to a patient with those conditions. Am I answering your question? No? I'm not. OK. Let me try again.

**Ms Martel:** What kind of health information do you have on file?

**Mrs Van Bommel:** What is in the file, like if the patient has HIV or cancer? Does all that show up in the file? If they have a mental health issue, does that show up in the file?

**Dr Haig:** It might, yes. It probably would. If I knew that a patient was seeing a psychologist for a mental health problem, then that would show up in my file. That's not something that I would have to share with a practitioner who was contemplating the purchase of my practice, but for example, if I had a practice that was primarily sports injury-related, as opposed to one which was primarily industrial back pain-related, those sorts of things are significant to someone who's coming in to purchase the practice. So while the person who might be contemplating the purchase of a practice obviously doesn't need access to all of the health information that's there, they need access to some of it.

**Mrs Van Bommel:** So in order to sell the practice, you would have to first go through all the records, separate the irrelevant information so that you could identify the nature of your practice?

**Dr Haig:** Yes. I guess what I'm saying is, it would be nice if there was a way that this could be accomplished without compromising anyone's information, because it is a function that has to happen somehow. The worst scenario is that I have to go to every individual patient and get their permission, which would be difficult.

**The Chair:** We will recess. Thank you very much for coming.

**Dr Haig:** Thank you.

*Interjection.*

**The Chair:** Oh, I thought I heard that. Sorry, the official opposition side.

**Mrs Witmer:** That's OK, Mr Chair.

Thank you very much, Dr Haig, for your presentation. I guess what I see throughout this presentation—and we've certainly heard that from others—is that you would recommend that the RHPA have supremacy over this legislation and that you can feel that much is already covered there. Certainly I could support that.

I guess, at the end of it, you talk about the commissioner and you do feel at the end of the day, for consistency, that that individual, whoever that may be, is in the best position to provide the education and the information sessions. Is that correct?

**Dr Haig:** I recognize that that's asking for a lot. I do recognize that, but the experience with PIPEDA was that the different interpretations were pretty divergent as to what people had or should do in order to comply with it. There should be some official authoritative direction, even if it's not to individual practitioners as much as it might be to, for example, the colleges or the associations.

There should be some authoritative direction on interpretation for individual health practitioners, I think.

**Mrs Witmer:** OK, and that in itself could be fraught with some problems as well. Thank you very much.

**The Chair:** Thank you for your presentation. Now we will recess for an hour. We have to be back in this room by 1:05.

There's been a mistake, a typing error on the agenda. On the second part, the group Strathroy Middlesex will have 20 minutes like the others. So right now, it will be 2:15 instead of 2:35.

**Clerk of the Committee (Ms Tonia Grannum):** It's the last presentation, at 2:35.

**The Chair:** Yes, 2:35 is the last presentation.

We'll see you at 1:05.

*The committee recessed from 1206 to 1313.*

#### ASSOCIATION OF FUNDRAISING PROFESSIONALS

**The Chair:** I would ask the Association of Fundraising Professionals—they're here already. Good afternoon. Could we have your name and your position with the association?

**Mr Kevin Goldthorp:** My name is Kevin Goldthorp. I'm the associate vice-president, development, for the University of Western Ontario and the president-elect for Sunnybrook and Women's foundation in Toronto.

**The Chair:** Thank you. You have 20 minutes, of which you can take the whole time or leave us some time for a question period at the end. You can start.

**Mr Goldthorp:** Thank you, Mr Chairman and members of the committee. Again, I'm Kevin Goldthorp, and joining me is my colleague Janet Froot, executive director of St Joseph's Health Care of London foundation. Janet is a member of the Association of Healthcare Philanthropy, another fundraising professional association that is national in scope. We hope to make a short presentation and take questions from the committee after our submission. Both Janet and I would be pleased to answer questions during that time.

On behalf of all AFP members in Ontario, I want to extend our appreciation for the opportunity to comment on Bill 31, proposed legislation that we believe will have a profound impact on health care for the people of Ontario.

I'm going to quickly outline the objectives in my presentation. In your handout package is a summary of each of the slides in our presentation, recommendations to the committee, background on AFP, our projected impact of Bill 31 on philanthropy and on health care organizations in the province, support for our recommendations and a quick summary.

We'd like to start with the recommendations and then use the remaining time to provide the context that shapes these recommendations. What I have to say today builds on the Toronto submission made to this committee by Pearl Veenema of AHP, but addresses the full range of organizations, not just hospitals, affected by this bill.

First, we recommend that the committee consider modifications to Bill 31 that would recognize a critical differentiation between health and non-health information for health care patients. We strongly believe that this differentiation, accompanied by differentiated requirements for patient consent, is essential to maintain and expand the role that private giving—philanthropy—plays in supporting an Ontario health care system that is accessible to all and provides the best possible medical treatment to all Ontarians.

We further propose that the bill be amended to explicitly recognize that basic contact information for any individual may be used for fundraising purposes, given that specific conditions are met. We agree with the bill's guidance that personal health information—that is, information related to treatment or which, to a reasonable person, would reveal treatment—should not be disclosed to related fundraising bodies of health information custodians unless express consent has been given by a patient. On that point, we are in accord with the proposed legislation. Further, in the case where express consent has been obtained, we advocate for language that would prohibit a transfer of that information to a third-party organization unless express consent is again obtained from the patient.

However—a differentiating point—in the case of non-health basic contact information, we urge this committee to modify the bill to accept implied consent for use of this information, with expectations that notice of use for non-health basic contact information, with an option to opt out of its use for fundraising, be given to patients at all reasonable opportunities in public displays, in organization newsletters and Web sites, in institution registration forms and in all solicitations.

We do recommend, however, that all such information not be transferred to a third party outside of the affiliated fundraising arm of the collecting institution without express consent. I note that by “affiliated fundraising arm,” we mean the fundraising department in the institution or the separately incorporated foundation dedicated to serving the philanthropic needs of the institution.

In summary, we are urging the differentiation of non-health and health information and believe that implied and express consent can help in the use and the privacy requirements around that information.

On page 5 of our submission, we propose the specific change to wording of the bill in subsection 31(2) to read:

“A health information custodian may collect, use or disclose identifying non-health, basic contact information about an individual for the purpose of fundraising activities, but only if:

“(a) the identifying information relates to an individual's name, address, phone number or e-mail address, and

“(b) the information is used only by the health information custodian or its affiliated fundraising entity or any third-party organization contracted by those two entities for fundraising purposes.”

This recommendation is consistent with the approach suggested by the Information and Privacy Commissioner

of Ontario, Ann Cavoukian, in her submission to this committee on January 27. In it she stated:

“In previous consultations on health information privacy legislation, it became clear that a requirement for express consent would have an adverse impact on a health care organization's ability to raise much-needed funds. We prefer and support a requirement that would allow for an initial contact of the patient by the health care organization for fundraising purposes. At that point, the patient must be offered an opt-out opportunity.”

Let me give you some background on what AFP is. We are a large association of fundraising professionals dedicated to best practices in philanthropy. Our conduct is covered by a code of ethics, first established in 1964, and our adherence to those ethical principles underpins our ability to perform successfully in our profession. We have also joined with our peer organizations to advocate for and endorse a donor's bill of rights and, with the introduction of federal privacy legislation, have adopted standards that indeed exceed the legislation's and the Canadian Standards Association's requirements. That bill of rights is included in your handout package, as well as our code of ethics.

AFP is an organization that represents fundraising professionals from organizations of all sizes and objectives. I happen to represent AFP today, not as a member of a specific group or large institution, although I am a fundraiser in an educational institution and will be in a health care organization.

#### 1320

However, AFP is representative of all grassroots charities, right through to the larger institutions, in our province, and we believe this bill will impact them all. Indeed, we project it will significantly impair our ability to raise funds to support the philanthropic missions of countless health care and health-related organizations in the province and could have the most severe impact on the smallest organizations in the province, those that do not benefit from wide public name recognition or have the volunteer and community relationships to withstand the impact of Bill 31.

I refer to our ethical standards. They are relevant because they expressly address the question of privacy. The full text is in our package, but let me underscore this one point in standards 12 and 14 of the code of ethics. First, “Members shall not disclose privileged or confidential information to unauthorized parties.” We take that commitment very seriously. Second, “Members shall give donors the opportunity to have their names removed from lists that are sold to, rented to, or exchanged with other organizations”—again, a limit on the use of information.

These standards ensure that fundraisers balance the obligations of their organizations to collect and record information with the right of the individuals to privacy. It's the same balance we seek to maintain with our proposed changes to Bill 31.

Allow me to speak for a minute on the projected impact of Bill 31. We believe that the bill, as currently

drafted, will have a significant negative impact on the public policy objectives of this province and of this government. Specifically, philanthropy underpins many of the capital and equipment programs of health care organizations, and impairing our ability to raise funds will impair the ability of the Ontario health care system to care for Ontarians. This extends to actual service delivery where, again, private giving augments or fully funds some services. Bill 31's impact will be felt beyond just direct health care service delivery: It will affect social service organizations providing programs for people with developmental disabilities; it will affect summer camps for children living with ailments or physical disabilities; it will affect cancer support groups. These kinds of programs often depend on philanthropic giving from individuals. That will be impaired by the proposed legislation in Bill 31.

Philanthropy plays an integral role to research, in improving how our system is structured and run, addressing the most significant budget line of our province. Private giving also is critical to support research, the hopes and dreams of all Ontarians to see medical breakthroughs that will improve and save lives. Further, we note that our collective ability to meet the challenges of the Romanow report or respond to a post-SARS world requires not just sustained but enhanced private giving. Yet Bill 31, we project conservatively, will remove between 10% and 30% of annual fundraising revenue for health charities.

Our province's goal of having an accessible and sustainable health care system cannot be met if Bill 31 passes in its present form.

Why do we ask for the information transfer of non-health information and the implied or opt-out consent provisions as our proposed solution, what we see as needed changes in Bill 31? Because we know that people give when they are asked and that initial gifts often lead to a much more significant relationship that results in much more substantial giving to charities. We know that donors want to be approached respectfully, in a personal manner and with an appropriate request, and we know that donors want to give where they have some connection and in a manner that seems appropriate to that connection.

As you've heard previously at other submissions to this committee, research in Toronto has shown that patients do not want to make decisions during the actual treatment or health care intervention. They want to focus on care, and will address the issues of giving separately, at a separate time.

As well, we strongly believe that there should be absolutely no perception of a link between care and giving. We know that there is no such connection. Let me underscore this point. However, we want to ensure that there is no perception of such a connection ever existing. It should not and must not happen.

Other research has shown that caregivers believe that any consent collection done by them will interfere with the care process and an already overburdened health system. We concur and argue that such consent should be

implied with multiple interventions to inform, educate and allow potential donors to opt out, particularly in the solicitation process itself.

Finally, we make the point that express consent proposals disadvantage health fundraising at the very time when the province needs increased health fundraising to meet its care and fiscal goals.

Let me summarize by giving the three points I really want to leave with you: that philanthropy is critical to health care in Ontario; that fundraising is done in a respectful, ethical context, allowing health care recipients to opt out at any time in the process; and that Bill 31 can be easily amended to differentiate among types of patient information and consent requirements, meeting both privacy objectives and health care needs.

I thank the committee most sincerely for the opportunity to present our submission on behalf of the Association of Fundraising Professionals, and now I ask for any questions you may have of either me or Janet.

**The Chair:** Thank you. We have six minutes left, two for each party.

**Mr Leal:** If I could just go back to page 4, where we look at the projected impact of Bill 31: You indicate in here that health philanthropy in Canada raises as \$1.5 billion to \$2 billion annually. Do you have the Ontario numbers so I could find out what the impact would be right here in Ontario?

**Ms Janet Froid:** I can respond with regard to health care philanthropy in terms of Ontario and through the membership of AHP: \$500 million is raised annually.

**Mr Goldthorp:** Mr Chairman, if I could supplement the answer, it's \$500 million through hospital foundations in the province. That does not count the other millions of dollars through other non-hospital health care foundations.

**Mr Leal:** So that's strictly hospitals.

**Ms Froid:** It's from 225 public hospitals.

**Mr Leal:** So I can just do the quick calculation of the 30% of that, which might be siphoned off with this legislation.

**Mr Goldthorp:** Yes; \$150 million.

**Mr Fonseca:** Thank you very much for your presentation. Would you not agree that providing a patient list to a foundation is personal health information? After all, it's linking the individual to the hospital or to the organization.

**Mr Goldthorp:** We actually would argue that it's not health information; it's user information. We know that the individual is a user of the hospital. We have no knowledge whatsoever of the type of treatment or the reason for attending the hospital. It goes back to the point of wanting to approach someone on a point of connection. If we don't know that the person is a user of the hospital, then there's no connection between us and the user. We're simply asking for the ability to have an attempt to establish a relationship and have multiple points of opt-out where that potential donor or user can tell us and we will respect the request not to engage in any fundraising conversation.

**Mr Fonseca:** But there may be a case where you have an individual who doesn't want family members to know that they've been at a hospital or another institution, and if they didn't opt out, by just not knowing the process or they weren't touched by it, and they start receiving that information, they may feel that information has gotten out.

**Mr Goldthorp:** I'll let Janet respond first. I will respond separately.

**Ms Froot:** I think that is a valid concern, and it is one that for years—because we have had the opportunity to connect with patients, we in the many health care organizations already have a practice in terms of certain sensitive patient groups that we exclude. For instance, we do not contact psychiatric patients and we do go through a process of identifying other vulnerable or deemed-to-be-sensitive scenarios. So there is already a high level of exclusion that happens, and that is done in consultation with our hospital organizations that we serve. I can say from experience, having worked in the health care sector since 1994, that the level of complaints and negative feedback is very nominal. In fact, the AHP numbers quote a 1% to 2% complaint rate from 10,000 to 20,000 people contacted. I would say the converse is that people often are very open and very thankful for the opportunity to demonstrate that they are grateful for the care received.

**The Chair:** I will now go to the official opposition.

**Mrs Witmer:** Thank you very much for your presentation. I would agree with you: I think people really are quite grateful for the opportunity to support the hospital. The other thing that I find happens is the communication with people in the community as to what is going on at the hospital, some of the new initiatives that are going to be undertaken, some of the successes they've enjoyed. So it's really a form of additional communication which I think is really important.

1330

We've heard from others, and I'm certainly very supportive, as is our party, on making some amendments here. You're suggesting that it could remove 10% to 30%. I think we've heard from other presenters that it could be far more than this.

**Ms Froot:** I think it's a domino, though, in terms of that's just from a first gift. What we see is that a \$100 donor can in their lifetime turn into a donor of a planned gift or a bequest which is \$1 million or more. Our other concern is that at a point in time when the need for philanthropy to support our health care missions is increasing, to minimize the opportunity to develop the relationships with the very people who are being served, there's a disconnect there.

**Mrs Witmer:** Yes. That's right.

**Mr Goldthorp:** If I may, our presentation was deliberately conservative. Our objectives were not to dramatically overstate the case. It is very clear to us that 10% to 30% is a minimum. As Janet referred, it does not count into what we call the major gift of large donations

coming in after a relationship is developed that will never be found because of this legislation.

**Mrs Witmer:** Exactly, and we've heard numbers that would indicate that the majority of the money that's raised would no longer be available once this trend started.

Anyway, I appreciate your presentation. I think there is recognition that certainly the government doesn't have all the money, and this serves as more than just fund-raising. I think it serves as a vehicle for communication as well, which I think is just as important.

**Ms Martel:** Thank you for being here today. We've heard similar presentations and I'm sympathetic to the need for change. Something just struck me that should have a long time ago. If we do the amendments, and what the foundations are essentially given are name, address, telephone number and e-mail address, how do you take the next step of taking off your list people who have sensitive treatment concerns?

**Ms Froot:** That happens at the hospitals. The hospital does that now.

**Ms Martel:** Even before—

**Ms Froot:** It's a precursor, so we only receive information that is deemed to be appropriate for us. I know in St Joseph's Health Care, London, a process of review is—we're looking at, what are we already excluding, what else should we consider doing, given the heightened awareness? I think we're getting to a verification point; we've already been doing quite a good job, so we just don't even get certain information at the front end.

**Ms Martel:** The hospital is doing it themselves before that is ever transmitted.

**Ms Froot:** Yes. We also have other mechanisms, because foundations also, over the course of having relationships—we may receive from our own donors an indication to no longer solicit. So we also have another layer of exclusion that happens and it is a constantly updated process.

**Ms Martel:** So your suggestion is that we add in the definition section, under section 4—we've got a definition of what personal health information is and you're suggesting we should have a definition for—

**Mr Goldthorp:** Personal non-health information.

**Ms Martel:** —personal non-health information, and we could put in the legislation or in regulations that that would include name, telephone number, e-mail address and address so it's very clear what that means.

**Ms Froot:** Yes.

**Mr Goldthorp:** Correct.

**Ms Martel:** Then that would link directly to the amendment for 31(2), where you reference non-health information. It would have been defined somewhere else.

**Ms Froot:** Yes. And those amendments would be very consistent with what most hospital foundations are already doing anyway. It's really reflective of what is current practice, which has been working well.

**Ms Martel:** Thank you. I appreciate that.

**The Chair:** Thank you very much for your presentation. I appreciate that you took the time to come here to tell us about your concerns about this bill.

**Ms Frood:** One final comment in terms of the overall support: Both associations absolutely believe that this is the right thing, and for those of us in the health care sector to see legislation specific to health information is more meaningful than the global PIPEDA. So we see it as a very positive thing.

CANADIAN MENTAL HEALTH  
ASSOCIATION, ELGIN BRANCH

**The Chair:** Now we'll call on the Canadian Mental Health Association, Elgin county branch. On behalf of the standing committee on general government I'd like to welcome you and thank you for taking the time to come up with your presentation. You have 20 minutes, and you can either take the whole 20 minutes or leave some time at the end for questions from the three parties.

**Ms Heather De Bruyn:** I'm Heather De Bruyn. I'm with the Canadian Mental Health Association, Elgin branch. I'm the executive director there.

I wanted to start by giving you an overview of our association and then go through our support and then what we would see as some positive changes in the proposed bill.

The Canadian Mental Health Association, Elgin branch, is an incorporated, registered, non-profit charitable organization chartered in 1961. Throughout the province we have 33 local branches providing a range of services, as well as our provincial office. Our particular branch provides a seven-bed supportive residential program, 24 geared-to-income rental apartments in our independent housing program, a homelessness program that provides 24 apartments across the county, an intensive case management program that provides 24/7 support, a sessional fee program for psychological assessment, a rural community support program providing culturally specific outreach to our Low-German-speaking Mennonite population, a three-bed crisis/safe bed program, individual and group supportive therapy and three activity centres across the county.

I just wanted to mention that we have such a wide range of services and different locations because it would impact on the implementation of the bill.

The goal of these services is to support individuals in their recovery from mental illness. Our agency's mission is to contribute to an integrated mental health system by providing community-based mental health services and to optimize mental well-being through education, advocacy, research and support services.

In recent years, in response to client needs, our branch has developed a mental health network that includes core and associate members from across the county. We have been working with other service providers in our community to streamline access to services through a common assessment tool and have been improving the integration of services through innovative alliances, networks and partnerships. I believe you would have

heard more of that with regard to London's position this morning.

Information sharing is an integral part of these strategies. New approaches include developing common client records to be shared by the different agencies or services with which a client may be involved, to avoid duplication and to ensure that each agency working with the client has the most up-to-date information. It becomes incredibly important, especially when dealing with crises.

As more and more people with serious mental illness are able to live in their own community with the support of services such as are provided by our branch, it is even more important that hospitals and communities work well together.

The Canadian Mental Health Association, Elgin branch, has a long-standing interest in the protection of personal health information. We know first hand the stigma and discrimination that people with mental illness and their families continue to face in all aspects of life. The public perception of people with mental illness, a serious and sometimes fatal disease, is often based on stereotypes that portray the person as violent, incapable and unstable. The fear of stigma interferes with individuals accessing the services they need when they need them.

Then I have the example from 1977, when there was the creation of the commission of inquiry into the confidentiality of health information. Incredibly enough, it was something we were still dealing with last month, when it was discovered that Parliament required applicants to disclose whether or not they had been treated for a mental illness. Fortunately, those things were dealt with very quickly, but it still has the underlying perception of mental illness that concerns us with regard to the level of stigma.

This submission reflects our agency's strong belief that individuals have a right to maintain the privacy of their health information and to control its collection, use and disclosure. At the same time, as service providers, we are also aware that there are limited circumstances when disclosing information may be essential to save someone's life.

We strongly support the bill and we urge the government to enact it as soon as possible. Although we identify some concerns and would make some recommendations designed to improve the legislation, this bill has incorporated many of the concerns that we have identified in previous versions of health information legislation and policy. It also achieves several of the goals that we identified as essential components of effective legislation.

The primary goal of the legislation should be the protection of personal health information, providing an individual with access to their own information and the right to correct that information.

The legislation also should recognize limited circumstances in which information could be collected, used or disclosed without consent.

The legislation should facilitate the sharing of information to improve health care, while still respecting the individual's rights.

**1340**

The Information and Privacy Commissioner should be responsible for the legislation. As an independent body, the commission has the expertise and experience necessary to carry out this important role.

The legislation should be clear and easy to understand and use, and it should not create an unnecessary administrative burden.

This legislation goes a long way to achieving these goals. The following comments and recommendations are intended to strengthen the legislation, consistent with these goals.

Our review of the legislation for this submission was guided by recommendations from our provincial office, based on feedback of the experience at the local branches, and in particular on the barriers that currently exist to providing effective health care, whether those sections of the legislation which permit the collection, use or disclosure of information without consent are limited and clear, and whether there is enough guidance in the legislation or the regulatory powers so that individuals understand and can assert their rights and so that providers can effectively implement the legislation.

Overall, the recommendations fall into six categories: regulation-making authority; scope; accountability and implementation; consent; capacity and substitute decision-making; and disclosure of information.

The regulation-making authority under this legislation is expansive and affects every aspect of the legislation. In some regards, it is overly broad and would, in our opinion, undermine the legislative intent. There are also some gaps in the regulation-making authority that we would recommend be added.

Overall, providing flexibility through regulation is a necessity for this type of legislation, which is applicable to a wide range of persons, from a very small organization to huge institutions with thousands of employees. Our concern is that the ability to exempt persons or classes of persons from the definition of “health information custodian” has the potential to undermine the comprehensive nature of the legislation and return to the current situation in which there is a patchwork of legislation or, as in the case of community mental health, no legislation at all.

Similarly, by excluding information from the definition of “personal health information,” the potential exists for sensitive information to have no protection at all.

The regulation-making process does provide some protection. By requiring public consultation on regulations, with limited exceptions, it allows the public to raise concerns if proposed regulations undermine the legislation. In order to strengthen the legislation and further protect against its erosion through regulation, we would also recommend that the regulation-making power specifically refer to the purpose of the legislation set out in the preamble. In doing so, it provides a measure against which to judge whether a regulation is consistent with the purpose and intent of the legislation or whether it would weaken the protection provided. This approach

would balance the expansive regulation-making power and hopefully retain the core values of the legislation.

The recommendation would be that section 71 be amended to require that the regulations must be consistent with the purpose of the legislation and result in the strengthening of the legislation. Regulations which reduce the protection of an individual’s information would not be valid.

I can go through and I can keep reading these things, but there are a number of other pieces and I know that Ontario division also presented these amendments, so you will have heard them. I wanted to give you a local perspective on examples of things in a rural community around sharing information that they wouldn’t want to have impeded because of the legislation.

With regard to the unnecessary administrative burden, I also wanted to remind folks around the table that for community mental health agencies there has been no base budget increase since 1992. As you can see from the difference in costs of services, we prioritize the services for our consumers and therefore there is an erosion of some of the administrative duties, so we would not want to unduly burden in that area.

We are the only community mental health agency in Elgin county, so there are times when we are asked to do things or assist people that wouldn’t necessarily come under mental health services. Because sometimes people don’t know where to go and they see the sign in front of your door, you are it. For example, we receive calls sometimes from Ontario Works when they have somebody in their office who is displaying mental health problems and is unable to fill out the mandatory requirements for the paperwork that is necessary for them. They have verbal permission from the client to contact our office, and we would be given the name and phone number to do assertive community outreach—to go back to that individual and offer them support in filling out the forms. It’s not necessarily something that has been covered because, again, it’s informal. It’s not necessarily part of our mandate, but in a small community, the people who are mobile and can assist are needed in all different kinds of areas.

Another example would be that sometimes the police will pick up somebody following complaints of bizarre behaviour. Unable to get information from the individual but not wanting to lay charges, they may come by our office and say, “Do you recognize this person in the car?” In one example, the officer asked me and I looked and said, “No, I don’t recognize that person. Did you think of asking her for her identification?” He said, “No, I guess I can do that.” So he went, and then he came back and, because I’m a health agency, I could then call our local psychiatric hospital and ask if somebody was missing from one of the wards, which we did find out, and they were able to transport her back to where she needed to be without unduly burdening the legal system or charging her with any sort of misdemeanour.

Other times we have been asked to go down and identify people being held in the cells at the police station.

Again, a similar experience: Somebody is picked up for bizarre behaviour and is not able to speak for themselves too readily, and they're not willing to share information such as their identification with the police. But if they see a community support worker, then sometimes they are willing to say, "This is who I am, and this is my contact person" or "this is my worker."

On a daily basis, we call our local psychiatric hospital and ask if any of our clients have been admitted, because we have 470 clients across the county. Some live independently, and some live in remote areas. If we do not receive information about whether or not they need our assistance, then sometimes for them to move back to their home or if they have pets that need taking care or their medication has been left behind at home, they need to have that linkage for their worker to be able to pick that up, or sometimes take clothes or shoes so that when they actually are ready to go home, there is not a disruption in the services they get.

When clients come in to our agency, we use form 14 and we really do strive to have the highest regard for confidentiality because of the stigma, and certainly do, as we work with them, talk to them about what things we would share, such as if we called the psychiatric hospital, or would they want us to check on those kinds of things. But when people are actually going into a facility in a state of crisis, they are not always able to give informed consent.

So it has to be a strategy that we work with individuals ahead of time, before the crisis. In fact, sometimes when people go into the crisis unit, if they have had some sort of issue with family, they may state quite vehemently that they do not want their family to know about the situation. So you have to modify the goal, because it could have been in their crisis plan that you always notify their mother when they go into the hospital, and yet this particular admission is because of some clandestine fight they have had with their mother and they don't want her to know.

Those are the things—those are the pieces and the respect around confidentiality that we have in existence, but still try to maximize what we do in the best interests of the client. In a small community, you get called on for all kinds of reasons. The United Way received a number of calls because we had a young fellow living in a dumpster. You have to keep in mind that in Elgin—I'm not saying we don't have homeless people, but they are well hidden because of the rural nature. They didn't know what to do. They don't have outreach workers, so they called our agency and said, "Can you go over—this young fellow is there—and see if he needs some assistance?" So we would go over and deal with the situation and make the appropriate referrals, but not necessarily one to regional mental health care and not necessarily one to the crisis unit, because the mental health issue may not be a serious mental illness that we or they would deal with.

I just wanted to bring more of the local perspective to the presentation you received from our Ontario division last week.

**1350**

**The Chair:** Thank you. We have six minutes left. The official opposition.

**Mrs Witmer:** Thank you very much for your submission and also for speaking to how you conduct your business and the interaction you have with people in your community and how that might be quite different than in an urban setting. You've made some recommendations for changes within this legislation. Where do you think it is most critical for your association that changes be made?

**Ms De Bruyn:** If you look on the last couple of pages, there's a summary of the recommendations. I guess what I wanted to make loud and clear is that when dealing with mental health issues, sometimes it is more difficult to determine the level of urgency needed with regard to disclosing information without consent. It's not as simple as somebody going into a general hospital emerg and they're unconscious. Then you can say, "OK, they cannot consent." If they go in with a broken arm, it's pretty straightforward that they can consent. So I think the biggest part—every mental illness is different, so it's not even one fix for everybody; it certainly depends on the situation and it has to be looked at individually. So it's that flexibility around giving information in the client's best interest without consent.

**Mrs Witmer:** And it's a little bit murky to be writing legislation or regulations that somehow capture that need for flexibility.

**Ms De Bruyn:** Yes it is. I can already tell you from the peer support group that we have locally—their executive on their board are also consumers, and one of them went into the hospital since January. When they called to see how he was, because he has no workers and no mental health formal supports, the initial response from regional mental health care was, "I'm sorry, we're not allowed to divulge that information." So they were not there. He has no family locally; he's high-functioning, so he only deals with the peer support group. That is a negative impact on people's understanding of how to implement the legislation. I still think there needs to be a lot of education on how you use the legislation. For larger institutions, even with form 14s in the past, it sometimes is an exclusionary piece as opposed to an inclusionary piece.

**The Chair:** It's time for Ms Martel.

**Ms Martel:** Thank you for coming today. I may go over this again, and I'm sorry—I'm struggling, I think, with the provision that says a facility "can disclose." If you call, information can be disclosed, and we're very conscious that the identification of a particular wing will certainly disclose information that people may not want.

One suggestion was that if people come in and can state their preference on admission, that they do that. But you would have a number of clients in an acute episode who would be unable to do that on admission. Do you have some ideas about what we could do, under that circumstance, if they're not able to give express consent, that it be known that they are actually there?

**Ms De Bruyn:** What we do with our individuals at this point in time is create a crisis plan ahead of time, so that you have permission ahead of time for the release of certain pieces of information. But it does become murky and it does become difficult, and it is not the same as other pieces of health in that even sometimes when our consumers are presenting well, it isn't necessarily the most logical presentation that they're giving. So when they're going into a crisis unit—and you will know this from things you have read in the newspaper. Sometimes they could be in a crisis, go into a crisis unit, present very well, be released, but not be well. So there still is a glitch with regard to assessing whether or not they are capable of giving consent.

**Ms Martel:** In the same section around disclosure, we also heard concerns about a health care custodian contacting a relative or friend of the individual if the individual is injured, incapacitated or ill, and a concern was raised there that family or friends may not know of a mental illness or HIV/AIDS, for example. One of the suggestions that came forward in previous presentations was that you deal with the substitute decision-maker. That might be OK if you have one. I take it that perhaps a number of patients who have mental illness would not have a substitute decision-maker, so you couldn't use that as an alternative.

**Ms De Bruyn:** In our area, a number of them would not have a substitute decision-maker, because when they are doing well they are doing extremely well and do not need one. If they have community supports, whether it be peer support or case management or any of the outreach teams from the hospital, sometimes that would be the extent they would have. I would think the substitute decision-maker would be in place for people who, even when they are doing well, are not achieving the same levels as their counterparts.

**Mrs Van Bommel:** Thank you for coming in today. The bill is about protecting the privacy of individuals and their health information, and you referred to the rural community. Could you elaborate for the committee about the rural culture and the difficulty of maintaining privacy, even in terms of being seen in certain buildings, walking through certain doors, having certain people visit with you?

**Ms De Bruyn:** Certainly. In a rural community, I am known by the vehicle I drive: "Oh, are you the one who drives such-and-such a vehicle?" So if I went to visit somebody at their home—I'm already known. People know where I work. They know the vehicle you drive, so if you're actually doing home visits, people know that you're a mental health worker going into somebody's home.

The nice thing about having—we have partners across the county. In the west end of the county we are out of the community health centre, so people can go into the health centre without anybody necessarily knowing that they're going for mental health supports. Some people choose to do that for anonymity reasons; other people are fine with having you go to their home. Transportation,

though, does remain an issue. Some people are reduced in the choices they can make because of the transportation.

We certainly strive to keep neutral settings for our workers to work out of. We have activity centres around that aren't necessarily targeted as, say, mental health agencies, and we have partnering agencies that we have offices out of so people can have some anonymity. We will meet individuals wherever they would like to meet, so if that happens to be the doughnut shop and then go from there, that's the way the business is done. It's all done individually with regard to the client's wishes, to maintain that.

The difficulty in a rural area is that if you live there and you work there, you have no anonymity. Everybody knows. And everybody knows, when you're going to somebody's house, exactly why you're there.

**The Chair:** Thank you for giving us the opportunity to hear about your concerns and taking the time to come down today.

STRATHROY MIDDLESEX GENERAL  
HOSPITAL FOUNDATION

FOUR COUNTIES HEALTH SERVICES  
FOUNDATION

ASSOCIATION FOR HEALTHCARE  
PHILANTHROPY

**The Chair:** The next group is the Strathroy Middlesex General Hospital Foundation. On behalf of the standing committee on general government, I would like to welcome you to this hearing. Would you tell us your name and title?

**Ms Susan McLean:** My name is Susan McLean. I am the chief executive officer of the Strathroy Middlesex General Hospital Foundation. I'm speaking to you today on behalf of the two hospital foundations that form the Middlesex Hospital Alliance. I do have a presentation that I'd like to present to you as well. It will take us just a short minute to get it up and running. I certainly appreciate this opportunity to have the chance to provide some information on behalf of community hospitals in Ontario.

I'll just go through and tell you a bit about the hospital alliance that I represent and also the greater partnership that I have with the Association for Healthcare Philanthropy. As I said, I am speaking on behalf of the two hospital foundations of the Middlesex Hospital Alliance and also as a member of the Association for Healthcare Philanthropy.

**1400**

The Middlesex Hospital Alliance was formed three years ago and is an equal partnership between two Middlesex county hospitals—actually, the only rural hospitals in Middlesex county—Four Counties Health Services and Strathroy Middlesex General Hospital. I'm also here today as a representative from the Association for Healthcare Philanthropy, a group of health care fundraising executives and health care institutions that are

dedicated to the advancement of philanthropy in Ontario and Canada.

Do you want me to wait until this gets up and going or would you like me to continue?

**The Chair:** You could proceed, because we only have 20 minutes, and if you take the whole 20 minutes, there won't be any time for questions.

**Ms McLean:** Just following along in your notes, last year in Ontario the Association for Healthcare Philanthropy members raised over \$500 million for the Ontario hospitals that they support.

I know you've received a presentation from my colleagues the Association for Healthcare Philanthropy on January 27, I believe, in Toronto. It is my hope that in addition to reinforcing the very valid comments they would have and the concerns regarding Bill 31, I'd like to give you an insight into the impact that the implementation of this bill, as it stands now, will have on community hospitals and their supporting foundations.

I would also like to introduce to you my colleague, Ed Wheatley, who has been working with our foundation for a number of years and was actually instrumental in the program design and transfer of data for our first grateful patient mailer, now more than three years ago. Many hospitals will refer to patient solicitation as a grateful patient mailer and, as many of you would understand, most of them are very grateful for the services they have received in our hospitals.

Funding the growing cost of health care continues to be a challenge to governments, hospitals and the foundations that support them. Not only is each hospital and its community responsible for funding the annual cost of new and replacement equipment, but also, as much of our hospital infrastructure becomes outdated, which we see all over the province at this time, the cost of capital projects.

Presently, the ministry caps capital project costs at between 50% and 70% of the total expenditure, therefore requiring communities to raise the balance. In my particular case, working at this right now, we face a need to raise \$7.5 million within our community of 32,000 persons. The majority, other than the town of Strathroy, are rural-based. This is a sizable task when combined also with the need annually to raise between half a million dollars and \$1 million to cover the annual capital equipment cost from the same community.

I want to talk a little bit about the relationship that a community hospital enjoys with its citizens. I can speak to you about the tremendous source of pride that residents in the community have for their hospital, for the institution that provides them with the care that really is their day-to-day needs. It might be looking after your grandmother's stroke or it might be your child's appendicitis. It can be anything that is not needed in the tertiary hospital setting. It has been my experience, and I believe it could be confirmed by any one of my colleagues, that there is a strong sense of pride and ownership in their local hospitals. It is not considered an intrusion, or offensive, when the community hospital asks for support.

All hospitals approach individuals and organizations to raise funds for a variety of needs. These needs include building and renovation projects, as we are in right now; patient care equipment needs; funding for emerging technologies, which we can barely keep ahead of; and education, recruitment and retention of medical professionals. I doubt that I have to tell this group how important it is to be able to maintain physicians and other medical professionals in the hospitals already in place.

One of the key differences between fundraising in urban areas and community hospitals is the number of development opportunities that are readily available, whereas the list, as you can see, of potential programs available in large centres is far larger than that available for community hospitals. When you look at our opportunities, the plans that we can cost-effectively manage are almost half. So we need to look at programs that will provide us basically the most bang for the buck without using any other kind of terminology.

Hospital foundations are very effective at raising funds, and we do this in every community across Ontario, but all of us face a limited pool of potential donors. In the case of Strathroy, we are in the midst of the largest fundraising campaign ever launched in our community. Presently, we have raised over \$6.5 million toward a \$7.5-million goal, funding a \$15-million project funded at 50% by the Ministry of Health and Long-Term Care. We're very grateful for this opportunity to build a new addition to our hospital, but also very concerned about the funding that's available, particularly when you look at the size of the community.

As is traditional, we have received tremendous support from both individuals and the corporate community, but the remaining \$1 million is still a question mark. We must continue to expand our donor base to reach this goal.

Central to our efforts are grateful patients and the ability of hospital fundraisers in Ontario to reach out to these patients and their families in the hope they will provide a gift. Once established, hospitals need the ability to cultivate and maintain these relationships, and in most cases donors appreciate the continuing opportunities we provide to them for both education and ongoing solicitation.

Virtually every health care institution in the province of Ontario now is currently contacting patients as a primary source of new donors. Grateful patients and their families create the single largest pool of health care supporters available.

Barriers to the relationship development, as could be put in place with the draft legislation, will be detrimental to the philanthropic sector, resulting in significant and increased administrative costs, greater costs per dollar raised and lower net funding for health care programs in the end.

Hospital users, our patients, are more than pleased to assist their hospital. As you can see in the presentation, our most recent patient mailer, which accounted for a whopping 15% of our annual direct mail income, tells the story of one of our patients.

The appeal was directed to others who used the emergency services as well. Patients feel a great sense of gratitude for the care they've received and want to help when asked. It should be noted that in our case, the response to this patient-focused mailer out-performed according to industry standards. This is yet another confirmation to us that patients want to have the opportunity to contribute to their hospitals.

I'm going to provide you with three or four local examples gathered from my colleagues throughout Ontario of what patient mailers and grateful patient programs mean to these hospitals.

One example: Last week, a couple visited my office and said they had recently moved to Milton. Mr X had used our emergency department and had received a grateful patient solicitation letter. The gentleman had suffered a heart attack and was stabilized at Milton District Hospital emergency before being transferred to a Toronto hospital. He wanted to express his gratitude by donating \$10,000.

Another example: A young lad was struck by a car while crossing county road 14 about four years back. He was brought here to Four Counties, stabilized and airlifted to Children's Hospital of Western Ontario, one of our partners. Rapid treatment was credited with saving him from severe brain damage. When we were in our Helipad campaign of 2003, the grandparents of the young man made a generous donation to the campaign in his honour.

This is my particular example: Memorial donations represent a large portion of gifts made to community hospitals. Grieving families feel that by naming their hospital as a recipient of memorial contributions, it's their way of saying thank you for the care a loved one has received.

Hospital foundations will no longer be able to have access to this information, allowing us to send a note of appreciation to the next of kin—not only a matter of common courtesy, but the right thing to do. There's another example that's not in your handout. This is from a northern Ontario community hospital that last year sent out a combined mailing to lapsed donors and patients to bring in about \$12,000 gross revenue. This year it sent only to lapsed donors and the revenue is only at \$5,000 so far.

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When we talk about grateful patient programs and the return on investment, I want to talk to you a bit about the cost of fundraising. I'm sure many of you have been involved in your hospitals. The cost of fundraising is of constant concern to the community, professional development staff and to our volunteer boards.

Donor acquisition is the most expensive form of fundraising there is. In order to ensure that administrative costs are contained within hospital foundations, community hospitals must continue to seek new donors who are acquired in the most cost-effective manner possible.

Grateful patients represent one of the most cost-effective methods available. They are already interested

and involved and most likely will support a request from the hospital when the request is sent.

I wanted to also provide you with a bit of accountability on hospital foundations. This is taken from the Canadian Centre for Philanthropy's recent publication on charitable fundraising in Canada: "Hospital boards are more frequently reported to be involved in almost all evaluation activities than are the boards of other types of charities." What this, I'm hoping, is telling you is that we have to make sure our costs are reasonable and in line and that hospital boards are very diligent in ensuring that.

I wanted to give you some examples of what our grateful patient revenue actually will fund for us this year and what could happen. As I mentioned earlier, 15% of SMGH Foundation's annual income is derived from our grateful patient program. The numbers are similar throughout community hospitals in Ontario. Translated into patient care equipment, this represents the ability or the inability to purchase three cardiac monitors, eight patient stretchers, 10 defibrillators, or perhaps two years' support, our educational bursary fund, which assists in the ongoing training of not only physicians, but medical professional staff as well.

How do hospitals and their foundations make the choices as to what is funded and what is not? Based on SMGH figures, \$75 million generated by grateful patient programs in Ontario are at risk. I ask you, as revenue from grateful patients declines and hospital needs continue to rise, is the provincial government prepared to fund the shortfall?

I would also like to offer you an alternative to the present form of Bill 31. I have two options, both of which are supported through the Association of Healthcare Philanthropy in Canada and its members at large. The first is the option to offer implied consent through notice, with both hospitals and foundations handling the opt-out process. The second would be implied consent through notice, with hospitals only handling the opt-out process.

To summarize—I am going to hit on some key points that my colleagues have already addressed with you so I'm not going to take a lot of your time here—hospital foundations cannot support an express consent requirement for health care fundraising for the following five reasons: the potential negative impact on patient care; privacy expectations on the part of Ontario patients are inconsistent with the express consent requirement; the potential loss of revenue to Ontario hospitals comes at a critical time in healthcare reform; over the next two years, hospitals will depend increasingly on their foundations to fund research in communicable diseases and new infection prevention and control measures in light of the severe effects of SARS; and finally, the discrepancy in consent requirements in Bill 31, as it is currently written, would create different privacy rules between Ontario health care fundraisers and their charitable counterparts in other sectors. This is an unfair requirement to hospital fundraisers.

I thank you for your time today and, once again, for the opportunity to present the feelings of community hospitals and of the Middlesex Hospital Alliance.

I'm happy to try to answer any questions you may have as well.

**The Chair:** We have one minute left, and I will give this time to Ms Martel.

**Ms Martel:** Thank you for your presentation today. We've heard a lot about fundraising, as you can well imagine. Here's my concern. There has been some suggestion that perhaps we can get express consent from people upon admission. I have two concerns with that. I suspect a number of people come to your hospital, and mine at home, because they come through emergency and so have no opportunity to give express consent at all. Second, I really am worried that asking that of people upon admission would make many people feel like their level of care is going to be dependent on how they answer.

**Ms McLean:** Exactly.

**Ms Martel:** So I wonder if you can just comment on those two concerns.

**Ms McLean:** I will try briefly to comment on those. The first comment that we have is that most people when they enter emergency are not feeling like talking about what we're going to do with their information, other than knowing that it's secure within the institution they're entering.

We feel that they will have a tendency to decline to provide their information. They really are not thinking about it. They don't want to have to think about fundraising and hearing about us in the form of a newsletter or providing them with other kinds of educational opportunities when they're not feeling well. It's inappropriate to do that to someone.

We also know that our physicians do not support this, and we feel it will have a very negative impact on the number of people who will provide consent. It's a trickle-down effect: You don't provide the consent; we can't get the information; they're not feeling right at the time. It's just not the appropriate time to be doing that.

**The Chair:** Thank you very much, Ms McLean, for taking the time to come up and inform us about your concern.

**Ms McLean:** Thank you for asking.

#### MIDDLESEX HOSPITAL ALLIANCE

**The Chair:** Our next group is the Middlesex Hospital Alliance. On behalf of the committee, welcome to the public hearing on Bill 31. You have 20 minutes. You could take the whole 20 minutes or you could leave some time at the end for a question period. If we could have your name and title.

**Mr Mike Mazza:** My name is Mike Mazza, and I'm the chief executive officer of the Middlesex Hospital Alliance, made up of two hospitals: Strathroy Middlesex General Hospital and Four Counties Health Services. With me today is Sarah Padfield, who is the administrative coordinator at our Four Counties Health Services site.

**The Chair:** Very good. You may proceed.

**Mr Mazza:** Strathroy Middlesex General Hospital is an 87-bed community hospital located in Strathroy, Ontario, about 20 minutes northwest of London. Four Counties Health Services, located in the village of Newbury, approximately 40 minutes west of London, is a small rural hospital in the middle of southwestern Ontario with about 20 beds.

First, let me begin by saying how important this legislation is for hospitals in Ontario. I'm really delighted to have the opportunity to speak to you about this legislation and support it. Unlike the federal legislation that hospitals have been struggling to implement since January 1, 2004, this legislation specifically addresses the complexities and challenges of health care delivery organizations.

This legislation has a number of strengths that will allow hospitals to implement important measures that will protect and respect our patients' personal privacy while at the same time allow health care practitioners to continue to deliver health care both efficiently and effectively.

The government should be commended for their consideration and articulation of the implied consent framework; and I mean government in general, not necessarily any particular party. Having worked in the industry for many years, I can tell you that I have received many more complaints from patients that their information has not been shared with the system or their health care practitioners. It is a rare incident indeed when a patient has actually complained that we have in fact passed their information along, and I'm talking about 26 years in the health care industry.

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Health care is entering a new age and forging a new direction. Canadian patients are becoming health care consumers insofar as we are witnessing a much more informed patient population than ever before. These same patients are demanding higher levels of patient service and quality. In a country where individuals can easily access their banking accounts and financial information at any local ATM, health care consumers are beginning to demand this same type of client-focused care.

The legislation is important in that it builds in a review process and a ministerial approval processes for multi-facilities. This will be important as strategies such as regional initiatives—like teleradiography or the PACS project that the Thames Valley Hospital Planning Partnership is involved in—and further integrated services develop. These will be important strategies that will mitigate the shortage of health care professionals and physician labour and hopefully stabilize some of the escalating health care costs. It is important that barriers that would oppose the development of these strategies not be put in place by the government. While we respect the need for patient confidentiality, it is also important to recognize that the days of isolated hospitals and health care practitioners are no longer the way the system operates.

It is my feeling that this legislation reflects that reality effectively and will not pose a significant barrier in the

further development of the future of our health care system.

One of the areas of concern for hospitals, however, is the provision to limit consent, or the lockbox provision, which essentially allows patients to withhold or block critical information from their health care providers. It's particularly problematic in a hospital like Four Counties Health Services: 20 beds, small emergency department, ancillary services. From about 4 o'clock in the afternoon until about 8 o'clock in the morning, there is only one medical staff serving the entire hospital. So if a patient comes in and has an issue with that particular medical staff, I'm not sure how the hospital could provide services. The physician has to know what is going on regarding the patients he or she is responsible for. I don't understand how we would be able to address that part of the legislation.

From a management perspective, this will be an extremely difficult provision to manage. In the event that a patient does choose to withhold information from their health care practitioner, the hospital will essentially be charged with developing a cumbersome administrative process, not to mention the impact on the quality of patient care delivered in these circumstances.

Like many new legislative initiatives, the implementation of this privacy framework will have costs that will be incurred by hospitals and other health care delivery organizations. Hospitals such as Four Counties and the Strathroy-Middlesex General Hospital are not large enough to support full-time personnel devoted to the development of privacy policies, the assurance of accuracy, completeness and timeliness and other administrative processes without the financial support from the Ministry of Health and Long-Term Care.

A second but related area for concern relates to the potential regulations and requirements around the electronic collection and dissemination of personal information. Currently, any information systems do not have the capacity to lock out some users from general information. As the information systems in hospitals evolve, however, it is our hope that software applications will have this capability. These investments in technology and information systems are substantial and largely unsupported financially by the Ministry of Health and Long-Term Care for hospitals the size of Strathroy and Four Counties. As these investments are not correlated directly to the provision of patient care, they are often unjustifiable for our board of directors and as such have not been addressed.

Costs for software and other information technology infrastructure systems should be recognized and the ministry should be encouraged to support hospitals and health care delivery organizations as they implement this legislation.

Finally, I want to touch on the section that deals with fundraising and the release of personal information for the purposes of fundraising. It should be noted that the collective request to the Ministry of Health and Long-Term Care for capital investments as they relate to infrastructure total more than \$8 billion for 2004-05, accord-

ing to the Ontario Hospital Association. Hospital foundations and fundraising are extremely important for all hospitals. Given the serious financial situation of Ontario's hospitals, without the ability to raise funds and thereby make important capital investments and upgrade patient care equipment, it seriously jeopardizes the hospitals' ability to offer the highest quality health care possible.

Again, this legislation is an important and positive step for Ontario's hospitals and other health care delivery organizations and the government should move to enact it as quickly as possible.

Thank you for the opportunity to speak to you.

**The Chair:** Thank you. We have approximately nine minutes left and, it is the time of the government side.

**Mr Fonseca:** I'll put this question toward the fundraising. In regards to fundraising, do you not feel that if you were to ask for consent, if somebody were not to give you that consent, they're saying that they don't want to be solicited for funds?

**Mr Mazza:** Yes, I would agree with that. If somebody indicates to the hospital they don't want to be solicited, then they should be removed from further solicitations.

**Mr Fonseca:** Or if the hospital were to ask for that consent and the individual just said, "No, I do not want to be solicited," would the individual not be saying, "I don't want to receive anything"?

**Mr Mazza:** I can tell you that very recently—this is only anecdotal—a patient was talking about another hospital that we refer to and had gone for a pre-admit visit, a workup. Between their pre-admit visit and their surgery date, they got a letter from the hospital requesting a donation. The patient did wonder how their surgical outcome would be affected by the hospital's solicitation. So if we put solicitations that are explicit at the beginning, I think it can impact on the patient's perception that the money is somehow tied to the services the hospital is giving them individually.

Having said that, I don't think in today's world, at least as far as I judge by level of complaint, that people are necessarily turned off by receiving letters in the mail about requests for support for particular campaigns. They either tear them up and throw them out because the hospital foundation logo is on it, or else they ask to be removed from the foundation's donation list. In my experience, if anybody asks to be removed, we're very careful that that is done. The last thing we want to do is annoy our patients.

**Mr Leal:** Mr Mazza, do you have any preliminary estimates what it would cost you for software and other related activities for the implementation of this?

**Mr Mazza:** No, I don't have that. Actually because of the integration, particularly in the Thames Valley, the area outside of London that we're connected to, almost all the systems that we're moving to are multi-hospital systems, large software applications. So I'm not sure what those costs will be.

**Mr Leal:** Do you think this could be completed by July 1, the time frame that's been suggested in the legislation?

**Mr Mazza:** I think that would be problematic. The good thing is, of course, that if it becomes legislation, then these are large companies and they will respond because they're not doing it for individual hospitals. That cost will be definitely passed on to us, the hospitals. But some of these systems are fairly complex and many of them are American in origin. So legislative changes do take time when they come from the Ontario government.

**Mr Arnott:** Thank you, Mr Mazza, for your presentation this afternoon. One of the key themes we've heard about today, this morning and this afternoon, has been the issue of fundraising, and a number of presentations have been brought forward. I'm sure you're aware that your foundation made a good presentation in that regard.

**Mr Mazza:** I thought they did a good job.

**Mr Arnott:** But you've made reference to it too, and I think it's a very important point. I'm privileged to represent a riding that is about 80% small town and rural and I represent a couple of hospitals, and a couple that are adjacent to my riding that are small. One in particular, in the Fergus area, the Groves Memorial Community Hospital, is engaged in a significant fundraising campaign. They need to raise about \$15 million for a \$30-million capital redevelopment project. Obviously, I'm supportive of that and supportive of their application to the government. But I'm disappointed to hear some of the government members' line of questioning. It seems to imply that they don't agree that there needs to be some reasonable direct approach to, as you say, the grateful patients who have access to health services and are wanting to support the hospital. I just can't understand why a reasonable approach to grateful patients would be something the government would oppose.

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**Mr Mazza:** I would say that of course there's always a concern that patient services in some way are linked with financial donations, and I think that's quite a legitimate concern. But on the other side, there are patients who have resources that they are quite willing, as you point out, to give to their hospital in order to improve services.

**Mr Arnott:** I don't believe there's ever been an instance in a small-town hospital in the province of Ontario where care was delivered on the basis of people's ability to pay after the fact.

**Mr Mazza:** Even in small locations where, yes, I heard the mental health person say that they do know the shape and size and colour of the car, we do a pretty good job of keeping those two things separated. I can tell you, from an administrative point of view, that we really go out of our way not to have information about particular donors.

**Mrs Witmer:** Thank you very much, Mr Mazza, for your presentation. I want to go back. I think Mr Leal was on this issue. What you've been able to point out, and I think it's important sometimes that we do hear the more rural perspective from the small hospitals, is the fact that you don't have the human resources to put this process and this bill into place and you don't have the financial

resources either. We've been hearing from people as well that there is a need perhaps to put the timeline for implementation back. One of the dates that has been recommended, instead of July 1, would be January 1, 2005. Would that allow you a little more time to prepare for the implementation of this legislation, if there was a six-month delay, perhaps?

**Mr Mazza:** I would be very supportive of the idea of going January 1. I certainly don't want anyone to misunderstand how important this legislation is and how long we've been waiting for it, in terms of integrated systems and passing information on. But by putting a date of July 1, the hospitals simply won't be able to respond because our vendors are large multinational companies. So even though they're responding to the Ontario market, compared to their entire market, it's relatively small. So making those changes will take some time. Also, in terms of small hospitals, we will develop templates. The OHA is supportive of this legislation. That will work through the system. Not a lot happens in the summertime in our industry. I don't know what it's like in Parliament, of course, but not a lot of things get changed during the summer—vacation periods etc. January 1 I think would be an ideal target date.

**Ms Martel:** Thank you for being here today. I have two questions, one on fundraising and one on the lock-box.

I am concerned about the line of questioning too, from the other side, because everything I hear suggests that we need to have an amendment here. I don't think any of us are suggesting that if a patient doesn't want to give, they shouldn't be allowed not to give. The question is, when do you make that approach? I just really think that if you ask for express consent and you make that a condition of someone upon admission—they're being admitted and you're asking them about whether or not they want to donate—they sure are going to link their donation to their services. We should be looking for a way that the approach is made later, and I think the approach can clearly be made if the foundation receives only name, address and telephone number, no information with respect to health care, and you do it a couple of months later or a couple of weeks later, where there's no ability at all to tie care and the provision of it to a donation.

**Mr Mazza:** That's right.

**Ms Martel:** So we'll be moving some amendments, I think the two of us, in that regard.

Let me ask about the lockbox, because I have been struggling with clearly the breakdown that is following here: hospitals and health care institutions saying, "For the provision of quality care we need to know," and a number of community groups who are coming forward on behalf of patients with mental illness or patients with HIV and saying that these are the groups that are most disadvantaged when some of this information is released. So let me ask you this. A patient makes a conscious decision that they don't want their HIV-positive status known. Why would that affect their quality of care, coming into a hospital for a broken leg, appendicitis? Do you see what I'm getting at?

**Mr Mazza:** They all have different issues, but HIV should have absolutely no ramifications whatsoever, because we treat every single patient as though they were HIV-positive. You understand how that works. So it should have no impact.

I would be more concerned that in a small community sometimes there is an issue between a patient and a particular health care provider, so in our small hospital they don't want Dr X to know certain kinds of information. Well, in our small hospital, if you provide the authority to do that, we can't provide service to the patient. I don't know how we'd respond, to be quite honest.

**Ms Martel:** In a small community, would Dr X not usually end up to be their family doctor, though?

**Mr Mazza:** No, in our small hospital there is usually a rotation of family doctors. The eight doctors in the village take turns covering in-patients on a weekly basis in turn. So they would see patients from the other family doctor. The patient may have a problem with this doctor. That's where I think a problem would occur. I have to tell you that it doesn't happen very often, but if it did, with legislation, then I'm blocked. I don't know how exactly I would handle it because I would be in contradiction of legislation.

**Ms Martel:** Can you give me a theoretical example? I understand the potential for personality problems, but it's the issue of the health care matter that the patient is choosing to disclose or not, right? Either they want to disclose a particular condition or they don't. Wouldn't that normally not really be impacted by who the physician is as much as they don't want the release of that condition to be known in any kind of environment? Do you understand where I'm trying to go?

**Mr Mazza:** Yes, you're talking about mental health, so they are schizophrenic but they're in for a broken leg and they don't want anybody to know they're schizophrenic. I'm not a medical expert. I would say, generally speaking, that shouldn't impact on their care. The only problem is we don't currently have the ability to lock down that kind of information. That's a different set of problems.

Your mental health diagnosis should have not too much direct impact on your medical treatment. In terms of mental health treatment, I'm not so sure how that would work, to be quite honest.

**The Chair:** Sorry, our time is up. I thank you for taking the time to inform us about your concerns and also for your comments.

COTA COMPREHENSIVE  
REHABILITATION  
AND MENTAL HEALTH SERVICES

**The Chair:** The next group will be COTA Comprehensive Rehabilitation and Mental Health Services. Once again, on behalf of the committee, welcome to the public hearings on Bill 31. You have 20 minutes, which can be taken by yourself or leaving time at the end for question

period. Please come up with your name and position so it could be recorded.

**Ms Linda Marshall:** Good afternoon, Mr Chairman and fellow committee members. My name is Linda Marshall. I'm the director of client systems and support services at COTA Comprehensive Rehabilitation and Mental Health Services. Accompanying me this afternoon is Mr Mark Schroeter. He is COTA's communications specialist.

**The Chair:** Thank you. You may proceed.

**Ms Marshall:** I would like to thank the committee for this opportunity to provide input on Bill 31. Our intention today is to provide you with a brief background of our organization and to share with you our perspectives on the proposed bill.

COTA is a not-for-profit, accredited community health and social services organization based in Toronto. Established in 1973, we are a proven leader in providing comprehensive rehabilitation, mental health and support services to people of all ages. Last year, we delivered client-centred care to over 21,000 individuals, enabling them to achieve greater independence by remaining within the community setting.

As a community-based service provider, COTA interacts with all other parts of the health care system, including the community care access centres, physicians, hospitals, school boards and other community partner organizations.

We are currently contracted with seven community care access centres in the greater Toronto area and, most recently, we have partnered with the CCAC of London and Middlesex to provide rehabilitation services to local residents.

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Our scope of service now extends from Peterborough through southwestern Ontario. We look forward to participating in the evolving system of community supports and services that enhance the quality of health care available to clients.

As one of the largest direct providers of community-based health care in the region, COTA supports clear and effective privacy legislation for a number of reasons.

We want to protect our clients from unnecessary disclosure of their confidential information. But we also want to ensure that our service provider personnel understand their role in maintaining confidentiality practices, both for their clients' protection as well as their own. In addition, we want to provide appropriate privacy policies and procedures that will enhance the effectiveness of our risk management program.

We really appreciate the consultative process this government has undertaken in relation to this bill. We strongly believe ongoing consultation with stakeholders is the right approach to ensure that health information custodians are in compliance with new processes regarding the collection, use and disclosure of client health information.

COTA understands that privacy of health care information is a sensitive and highly complex issue. In the

absence of clear provincial legislation to date governing the protection of health information, there has been considerable confusion around the scope of application of the federal legislation as it relates to community-based service providers.

Introducing privacy legislation specifically for health care information is a great improvement over the existing federal privacy act. We commend the government for moving forward so quickly to address the current issues around the protection of health information.

COTA supports a number of the key features of the Health Information Protection Act as well as the introduction of the Quality of Care Information Protection Act. For example, we regularly conduct applied research and program evaluations through our in-house research and development team. We are, therefore, very pleased to see that subsection 36(3) addresses the procedure for using personal health information for research processes.

COTA was recently accredited for the second time by the Canadian Council on Health Services Accreditation. This represents an important component of our ongoing quality management program and we welcome the inclusion of clause 38(1)(b) to clarify how personal health information can be disclosed to a person conducting an audit or reviewing an application for accreditation.

A final key feature that we find noteworthy is subsection 39(1) pertaining to disclosures related to risk. The legislation clearly supports the duty to warn and addresses how our service provider personnel may disclose personal health information in the interest of eliminating or reducing risk of bodily harm to another person.

Overall, we believe Bill 31 provides a reasonable balance between the protection of personal privacy and the effective delivery of health care, and the government should be commended for its efforts.

Like other presenters before us, we do share some concerns with certain aspects of this legislation. Rather than repeating in detail what you have already heard in previous presentations, we wish to present four key points that pose a potential impact on an organization such as ours.

First, the so-called lockbox provision is an area we believe deserves closer attention. COTA appreciates the need to ensure clients have an opportunity to control their personal health information. This is in keeping with our mission to deliver client-centred care.

However, some of our more vulnerable clients, such as those living with a mental health illness, may not always be able to discern what is in their best long-term interest. Should such an individual choose to withhold consent or block critical information from their community-based service provider, it may negatively impact the quality of care they receive.

Over 40% of COTA's client programs have a mental health focus. Our expertise in dealing with this population reinforces our belief that complete sharing of information between partner organizations is critical to providing the best possible care to society's most vulnerable population.

Both as recipients of health information from community care access centres and hospitals as well as providers of information to in-home service providers and community partner organizations, we believe the disclosure of all medically necessary information is essential to ensure the delivery of appropriate treatment at the appropriate time. We would therefore suggest that the government give serious consideration to removing these provisions as they pertain to patients living with a mental illness.

Second, we respectfully suggest that the government not underestimate the public education and preparatory work still required to ensure successful implementation. Our own experience preparing for PIPEDA legislation as of January 1, 2004, revealed the time and education required across the organization to ensure compliance. Activities that we find particularly time-intensive include developing an understanding of the legislation and its implications; reviewing, revising and developing policies that reflect the new legislation; and understanding how the act fits with other legislation.

The proposed implementation date of July 1 appears to be too soon for all required elements to be in place and understood by all stakeholders. We recommend a later implementation date that allows sufficient time to ensure successful implementation. In addition, we recommend broad-based education, targeting health information custodians, health care workers and the general public, to promote compliance with Bill 31.

Third, we urge the government to review the language of Bill 31 to ensure there is sufficient clarity to guide all participants involved in the delivery of community-based health care. Many community-based organizations such as ours may not be covered by the definition of "community service" as it pertains to community services primarily providing health care.

To illustrate, COTA is also a transfer payment recipient from the Ministry of Health and Long-Term Care. We utilize this funding to provide case management and housing site support services for our mental health clients. To guarantee compliance with Bill 31, we request clarification of the definition of community service as it applies to an organization such as ours.

Fourth, and finally, we feel that the regulation-making powers outlined in section 71 may compromise the original intent of the legislation. In response, COTA supports the process of ongoing public consultation to ensure that these regulations address their original objective; namely, the protection of personal health information.

In closing, I would like to repeat COTA's strong support for the principles outlined in Bill 31. Once again, thank you for the opportunity to make this submission and for your consideration of our concerns and recommendations.

**The Chair:** Thank you. We have approximately nine minutes left. I'll go to Kathleen Wynne.

**Ms Wynne:** I had a question about section 71. You want ongoing consultation. Can you talk about how that differs from what's in the act?

**Ms Marshall:** I don't think it differs. We're supporting ongoing consultation.

**Ms Wynne:** So is there anything about what you're suggesting that's—

**Ms Marshall:** It's not specific to any one statement that's made; it's more the philosophy of the intent of the legislation and making sure the regulations do reflect what the legislation is saying.

**Ms Wynne:** How might they not? I'm just trying to understand how what's written in section 71 might actually undermine the original intent. I just want clarification on that.

**Ms Marshall:** I think looking at if there are any loopholes where people will not be included or information that might not possibly be included.

**Ms Wynne:** Can you give a specific example from the legislation?

**Ms Marshall:** I don't think I actually can at this point. It was more a philosophy than specific.

**Ms Wynne:** OK. Is there any possibility that you could get us—I don't quite understand exactly where the concern would be and in which section of section 71.

**Ms Marshall:** I'll take that back to our organization, and we'll submit it to you.

**Ms Wynne:** I'd appreciate it. Thanks.

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**The Chair:** I will now go to the official opposition.

**Mrs Witmer:** I'm looking here at page 6. You're saying that you believe disclosure of necessary medical information is essential. However, are you suggesting that we remove all the provisions as they pertain to people living with mental illness?

**Ms Marshall:** We've really struggled with this—everyone has a right to confidentiality of their health information. I think we're looking at the words "health information" and really trying to understand what that means.

One of the concerns we were thinking about, for example, is a client with a mental health illness who has a history of aggressive behaviour. Would that be considered part of their health information? You can see that someone with a mental illness has a history of aggressive behaviour because of that mental illness. If that client can withhold that information, we have service providers going in to see people in their homes, and it puts health care providers in a vulnerable position.

So it's really looking at that kind of situation. We really support confidentiality of information, but it's that fine line between what is essential so we can provide the services we need to but in a safe environment.

**Mrs Witmer:** That would become quite complex. Do you have any recommended amendments?

**Ms Marshall:** I don't have any with me here, but again, I can send that in from our organization.

**Mrs Witmer:** OK. You probably know that we're going to start looking at the amendments on Monday, so the timeline is short. It's tomorrow.

I guess there are some people who came before us who are recommending that we remove anything related

to the lockbox altogether. I think we're certainly recognizing that there are some huge problems related to the lockbox provisions. There's a need for flexibility, but I guess it's difficult. You really can't discriminate against one group of people either.

**Ms Marshall:** Exactly.

**The Chair:** Ms Martel.

**Ms Martel:** Thank you for being here today.

That's where I was going as well, because we've seen a breakdown in terms of sides, essentially between hospitals, which say this is not going to work, and then community-based organizations that are supportive. Now we're seeing two different views within the mental health community as well, because the CMHA has essentially come forward and been supportive of the provision that would allow clients essentially to withhold some information. So I was going to ask you to give me some examples, because I am really struggling as well to see clearly how this would impact on patient care, which I don't want it to, but at the same time make sure that people who are more vulnerable than others, who have a stigma attached to them because of their illness, are not even in a worse state worrying about whether information like that is released.

**Ms Marshall:** The stigma concerns me too. We don't want to stigmatize this population, but we want to have a balance of what is appropriate and what's needed for a safe environment, really.

**Ms Martel:** The example you gave us was that you have workers working with patients with a mental illness who have a history of violence. I can appreciate that you'd want to be very clear that your workers would know that, especially if they're going into an environment where they're working one on one. I can appreciate that. But I don't have an answer to this. I've been struggling with what we do, because there has certainly been a call to have the provisions removed altogether, and then, on the other side, what I think are very legitimate concerns about why certain groups are much more at risk if their information is disclosed.

**Ms Marshall:** Yes.

**The Chair:** Thank you very much for your presentation. As you heard, clause-by-clause is starting on Monday and two members have asked you for some additional information, which I think might be quite important for them to receive. Thanks again.

**Ms Marshall:** Thank you very much for the opportunity.

#### ONTARIO JOINT REPLACEMENT REGISTRY

**The Chair:** The next group is the Ontario Joint Replacement Registry. You might be the last, but you're surely not the least.

**Ms Susan Warner:** I hope not.

**The Chair:** You have 20 minutes. If you take 20 minutes, there won't be any time left for a question period. It is up to you to decide if you want to leave some

time for a question period. Could we have your name and title, please?

**Ms Warner:** Certainly. I'm Susan Warner. I'm the managing director of the Ontario Joint Replacement Registry, and I'll shorten that by saying OJRR.

**The Chair:** Thank you. You may proceed.

**Ms Warner:** Thank you very much for this opportunity to speak to this very important bill, which will really help and guide those of us who are involved in collecting, disclosing and using personal health information in doing our utmost to ensure the privacy of personal health information. I thought it would be important to give you a bit of background on the Ontario Joint Replacement Registry, so that's where we'll start, and then we'll move into talking about the implications of some of the provisions in the proposed bill and their impact on us.

We are a registry funded by the Ministry of Health and Long-Term Care. We are funded through the London Health Sciences Centre, and they are named as our host institution. As such, that sort of puts us under the legal umbrella of the London Health Sciences Centre, and I believe you heard from them this morning. However, we take our direction directly from the Ministry of Health and Long-Term Care. So the relationships are a little bit confusing. We also have an administrative and data agreement that is in process with the Ministry of Health and Long-Term Care, and they will guide and direct us, particularly around the data collection piece.

Our mandate is to maintain a registry database that informs and promotes evidence-based practice to the Ministry of Health and Long-Term Care, surgeons and hospitals on primary and revision total hip and knee replacement surgery in Ontario. We are charged with providing regional and provincial wait time data and operative data to the Ministry of Health on total hip and knee replacement surgery. We also serve as the Ontario portion of the national registry, known as the CJRR, the Canadian Joint Replacement Registry, which is housed at CIHI. Hence, we are the Ontario flow of information to the national registry.

We collect data directly from 169 surgeons across Ontario. They have obtained consent from their patients to submit their demographic, waiting time and surgical data to the registry. Our consent process is informed and explicit. Patients receive a written information sheet, and they also sign a form. That information sheet identifies our purposes, uses and disclosure of the data, and they are also instructed on what to do if they wish to change their mind and withdraw their consent.

If you look at page 3, I've put together a schema that shows you how information flows from the patients and surgeons to us and what we do with it, and then what the other groups who receive our data do with the data. Starting with the patient, they give us some information directly, with consent, and the surgeon also gives patient information to us, again with patient consent. We analyze the data, aggregate it and report on it. In order to do that, we need to do a few things with it.

The first thing we need to do is send it to the Ministry of Health and Long-Term Care. If you follow down the

left column, we send identifying information to the ministry for linkage with the OHIP billing files so the data can be verified. Then it comes back to us, and we aggregate it and prepare a report. Actually, our first report is about to come out publicly in about a month or two, which we're very excited about—we're still new at this.

The other piece the ministry receives the identifying information for is the submission to the Canadian registry. So our data flow to the Canadian registry is through the ministry. But again, it's personal health information that needs to go to the ministry for that purpose. The ministry also uses the aggregate information for system planning.

Surgeons receive back the personal health information of their patients. If they wish, they can receive back the raw data. They can also go to our Web site and view how well they're performing compared to the aggregate. That's secure, so a surgeon can only see the data for his or her own patients compared to the aggregate. Again, they use this information for evidence-based practice, for wait list management and for quality improvement and implant surveillance.

The Canadian Joint Replacement Registry receives the data from the ministry. Again, it's the personal record level information that they receive. That then is linked with the DAD, the discharge abstract database, and that is then summarized and compiled with the rest of the data that comes in to them from the rest of Canada and reported on, again publicly in aggregate form.

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Third-party researchers: Assuming that they have gone through an REB, and assuming that their proposal has been approved by a research subcommittee and/or the Ministry of Health and Long-Term Care, they can then receive depersonalized information for research purposes. Device manufacturers can receive aggregated data for their quality assurance and for implant surveillance.

Flipping over to page 4, I want to talk about some of our unique features that pose a challenge but also give us great strength. First of all, we collect our data prospectively, which means we collect it when it happens. When somebody starts waiting, that's when we get information. When the surgery happens, that's when we get information.

The other part of our registry that makes us unique is that we track forward. For instance, we watch to see how devices perform in people over time. Again, the purpose of that is to reduce what's called the revision rate, which means re-operation. So we receive data and track it at different points in time. If you look at the timeline down below, that probably is the best way to describe how we function and how we need to function to fulfill our mandate.

We have John Doe, who starts waiting for his surgery in January 2004. We receive his personal health information at that point in time, just a small bit of it, which then tells us somebody is waiting. Then, in October 2004, nine months later, he has his surgery. Then, in March

2014, he has a revision surgery. In January 2020, he has a subsequent surgery. We need to be able to track that person through that time period, so we need a unique identifying number that, of course, in our system would be the health number.

In other words, for us to be able to fulfill the mandate that is provided to us by the Ministry of Health and Long-Term Care, we have to collect, use and disclose personal health information and the health card. In our opinion the legislation, the way it is currently written, doesn't provide for us to do those things, at least not in a way that's explicit or clear.

Therefore, we would like to recommend that the OJRR is identified, first of all, as a health information custodian under section 3 of the legislation. Without the designation, the implications for us include unclear direction to the Ministry of Health and Long-Term Care in the drafting of our administrative and data agreements as to how we can function. Also, if we're not identified as a health information custodian within the legislation, if our relationship were to ever sever with the London Health Sciences Centre, that then stops us from being able to do our business.

Second of all, we would like to recommend that in section 33 we are prescribed so that we can collect, use and disclose health card numbers. I'm going to flip over to page 4. Either we are prescribed under clause 33(2)(c) as a "prescribed health information custodian" that "is collecting or using the health number in circumstances that are prescribed," or that there is clarification that we be included in clause 33(2)(a) as "a provincially funded health resource." We're not certain on what that means and if we fit in there or not. Essentially we'd like clarity so that we can collect, use and disclose a health card number.

Our third suggestion or recommendation is that we are prescribed under clause 38(1)(c) as a disease-specific registry, so that we can receive personal health information. Again, under clause 37 or 38, (1)(a) and (1)(b), they don't apply to us, yet clause 38(1)(c) makes very explicit reference to registries that need to be prescribed. Again, that is our request.

In conclusion, we are well established, I believe, to comply with this legislation, particularly under consent. I'm very proud of our consent process. We have had the privilege and opportunity to be established during a time period when privacy has been a very hot issue, so we have set ourselves up right from day one with consent practices and with privacy policies and direction. So that's not a concern for us. The concern for us is simply establishing clarity on where we fit within the legislation and how we can carry on with our business. Thank you.

**The Chair:** Thank you very much. We have approximately six minutes left, and it is up to the official opposition.

**Mrs Witmer:** Thank you very much, Ms Warner, for your presentation today. I guess basically you're asking to be identified as a health information custodian in the same way that Cancer Care Ontario is and also the Cardiac Care Network. We heard from the London hospi-

tals this morning, which seem to be going in a slightly different direction, but I think you've made a good case here and certainly we're prepared to consider that within our amendments.

You're also then looking to be able to collect, use and disclose the health card numbers, and you've made a recommendation here that that would be prescribed under clause 33(2)(c), I see.

Number 3 says you want to be prescribed as a disease-specific registry. Can you just expand on the implications of not being able to do that?

**Ms Warner:** My understanding of section 38 is that it defines who may receive personal health information. If we're not prescribed as a registry under 38(1)(c), then my understanding is that we can't receive personal health information, and if we can't receive personal health information, we can't fulfill our mandate, because we won't be able to follow the people, particularly under the device surveillance portion of our mandate.

**Mrs Witmer:** So to continue to do the work that you were set up to do, it really is important that all three of these amendments would follow.

**Ms Warner:** Right.

**Mrs Witmer:** OK. Thank you very much.

**The Chair:** We move to Ms Martel.

**Ms Martel:** Thank you for being here today. I want to go back to a question that was raised by Ms Witmer because, of course, in an earlier presentation we heard something completely different from what you have given us. I appreciate we're hearing the other side of the story.

Essentially, the argument that was made was that it would be difficult to figure out who had the appropriate responsibilities under this act. I take it you don't see that problem.

**Ms Warner:** We've been in conversation, and I'm well aware of the hospital's position on this. Clearly, a lot more clarification needs to happen around this. I think it would be difficult both ways. I think it will potentially be even more difficult for the hospital if we are not prescribed as a health information custodian, because the implications that we're still trying to sort out, for instance—we are receiving data from different custodians throughout. Again, we're still trying to understand the implications of the legislation and who's an agent and at what point they're an agent and at what point they're a custodian, as it relates to a surgeon. But its potential is that, at the point in time that somebody starts the wait, we receive data directly from a community surgeon in private practice. Then, at surgery date, we receive the information from the same surgeon, who then is potentially an agent of an institution, because he is operating at a hospital. So does that mean the different data sharing agreements are required throughout?

In terms of complexity, that would mean that the hospital would have to manage data sharing agreements with 169 surgeons as we sit today, potentially 244 surgeons, plus all of the hospitals in Ontario that do joint replacement. It's complicated either way, I believe, but

our position again remains consistent with that of the other registries.

**Ms Martel:** I appreciate that.

**Mr Lou Rinaldi (Northumberland):** Thank you for your presentation. I guess my question's along the same lines. I'm just trying to understand it. If you were given health information custodian status, would that solve all your problems?

**Ms Warner:** If we were given health information custodian status without the other amendments?

**Mr Rinaldi:** Yes.

**Ms Warner:** I don't believe so.

**Mr Rinaldi:** An agent would be the same thing, I presume.

**Ms Warner:** Pardon me?

**Mr Rinaldi:** If you were given agent status, would that do the same thing? I guess you'd be restricted the same way?

**Ms Warner:** I don't believe so either. I believe we would still be restricted. Correct.

**Mr Rinaldi:** That's right. So either/or.

**Mr Ramal:** Thank you for your presentation. It was well done. I have a question. You said at the beginning you're working under the umbrella of the London Health Sciences Centre. Being under this umbrella would allow you to receive information and function, and this wouldn't be affected by the law?

**Ms Warner:** This wouldn't be affected by the law? Is that what you're asking?

**Mr Ramal:** Yes.

**Ms Warner:** Correct. But what it would do is it would guide the definitions of what a host institution is, because we still haven't defined what the parameters and rights and responsibilities of the host institution are, and that is still being worked through in the administrative agreement with the ministry. So clarity within this legislation would direct that and help us to do our business a little bit more effectively.

**Mr Ramal:** So basically you're asking for more details concerning your organization?

**Ms Warner:** Yes.

**The Chair:** Thank you very much for taking the time. We really appreciate your presentation.

**Ms Warner:** My pleasure, and I wish you well in your deliberations.

**Ms Wynne:** Mr Chair, I just wanted some clarification on what's going to happen on Monday.

**The Chair:** Just before we proceed, all amendments have to be submitted by 3 o'clock tomorrow afternoon, Friday, February 6, at Tonia's office: 3 o'clock tomorrow afternoon for any amendment that has to be submitted.

Then on Monday we resume for the clause-by-clause at 10 o'clock in the morning in room 151.

**Ms Wynne:** OK. When we resume at that time, is there going to be a general discussion? It seems to me there are going to be a number of amendments, some of which we'll all agree on and some of which we won't. I haven't been through this process before. Will there be a discussion about which ones we all agree on and we can just agree on those and then discuss the contentious ones?

**The Chair:** We have to go through every one of them. Sometimes it could be sections 1 to 5, if there is no amendment, that we could see carried without any discussion.

**Ms Wynne:** OK. So there is that possibility.

**The Chair:** I'm glad that you brought up this point. Really, at 10 o'clock we should explain to all the people how we will proceed.

**Clerk of the Committee:** We could agree to have opening statements if you wish, like five minutes per caucus—the committee can agree to that—or you could just start from section 1, “Are there any amendments?” and then discussion, and you just keep going.

But I should also let you know that because this bill isn't time allocated, there are other opportunities to raise amendments as we go along. So if we get on a section and somebody thinks, “OK. There's an amendment that we need to put forward,” it can be done at that time as well.

**The Chair:** In other words, amendments could be brought in during the clause-by-clause.

**Clerk of the Committee:** Yes.

**Ms Wynne:** Oh, they can. So 3 o'clock tomorrow is—

**Clerk of the Committee:** By 3 o'clock we still need the bulk of the amendments. Otherwise, you will not have a package and you will not know what you're dealing with. So it's just if you've missed something.

**The Chair:** OK? Thank you very much for your co-operation. We started on time and we finished exactly 10 seconds before.

We're adjourned now.

*The committee adjourned at 1514.*

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Mr Khalil Ramal (London-Fanshawe L)

### **Clerk / Greffière**

Ms Tonia Grannum

### **Staff /Personnel**

Ms Margaret Drent, research officer,  
Research and Information Services

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