Title: Wednesday, August 25, 2004 HIA Review Committee
Date: 04/08/25
Time: 9:02
[Mr. Jacobs in the chair]

The Chair: We will call the committee to order. It is a few minutes past 9. Welcome, everyone, to the committee today, and thank you very much for coming again and helping us move the work forward. I appreciate that very much.

Before we approve the agenda or get into the agenda discussion, I will ask committee members to introduce themselves for the record, and we'll use the normal protocol, and we'll start with Lloyd.

[The following members introduced themselves: Ms Blakeman, Mr. Broda, Mr. Goudreau, Mr. Jacobs, Mr. Lougheed, Mr. Lukaszuk, and Mr. Snelgrove]

[The following departmental support staff introduced themselves: Ms Gallant, Ms Inions, Ms Miller, Ms Robillard, Ms Swanson, and Ms Veale]

The Chair: Okay. Welcome again to everyone, and thank you for your attendance again.

I'm going to ask Mrs. Sawchuk if she will go over the revised agenda for us before we seek approval for the agenda.

Mrs. Sawchuk: Thank you, Mr. Chairman. The only changes that were made on this agenda were the addition of the Alberta government presentation at 2:30 this afternoon and we also added in names of presenters for the organizations that were already shown on the agendas that went out last week in the members' meeting packages. I believe that's it.

Oh, Mr. Chairman, I guess I should correct one other thing. We did circulate in the members' packages under item 3, Preliminary Draft of the Pan-Canadian Health Information, the framework, and it turns out that that truly was a draft. We've got a complete copy printing off now for the members. We'll be distributing it shortly.

The Chair: Thank you very much.

Under Other I would also like to make the observation to the committee that with your approval I would like to suggest that we consider finishing the submissions that we didn't get done yesterday. There are about 10 pages left. If we get time either this morning or this afternoon, would the committee consider that we take a few minutes and do that?

Hon. Members: Agreed.

The Chair: Okay. Also under Other we will continue the discussion on calendaring, and I do have some new information on that item, so we'll do that then.

Could I have a motion to approve the revised agenda, then? Thomas Lukaszuk, thank you very much. All in favour, please say aye.

Hon. Members: Aye.

The Chair: Opposed, please say no. Thank you. Approved.

We're very happy this morning to welcome back with us Catarina Versaevel, who just flew in from Ottawa especially for this meeting. She's going to update us on the pan-Canadian and harmonization aspect of the committee's work.

Catarina, we welcome you this morning, and we're very happy to turn the time now to you for your presentation and questions this morning. So welcome.

Ms Versaevel: Thank you and good morning. With your permission, I will sit to speak with you.

As noted by the chair, this presentation is on the pan-Canadian privacy and confidentiality framework for health information. As Karen mentioned, the version you have in your binders indeed should be discarded. It was not the version that was intended to have been provided to you. So you will receive the draft – still a draft – of the pan-Canadian framework shortly, but I don't think that will interfere with the flow of what we're doing. The time you need to refer to it hopefully will be the time I start addressing the content specifically of that document.

The outline of what I propose to do on the framework is to give you an overview of the framework itself, why this framework is critical, and a sense of its overall content – likely what is most significant to the select committee is the second item, which is a comparison of the framework provisions with the Health Information Act as it currently exists – and speak to you about the linkage of the consultation that is occurring on the framework draft at this time with the review of the Health Information Act and let you know what consultation is underway on the framework and the timing and how that might intersect, hopefully properly, with the timing that the committee is working with.

Then I will discuss with you the consultation template that we've provided to selected stakeholders for their commentary on the framework – that is more for your information – as well as a consolidated version of the provisions that stakeholders are commenting on. I do not propose to walk you through those two documents, but I did want to let you know the nature of the consultation that's happening and the kind of input we'll be receiving, analyzing, and providing back as an input to you. We have asked people, which I will speak to at the end of the presentation, for written comments. Again, we'll give you the timing of that and how we expect that is going to occur. So with that I'll just start the discussion on the framework itself.

When the document arrives, soon, then you will note in the document – and I'll pick up where I am in relation to the document once you receive the document. But, as I say, I think I can just keep speaking even though you don't have the document.

The background, as part of the framework, looks at, in the document that you'll see shortly, why the health system within Canada needs this framework. There are several reasons why health jurisdictions across the country, including Health Canada, all the provinces, and territories, have been looking at this framework.

To illustrate the why, I will just go back in time to the fall of 2002 into the winter, when jurisdictions became increasingly aware of the impact of the federal PIPEDA legislation, the federal privacy act, on the health system, basically on the collection, use, and disclosure of health information. We've spoken of this early on when we did the orientation and information background for the committee, but I thought that in this context I would just speak more specifically about that work.

9:10

The conference of deputy ministers – federal, provincial, territorial – and the ministers put forward a very strong, articulate recommendation to the federal government to exempt health organizations from the application of the federal law. That was dealt with at the federal government. It was debated by Health Canada, by Justice, by Industry Canada and a determination made that it was not possible to exempt health organizations from the application of the federal law.

When jurisdictions made that recommendation to the federal government, they did so based on a detailed analysis of the federal

law, based on the health system. When they recommended exemption of health organizations from the application of PIPEDA, it wasn't: exempt and leave it be. It was: exempt health organizations from the application of PIPEDA, and jurisdictions are committed to the development of harmonized privacy and confidentiality collection, use, and disclosure rules that would guide the flow of information. The privacy of the individual and the confidentiality of their information would be protected.

Basically, the recommendation was that it's the health system and governments responsible at the provincial/territorial level that should be determining the most appropriate collection, use, and disclosure rules for health information, that the federal privacy law did not adequately reflect the realities and the complexities of the health system.

The analysis was presented in June of 2003. In the fall of 2003 it was determined that an exemption of health organizations was not possible and that it was also not possible to do the next step. The next step that jurisdictions put forward was to ask the federal government: kindly defer application of the federal privacy law to collection, use, and disclosure of health information – i.e., application to health organizations – until such time as jurisdictions are able to develop and put in place a harmonized approach to collection, use, and disclosure of health information. That was also not possible for the federal government to do.

So, as you're aware, as of January 1, 2004, the federal privacy legislation applies to health providers engaged in commercial activities within Alberta's health system. Generally, we're talking about physicians in private practice, pharmacists, laboratories, allied health practitioners.

Why Canada needs this harmonized approach is still to put forward a solid argument through the development and having jurisdictions amend and revise or enact, as appropriate within their legislation, harmonized rules, which is the strategy, with the framework that jurisdictions, based on the agreed-to rules, would amend, revise, reflect these provisions within their legislation.

The document that you will receive makes it very clear that no policy piece of work can commit any government to enacting provisions in legislation. That obviously is an issue of the Legislature, is an issue of public consultation, and the document certainly reflects that. But the recommendation implied and the position implied in that document are that with these provisions harmonized across the country, there is a solid argument to exempt health organizations from the application of PIPEDA.

The second reason why the health system needs this framework is because of the development, again, which we talked about as part of the earlier orientation, of an electronic health record, an interoperable electronic health record across the system. When you see the version of the document shortly – and you'll appreciate it as I go through the provisions – you'll see that there has been a difference made in the document between what are called core provisions in the framework. The core provisions are those which are recommended to be harmonized across the country.

Then there are provisions which are called ancillary provisions, where the document indicates that it is up to the jurisdiction to determine whether those provisions make sense, so to speak, within their legislation, recognizing that most jurisdictions with health information legislation have the ancillary provisions that are outlined in the framework in their legislation. Alberta's Health Information Act as it currently is drafted is certainly an example of that.

A third factor as to why the requirement for this framework speaks to reports like the Romanow report and the Kirby report, the Senate report on what is happening with the health system and health system reform overall. They certainly also reflect the critical nature of having evidence-based decisions in the health system, which certainly relies on health information. So this work builds on many, many reports.

So that, in a summary way, is the why of the requirement for a privacy and confidentiality framework that harmonizes rules across the country.

In the document that you now have or will have shortly in front of you, basically what I am speaking to is reflected on pages 9 and 10 and 11 of the document. Part of the background, too, in terms of harmonization is the work that has gone on for many years across jurisdictions to harmonize collection, use, and disclosure rules. All the ministers of health except Quebec – I mean provincial/territorial ministers – in 2001 signed a harmonization resolution which committed us and all jurisdictions to harmonizing collection, use, and disclosure rules according to the principles and the variables in that harmonization resolution. Again, we have talked about that.

The framework provisions that are outlined in this document certainly carefully addressed the existing health information regime in this country. Jurisdictions that do not have health information legislation – and there are, as you know, many of them. There are only four jurisdictions that do: three with legislation enacted, one, Ontario, with legislation likely to be enacted in November. All jurisdictions, though, with respect to collection, use, and disclosure of health information have statutes, be they sector or program specific, like public health statutes, freedom of information and privacy legislation, which applies to public bodies generally. Jurisdictions are guided by an approach which reflects fair information principles, but certainly the rules do change across the country, especially with reference to scope of legislation, which I'll speak to specifically.

So the document on pages 11 and 12 outlines for you the picture across this country in terms of privacy laws in Canada that impact privacy and confidentiality. I mention and draw your attention to that because part of the challenge, I think, in analyzing the impact of the framework provisions on the review of the Health Information Act is perhaps recognizing – and it's reflected in one of the elements of the terms of reference – that the review of the Health Information Act is certainly about Alberta's legislation, but at this time in the evolution of health information privacy and confidentiality issues, it's in a broader Canadian context. This section basically gives you, in a summary way, an insight into that broader Canadian context in terms of privacy and confidentiality.

9:20

On page 13 of the document you'll see in those bullets the typical elements that do exist in existing provincial and territorial jurisdictions and their treatment of privacy and confidentiality issues. Again, I don't think we need to go into more detail other than to just mention that as part of the context.

The electronic health record developments in Canada – and again you have had a presentation on EHR – on pages 14 and 15 of the framework document basically give you a broader picture of electronic health records within Canada's health system and that indeed it is a priority of the ministers of health and the federal/provincial deputy ministers of health. The provisions in this framework are intended to apply to electronic health records, meaning information flows, collection, use, and disclosure issues within the electronic as well as the paper-based environment.

I know I've just reviewed things that we have discussed, but I just thought I would do that before we get into the detail to put the context forward.

Now I'd like to discuss the framework itself more specifically and to bring it more to life. What I'm presenting to you is not necessar-

ily an Alberta perspective and analysis on the framework. I'm presenting to you the content within the framework document. As we proceed with the discussion, as I mentioned, I'll talk about the consultation that is underway, and once we do the consultation and hear from stakeholders on the framework provisions in Alberta's context and do the analysis, only then will it be really possible to say: here is what we're hearing in terms of the framework provisions and its impact on Alberta's health system.

But now bringing the framework and its content more to the fore, the framework document begins really, I think, like the drafting of a piece of health information legislation. It begins with talking about scope: what entities should the framework provisions apply to, and what type of information should the framework provisions apply to? What the framework document says is that all jurisdictions should have these common core provisions within their legislation apply to "any organization that collects, uses or discloses health information for the purpose of providing care and treatment to the individual, and for the purposes of management of the health system and . . . research." Research, of course, would include pieces like health, health research, so that basically includes organizations within provincial, territorial, and federal jurisdictions.

We're talking about entities like health service providers, similar to what we have within the Health Information Act; a minister and a department of health; regional health authorities where they exist – regional health authorities don't exist, obviously, in all jurisdictions – hospitals and nursing homes and identified other health care facilities; pharmacists and pharmacies; boards, agencies, committees, and organizations that a jurisdiction might identify in their regulation; agents, affiliates. Again, there is sometimes confusion around those words, but basically in our legislation, in part 1 under Interpretation, where we define "affiliate," we're talking about those types of entities – cancer boards, medical health boards, ambulance operators, and persons – who maintain and administer an electronic health record.

Were you asking me something?

Mr. Goudreau: I was just wondering, Catarina. In this list would that include groups like Blue Cross and WCB?

Ms Versaevel: No. I'm getting to that point, indeed, next.

Mr. Goudreau: Okay. Thanks.

Ms Versaevel: What the framework is saying is that those are the types of entities each jurisdiction's legislation should cover. Those are the examples, called different things in different jurisdictions. However, the determination of whether health professional regulatory bodies, insurance companies, workers' compensation boards, and other government departments and local public bodies should be engaged or not – there was no debate specifically on Blue Cross within the framework provisions, and it varies, again, across jurisdictions.

But for these types of bodies and elements of service through a Blue Cross like our Alberta Blue Cross, what the framework says is that jurisdictions need to determine that based on the debate within their jurisdiction and the health delivery service model that they have in place. However, the framework does speak to, for those entities that aren't covered within a jurisdiction, there being some principles or guidelines that are put forward.

What the scope basically is intended to do is flow with the argument that any organization that collects, uses, and discloses information for care and treatment, for management of the health system, and for research be exempted from PIPEDA, which was the original recommendation to the federal government a year and a half or so ago. I'm going to talk a bit more about scope in a moment.

But before I do, I want to talk about scope as both a question of what types of entities and what type of information. So I want to talk about what type of information and then come back to scope and talk specifically about our Personal Information Protection Act and the scope issues within PIPEDA as well, at least as the PIPEDA issues have been interpreted by the federal government and what Alberta Health's position was with the Personal Information Protection Act and how that does impact the scope issue of the framework debate. But I'll come back to that in a moment.

The type of information that the framework is speaking to is recorded information about an individual, so it's recorded information about an identifiable individual. The framework also, you'll see on page 17, addresses the issue of genetic information.

What the framework is saying and what we heard in a recent consultation with experts in genetics in Ottawa is that although there is not agreement on specific issues in the literature on genetic information or by people who are experts in genetics, what people generally agree with is that there should not be an exceptional legislative regime for genetic information, that genetic information should be seen as an element of personal health information, but that it may be necessary, which is work that we're doing, to look at the characteristics of genetic information as they might be different from general personal health information and see where rules may need to be nuanced a little differently because of those unique characteristics of genetic information, in particular the discriminatory aspects, whether we're talking about insurers or employment, and recognizing that genetic information although it's about the individual is also about the family member and that issues like access to one's own information get a little complicated when you're talking about genetic information.

9:30

We're doing some of that analysis now. That is not complete, but basically, as part of the scope issue, the framework document and the thinking done to date is that there should not be an exceptional legislative vehicle for genetic information. So all of that to say: what kind of information is recorded information about the individual?

I said I would return to scope, which is what I would like to do for a moment.

Is this okay or too much information?

Mr. Snelgrove: It appears that we're both heading down the same road. You're talking to the stakeholders in this thing, the same stakeholders we probably are. I know that you're not sitting in here, but is it just me or are we not doing the same thing?

Ms Versaevel: One of the points I mentioned that I would talk about is the link between the three-year review by the select committee and the consultation that we're doing on the framework and how we believe it will come together and come together well.

Mr. Snelgrove: Well, that's what I mean. It looks like it's together. What you're saying is exactly where we're moving along. Not that I don't enjoy every minute of every committee, but if we're both inventing the same system or reviewing the same system, maybe we should all be in the same room.

Ms Versaevel: I don't think we are necessarily inventing the same system, and I think it is not only complementary, as you say, that we're having a debate on some similar types of issues, but I think we have resolved it with the stakeholders that we're consulting with on the framework and how this is going to be integrated.

I can talk about that now rather than later if that would be better, to talk about how we see it coming together. Would you like me to talk about that now? I was going to do it a little bit later once we talk about the content here.

The Chair: I would suggest you continue. I certainly understand the question that's being presented – and I have similar questions – but perhaps we need some more background. I think it's important we talk about the question that Mr. Snelgrove has raised.

Ms Versaevel: Absolutely. That's the item 3 on the discussion outline, to talk about that. I am prepared to discuss that, and with the direction of the Chair I'll get to that once I go through the overview, but, yes, that's a very important question.

So to go back, then, to the discussion of scope in terms of who: what types of entities the framework provisions are intended to apply to. The framework provisions as they're drafted are not intended to apply to health service provider information, and they're not intended to apply to personal information in an employee health record for employment purposes.

Why? In terms of health service provider information most jurisdictions with health information legislation, the four that I mentioned – we are the one of the four that includes health service provider information in very specific ways within the scope of our Health Information Act. We did so in terms of the legislation for what were articulated reasons that were certainly debated as part of the legislation. But it was not felt to be appropriate to put a recommended requirement in that that be harmonized across the country but that each jurisdiction, like Alberta, would debate that and look at that as part of their own legislation.

So the Health Information Act review may be considering the question of health service provider information, but the framework debate is not considering that, because we're having a debate on what's being recommended as harmonized across the country. We'll talk about that more when we respond to the question on how it links. There are certain issues that this debate on the framework is not getting into.

Some jurisdictions wanted to include information in employee health records. Other jurisdictions felt that it was not appropriate. So, again, it was left as not a harmonized approach but for each jurisdiction to think that through.

As you know from earlier discussions, we have a very interesting myriad of health legislation across this country. In British Columbia, for example, we have that jurisdiction with the Personal Information Protection Act, similar to Alberta's Personal Information Protection Act, that was enacted in January 2004, so that we would have substantially similar legislation to PIPEDA for the private sector so that Alberta's law would apply.

When PIPEDA was being drafted, the policy intent of Alberta Health and Wellness was that that piece of legislation, our PIPA, then, not apply to health information as defined in the Health Information Act that was collected, used, and disclosed in the health system for health care purposes, including health research and management of the health system by a custodian or an affiliate as defined in HIA. So the policy position and the basis of the drafting of PIPA as it relates to health information was basically to exclude health information as defined in the Health Information Act.

Also, the Personal Information Protection Act in terms of the policy intent in how that legislation was drafted was that it does not apply to health information as defined in HIA that was collected, used, or disclosed for health care purposes, including research and management of the health system that's held by noncustodians. So PIPA as drafted, at least as intended, was not to apply to health information as defined in HIA, whether held by a custodian or a noncustodian.

PIPA was intended to apply to health information as defined in HIA that's personal employee information. That would include information collected by an employer when needed to establish, manage, or terminate an employment relationship, pending the three-year review, i.e., the review that is occurring now.

I mention the Personal Information Protection Act and that it is not, in terms of the policy input to the drafting, intended to apply to health information because it is part of the scope. It's part of the scope debate, as well, within the three-year review of the Health Information Act, and it is part of what we're debating as part of the framework provisions.

Now, whether section 4 of PIPA in terms of an interpretation reflects the policy intent depends on lawyers doing the interpretation, but the way PIPA was drafted, it was not intended. That was intended to remain within the scope of the Health Information Act.

9:40

So the issue of scope within the framework provisions is being debated by stakeholders across the country. It certainly is an example of an issue we're intersecting with the three-year review, meaning we're likely covering some of the same territory that we need to harmonize within our own reviews of the legislation, our Health Information Act and this framework development.

The other part of the scope is basically to make the point that it continues to be a very challenging area for all of the debates happening across the country in terms of what entities should be covered by these framework provisions. That's not unique to that kind of a debate. That's part of this debate too.

The document also speaks to purposes and underlying principles. Now I'm at page 18, carrying on all the way to page 21 of the framework document. You'll see there "purposes." You'll recognize, I'm sure, when you have the opportunity to review through them, that they reflect section 8 of the Health Information Act. They are very similar, if not in wording, to the intent and spirit of what's in HIA.

Then the document goes on to give principles that underlie all of the provisions in the framework. Our Health Information Act does not have that level of detail in terms of principles, but I think you'll find them of interest when you have an opportunity to review them because they basically put in principle and purpose language the broad statements around privacy, protection of the individual, and confidentiality protection of the individual's information.

So far in the consultations we've had some comment on the purposes and principles as feedback, which we will talk with you about within a few weeks, but generally speaking there aren't a lot of issues being raised on the purposes and principles to date.

What I'd like to speak with you about are the framework provisions themselves. I'm now on page 22 of the document.

The definitional section of the document takes you to the top of page 26. Basically what the document does is put forward definitions that are being recommended to jurisdictions to look at so that when they put harmonized provisions in place they do so using intents and meanings of definitions that are common. So when people talk about collection, they're talking about the same thing. When they talk about use, they're talking about the same thing.

But what the framework provisions indicate is that no jurisdiction is being asked to harmonize exact wording that you see in these definitions. That's obviously up to the drafter of any piece of legislation in any jurisdiction. But they're all detailed because they're intended to harmonize the intent and meaning of words as Canada's health system uses them.

Again, when you look at those words, there is a lot of commonality with the definitions that we have within our Health Information Act, although there certainly are differences as well. Those definitions were compiled by looking at the legislation that exists for health information in the various provinces, in particular Alberta, Manitoba, Saskatchewan, and Ontario. Those definitions were arrived at looking at the U.S.A. legislation, New Zealand, Australia, and the United Kingdom. In fact, all of the provisions that I'm going to mention to you were based on a review of what is happening in those countries as well as what has happened in terms of legislation in Canadian provinces. Again, I'm not intending to spend time on the definitions. I don't think there are a lot of, as I say, significant differences with what we have within the Health Information Act.

Page 26 of the framework document speaks to you of the duties and obligations of the custodian to protect personal health information. There is a provision that is put forward in the document that speaks to privacy impact assessments, and that provision is on page 27. If you had a coloured version of the document, you'd see that what's shaded is in dark, and it is recommended as a core provision. It's recommended that all jurisdictions adopt a similar type of provision, again not the exact wording but that the intent be there.

Within Alberta we are a somewhat unique jurisdiction because we do have within our Health Information Act currently a requirement for privacy impact assessments. The provision that is here is more broad than what we have in the Health Information Act but generally consistent with the Health Information Act requirement as it currently stands and our PIA practices, but there are differences. For example, our OIPC does publish summaries of PIAs but not full PIAs.

With respect to the next duty, which is cross-border transfer of personal health information – and the rules there are on page 30 – there is one provision at the top that's recommended as core, to be harmonized across the country. The rest are recommended as ancillary, meaning that jurisdictions may or may not be adopting that within their legislation. Already some of the feedback that we're getting is that some of these ancillary provisions should indeed be harmonized across the country. When you look at our Health Information Act, the proposed rules within this framework are consistent with what we have with the Health Information Act.

Then on pages 30 to 31 there are core requirements – i.e., recommended to be harmonized across the country – on policies and procedures. Again, I'm not lingering with each of them. It's more to differentiate. We'll come back with a more detailed analysis that fits in with the analysis of HIA. But just to mention that the rules or provisions that are here for policies and procedures are consistent with the Health Information Act and with policy statements.

There is a difference, though, as you go through those proposed provisions, and the difference is in the proposed rule to "designate a contact person to help ensure compliance with the legislation, to respond to inquiries about information practices, and to receive complaints from the public." However, with our Health Information Act, although it doesn't have this explicit rule or provision within the legislation, the EHR Data Stewardship Committee, that was spoken of many meetings ago here – that protocol does recognize the need to assist the public, to respond to EHR inquiries. The proposed rule that is different than our Health Information Act that I'm just highlighting arguably is also consistent with the principles of openness and transparency with the public.

Another duty that the provisions speak to is the information manager, and there's one recommended as core, and the rest are put forward as ancillary. In analyzing the framework and comparing it to HIA, it's our view that the proposed rules are consistent with the Health Information Act as it is currently drafted.

9:50

The framework provisions in terms of duties and obligations on the custodian also talk about transforming identifying personal health information. Our Health Information Act, as you know, has a regulation-making power to put forward a regulation on transforming and encoding personal health information to render it nonidentifying. However, at this point there is not that regulation. There are policies and procedures in our guidelines manual, but our legislation, like most legislation, doesn't have actual rules or provisions put in this area, and the framework doesn't either. The framework doesn't propose provisions, and, as I say, HIA also does not have provisions on how to transform, strip, encode. So what's in the document here aren't provisions. They were put forward as best practices and guidelines for people to think about, to look at.

The same with data matching. When I say "the same," I mean that no provisions are put forward in the data matching area. It's recognized that jurisdictions vary in their health information legislation in the approach to data matching and record linkage provisions. So there are no proposed data matching rules. There are guidelines that are consistent with the approach. So in terms of the review of the Health Information Act vis-à-vis the framework there is nothing to really compare because there are no rules, provisions, that are put forward.

On the area of physical, technical, and security safeguards – I'm now on page 35 – there are provisions, two of them in bold, that are recommended to be harmonized across the jurisdictions, and the third one you'll see there, close to the bottom of page 35, is not recommended as harmonized but rather ancillary. Again, the rules that are put forward in the framework draft are consistent with the intent of the Health Information Act rules except for the proposed rules that custodians with electronic health records should establish and implement audit, security, and availability safeguards. Our act, as you may have discussed, does not currently require audit safeguards. But the other point to note is that that is embedded in the third provision, which at this stage is not recommended as core.

Then there are provisions put forward for retention, storage, and destruction of personal health information, and the provisions that are in the framework are consistent with the Health Information Act as it is currently drafted. So there is not a difference there that we see.

Then there are provisions put forward on accuracy and authentication. Those are close to the middle of page 36, and again those provisions in the framework are consistent with the Health Information Act based on the analysis that several of us did on the Health Information Act and the framework.

With respect to personal health numbers, we have provisions in the Health Information Act on personal health numbers, as does the framework, but there are no core provisions recommended to be harmonized across the country, only ancillary. In any event, the provisions that are proposed here are consistent with our Health Information Act, including that the same statement would apply to fines and penalties. The provision that is there in the framework is consistent with the Health Information Act.

In the Health Information Act, as in the framework, we have provisions on immunity from suit. Of the provisions in the framework, one of them is recommended as core, and two are not. Two of the proposed provisions here in the framework are consistent with HIA.

However, the proposed rule you see here is that "any person who has reasonable grounds to believe that another person has contravened or intends to contravene a provision within a . . . jurisdiction's legislation may notify the Commissioner/Review Officer." When

you go through, you'll see words like "health information privacy commissioner" or "privacy commissioner" and words like "Ombudsman" and "review officer" because they're called different things across the country but basically talking about who we know of as the commissioner. In any event, that provision is not part of our Health Information Act. What I've just highlighted for you is different. However, it was seen as an appropriate rule for consultation and, arguably, an acceptable fair information practice. We've not yet heard from the stakeholders on what they feel about such an inclusion as is currently in this draft framework.

So those are the provisions that are put forward for consultation that we've categorized in the document as duties and obligations of the custodians/trustees. As you can appreciate from what I went through, for the majority of those provisions it's the exceptional instance when those provisions are not what we have in the Health Information Act currently. I'm obviously not speaking to what the select committee may be recommending, only to what we have as the legislation currently. So there is general consistency in the duties and obligations.

I will continue, or do you wish to stop and ask questions, or do you want to stretch your legs?

The Chair: I think we could continue for another 15 minutes and then take a break. We are limited inasmuch as we have a public presentation at 11:20, so we will need to take some time for questions. But if you could sort of take the next 15 minutes or so, then I would suggest a break.

Ms Versaevel: Fine. So I'll take 15. I'll be careful of the time, but maybe, Karen, you can throw something at me.

On page 37 of the document you'll see reference to three areas that are not put forward as provisions within the framework. They're not put forward as provisions to be harmonized across jurisdictions, but they are commentary of assistance or intended to be of assistance to jurisdictions. One is a statement on affiliate/agent limitation, and that is again consistent with our legislation, that an affiliate/agent may not collect, use, or disclose in a way that's not in accordance with that affiliate/agent's duties to the custodian.

There is also a commentary that a custodian/trustee – just to mention again, we use the word "custodian." Manitoba uses the word "trustee" in their legislation to refer to what we talk about as custodian, and Ontario talks about a health information custodian, but basically, again, we're talking about the same thing. Again, you'll see those words interspersed, were you to read through the whole document, but basically it means the same as we think of, generally speaking, as custodian or the use of the word.

So, basically, any way that a custodian or trustee when they collect information that's not recorded – keep in mind that the provision, like in our legislation, applies to recorded personal health information, but there is the obligation that they may use and disclose only for the purpose for which the information was provided to the custodian. We have a generally similar type of confidentiality requirement.

10:00

Although the people who worked on the framework did a lot of work on registries similar to our cancer registry, for example – but there are many different kinds of registries – we did a lot of debate recognizing that jurisdictions do maintain registries of personal health information for purposes like health surveillance or improving the provision of health research, and we recognize that consent is generally the starting point but not always when you have debates with jurisdictions across the country. But the people working on the framework felt that it is not possible to responsibly put forward provisions for registries, that more work and evolution needs to occur and that it would be up to the jurisdiction to put forward any provisions to define and specify any registry requirements and, basically, consent requirements.

So I mention that more as a commentary. No provisions were put forward. Through the stakeholder consultation that's occurring across the country we may hear more of that, meaning we may hear more about registries, and we will certainly let you know that within a few weeks' time.

The next section in the framework talks about the right of the individual to access their own information. When we did the review across the country and with those other rules in the other countries that I mentioned we looked at, we generally saw that there are commonalities across the rules around the right to access one's own information.

There are also differences, as you will see, in the framework document. For example, most jurisdictions but not all request that a request to access one's own information be in writing. Some jurisdictions have that; some jurisdictions don't. The rules or the provisions that are put forward, which you'll see on page 39, are consistent with our right to access rules in part 2 of the Health Information Act. So what you'll see there will not look unfamiliar because they are consistent with the legislation.

Then there are provisions on the collection of personal health information, and there is one core provision proposed to be harmonized across the country, and then there are several ancillary where, as I say, it is up to the jurisdiction. So, again, those collection provisions are consistent with the Health Information Act. Generally, the right to access one's own information is enshrined in law beyond health information in terms of the general right to access.

What these provisions do not reflect, which there likely will be commentary on once we do the consultation, is the point I referenced in terms of genetic information and access to one's own information and any nuances when we're talking about genetic information.

The next section of the framework is on consent, certainly not a section that I will get through in the next 10 minutes. Rather, what I'd like to do in the next 10 minutes is sort of set the discussion up and then let you know what the provisions are that are proposed and why they are so significant in terms of the substantially similar issue to the federal privacy law.

The Chair: Catarina, maybe it would be appropriate, then, to take questions to this point if that's your intent.

Ms Versaevel: That would be.

The Chair: I see we have some questions. Mr. Broda.

Mr. Broda: Yes. Catarina, you mentioned earlier in your presentation about Quebec being exempt under the harmonization, I believe is what you said. How are they different from the rest of the country?

Ms Versaevel: What I had mentioned, I believe, or intended to say is that Quebec did not sign the harmonization resolution that was signed by all provincial and territorial ministers in 2001. Quebec chose not to participate in the harmonization resolution.

Similarly, Quebec is not participating in the development of the framework provisions that we're discussing with you today. They sit as a member of the advisory committee on information and emerging technologies that advises the conference of federal/provincial/territorial deputy ministers of health. They monitor

progress, but they do not participate. Quebec's legislation has been deemed to be substantially similar to the federal privacy law. Quebec currently is engaged in a Charter challenge, which is spoken to in the preamble to this document.

So Quebec sometimes chooses not to participate, which I believe, Linda, does happen in other initiatives as well.

Ms Miller: Or almost always. That's a Quebec style of participating or lack thereof. They participate but don't formally agree to various national discussions and agreements that are reached. So that's a very standard approach adopted by Quebec.

Mr. Broda: Further to that, if I may, Chair, if they are not participating, what happens with your interprovincial information sharing? If, say, I am in Quebec and I have some medical services provided, would there be a restriction from us accessing the information from them?

Ms Miller: I suppose there could be. However, what typically happens in other situations in today's world – say that you were in Quebec and you had an accident or you were a Quebecker and you were in Alberta and we needed to get the information from Quebec. Typically that exchange happens based on care and treatment purposes and arrangements between the respective providers. However, at the political level there are different actions taken.

Mr. Broda: Okay. Thank you.

The Chair: Thank you.
Mr. Goudreau.

Mr. Goudreau: Thank you very much, Mr. Chairman. I'm just trying to understand what level these consultations and the discussions on the pan-Canadian are at presently. A few months ago we talked about them being at the deputy minister committee level. Is it my understanding now that you've gone beyond that and you're actually discussing it with the public and beyond the select committee?

Ms Versaevel: Yes. Again, that's part of the third item that I was intending to speak to, to talk about how the consultation is proceeding: the timing, how we're proposing it will link with the three-year review. So, yes, it is in the process of consultation, and I'll speak more specifically about the how, the timing, and the linkage shortly.

Mr. Goudreau: Thanks, Catarina.

The Chair: Okay. Thank you. Any other questions?

I'm going to suggest, Catarina, that we take our break now and then we'll come back and finish your presentation.

Yesterday when we had a public presentation from one of the presenters, I think a point was made that probably lends validity to what we're doing. The comment was made that there needs to be some consistency with privacy legislation, health privacy information across Canada because some businesses do operate businesses in several jurisdictions. So if each jurisdiction were to have their own rules, I can see it would be an impediment to business. That point was made yesterday. So it probably is important for us to get some background and have a look at what the pan-Canadian situation is trying to develop. So we thank you for bringing us up to date on that, and could we come back at 10:30.

[The committee adjourned from 10:09 a.m. to 10:29 a.m.]

The Chair: I will call the committee back to order. We're going to finish Catarina's presentation. Our target is 11:15 so that we'll have about a five-minute break before we take our first public presentation at 11:20. Catarina is going to go into consent now, and following that, then if there are questions, she would take questions sort of by topic, so I'll leave that to her discretion.

Catarina, please proceed.

Ms Versaevel: Thank you very much. The part of the document that we're on now is consent. Consent is, I would say – and I think we'd all likely agree – one of the more difficult topics, difficult in the sense of arriving at an agreed-to approach. There are differences of views in every meeting that one goes to on consent debates.

The reality of that statement, I think, is reflected in how the four jurisdictions with health information legislation have arrived at their consent provisions that they have in law. We have in this country, as you know, currently four jurisdictions with health information legislation either in effect or soon to be in effect. Each of those jurisdictions grapples with consent for care and treatment differently. They have arrived at different conclusions in how best to approach that.

What I'm going to summarize quickly is explained in detail by giving the reader of this framework document an overview of Saskatchewan, Ontario, Alberta, and Manitoba's legislation as it pertains to the consent issue. So that's all described on pages 39 to 46. I want to summarize before we get into what the framework is putting forward as provisions for consent for care and treatment and the consent issue overall. Consent is more than care and treatment debate, but care and treatment is a very important, critical beginning place here.

Saskatchewan has an approach where they say in terms of care and treatment that it's deemed consent, and the individual does not have an opportunity to withhold or withdraw their consent for care and treatment.

Ontario talks about a knowledgeable implied consent, with the individual to withhold or withdraw consent in whole or in part at any time.

Alberta's approach is that we have no consent for care and treatment, with the duty on the custodian to consider the express wishes of the individual in determining how much information to disclose along with other factors that the custodian considers relevant. Now, with our legislation that does not mean that it's a free flow of information. There are very strict restrictions on the flow of information: least amount, need to know, the various principles that have been spoken about here.

Manitoba also has no consent for care and treatment, and they have an ability for the individual to lock away information about themselves, so to speak, but the experience with that legislation since 1997, when it was put into effect, is that that provision has not been made use of. So it's there, but it has not been a used provision, so to speak.

In summarizing those, I don't mean to not give a proper description of the nuances of all those jurisdictions' legislation, because there are nuances, but only to say that we have a difference in the area of consent, differences that the people who worked on these provisions grappled with significantly in arriving at a recommended harmonized approach across Canada for care and treatment for all consent, but we're talking initially about care and treatment.

Arriving at harmonized provisions in the consent area is very critical for two reasons. An interoperable electronic health record, people argue, is not possible without harmonized rules for care and treatment. That may apply to other uses in the future, but people generally, in terms of the EHR evolution in this debate, are talking about care and treatment.

The other reason why harmonization in this area is so critical is again because of the federal privacy law. Consent is considered to be the critical privacy issue. Privacy, in the minds of many people who work in this area, equals consent. Some people argue that since privacy is the right of the individual to determine to whom how much information about them will be used and disclosed, privacy is de facto a consent issue. Other people may argue otherwise. I'm just giving you that argument to emphasize how critical, again, harmonization in this area is.

10:35

PIPEDA has taken the position in that law that consent within PIPEDA means that you have informed implied consent, knowledgeable implied consent, to use the language of the framework. This PIPEDA position isn't only Industry Canada. It's Justice, Industry Canada, and Health Canada, but it is on Industry Canada's web site. They did PIPEDA awareness-raising tools for the health sector, which is neither here nor there except for those who want to go into Industry Canada's web site and read many questions and answers on PIPEDA and the impact on the health sector.

What is very critical to this discussion and to the framework provisions is that consistently now the federal position has been that PIPEDA requires knowledgeable implied consent, or informed implied consent. Now, we may have lawyers who might look at PIPEDA and say, "Hmm. I don't know." The position that the jurisdictions have taken is that the lawyers in Industry Canada, Health Canada, and Justice have arrived at this position given the federal privacy law, so the jurisdictions were very aware of the federal position on that legislation.

Jurisdictions also, in working on the consent rules, were very aware that Ontario has introduced, passed, will enact likely in November legislation that is arguably substantially similar to the federal privacy law and has knowledgeable implied consent. The B.C. legislation, that also includes health information, also arguably is spoken of as substantially similar to PIPEDA. It also talks about implied consent.

Now, you may ask: well, if in Alberta our consent provisions as we have them in the Health Information Act are deemed to be the most appropriate within the health context for Alberta, then why would PIPEDA impact us? Certainly, the constitutional issue is an issue that can be debated.

There is, it's recognized generally, a legal division of power between federal, provincial, and territorial jurisdictions. When you do reading in this area, you can see references to the Supreme Court of Canada, where they've confirmed that provinces and territories have general legislative jurisdiction over hospitals, the medical profession, the practice of medicine, and general jurisdiction over health matters within a province or a territory and that the federal government has trade and commerce powers. So one could have a debate on whether the constitutionality of PIPEDA is a possible encroachment on provincial powers. That debate on PIPEDA certainly has been had by many constitutional lawyers across this country, I'm sure.

As we were mentioning before the break, the Quebec government issued an order in council in December saying that part 1 of PIPEDA is beyond the legislative competence of the federal government. They put forward concerns that the legislation intrudes on provincial jurisdiction over property and civil rights, and they also question the mechanism for saying that a certain entity, a provincially regulated sector, is excluded from the operation of the federal act, meaning that it's inconsistent with the principles of federalism. So PIPEDA is certainly debated in that regard.

In all of the debates that jurisdictions have been subject to, including constitutional issues, the framework acknowledges that PIPEDA is there, that as of January 1, 2004, it applies to entities that are currently subject to the Health Information Act in that the issue of arriving at substantially similar legislation or provisions that reflect the intent and spirit of PIPEDA is an important consideration as we work on the framework provisions.

When we look at the issue of consent, which is where I would like to take us now, starting on page 47, the consent debate is a very important debate within the context of looking at harmonized provisions across the country. On page 47 elements of consent are put forward. In the darkened area are core provisions, and what's in light are ancillary provisions. So the framework, whether we're talking about knowledgeable implied consent or express consent, says that for consent to be legitimate or valid, a valid implied or express consent must be voluntary, given by the person to whom the information relates or by a substitute decision-maker, relate to the information, and that it must be knowledgeable. I'll linger there for a moment because that's relevant when we talk about consent for care and treatment.

A knowledgeable consent is one where it's reasonable in the circumstances to believe that the individual knows the purposes, that they may provide or withhold consent, and that they become knowledgeable through notices, brochures, pamphlets, or discussions in the normal course of exchange that takes place, and any valid implied or express consent must be able to be withdrawn or revoked. Those elements of consent, again, are in our section 34 of the Health Information Act where we speak to consent. Those elements are generally consistent.

Where we have differences is that the proposed rule within the framework of knowledgeable implied consent for use and disclosure for the purpose of care and treatment is not consistent with the Health Information Act. Our legislation is subject to many provisions, principles, and duties and obligations on the custodian to protect confidentiality. We have a model of no consent for care and treatment along with the duty to consider the express wish of the individual.

The proposed provisions on knowledgeable implied consent are consistent with the intent of PIPEDA and are considered by the federal level to be basic to the argument to exempt health organizations from PIPEDA. As I mentioned, those provisions do reflect the provisions in Ontario's Bill 31.

10:45

Now, the issue of consent for care and treatment for sure has been subject to a lot of debate. It will be subject to debate, I'm sure, within the select committee, given feedback from the consultation guide, because in the consultation guide this issue of knowledgeable implied consent was put front and centre as part of the debate. Some of the feedback that we've already received from a few stakeholders – we've not heard from many as yet on the framework – is questioning whether knowledgeable implied consent, given our experience with the consent approach we have in the Health Information Act, indeed is where Alberta would want to go, which is why consultation obviously is very critical. While looking at any of these provisions, including knowledgeable implied consent for care and treatment, it needs to be debated within each jurisdiction's context. Then we need to put it all together and see, based on the consultation overall in this country: is knowledgeable implied consent the most appropriate approach?

But it would not be proper, in having this discussion, to not emphasize for you the issue of PIPEDA and the consent debate within the substantially similar argument, meaning, as we've said, that part of the intent is to arrive at harmonized provisions for the

collection, use, and disclosure of health information and that that would be a solid argument with those harmonized rules to request exemption of health organizations from the application of PIPEDA. Again, that's why it's significant that this rule is seen to be basic to that argument to exempt health organizations, but that factor has to be balanced with other factors for sure.

Basically, on page 49 what the knowledgeable implied consent provision for care and treatment says, in a nutshell, is that the individual, based on posters and brochures, is considered to be

> knowledgeable about the collection, use and disclosure of personal health information.
>
> Given that the individual is knowledgeable, the custodian may imply that the individual has consented to the use and disclosure of their personal health information for care and treatment.

The individual may, based on knowledge, based on what they read in posters or brochures or as part of a discussion they may have with their provider, take the initiative to give notice to their provider that they withhold or withdraw consent "for use or disclosure of their health information in whole or in part." They may choose to hold or withdraw their consent at any time, recognizing that part of a valid consent is that you are able to withdraw your consent.

As I've mentioned, that approach is proposed because it is consistent with the federal position on PIPEDA as outlined in these awareness tools that I mentioned. It's consistent with where Ontario has gone, and given that it's a pan-Canadian approach, consistency with the Ontario approach was important to consider for debate and consultation.

Again, everything in this document and everything I'm highlighting for you is preliminary and is intended for consultation purposes. That's very important. This framework is not saying that this and this and this should occur. It is saying that this is an important debate to have at this time given the evolution of health information legislation.

When you read through the document, you'll see that there is recognition that there are potentially significant cost implications associated with masking, because how you withhold parts of your information in an electronic health record is using the tool of masking. Those costs that will be identified as part of the consultation and the analysis that we are doing will be an important factor for jurisdictions to determine whether a knowledgeable implied consent model for care and treatment will be supported. That is recognized as part of the debate. The initial debate, though, is what is the most appropriate policy position, recognizing that it is very difficult to not quickly address cost and technical implications as one grapples with the policy debate.

So that's knowledgeable implied consent in a very summary way, trying to explain why the framework approach took the approach that it did with knowledgeable implied consent.

On page 50 the provisions speak to collection, use, and disclosure requiring the individual's express consent. The provisions that are there are seen to be consistent with the Health Information Act except for one of the rules, and that rule says that disclosure by a custodian to the media requires the individual's express consent even when that information about the individual is publicly available. Although that provision is not explicitly stated in the Health Information Act, it reflects, one can argue, an acceptable fair information practice.

Now, in the express consent provisions again the dark are those that are core, that are recommended to be harmonized across jurisdictions, and the others are ancillary. So in the area of express consent only two are recommended as core or put forward for consultation debate as core.

One that is not is fundraising. The framework puts forward that a custodian shall not collect, use, or disclose personal health information about an individual for the purpose of fundraising activities unless the individual expressly consents and the custodian collects, uses, or discloses the information subject to the prescribed requirements, et cetera. The Ontario approach is different than that. The Ontario debate as part of Bill 31 had submissions from different hospitals, different foundations arguing that it is very difficult for hospitals to support infrastructure, that they rely on fundraising dollars, and express consent would not be in that context. It was argued that it would be difficult. The framework provisions being worked on were aware of that and put forward this approach with fundraising for discussion nonetheless, and that approach for fundraising is certainly consistent. I shouldn't say "certainly"; it is seen to be consistent with the Health Information Act.

The next area that the framework speaks to is disclosures without consent unless individuals express otherwise. Basically, those provisions are seen to be consistent with the Health Information Act. None of those are put forward as core. The last provision in that context in terms of a successor is different for sure in its articulation and its broadness as compared to the Health Information Act.

On page 52 at the bottom we speak in the framework to purposes/uses with no consent. Those are described on pages 52 and 53. In looking at those, again you'll see that none of those are recommended as core to be harmonized across jurisdictions, and those purposes and uses with no consent are seen to be consistent with the Health Information Act.

10:55

Now, what is very, very critical with any provision which speaks to no consent is the rationale that these provisions are considered to be in the public good, required for the custodian, at times at a broad level, to manage the health system, and they're permitted without consent, meaning as proposed here, recognizing that the custodian has a duty to use least amount, highest level of anonymity, need to know, and not publish in a form that could identify the individual. As with our Health Information Act with those same types of duties that the framework puts forward for harmonization, for these types of uses that we have on pages 52 and 53, which we generally have in the Health Information Act, a custodian obviously has to put their mind to whether information about the individual is required in terms of the need to know.

On page 53, Disclosures without Consent, same type of preamble. Again, these provisions, except for two, are not noted as core provisions, and these rules also are consistent with the Health Information Act except for one rule, one provision. One of the provisions and disclosures without consent is disclosure to another custodian for monitoring prescriptions for certain drugs, for example triplicate prescription programs. This provision is not in the Health Information Act. The experience, though, with our legislation has identified that that is an issue, a consideration that needs to be grappled with, and is highlighted as well in the consultation guide.

That brings us to the area of disclosures to police. Certainly at the time that the Health Information Act was introduced in December of 1999 and prior to that and continuing in terms of debate to the time the legislation was enacted in April of 2001, disclosures to police in Alberta has been a very significant issue in the sense of trying to find that proper balance between privacy protection for the individual and access for the police toward ensuring public safety and security. So it's been a very challenging issue. Police services not only in Alberta but police services in jurisdictions argue generally that access to personal health information is required to investigate an offence, toward ensuring public safety and security, and police argue that the individual's privacy has to be balanced with the community expectation for protection and safety.

Since our Health Information Act was enacted and implemented,

specifically in Ontario in June the Mandatory Gunshot Reporting Act was put forward. Notwithstanding the issue of privacy as an essential principle in medicine and that a facility should be safe for care and treatment, the medical profession is looking at the issue of this legislation. So the framework people who worked on this had similar debates to what we had in Alberta. In terms of the select committee debate we also likely have a discussion on police, and I'm aware that there have been discussions on police issues.

The provisions that are put forward in the framework are consistent with the Health Information Act as the Health Information Act is currently drafted. Only one is put forward as a core provision to be harmonized across the country. Again, I suspect that as the framework consultation occurs, there will be discussion on the police disclosures.

Pastoral care. There are no provisions put forward for pastoral care. There is a discussion. There are guidelines. Manitoba and Nova Scotia in particular have had a lot of issues trying to grapple with pastoral care and chaplains and spiritual advisers. Ontario, certainly in their *Hansard* on Bill 31, also have had debates with input from chaplains and spiritual advisers. So no provisions are put forward, but guidelines commentary is put forward for jurisdictions.

In the area of public health surveillance, again no core provisions are put forward, but there are ancillary provisions put forward for public health surveillance. As you know, within the Health Information Act we don't have specific disclosure rules for public health surveillance. We do have a use statement in section 27 that states that custodians such as the department and regional health authorities may use personal health information subject to overriding circumstances for public health surveillance, but the provisions in the framework are not explicitly stated in the Health Information Act. They're not necessarily in conflict either, but they're not specifically stated in that way.

The minors' rights provisions. Again, they're not recommended as core, but they are consistent with the Health Information Act. So in our section 104, which makes reference to persons under 18, there is consistency with this provision.

I'm going to just carry on, given the time. On the issue of use and disclosure for management of the health system, which is on page 57, bottom of page 58, top of page 59, this provision puts forward that the role of organizations should be specifically established, meaning that organizations should be designated to analyze health information to support improvements in the health system, that that role should be recognized as it relates to use of personal health information, and that those entities be authorized or designated to collect and use that information for research and analysis, recognizing that certain conditions are met. The framework puts forward what Ontario has done in that area. Again, it's a provision that is not in the Health Information Act, and it is one that we are consulting on in terms of the framework provision.

The document that you have does make reference to the Alberta Health Quality Council and to some other entities, like Canada's Patient Safety Institute at the national level and the B.C. Centre for Health Services and Policy Research and the Manitoba Centre for Health Policy, bodies that are looking at some of this information. So the framework articulates the issue, puts forward an approach for consultation, but does not put forward any core provisions for harmonization.

The substitute decision-maker provisions on page 60 are consistent with our Health Information Act. Well, enough said. They're consistent with our legislation.

11:05

Use and disclosure for research purposes. The framework development benefited from having CIHR at the table because they were doing their best practices consultation at the same time as this work was being done. Statistics Canada and the Canadian Institutes of Health Research were at the table, all part of grappling with the research area.

The provisions on pages 64 and 65 are consistent with the Health Information Act research provisions as they currently stand except for the provision that puts forward that there should be a definition for research ethics committees, that they should be defined in a similar way across the country. The framework document recognizes that research ethics committees are increasingly being delegated legislative authority, so to speak, to review and approve research proposals, including grappling with the important issue of consent.

So jurisdictions in the framework, because there's not consistency in what happens, are being urged to consider a formal mechanism for recognizing and authorizing research ethics committees, such as what we have done here in Alberta, and to collaborate with national bodies because of research – researchers are asking for that; they did through the CIHR consultation – as information moves from jurisdiction to jurisdiction.

But the important point to highlight for you in this is that the research provisions as put forward for consultation are consistent other than, as I say, we do not have a definition for an ethics committee.

The last provision is on the area of commissioners, review officers, ombudsmen. As I mentioned, that role is titled, spoken to, differently. Jurisdictions vary in terms of the nature of their oversight body. The provisions that we have put forward are all put forward as core. The oversight mechanism provisions are seen to be core, and they should be harmonized across the jurisdictions. Again, the proposed provisions for consultation are consistent with the Health Information Act.

Basically, as we've gone through this – and I'm going to close off in one second so we can have some brief discussion before your next presentation – the provisions that are being consulted on are seen to be consistent with the intent and spirit of the PIPEDA legislation. I've highlighted how they're different than the Health Information Act.

I want to quickly just address the issue of how we see the consultation results linking with the analysis and the work being done for the committee on the review and input on the Health Information Act. We have given to selected stakeholders the framework that I've just highlighted for you. We've given them a consolidated version with all the provisions, which you've been provided, and we've given them a template so that all jurisdictions across the country ask the same questions. That's just for your information.

What we have discussed, the technical supports representatives and myself working on the framework, is that we, I, in terms of working on the framework consultation results with stakeholders – and they, too, have been advised where the differences are with the Health Information Act as it's currently drafted and the framework consultation – will integrate the analysis of the framework input so that when you receive the analysis paper – I don't know the proper name of the paper but the paper that you will receive doing an analysis of the issues based on the input and the discussions – that paper will integrate . . .

Ms Miller: It's called a summary analysis chart, if that helps you.

Ms Versaevel: Thank you. The summary analysis chart will integrate the framework input. So when an issue is being discussed, you will see it linked to the harmonized issues that we are grappling

with with the framework. So you won't be sitting there thinking: "Now, okay. I understand that in terms of the input on HIA, but what about what we heard on the framework?" It will be an integrated document. On September 27, to be confirmed, or whenever . . .

The Chair: Right.

Ms Versaevel: Yes. That's, I believe, the date. Then the intent will be that I will return to you to give you an update on what has happened with the consultations on the framework across the country. Since there is a challenge to look beyond Alberta, it will be of interest, I'm sure, to you to know what has happened to this, so we will do that. But even prior to that you will have the analysis integrated into your summary chart.

The Chair: Thank you very much. We probably have time for one quick question. Well, we'll take two quick questions. Ms Kryczka.

Ms Kryczka: I can form mine in the way of a question, but it's more of a comment.

The Chair: Okay.

Ms Kryczka: I would like to go back and take some time to read carefully, for instance, two particular areas that I'm most interested in. One has to do with the research issue, around that, and the other having to do with access of information to police. But there are many pages on the research issue, which is very good.

Thank you.

The Chair: Thank you.

Mr. Lougheed: There's quite a bit of discussion about consent. I was curious: on page 49 it mentions that "the proposed provision is consistent with Ontario's Bill 31" and seeing as how it's pan-Canadian, "consistency with the Ontario model is viewed as preferable." Why?

Ms Versaevel: It is viewed as preferable. Again, that may not be the view of people we consult with. The people who put this together felt it was preferable because we're trying to harmonize provisions across the country. Ontario looked very critically at PIPEDA and arrived at provisions that they felt were consistent with the intent of PIPEDA. Putting those two together, it was seen as preferable to try and harmonize with the approach in terms of knowledgeable implied consent that Ontario has taken in their legislation since we're trying to harmonize across Canada. To take a totally different approach than Ontario did, it would be very likely that we would not be able to achieve harmonization I think was part of the thinking.

Mr. Lougheed: Just a little question. Consent is a whole big part of this, and there are all sorts of definitions in there. Why wouldn't consent be in the definitions?

Ms Versaevel: Consent isn't defined in the definitions, but what constitutes consent, what the elements of consent are, is defined in the document. That, in effect, would represent in my view the elements of an implied or express consent, that consent means this, what's outlined on page 47. That doesn't mean that a specific definition may not be worth while, but that is what it means.

The Chair: One more quick one. Mr. Goudreau.

Mr. Goudreau: Catarina, following on what Mr. Lougheed is indicating as well, on page 48 they talk about the possibility of a custodian "to override a withdrawal of consent in an emergency situation." We don't define an emergency situation, and I would suspect that all of us would have a different definition of what may constitute an emergency. Is that part of that discussion?

11:15

Ms Versaevel: In fact, when we had a discussion with several stakeholders on the framework a week or so ago, that point was raised. It was not necessarily concluded, but one of the comments that was made is that it will be up to the physician, to the health provider, generally the physician, to make the determination as to what constitutes an emergency situation for that individual. So it was felt difficult to define emergency because it has to do with the condition that the individual is presenting. Again, we may hear more, but I think, Linda, that's how we concluded.

Ms Miller: Yeah. I would concur with those recommendations by the stakeholder group within Alberta. It's very much based on the clinical judgment of the provider, the situation of the patient. What may be an emergency situation for one individual with the same disease, as an example, may not be for another. So that's where clinical judgment plays the most critical role.

The Chair: Thank you, Hector. A good question.

Catarina, on behalf of the committee may I thank you very much for an excellent presentation on some important information, which we certainly will give serious consideration to as we go forward. Again, thank you for taking time to come this morning to present to the committee.

Ms Versaevel: Thank you. It was my pleasure.

The Chair: When we reconvene in a couple of minutes, we will do so with the public presentation in mind.

[The committee adjourned from 11:17 a.m. to 11:20 a.m.]

The Chair: We will call the committee back to order. I certainly want to welcome our Information and Privacy Commissioner, Mr. Frank Work, and of course Ms Inions. Noela Inions has been with us throughout much of the committee deliberations, so we also extend a welcome again to her and thank her for her input to the committee.

We have suggested to Mr. Work that we have approximately 40 minutes, and he is certainly free to take as much of that as he wants for presentation, but we have asked him if we could reserve time for questions, comments from the committee. He's agreed to do that.

So I think that what I'll do first is have the committee members introduce themselves, and then we'll turn the time to you for your presentation. Maybe make the presentation and then we will take questions following.

[The following members introduced themselves: Ms Blakeman, Mr. Broda, Mr. Goudreau, Mr. Jacobs, Ms Kryczka, and Mr. Lougheed]

[The following departmental support staff introduced themselves: Ms Gallant, Ms Miller, Ms Robillard, Ms Swanson, and Ms Veale]

The Chair: Thank you, everyone.

Again, welcome, Frank, and we certainly look forward to your presentation.

Mr. Work: Well, thank you very much, Mr. Chairman. It's not just politeness that leads me to say that I am really pleased to be here this morning. I'm very pleased to have an opportunity to talk to the committee. This is important stuff. Unfortunately, it maybe doesn't receive the public recognition that it should as being important stuff, but it is very important stuff.

I'll be delighted to follow your suggestion. I'll make some very short remarks. I won't belabour my office's submission at length. I'd like to leave as much time as possible for dialogue with the committee. If there isn't the dialogue, I guess I'll revert to the submission and pound away at that.

I did have a brief statement I'd like to make to you, and it goes like this. As a society and as individuals we have less control over our health information than we did in the past. The complexity of medicine, the need to sustain our health care system, and our own expectations of our health care system make this so, but this does not make it a free-for-all. The Health Information Act was ahead of its time in anticipating the realities of health care for the 21st century. Only now are some other jurisdictions catching up with the concepts pioneered by Alberta's Health Information Act, and you heard a great deal about that from Ms Versaevel.

I recall sitting on the minister's steering committee some years ago which was reviewing the draft legislation which was to become the Health Information Act. I think all of us on that committee shared the sense that we were doing something important, something somewhat radical, somewhat controversial, but I think all of us on the committee shared a sense of concern, a sense that this had to be done right because there was so much at stake both for patients and for the system.

Despite the controversy – and there's no doubt that the Health Information Act has been controversial – I think we've got it pretty close to right. What I think is right is that the HIA, which I will refer to it as – we live in an age of acronyms – creates an arena for information. It lets people who need – and I know that "need" is a subjective term – to know be in the loop. They get to be in the arena. The HIA gives rules on how information is to be handled. It sets out some general principles that are very important – for example, use the least amount of information necessary to do the job – and, important to me, it empowers my office to take complaints from the public and investigate them. It gives my office the powers of redress which are needed to resolve complaints and make sure that accidents and incidents happen only once.

The Health Information Act requires health care providers to vet their information systems through privacy and security through the vehicle of a privacy impact assessment. As an aside, Mr. Chairman, if there is one aspect – and it's probably foolish to do this – of the HIA that in my mind stands out as being pre-eminent, it is probably the role of the privacy impact assessment, because that's how you get to the health care providers and get them in line with the legislation and get their systems in line with the rules.

The Health Information Act does these things because the HIA also removed a certain amount of individual control over health information. In exchange for that loss of individual control – and this is how I view it – the HIA set rules and standards and empowered my office. I look at this as an agreement of sorts, maybe a social contract if any of you are students of history, between public bodies, the health care system, and the individual, the patient. That agreement about how it's going to work is embodied in the Health Information Act.

Mr. Chairman, your committee is, if you will, now reviewing that contract, that agreement. This has to be done, and I can think of no better group to do it than a committee of elected people. You are elected, so you will be sensitive to the thoughts and concerns of your constituents, and you are probably all at one time or another customers of the health care system, patients. So you will be able to identify with those concerns, and I'm asking you to do that.

You will, no doubt, get a lot of submissions requesting access to the arena or access to health information or requests for fewer restrictions on how health information is collected, used, or disclosed. You may not get a lot of submissions from patients, people with health issues – AIDS, mental illness, drug problems – people who have genuine concerns about what happens to their health information. I'm sure you know this, but I'm asking you to consider those people in your deliberations. Consider that these people have given up a certain amount of control over their health information in return for a package of rules, rights, and remedies that are offered by the Health Information Act.

Those organizations and individuals who want into the loop, who want to seek admission to the arena, must be prepared to shoulder the responsibilities that come with that. Those who want more health information or want to use health information in different ways have to shoulder their responsibilities to the patient, the person the information is about. There is no law in Canada that health information belongs to anyone, but the person who has the most to gain from its proper use and the most to lose from its improper use is certainly the patient, the person the information is about.

I wanted to make a specific remark about the fragmented jurisdiction of the HIA, and you've probably heard a great deal about that in the course of your hearings. The best way to explain my concern – and it is addressed in our submissions – is to give you an example. You probably saw in the paper about three weeks ago an incident where various health care providers had missent, for want of a better term, misfaxed – is that now an English word?

The Chair: It is now.

Mr. Work: It is now. Like Googled. I didn't realize that Google was a verb.

They had missent, misfaxed health information about some of their clients. When we set about investigating that, we found that out of nine missent faxes, nine wrong numbers, we only had jurisdiction over three. As a result of the fragmented jurisdiction of the HIA, the Personal Information Protection Act, and the federal PIPEDA, the federal Privacy Commissioner had jurisdiction over the other six.

We get along very well with the new federal Privacy Commissioner. She's an outstanding individual, and her approach to the provinces has been one of co-operation, so there has not been any acrimony as a result of this fragmented jurisdiction. But suffice it to say that I would have preferred to have been able to investigate all nine of those incidents.

11:30

We have almost closed the loop with respect to privacy in Alberta, and I would suggest to you that Alberta far and away leads Canada in that regard. We have the Freedom of Information and Protection of Privacy Act for the public sector, we have the Personal Information Protection Act for the private sector, and we have the HIA for the health sector. The HIA covers some but not all of health care providers, and as a result there are some health care providers that are not covered by any Alberta law. Those entities will default to the federal law.

Regardless of whether or not the Health Information Act is viewed by the federal government as substantially similar to the federal law, I think your committee's deliberations and your mandate is an opportunity to close the loop. I would like the power to deal with

health information as it moves from patient to public body to private sector, as indeed health information must move in this day and age.

I would just close my remarks by expressing my appreciation for the onerous chore that this committee has and just once again reiterating that I think the agreement analogy, that you are reviewing a bargain that was made between government and the people of Alberta, is probably a good perspective to take on this.

Now, Mr. Chairman, this is a good point to either take questions or I can launch into the submission, as you wish.

The Chair: Okay. Let's see what happens. Thank you very much for your introductory comments. I appreciate very much those comments and the points you made.

Before we proceed with questions, I need to apologize to your compliance officer, Ms Gallant, for failing to recognize her with you previously. She's been here almost every meeting, I believe, and has contributed significantly to the process. The only excuse I have for doing that is that I keep tripping the emergency alarm here, and security has me so worried now that I'm just trying to be extremely careful of what I do, because they told me that if I do it once more, consequences will be significant. So if you see me dragged out of here, you'll know that that's what happened.

Mr. Work: You don't want to mess with the Leg. security.

The Chair: That's right.

Mr. Broda: Okay. Phone them up, and let's see what happens.

The Chair: I probably will before the day is over, inadvertently.

Are there questions from the committee? Yes, Ms Blakeman.

Ms Blakeman: Thank you. I actually have a number of questions, but I'll do two at this point, if you will allow me.

You're not making any specific recommendations about designating additional custodians under the HIA regulation, but you do talk about it. You recommend that the committee should consider it, but you don't make it a formal recommendation. Can you tell me why you're in favour of this but you don't make it a formal recommendation?

Mr. Work: Well, as I said, we are aware of the need to close the loop. I didn't feel that we were in a position to say exactly which specific entities should go HIA or which specific entities should go under the Personal Information Protection Act, and that's kind of the saw-off. I don't think it's reasonable to suggest that every entity that ever handles health information should go under the HIA. The reason for that is that you get certain privileges if you go under HIA. You also get some obligations.

But to use the arena analogy, I didn't want to actually specify who exactly should be led into the arena and who should be left out of the arena. So there will be some organizations that have health information where it would suffice to have them covered by the Personal Information Protection Act of Alberta. There will be other organizations, other entities, that deal to a sufficient extent with health information that they should become custodians.

For one thing, I'm aware that there has been significant dialogue going on right up to the present between Alberta Health and Wellness and those various stakeholders about who is going to go where. I think that's going to have to be a fairly technical exercise: deciding which ones go HIA, which ones go PIPA. I'm prepared to defer to some extent to the technical advice on that, but I would like the loop closed. Everyone should be subject to one or the other.

Ms Blakeman: Well, I guess my reaction is: if not you, then who? As the Privacy Commissioner, can you not give us some observations or recommendations as to who you would see as being most necessary to close the loop?

Mr. Work: Sure, Ms Blakeman. Certainly, I think the easiest one is that the existing distinction in the HIA about how health services are paid for is highly artificial. I appreciate that at the time that the HIA was passed into law, it was probably thought necessary. That distinction should be done away with now. It shouldn't make a difference.

If you have a physiotherapist, for example, who attends some patients paid for by Alberta health care and some other patients paid for by private plans, the health insurance paid information is subject to HIA; the privately paid information is not. We need to get rid of that distinction. If this physiotherapist is sufficiently involved in the health care system that they need to be in the arena, then take them in. So that means that if they need both the ability to exchange disclosed health information in the arena somewhat freely and they also need the imposition of the rules, then let's bring them wholly into the arena.

That's not the most direct answer to your question.

Ms Blakeman: Well, if we amend the health service definition as the payment problem that you've identified, would we then, in doing so, have dealt with the problem of naming the custodians?

Mr. Work: Largely.

Ms Blakeman: Okay. Thank you.

The Chair: Thank you.

Mr. Goudreau.

Mr. Goudreau: Thank you very much, Mr. Chairman. Certainly you've identified a need to enter into agreements with other commissioners from other provinces, and you've used the example of the faxes that were missent. I guess the reverse can also happen, and in my mind I'm seeing seven, eight, or 10 other commissioners having access to Alberta and Alberta records. How do you propose to work with other commissioners?

Mr. Work: I guess the primary concern is, of course, the federal commissioner because of the jurisdiction of PIPEDA. Pretty well all the commissioners in Canada have the same need-to-know kind of restrictions in their legislation that we have.

The one that's been problematic for us most recently is that we have a provision in the Health Information Act that says that my office shall not disclose any information that comes into our possession by virtue of the act to any other person. Taken literally – and maybe as a lawyer I tend to be a little literal – this meant that we, for example, couldn't share those missent faxes with the federal commissioner. So you get into sort of a bizarre and probably somewhat annoying situation for the organizations involved where you get the provincial guy coming in and saying: we need to talk to you about how this happened. Since I can't communicate with the federal commissioner, then the federal commissioner comes in and asks the same question. It's annoying, it's difficult, and it's resource consuming for everyone concerned.

So it would be advantageous to be able to share that information with other commissioners and to even contemplate joint investigations so that it's just one investigator dealing with the issue and the other guys agreeing to share the information or abide by those

recommendations. As you know – I mean, it's presumptuous of me to even say this to you – in the information age political boundaries mean nothing. So the more we can harmonize and facilitate the ability of commissioners to investigate once authoritatively, the better.

11:40

The Chair: Thank you.

Ms Kryczka: I read your recommendation with interest, your new submission today. I think it's really great that you're speaking up and saying: I think that Alberta should be on an even playing field.

I'm just curious. Are you a lawyer, or are you something else? What's your background? With the other provincial and federal commissioners, do you have any idea how many of them are lawyers? Personally, I think it would be an advantage to be a lawyer in this job.

Mr. Work: Sometimes. I think it's about 50-50 amongst commissioners. About half of us are lawyers, and about half of us come from other walks. In Manitoba Mr. Tuckett is an ombudsman as well as the health information commissioner. He's not a lawyer. Mr. Fardy in Nova Scotia is a former journalist, not a lawyer. But Mr. Loukidelis, myself, Mr. Dickson in Saskatchewan, and Mme Stoddart in the federal office are lawyers. Sometimes it's an advantage.

Actually, I'm glad you asked that, and I'll go back to a question that was asked of Ms Versaevel earlier about defining what an emergency is for the benefit of health care providers. One of the really difficult things about this legislation and, at the same time, one of the real bonuses about it is that it leaves a lot of discretion in the hands of health care providers, and that was basically Ms Versaevel's response to the question.

As a lawyer to some extent you might expect that I would want to see more certainty, but that can be as big a problem as it is a benefit. In this day and age society is very critical of authority figures. No one knows that better than you. At the same time, you have to trust people that are in authority to be able to make decisions. So as a lawyer I might be tempted to say, "Let's try to be more specific; let's try to set out clearer rules," but as a commissioner or maybe as someone that has dealt with health care providers and a number of other bodies in the other laws I have, I am content to trust in their judgment to a large degree, trust in their discretion: when to disclose, when an emergency exists for one patient and not for another, things like that.

I think my view is that the preferable path to take until we're proven wrong is to allow that discretion to continue to prevail. If someone gets it wrong, there's a right of complaint to my office. We'll normally have an inquiry, hear from both sides, see if we can resolve it, and out of that inquiry often comes greater clarity, greater certainty about what an emergency might be or what a need to know might be. I can't think of other examples. That's kind of my nonlawyer approach to the amount of discretion and judgment that the act calls for. It's tough for these people to apply, but I think it's the best way.

The Chair: Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. Just to tie a few of your comments together, you just alluded to the public's need to trust individuals in authority and trust that they will make the best decisions possible in good faith. Earlier you made comments relevant to a social contract that the government entered into with the public by way of drafting this act and trying to strike the right balance. What are your feelings and your observations relevant to the recent requests that this committee is facing from law enforcement agencies where in order for them to do the work that we entrusted them with in good faith, they are required to somewhat shift that balance, that contract that we have signed with Albertans, to do their work properly? What are your views on it?

Mr. Work: A good question, a hot topic. In reading the paper this morning, I was struck by a headline on about page 4 or 5 about hospitals being havens for criminals. I thought that was rather unfair. In fact, I thought it was incredibly unfair. It's certainly not the case.

I'm sympathetic to the police. Being a lawyer, I'm very fond of due process. I'm sympathetic to the police or law enforcement agencies to the extent that they are not able to get the information they need to engage due process. In other words, I can see the argument for being able to get what the act calls registration information in order for the police to embark on due process and get a warrant.

Now, I know they don't always like having to do that, but I think that we have to look at the priorities in a hospital. The mandate of the police, to serve and protect, is to catch bad guys. The mandate of a hospital or a health care provider is to heal people. The priority, therefore, in a hospital has to be healing. It doesn't mean that you exclude the police, but it means that they have to accept that in that situation there's a secondary role.

It's much like the case of a high-speed chase. You want to get the bad guy, but you don't want to endanger other people by tearing through the streets, you know, at an unreasonable speed and let's get that bad guy at all costs. So there are rules and guidelines about when you call off a high-speed chase in the name of public safety and similarly in health care scenarios.

The Chair: A supplementary, Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. So that covers the scope from, on the extreme end, giving them no information whatsoever to the other extreme, releasing all medical information or any and all information that may be in the custody of the hospital.

Mr. Work: Yes.

Mr. Lukaszuk: One always has to consider the source. Media may not always be the source, but reading from the media and from the presentation here, the police are only asking for registration information, which means acknowledging the presence and/or absence of a given patient in a given facility. Do you find that this is still within the realm, the parameter of reasonable?

Mr. Work: Yes. I would think that that's reasonable, with the understanding that the reason they're getting that information is that they can then go to due process and get the warrant. I appreciate the frustration of law enforcement authorities when they can't even get a name to take to a judge in order to get the proper warrant, clearly not a good situation.

It has been a difficult debate, and I suppose, as Ms Versaevel said, it always will be. You know, for every anecdote – and at this point, again, I'm being a lawyer – for every story, which is all I've heard so far, that I hear about the police being thwarted in hospital, I've also heard stories about hospital staff feeling bullied or intimidated by law enforcement authorities to hand over information. They're not sure whether or not they should. On the one hand, they have an

officer there saying: I need this information; you could be obstructing. They don't know what to do. My submission to you is that health care providers shouldn't be put in that position. They're there to deal with patients. They shouldn't be struggling in their own mind with their judgment about: what do I tell this officer? No one wants to obstruct the police, but the health care provider's priority is health care.

So if the recommendation in the act is to make it very, very clear exactly what law enforcement authorities should get and no more and if it's just enough to enable them to go to their due process, I think that's a good result.

11:50

Ms Blakeman: I'd like to probe a bit more on that same topic. Given that we are talking about non life-threatening situations and given that registration as defined in the act includes not only the physical location of the person – in other words, are they in the hospital? – but also identifying information about their home telephone number and their residency and their demographic information, billing information and health service eligibility, et cetera, et cetera, I think that if I'm understanding this right – you're the lawyer – we have a situation where the police are seeking information that would either allow them to serve a warrant, subpoena, or court order because they now have the location of the person confirmed. They're in bed 4B. They could go into the hospital, then, and serve the person with a warrant, subpoena, or court order, or alternatively they could be asking for and receive the registration information that would allow them to then go back and get the warrant, subpoena, or court order. So there are two ways that this would play out, all of this in the context of non life threatening.

Mr. Work: Yeah.

Ms Blakeman: Okay. I'm not really understanding what your opinion on this is coming down as. You said that it was okay to release the registration information or to require a change to the act so that health personnel would be required to release the registration information.

Mr. Work: Yes. That's correct. Now, because law enforcement gets registration information doesn't mean that they get diagnostic, treatment, and care information. It also, I would think, doesn't mean that they get into Alberta Health and Wellness databases even if they have the health insurance number.

Another option for the committee is certainly to not go by the registration information category. I mean, you don't have to give that whole category to law enforcement if you so choose. There's another option to give them only the information that they would need to obtain a warrant, which would be probably demographic without the personal health number, location information. I'm not an expert in criminal law, so I'm not positive what other information an officer needs to get a warrant from a judge.

The other option for the committee, if there is concern about the extent of registration information, is to narrow it to three, four specific pieces of information that will enable the police to get a warrant, to do their job.

I guess that as far as registration information goes, I'm not sure that a lot of that information will get the police very far, like billing information, and I'm not sure that they will get that in a hospital. I mean, they would have to go to Alberta Health and Wellness to get billing information once they had the health care insurance number, and I'm not sure that the police are interested in that kind of a chase. You know, in a typical emergency room situation I can't see the police asking for health service eligibility information or billing information in order to get a warrant. But it would certainly be valid for the committee to consider narrowing even the amount of registration information the police get.

The Chair: Okay. Ms Blakeman.

Ms Blakeman: Thanks. As part of your presentation you note under the category of Other that "the second FOIP review specifically recommended that consideration be given to harmonization of the FOIP and HIA during the three-year review of HIA." I'm wondering if you can outline what, in your opinion, are the main differences that exist right now between these two pieces of legislation. If you feel that they need to be harmonized, what are the major areas that need the harmonization? Where are the biggest differences, in your opinion, between FOIP and HIA?

Mr. Work: Let me find that.

Ms Blakeman: It's at the end of your submission, under Other.

Mr. Work: Under Other?

Ms Blakeman: It's the way it comes out to us in the summary. Sorry about that.

Mr. Work: Oh, in the summary. I'm sorry; my mistake. I was looking at the body.

Ms Blakeman: It's where you're talking about harmonization of FOIP and HIA.

Mr. Work: My page numbers are printed out differently. Do you have a heading?

Ms Robillard: From our summary we didn't have a question in the guide about harmonization, so we put it under an Other category.

Ms Blakeman: Sorry.

Mr. Work: That's all right.

In terms of harmonization between FOIP and HIA, philosophically the distinction between the two pieces of law, I suppose, is that FOIP says that you can only disclose under these conditions, and then it sets out the conditions under which you can collect, use, and disclose. HIA tends to have the opposite approach: you can collect, use, and disclose in the arena except for these cases.

Again, in response to the earlier question you asked, in terms of harmonization you want to be a little bit careful, I think, about who you let into the HIA arena. Again, just because someone handles health information doesn't necessarily mean that they should get into the arena, because once they're in there, they get a lot of breaks in terms of consent and rules respecting collection, use, and disclosure. Getting into the arena is a bit of a privilege really. So from a harmonization point of view I think it will fall to the committee to be the final screener, the final arbiter of that screening process.

There are some harmonization issues, some specific ones. Genetic information, for example, is dealt with under the Freedom of Information and Protection of Privacy Act as a result of the last review. I believe it's not dealt with the same way in the Health Information Act. That should be harmonized.

The commissioner's powers. I'm hopeful that there will be an amendment put forward to the Legislative Assembly this fall,

depending on a lot of factors I guess, respecting some of the things we discussed earlier with Mr. Lukaszuk: the power of the commissioner to share information with other commissioners, to enter into joint investigations, and so on. We've asked for those powers to be expanded under PIPA, the Personal Information Protection Act, and the powers under HIA I would hope would be harmonized with the powers we're asking for under PIPA in order to recognize the realities of pan-Canadian health care provision.

What other harmonization issues? What am I missing? Audits. Under the FOIP Act my office has the power to audit extensively. We may have the power to audit under HIA, but it's not explicit. In this day and age an endeavour like auditing an information bank is a pretty costly, time-consuming undertaking, so it would be preferable to have that audit power clarified in the HIA as it is in FOIP.

I can't think of any other specific harmonization issues at the moment. I've been aware of the information that the committee has gotten and some of the other recommendations that have been made to the committee respecting agencies like AADAC and Workers' Compensation and where they should go, and I haven't remarked on them. Well, actually, we did comment on those in the submission. I didn't remark on them verbally because I don't see a need to harmonize those organizations – AADAC, WCB, for example – by putting them under HIA.

12:00

The Chair: Okay. Thank you. We will take one more brief question from Mr. Lukaszuk.

Mr. Lukaszuk: Thank you.

Mr. Work: And I will try to be brief.

Mr. Lukaszuk: On a slightly different topic. In the recent past in one of this committee's meetings the Member for Edmonton-Gold Bar has been requesting that this committee compel your office to conduct a thorough investigation on the implication of the USA PATRIOT Act and how it may or may not affect the Health Information Act and that this committee withhold its work in filing of a report up until such time that you produce a report. What are your thoughts on that?

Mr. Work: Ever since the issue arose in British Columbia a few months ago, there's no doubt that the issue is of significant concern. As I said earlier, information in this day and age tends to ignore political boundaries. It moves where it needs to move.

Having said that, I am delighted that my colleague, Mr. Loukidelis, in British Columbia has taken the initiative on this. It was probably thrust on him as much as anything, but happily he has taken the initiative on this. While I appreciate the Member for Edmonton-Gold Bar's concern and I share his concern, I don't think there would be a great deal to be gained from my office trying to duplicate the efforts of Mr. Loukidelis. I know Mr. Loukidelis is getting some outstanding submissions on this matter, and we're following his deliberations closely. In other words, I'm content to let Mr. Loukidelis bear the cost and do the work and come up with the recommendations.

What I certainly think my office should do and we will do is review whatever findings Mr. Loukidelis makes, in light of the situation in Alberta, and we will certainly comment publicly on what we see those implications as being.

The Chair: Thank you very much to the committee for your questions, and to you, Frank, and your staff, thank you very much for a very informative time and for your presentations and for your summary recommendations and comments in your submission. That will be helpful to us as we go forward. Again, on behalf of the committee thank you very much for agreeing to and appearing before us today.

Mr. Work: My pleasure, Mr. Chairman.

The Chair: Thank you. We will now break for lunch. To the committee, we will reconvene at 1:10 p.m. sharp.

Thank you.

[The committee adjourned from 12:03 p.m. to 1:08 p.m.]

The Chair: Ladies and gentlemen, we will call the committee back into order and certainly want to welcome Mr. Barry Cavanaugh, chief executive officer of the Pharmacists Association of Alberta, and Brent Windwick, legal counsel, who is here to take part in the discussions today also. Gentlemen, welcome to you.

I'm going to ask the members of the committee, starting with Mr. Lukaszuk, if they will introduce themselves, and then we'll turn the time to you, Mr. Cavanaugh, for your presentation.

[The following members introduced themselves: Ms Blakeman, Mr. Broda, Mr. Goudreau, Mr. Jacobs, Ms Kryczka, Mr. Lougheed, and Mr. Lukaszuk]

[The following departmental support staff introduced themselves: Ms Gallant, Ms Inions, Ms Miller, Ms Robillard, Ms Swanson, and Ms Veale]

The Chair: Thank you very much, everyone, and again, Barry, welcome to you and your presenter today, and we'll turn the time to you.

Mr. Cavanaugh: Thank you. I'll be very brief, as my voice would suggest I should be, before I introduce Brent Windwick to you. Brent is an acknowledged leader in the field of health law and has been our legal counsel dealing with this issue for some time, so it seemed appropriate that he make the presentation for us today. We have a fairly relaxed approach to this, and you're welcome, of course, to question either of us, and I'll demonstrate my astounding lack of knowledge should you do so.

I think it's important to understand that there are some signal themes to our presentation and themes that you will have heard or will hear from pharmacy representatives, I'm sure, on other occasions. One of those themes is the distinction that needs to be made between the pharmacy business record and the patient health record, which may often comprise the same information, and we'll elaborate on that at some length.

I think that it's important to understand that pharmacists are very aware of this issue and very concerned and very interested. I note that you've received a presentation from Value Drug Mart and that you will receive from the Alberta College of Pharmacists. We've been very actively involved in this issue for some time now and, as various parties at the table will remember, have had a lot of concerns with the Health Information Act since its inception. So to address some of those concerns and to address some of what's good about the act as well, I would like to introduce Brent Windwick.

Mr. Windwick: Thank you, and thank you very much, obviously, to Barry for the invitation to address the committee, and thanks to the committee for giving me the opportunity to do this. Barry and I

haven't really highly rehearsed anything here, so I told him on the way over that he should just chime in to correct any errors I might make or to add anything that he thinks is appropriate. I, for my part, will try to be brief, and I'll try not to fall too deeply into this chair which is kind of canted at an odd angle.

I actually have to relate one small anecdote, and that is that last year I was speaking to a House of Commons committee in Ottawa, and right after me the former federal Privacy Commissioner, Mr. Radwanski, was making a presentation. It was on a different sort of a bill, on a privacy bill, but I do recall sitting in the gallery watching Mr. Radwanski sit down in his seat. It was a table much like this, and it might have had a privacy guard or whatever in the front, but I could actually see that his feet were dangling about three inches above the ground. When I first sat down in this chair here, my feet were dangling three inches above the ground, and I thought: oh no. But I found the height lever, so I think I'm going to be okay.

Obviously, on behalf of RxA a submission has been made, and I gather that you probably have a synopsis of that submission although it is all told only 10 pages or nine and a half pages long. So to the extent that my comments and whatever summary you have is not adequate, it won't take you very long to read through the entire submission.

What the RxA has attempted to do is to frame some key issues from their perspective, I think expecting that perhaps a committee would raise other issues in the form of questions, and Barry and I are happy to respond to that today. Essentially what our submission does is frames a couple of scope issues and then a couple of sort of rules issues, if I can put it that way, and finally, I think, urges efforts to be made to make the Health Information Act harmonious, if I can use that word, with other provincial legislation and with federal legislation.

I was in Toronto yesterday attending a consultation on the development of national best practices for using health information in research and listened to a lot of people talk about the obstacles that they saw to using health information in research because of, still, the great patchwork that exists across the provinces. I think probably people have repeated this to you on a number of occasions already, and people like me who have tried to consult and study it have sort of lived with this inconsistency and patchwork for quite some time. We're hopeful that soon it will be smoothed out, but anything that, I think, this committee can do to advocate changes that will assist that harmonization process will be a very good thing.

First of all, to deal with the scope issues – and I would invite the committee to interrupt me any time. I'm not really going to follow the written submission that closely, but I do want to touch on some of the specific issues and elaborate on a couple of the points that are made in the written submission. I thought it might be useful to just say a couple of things about a frame of reference of what, in our submission, this review should be about. I went back to the consultation guide, and I pulled a couple of things out that I thought were important.

1:15

One of them was a reference on page 4 of the consultation guide about the two basic rights that were kind of in play in consideration of how this legislation regulates these activities, which was protection of the privacy of Albertans and the confidentiality of their health information, and, secondly, access to health information. On page 5 of the consultation guide there's a statement that the committee's focus was "to determine whether an appropriate balance has been achieved between protection of the individual's privacy and access to health information where appropriate to provide health services and to manage the health system." I think the position that we're putting forward really has a lot to do with this idea that we're looking at a balance between the use of information in an appropriate way and in a way that assists the functioning of the health system and the protection of individual privacy.

The protection of these two interests, in our submission, really boils down to three things, and these are really basic principles of fair information practice that underpin HIA and all other legislation like it. I know from Ms Inions and Ms Gallant that you will have heard these oft repeated and through other submissions, but I'm just going to pick out a couple.

One is that you protect these interests by ensuring that information does not identify the patient as much as possible. Secondly, you protect it by ensuring that where it does identify the patient, there is some sort of consent process involved so that people are informed and are able to consent. Thirdly, you protect it by making sure that any sort of sharing of information is limited to the minimum amount that is necessary for the purpose.

The legislation should be capable of a flexible, sensible interpretation to achieve outcomes that are in the public interest, we would submit, even where individual interests are affected, provided that there is a legitimate policy justification for doing so, and in our submission that's really the kind of approach you should take to striking the balance.

Now, having laid that out, let me try to get to the RxA-specific submissions. The first has to do with the scope of HIA, and really the RxA wanted to address two particular points. One of them was the question of whether the scope of HIA should be extended to health care providers and health care services that are not paid for publicly, and that's a specific question that has been asked in the consultation guide. In our submission, the answer to that question should be yes.

I'm aware from discussions I've had with other stakeholders that there is a concern about kind of intruding into the sphere of other legislation, for example, like legislation that governs workers' compensation and so forth. However, I would suspect, making a calculated guess, that most of the people who are making submissions to this committee support the view that there needs to be a consistent set of rules that apply no matter who is paying for the health services and that the key to the whole thing really is that the organization or the individual service provider is primarily involved in providing health services, and if they are, the information that is collected and generated and shared as a result of those activities should be regulated by the Health Information Act.

I saw a presentation yesterday when I was in Toronto on the new Ontario legislation, which is going to be proclaimed in the fall, and that's basically the approach that they have taken. Where it's health services that are paid for no matter who is paying for it, the privacy legislation is going to regulate the information arising out of that.

It's the RxA's submission that that is appropriate, and I would say that pharmacists are quite well situated to make that comment because pharmacists have had to actually live with this model for the duration of the time that the Health Information Act has been in effect because they are regulated by it whether they are paid through the public purse or privately. I think the experience of the association and its members is that that has not proved to be difficult. In fact, I think you would find that anybody who has a mixed kind of a bag right now is adopting rules as if they are regulated under the Health Information Act anyway.

I apologize if I'm already running long. I'm just going to pull my watch off here and try to make it even more succinct.

The second question is a question about information that is, I guess, created by health service providers and what use can be made of that information without consent. I think that's really the issue

that is being addressed here. It's an issue that the Privacy Commissioner addressed in a ruling last year, which you undoubtedly have heard about, and I think that there are other speakers that will also address this.

This should be clear because I think it forms the bulk of the written submission. The association's submission is that health services provider information – I mean, you can't really disengage how it is defined in HIA from how it has been interpreted by the Privacy Commissioner because I think the two of them kind of fit together right now. So taken as a package, the association's submission is that health services provider information should be either taken out of the Health Information Act altogether or some amendments should be made to the act in order to, I guess, lessen the impact that the current situation has in terms of, in this case, pharmacists trying to deal with this information.

In our submission we basically lay out a number of reasons why this is so. One reason is because, in our submission, it is a legislative anomaly. I think that there is little in the Health Information Act that seems more out of place, really, when you come to think of it, than the health services provider information piece.

The second reason is, in our submission, there is no clear legitimate policy justification for it being in.

The third reason is, in our submission, there are clear and legitimate policy justifications for not regulating or less stringently regulating health services provider information having to do with both public interest objectives in allowing that information to be shared freely without the consent of the service providers, and also it has something to do, I think, with transparency and accountability. I should stop and say a little bit about that.

The association has not specifically addressed the question of whether there should be a specific seventh purpose added to the act, namely transparency and accountability. Clearly, that's something that is a part of fair information practice rules that are codified under the Canadian Standards Association code, which kind of underpins all health information privacy legislation.

But, you know, if one is going to do that – and the association takes no position on that – it really needs not to be kind of a hollow articulation of a purpose. Really, adding a purpose is kind of a hollow exercise if the substantive rules impede the achievement of such a purpose. I think one can see – and I can elaborate on this if the committee wishes – how transparency of the health system and accountability of providers for the way that they use health resources and provide patient care is enhanced by the ability to share information about providers whether those providers consent or not.

Indeed, the flip side of that, I think, is that if you operate on a need consent of providers model, you really run a risk of not being able to adequately monitor, audit, assess, study the system and the way that providers provide the care. I mean, there are a number of ways of doing this, and we've suggested a couple of options in the written submission. I guess what it really boils down to is, you know, we're talking about this balance between individual control and public interest. I think one would say, looking at HIA as it is now and the way it should be, that even in respect of patient information there are situations in which the public interest outweighs the individual right to control information.

1:25

For something like health services providers I would say that the argument is even stronger that public interest can outweigh the individual right of control. That's in part because, in our submission, the Health Information Act is intended to protect the privacy of patients. It's intended to protect the privacy rights and to impose an obligation of confidentiality in relation to patient information and give patients a right of access to get at their information.

I guess I'm probably about three minutes short of my time. I'm certainly happy to address this issue of the reasons why health services provider information should be not regulated by HIA or regulated less if people want to ask questions about it or want me to elaborate about it later, but let me get through to the end of my presentation to make sure that I've covered the other points.

The two other points that we felt it was important to cover are consent and then a specific issue relating to disclosure of information. The consultation guide asks whether an informed or knowledgeable implied consent model should be imported into the Health Information Act, and you're likely aware that this knowledgeable implied consent model is really coming out of the way that the federal legislation has structured itself.

For a while it looked like the federal legislation was going to be extremely restrictive in terms of health information because it looked like it was going to be express consent for everything, but through the interpretation guidelines that were issued late last year, it became clear that within the so-called circle of care, which I think is kind of the equivalent of the controlled arena under HIA, there would be implied consent to sharing of the information.

In our submission there's, practically, probably not much of a difference between the model of consent with exceptions to consent that exist inside of the controlled arena under HIA and express consent but implied if it's inside the circle of care under the federal legislation. Nevertheless, I think there is this significant difference of this element of needing to be knowledgeable and this whole practical idea that custodians of information have to provide publicly accessible, understandable information so that people understand what's going to be done with their information.

Pharmacists are very familiar with dealing with an implied consent kind of model. Pharmacists counsel patients about their drugs, but they typically don't counsel patients and have them sign consent forms in order to get prescriptions. So from the perspective of pharmacists it really is essential that a continuation of this implied consent kind of model be there. The association is prepared to provide the necessary resources and support to make sure that that implied consent is knowledgeable implied consent.

This all then feeds into this importance of making sure that there's harmonization between HIA and other legislation as well, although it's not too clear what it will take for HIA to be declared substantially similar to federal legislation and therefore get an exemption. Nevertheless, this is probably an element that is worth addressing as part of that process of making sure that HIA is substantially similar and gets the exemption.

The last point that is in the written submission that I wanted to raise had to do with disclosure of information to law enforcement services. Mr. Cavanaugh brought to my attention, as we were driving over, some media coverage of this. I understand that the committee has heard some views about this already.

The association is not here to really adopt a strong position on this issue. I think that it's fair to say that the association has a serious concern with moving away from what is really an established legal model of requiring police to have search warrants in order to get access to health information.

I noticed in the newspaper article that there was a quote to the effect that, you know, "The Health Information Act is preventing us from doing things," and it implied that it was really preventing the police from doing things that they were legally entitled to do before the Health Information Act. I've provided legal advice to hospitals for 20 years, and the rules that required search warrants for disclosure of health information including basic identifying information about patients have always been there.

The Health Information Act did two things, really. It really codified those rules, and I think that it's legitimate to say that it probably made custodians start to say to their staff: you know, you've really got to follow those rules. So perhaps in compliance that ended up being ramped up, but the actual legal obligation has been there, well established, and nothing was really changed by the Health Information Act. So the association has a concern about any change from that position.

Beyond that, what I suggested to Mr. Cavanaugh was that perhaps I could refer the committee to really, I think, well-thought-out debate on the subject that took place in the *Canadian Medical Association Journal* about six months ago. I don't have the citations here, and perhaps the secretary to the committee has already provided you with reference to that, but there was this issue that brewed up in the spring, I think, or last winter about the reporting of gunshot wounds and whether the law should be amended to permit that.

In the *Canadian Medical Association Journal* – we could certainly provide the citations; it's available on-line for free – there was this very spirited debate over the course of a couple of issues on this very point that kind of raised all of the policy arguments and ethical arguments on both sides of it. Although I'm not really expert on the details of it, having just read it briefly and quite a time ago, it seemed to me to be not a bad way of trying to understand all sides of the argument, and I would recommend that if the committee wants to consider it, that would be a good source to look at.

So I think that that probably exhausts the 20 minutes that are allotted for the presentation.

Barry, have you got anything that you want to add?

Mr. Cavanaugh: I think Brent has covered the matters fairly thoroughly. I would only want to add, with respect to the health services provider information issue, bear in mind that that includes pharmacists. Pharmacists stand before you in this presentation saying: we are prepared to be publicly accountable for our actions. We believe that health services providers generally should be publicly accountable in that way and that restriction of access to that information for professional colleges or for regulatory bodies of any kind is dangerous ground.

Thank you.

The Chair: Thank you, Mr. Cavanaugh and Mr. Windwick, for the presentation and especially, Brent, for your reference to the item that we may want to reference for more information. We will get that information to the committee.

We do have some questions. Ms Blakeman.

Ms Blakeman: Thank you. Welcome, and thank you for coming to speak to the committee. I'm going to go back to the question around scope because to my mind you're saying two things here, and I'm going to ask you which you prefer. In answering the question from the workbook that said, "Should the scope of HIA be extended to other health care providers?" you're answering in the affirmative. Later you say, and I'm quoting from page 3 of your submission, "Eliminating the distinction based on payment source has allowed pharmacies to develop consistent practices and policies." You verbally today said that eliminating that distinction about whether it's privately funded versus other sources of income would help. So which do you prefer: that we make the definition around the payment or that we include other named health care providers? Which one is preferable?

Mr. Windwick: Well, I'm trying to wrap my head around whether there really would be a distinction between the two things because, I mean, implicit in saying that this would be extended to other health care providers, and I'm assuming that that probably means health care organizations as well, I think what you're saying is that whether those providers are receiving money from public health insurance or they're receiving payment for the services from private sources . . .

1:35

Ms Blakeman: It's a distinguishing feature now, so if we eliminate that distinguishing feature and it doesn't matter who is paying you, then the information becomes protected.

Mr. Windwick: Right. I think what we're saying is that that distinction should not exist, and I think the implication of that, then, is that probably other services providers who are not currently being paid through the public health insurance system are going to be covered.

Ms Blakeman: Okay. Thank you.

The Chair: Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. I listened carefully to your presentation, and I'm noticing a couple of conflicts with some of your colleagues in the profession, and I'm wondering if you can clarify why the conflict. We have heard a presentation from Value Drug Mart, Rxellence, and Apple Drugs relevant to disclosure of information to peace officers. In their written submission, and they reiterated that verbally later: allow custodians discretionary power when releasing health information to peace officers when a criminal activity is suspected by the custodian and provide protection to the custodian who reports suspected criminal activity to a peace officer in good faith.

Now, in their written submission the Alberta College of Pharmacists submits: authorized disclosure without consent of individually identifying health information to police forces if the custodian has reasonable grounds for believing that the information reveals or tends to reveal that an officer under the Criminal Code, Controlled Drugs and Substances Act, narcotic control regulations, or Food and Drugs Act has been committed or is being attempted.

So they seem to be advocating just the opposite of what you're telling us over here. Why the conflict?

Mr. Cavanaugh: I don't think there really is a conflict, and if I can elaborate on that, those references are with respect to the disclosure of information by a custodian ab initio, as it were, when that custodian discovers a pattern which may suggest a criminal offence. We would want that custodian in those circumstances to feel free to disclose that to either the College of Pharmacists as a regulatory body or to a police agency where they have uncovered that evidence of abuse. I suppose that the best example of that is that a pharmacist sees that there's been double-doctoring, if you understand the term, of a prescription and is the only one in a position to notice that. Obviously, in that situation we want that pharmacist to be protected in the disclosure of that information.

However, where we have, I think, common ground and where we don't differ at all is essentially a police fishing trip. We face this in dispensaries all the time, where a police officer comes to the pharmacy and says: I want all the information you have on the drug records of so-and-so. I think that's entirely a different situation because at that point the pharmacist has seen nothing to suggest the existence of an offence, and at that point I think it's probably most appropriate – and I don't believe that Value Drug Mart or any of the pharmacy agencies would disagree with me – that we should fall

back on the protection of the law for the individual private information.

I don't think there's a distinction between our positions. I think that we are agreed on the protection that needs to be there for a custodian who discovers an offence.

Mr. Lukaszuk: Can you qualify your comment for me? When you say that you see it all the time, how often do you really have police officers coming to your members asking for that kind of information on a "fishing trip"?

Mr. Cavanaugh: Well, I've been the CEO at the Pharmacists Association now for four years, and on average I get a phone call once a month from a pharmacist saying: there's a police officer in my dispensary; what do I do? I get those calls because I'm a lawyer by background, but in speaking to the registrar of the former pharmaceutical association, now the College of Pharmacists, I understand that those calls have existed for years and that the problem that pharmacists face with that is the usual dilemma. They want to be co-operative, they want to be helpful, but they want to protect their patient's privacy, and their dilemma is twofold because not only do they have respect for the patient's privacy and that position under law, but to disclose that information is a disclosure contrary to their professional standards, and they could be in some difficulty with the college.

So it's fairly frequent. How often it occurs beyond the calls that I get, hard to say. But I know that we've provided a service now for some time with a well-known law firm, Field law, where our members can call for summary advice, and I believe they're getting calls on that topic too.

Part of the difficulty, of course, is that these things often happen in the evening when the police officer is working and has a suspicion that comes to mind right away, goes into the pharmacy and is met with an employee pharmacist who really doesn't understand what to do. I think we need to be very clear about the standards that are required.

The Chair: Ms Blakeman.

Ms Blakeman: Thank you. As part of your presentation, you were talking about knowledgeable implied consent and indicated that the Pharmacists Association was interested, willing, perhaps eager, to put resources into helping to develop more knowledgeable consent. Could you expand a bit on that? What exactly do you mean? Are you willing to run a public campaign? Is this posters in the pharmacies? Are you going to fund a chair at the university? Where are you going with this? What do you mean?

Mr. Cavanaugh: Well, I think I could safely say that we won't be funding any chairs at the university, but I can also safely say that as one of the two bodies that provides a substantial volume of continuing education to pharmacists, it's our intention to make sure that in these areas they understand exactly what's meant.

As you can appreciate, with the Health Information Act over the past few years pharmacists have encountered a great deal of difficulty in interpreting how that applies to their practice. One of the reasons you'll hear the kinds of submissions you will from pharmacy organizations is that these are the professionals who are on the ground, who are actually encountering these problems on a daily basis. Issues such as whether or not you can transmit information across provincial boundaries for billing purposes are very confusing and very difficult in terms of the administrative burden.

We consider it our responsibility to provide continuing education to pharmacists on legal topics and administrative topics as well as clinical topics, and we're prepared to make the commitment that we would support a definition of knowledgeable implied consent by ensuring that pharmacists are well provided with that information.

Ms Blakeman: A supplemental, then. So that's to educate your own members. Is it intended that it go further than that, to educate the public as to what knowledgeable consent means or to work with the public about this, or was your intention to educate your own members and stop at that?

Mr. Cavanaugh: I think that it's easy enough for me to say that we're prepared to participate completely in such a public education effort. Undoubtedly, all of you have seen the kinds of information that pharmacies provide from time to time to patients in general: bag stuffers, little pieces of information, or posters that are in the pharmacy. Those can't be comprehensive, obviously. They can be part of an overall effort, but I'm here today to make the commitment on behalf of our RxA that we'll do our part with respect to public education. We do think that we have the ability to connect with patients in a way that very few other health care providers or very few institutions do, and that may well be a useful source of information. I'm not suggesting that that'll cover the ground. I think it needs a wider public education campaign.

The Chair: Thank you.

Do we have other questions?

Ms Kryczka: Well, mine is probably more of a comment, but I think I respect, from what we've heard as an MLA, more and more the importance of the pharmacist being part of the health care team in terms of wellness and giving advice, et cetera, to the customers or the clients that they serve. Now that I'm in this area with the Health Information Act, I think that it even compounds the complexity of their job and the time. I know that for them compensation has been an issue since we've talked about a new and expanded role for them. So this is all very good information for us to put in the gristmill.

1:45

The Chair: Thank you.

Mr. Windwick, as a member of this committee with the challenge of trying to work with my colleagues to achieve the proper balance between protection of privacy and release of information, I think it truly is going to be a challenge for the committee to achieve the correct balance. But as I listen to you and others speak, we keep hearing implied consent referred to. I confess to you that I'm still struggling with how we determine whether implied consent is – you know, whether we really have covered that and whether we've really protected people. Could you perhaps make some additional comments on the concept of implied consent, what that means, and how we make sure that people understand they are giving consent when maybe they've read some signs or whatever?

Mr. Windwick: I think there's a wide spectrum of terminology around the kinds of consent, and it's quite natural for everybody to be confused by it. The way I understand implied consent is that I come into a pharmacy and there is information that is available to me in the pharmacy to look at on the wall or in a package insert, or I've had the benefit of an education campaign or something else that has given me information about how my information is going to be used. I walk up and I get my prescription dispensed, and there need not be any conversation between me and the pharmacist about the risks and benefits of giving him my personal information. He is entitled

reasonably to assume that I know enough about my rights that if I have a problem with any of what's going to be done, I'm going to raise an issue about it and I'm going to opt out of it and tell him that I don't want my information shared. That's at least one model of implied consent that I think is likely a practical kind of reality in a situation like this.

How are you going to ensure that people have proper understanding? It's kind of a practical question without an easy answer, but I think that probably right now there are pilots being done, research being done to try to get at the root of that very question, because the whole rollout of a knowledgeable implied consent model is so integral to the regulation of information in so many contexts now.

I heard people speak about it yesterday at this conference in Toronto, which is a group of people trying to develop, as I say, national best practices for researchers using health information. Everybody who is operating under the federal legislation in the health care arena is going to have to come to grips with this. I believe, although others may correct me if I'm wrong, that the new Ontario legislation that is going to be proclaimed this fall has this kind of a concept built into it.

So I would say that although I can't provide you chapter and verse, there must be information out there even now that would give some indication of how reliable or low risk this kind of a process would be. If it isn't out there right now, I would suspect that there are a lot of attempts right now to pilot this sort of a model to see how it actually is working.

I think that maybe an analogy that is worth thinking about is the previous consent to disclosure by electronic means that was the old section 59 of the HIA. That was a situation in which there had to be kind of a second consent, not only just a consent to disclosure of the information but also a specific consent that related to the putting of information into a database that then could be pulled from. You know, there are others, I think, around this table who are more knowledgeable about it than I am, but my understanding of the outcome of that really was that there were surveys done or focus groups to try to get to the root of whether that was really effective or ineffective, and what they found out was that the vast majority of people would have consented to the disclosure of the information even without that extra process. Then there was this huge administrative burden that was actually being borne by pharmacists primarily to do the explanation. So in that sort of a situation it became clear that the balance was really tipped too far in the wrong direction. I'm not saying that that's really a direct analogy to this because that was sort of a super express consent sort of model, but I think the outcome was that, in effect, an implied consent to the use of this information for databases was sufficient.

The Chair: Okay. Thank you.

I have one more question, unless there's someone else, to Mr. Cavanaugh. I would ask for your comments on harmonization of health information. You know, we heard a presentation this morning about the pan-Canadian network. From a pharmacist's point of view, is it significant to you that we get some harmonization, or should we just worry about Alberta? Could you just expand on that concept a little bit.

Mr. Cavanaugh: I'm happy to. I support and RxA completely supports the pan-Canadian effort at harmonization of health information. One of the serious difficulties that we face – it may seem trivial in some respects – is, as I mentioned before, the cross-boundary transmission of information. Two sets of legislation apply, and pharmacists don't know what they're dealing with. At this point in time our advice to them has been: assume that implied consent is appropriate, that when the patient presents the billing card, they're telling you that they consent to the transmission of that information.

Of course, the operation of the Health Information Act of Alberta is somewhat problematic for us. We have considered for some time that patients, as well, need to be free to move in this country and free to deal with their health information in a way that makes sense to them wherever they live. We have patients, obviously, in Alberta who are coming to us from other jurisdictions and patients from Alberta leaving, so on a broader policy basis we support the notion, but from a practical perspective of daily pharmacy practice it's important that we have some harmony between the provinces.

As you can appreciate – and it's an unfortunate fact of Alberta's life, perhaps something that we need to do something to change – most of the third-party insurers are headquartered in Toronto. That's why I talk about cross-boundary transmission as often as I do.

The Chair: Okay. Thank you very much.

We thank both of you for coming today and presenting to us. It's been interesting and informative, and we sincerely appreciate your efforts. On behalf of the committee I again thank you for taking the time to present to us. We certainly appreciate your submission. Thank you very much.

Mr. Windwick: Thank you.

Mr. Cavanaugh: Thank you.

1:55

The Chair: We will now move to the mental health presentation. We're very pleased to welcome the Canadian Mental Health Association reps here today, Mr. Peter Portlock and Mr. David Allen, and are looking forward to your presentation. Before we commence, I'm going to ask the members of the committee to introduce themselves for your information.

[The following members introduced themselves: Ms Blakeman, Mr. Broda, Mr. Goudreau, Mr. Jacobs, Ms Kryczka, Mr. Lougheed, and Mr. Lukaszuk]

[The following departmental support staff introduced themselves: Ms Gallant, Ms Inions, Ms Miller, Ms Robillard, Ms Swanson, and Ms Veale]

The Chair: Thank you very much.

Gentlemen, we've allocated 40 minutes. You know, the norm has been around 20 minutes for presentation and 20 minutes for questions. We leave that to your discretion, but we now would welcome your presentation.

Mr. Portlock: Thank you, Mr. Chairman. Good afternoon, ladies and gentlemen. I'm Peter Portlock. I'm here with David Allen representing the Canadian Mental Health Association, Alberta division. I bring regrets from Aleck Trawick, who is on vacation, and Ron LaJeunesse, who is on an assignment elsewhere. Ordinarily, they would have presented on CMHA's behalf today.

In the interests of time I've provided a brief handout, but we have elected to go low tech and not try to do a power point just in the interests of sort of set-up and take-down time. However, there is an electronic version of this short presentation that we can make available to the clerk of the committee if that's required.

We do thank you for giving us this opportunity to speak to you. As you're aware, CMHA has already provided a written submission, and we certainly don't propose this afternoon to represent that

submission other than very briefly to highlight the five recommendations that we made.

I should say also that since delivering our submission, CMHA was given the opportunity to participate in a consultation on the latest draft of the pan-Canadian framework on August 13. I attended that consultation, which was expertly facilitated by Catarina Versaevel and her team. So in addition to providing feedback at the moment during the course of that consultation, I submitted written feedback as well on behalf of CMHA earlier this week.

One of our recommendations in our written submission, Mr. Chairman, had been around the need for stakeholders to have the opportunity to review and comment on the latest draft of the pan-Canadian framework as a necessary component of this legislative review process. That opportunity did materialize, for which we are most appreciative.

Just to then highlight very, very briefly the recommendations that were contained in our written submission of August 6. We did provide extensive rationale for each of these recommendations in that submission. Very briefly, the five recommendations included a recommendation to expand the definition of nonidentifying information, to implement stricter controls on data matching, to limit or eliminate some of the possible disclosures without consent, to restore the lock-box provision that was contained in the earlier Health Information Protection Act, and, as I had discussed just moments ago, the opportunity for stakeholders to be given the chance to review the draft pan-Canadian framework and for the committee to consider the comments made by the stakeholders as part of this review.

With regard to the lock-box recommendation, I should add that it was clear from our review of the pan-Canadian framework draft that a lock-box approach appears to be gaining some favour amongst the stakeholders across the country, and we are certainly encouraged by that.

Our latest recommendation, the last one made regarding the framework, as I've already mentioned, was addressed through our participation in that framework consultation on August 13.

So today I just want to make a couple of key points on behalf of our organization in this oral submission, the first being our recommendation that persons or agencies legislated as custodians, in our belief, need to include police members of crisis intervention teams principally because we see the need for police members of such teams to be briefed by the medical members of such teams as to the condition of the client in crisis.

We also are recommending and feel very strongly that the committee might wish to adopt as part of this legislative review the definition of nonidentifying health information that is contained in the latest draft of the pan-Canadian framework. There is, in our opinion, a better definition in the framework than in the current version of the HIA in that the framework definition states that nonidentifying health information "means health information that cannot identify the individual or for which there is no reasonable basis to believe that it could be utilized, either alone or with other information, to identify the individual." Our current definition in the HIA only sets the standard as information from which the identity of the subject is not readily ascertainable. We believe there is more comfort with the definition of nonidentifying health information as contained in the framework.

Moving along, we have some concern in the area of data matching, as we submitted in our written presentation. We believe that there is a need for stricter controls around data matching and a need for such controls to be mandated in legislation. The HIA does not currently require that the matched data, which has therefore become personal information or individually identifying health information, be treated from then on as identifiable information. We believe there need to be stricter controls, particularly in the information age and also because there are audiences out there that are perhaps not governed currently under HIA that may see the need and the appeal for data matching as time goes on, and a need for some stricter controls around that particularly to be enshrined in legislation for those groups who may not directly come under the provisions of HIA.

Under the other comment that we were making, we believe that under no circumstances should a minister be able to compel a custodian to provide personal health information for health system surveillance monitoring purposes. We believe that with the majority of custodians under the control of or being funded by government, which system everybody has pledged to maintain, the likelihood of a custodian refusing the minister, saying it's not necessary, is probably next to nil. In our view there is no reason for the minister to get personally identifying health information from an individual or of an individual, only because in our view these kinds of provisions are ripe for abuse. So we make that point.

In addition – this, I think, speaks to an earlier comment made by Barry Cavanaugh in response to a question around harmonization – we believe that revisions to the HIA should incorporate at least the minimum standards contained in the pan-Canadian framework and to the extent that harmonization with provisions in the framework is practicable and doable, that should be the goal. We believe that the framework should not establish a higher standard than Alberta can meet as defined in Alberta legislation.

2:05

Moving on, other points as noted. While the health record may be the property of the custodian, the information that makes up the record is and remains the property of the individual. The Supreme Court has maintained that in the Mills case.

We believe we can't sort of say that often enough: the privacy right, as defined by and guaranteed by the Supreme Court, seems to trump all other rights. That is a finding that has to be kept in mind, I think, in the framing of any legislation or in consideration of any revisions to legislation. We believe, as I'm sure you have heard elsewhere in this process, such legislation as we have in Alberta needs to be strong enough to clearly exempt health information from the provisions of PIPEDA, and I think that comment has certainly been made in the latest draft of the framework that we have reviewed.

Our only remaining concern – and we recognize that there are certain constraints that are beyond our control. Certainly, the timeline for the review, which is occurring on schedule, is necessarily compressed, particularly in view of a possibility of a run-up to a provincial election. We note that there has been a very timely effort made to ensure the receipt of both written and oral presentations in this legislative review process. Given the extension of the deadline for the written for a period of time, it is going to make the committee's work that much more challenging because there is always the prospect of where this work may go should there be a call for an election.

We originally were concerned that this process appeared to be rushed, but given the constraints that you are facing, I know that you have tried to move this along as quickly as possible, and we will hope for a good outcome in sufficient time for your work to be captured and taken forward and acted upon before any other changes are contemplated in the legislative process later this year.

That, Mr. Chairman, really is the presentation that we wanted to make to you this afternoon. Given that we have already provided a written submission, we do thank you and the members of the

committee for giving us this other opportunity as well. We'd be pleased to try to answer questions.

The Chair: Thank you, Mr. Portlock. Thank you very much, and we appreciate your submission. In regard to your comments about the time frame and the challenge the committee faces to get their work done before a possible fall election, we are cognizant of that challenge and are going to do our very best to table a document with the Clerk before such a date may occur.

We do have some questions, and I recognize Ms Blakeman.

Ms Blakeman: Right. Thank you both very much for coming and speaking to us today. I have two questions, and both of them are flowing from today's handout sheet, appearing on page 3 under Key Points. I'm wondering if you can give some examples or statistics around why you feel with the issue of data matching that we need stricter controls and that it needs to be mandated in legislation. Help me to understand why that's important to the Canadian Mental Health Association.

Mr. Portlock: Well, principally, the ownership of the information is really paramount. I can't instance specifics of a patient scenario, at least not off the top of my head. But we believe that there has to be the opportunity for the individual to be able to define certain information which is not disclosable and which remains under lock and key, if you like. I think that really speaks to the problem that we encounter in the stigmatization of mental health and the particular sensitivity of that information.

Now, that was dealt with a little bit in the framework discussions, which were quite enlightening because of the discussion around the specific and particular nature of genetic information. I think a lot of the discussion at the consultation I attended seemed to favour the elimination of specific categories of information that are deserving of special kinds of attention. The point we had made on behalf of CMHA was that we believe mental health information is equally sensitive and equally needful, I guess, of heightened levels of control similar to those that were provided for in the draft framework on genetic information. There seems to be an approach favouring sort of taking those special cases out.

But be that as it may, in terms of lock box, the sensitivity of mental health information and sort of the immediate examples we see of people leaping to perhaps inappropriate conclusions about disclosure of even the most basic kind of mental health information, such as "I'm on antidepressants," gives us reason to believe that that type of information should, at the individual's discretion, be protected from scrutiny and be protected from sharing.

The Chair: Go ahead, Ms Blakeman.

Ms Blakeman: Thank you. My second question immediately follows. You've used very strong language for the next point that appears on the page: "Under no circumstances should the Minister be able to compel a custodian to provide personal health information for health system purposes." Now, if I can just confirm that what we're referring to here are the sections that refer to the minister being one of those exemptions that gets access to personal identifiable health information, appearing in sections 39, 40, and 46. That's very strong language, and I'm sure you didn't choose that frivolously. Can you again expand on why you feel so strongly in that particular case?

Mr. Portlock: Again, I think it speaks to the fact that in reality a custodian challenged by the minister to provide personally identifying information, given the scenarios of control and funding and so forth for a custodian, is not likely to feel able to say no to a request. While we would not wish to suggest that ministers would make frivolous and vexatious use of this provision, it is, as we've stated, a reality that is certainly ripe for misuse if not abuse, and we don't believe that there should be any scenario in which personally identifiable information needs to be made available to the minister for any purpose.

Ms Blakeman: Thanks.

The Chair: Thank you.

Mr. Lukaszuk: Those comments have also sparked some curiosity in me. In this province we have had health care providers now for over 100 years and ministers of the Crown for 99 years. Are you basing your comments on any actual cases of frivolous or vexatious use of information by a minister?

Mr. Portlock: No, sir. We're not.

Mr. Lukaszuk: Thank you.

Ms Kryczka: Well, I was going to let my comment go because Ms Blakeman did comment on the point that I wished to comment on, but I'd like to go a little further. I understand, because of the mental health people and those issues, your concerns about no special protection for sensitive information. I think what you did was you answered the first part: "Under no circumstances." I'd like to extend that and have you also expand, though, on: "should the Minister be able to compel a custodian to provide personal health information for health system purposes." That's the other part there. Could you enlarge on that? What do you mean? Because that's so broad: "for health system purposes."

Mr. Portlock: That's around monitoring the surveillance of the system, quality control aspects of the system.

Ms Kryczka: Possibly if it was not research related – I have to be careful about that – but effectiveness of the system, if it would be information but there's no relation to the patient's name at all.

Mr. Portlock: Then it would not in our view be identifiable information.

Ms Kryczka: As long as it's not identifiable information.

Mr. Portlock: Yeah. I guess that is the key.

Ms Kryczka: Yes.

Mr. Portlock: We would not see there being sort of blanket authority to provide identifiable information.

Ms Kryczka: That's easily understood then. Right. Okay. Thanks.

The Chair: Mr. Portlock, your comment about "under no circumstances should the Minister" certainly received some comment from the committee. I've been sitting here ever since you said that and trying to think of a circumstance where it would have been in the person's best interest if the minister was able to divulge information. Unfortunately, in my limited experience as a cattle rancher I can't come up with an example, but there must be one someplace. I'll

have to do some research. But that is a rather strong statement to make. I have to agree with some of my colleagues on that, but we respect your view. I guess you're just trying to protect privacy in making that statement.

Mr. Portlock: Yeah. We believe that that right trumps all others, Mr. Chairman. We would have no difficulty, I think, if it was nonidentifiable information, as is used for research, as is used for statistical purposes, but I suspect that the legislation must have contemplated a scenario where personally identifiable information would be required. We can't think of one where the minister would personally require such information, and we believe that that is perhaps an exit that needs to be blocked off.

2:15

The Chair: Okay.

Mr. Lukaszuk, then Ms Kryczka.

Mr. Lukaszuk: Thank you. I guess it would be your opinion that that right trumps all others. I'm wondering. In my role as a member of the Assembly often I do receive contacts from constituents who require various sorts of help relevant to provision of health care and where the minister, in order to assist that particular patient, needs to obtain that kind of information to be able to assist that patient in his or her ability to continue with continuation of care. Even if issues of quality of care for a given patient or his ability to avail himself of proper medical care were at stake, for the benefit of the patient you find that the minister ought not to be able to solicit identifiable information in order to carry out his duty as a minister.

Mr. Portlock: He should not be able to compel the provision of that information. No, we don't believe that's appropriate.

Mr. Allen: Another point is that, first of all, on this particular issue we certainly don't want to in any way impede the department or the minister in doing systems development and planning for the future. The question only is around the privacy issue of identifiable information.

In regard to an individual coming to a constituency office asking for help, then I believe that that would be consent having been given to proceed.

The Chair: Thank you.

On this point, Mr. Lukaszuk.

Mr. Lukaszuk: That's if the subject in point is in a position to consent. Unfortunately, with mental health issues the subject herself or himself may not be able to provide a consent, and the minister may have to obtain additional information.

Mr. Portlock: Again, not necessarily personally identifiable information, in our view.

Ms Kryczka: I guess I'm going to stay focused on this point too. I'm respecting, as you said, that you want to protect personally identifiable information, but I was thinking of an instance about a year ago where I knew the parents of a teenager who was having very severe problems with depression, and they were worried about her being suicidal. Really, the problem in Calgary was a lack of acute care beds so that she could be admitted immediately to be looked after.

I remember talking to a member on the Calgary health region board about this, but I didn't use the name of the people. I had no contact with the custodian or the doctor; this was strictly through the parents. But it was I think a really important dialogue to have because it gave the board member ammunition to say: you know, we've heard from an MLA out there of a situation. Actually, the story has a happy ending. She was admitted, and she was put on some kind of a special dosage of vitamins. The problem was genetic, I guess, within her system, and the problem was resolved.

Basically, people who are dealing with these kinds of situations I would hope are sensitive to the fact that you are not going to divulge personal names or information. You obviously are worried about people doing that.

Mr. Portlock: Again, we're perhaps parsing this down to a degree that is making it a bit complicated. It is around the compulsion to provide the identifiable as opposed to: I am prepared to give you this information if you are able to help me. In the instance that you provided, certainly the system was able to respond as the system should on the basis of essentially generic information, and that's fine. That's the way, we would submit, that the system should work. You should be able to say: we are aware of an individual in this circumstance in this region where, you know, admission is a problem because of these factors. The system has enough information, in hearing that, to be able to react.

Ms Kryczka: But, ultimately, if she had not been admitted and her situation addressed, I would have gone the next step with the permission of the parents. I mean, they are very realistic people. You know, they were worried about her life-threatening situation.

The Chair: Thank you. Do we have any other questions?

One final question, then, from the chair. I was interested in your comments on harmonization with the pan-Canadian framework. I think you make the point that you hope that our legislation is good enough that we wouldn't be subject to PIPEDA, if I understood you correctly. It seems to me that it is somewhat of a challenge for the committee to decide to what extent we want harmonization, and several presenters have suggested that we need some harmonization. So I wondered if you wanted to comment just a little bit more on that, because it certainly is an area we have to consider as a committee.

Mr. Portlock: Well, I think that certainly our reasons would be similar to those stated by Mr. Cavanaugh in his earlier presentation, particularly around the cross-border movement. Given the mobility of the population and given accessibility issues, portability issues, certainly there is merit in trying to achieve as much harmonization as is practicable. We would not want to see ourselves in a situation where, as we've stated, a framework kind of document or a pan-Canadian or a national document sets the bar perhaps higher than we do here. I think that there's a lot of hard effort going to strike a common denominator that is achievable by all jurisdictions, and we would see that as highly desirable.

Certainly, there are aspects of the framework, as we said in our written feedback to that document, that are worthy of emulation, I guess, in this jurisdiction. Certainly, Alberta is cited as an example to other jurisdictions in the framework document of how to do it right, and that's a good thing. But to the extent that we can't exist in silos in this day and age, particularly in the area of electronic transfer of information in the electronic age, we would just see that every reasonable effort should be seen to be made and should be made to strike some accord with the framework to the greatest degree possible.

The Chair: Okay. Thank you very much, Mr. Portlock and Mr. Allen, for taking time to come and present to the committee today, for your submission, for your oral presentation, and for answering the questions. We certainly appreciate the information. Again, on behalf of the committee, thank you very much.

Mr. Portlock: Thank you.

The Chair: We will go with the government presentation in a couple of minutes.

[The committee adjourned from 2:24 p.m. to 2:31 p.m.]

The Chair: All right. We will call the committee back into order and welcome from the Alberta government Mr. Todd Herron. He is here to present, and I see he's being joined on the hot seat by Linda, who's been with us for the whole time, so we get to interrogate her one more time.

Todd, do you know everybody here? Well, why don't we just introduce everyone, and then we'll turn the time over to you.

[The following members introduced themselves: Ms Blakeman, Mr. Broda, Mr. Goudreau, Mr. Jacobs, Ms Kryczka, Mr. Lougheed, and Mr. Lukaszuk]

Ms Gallant: Roseanne Gallant, office of the Information and Privacy Commissioner.

The Chair: Thank you everyone.

All right, Mr. Herron. We would be happy to hear your presentation.

Mr. Herron: Right. Thank you very much. I'm the assistant deputy minister of the health accountability division with Alberta Health and Wellness, and the health accountability division is responsible for the day-to-day administration of the Health Information Act.

Alberta Health and Wellness has a dual role to both support the committee and also to present the position of the government. As such, 15 substantive issues will be raised without articulation of the government's position at this time, and the remaining eight housekeeping issues will be raised with specific recommendations. The government departments being represented by Alberta Health and Wellness have reviewed all 23 items that I'll be discussing today. Alberta Health and Wellness will present the government's recommendations at a later date.

The first recommendation around the substantive issues has to do with scope, and there are three areas of consideration. Should the scope of the Health Information Act be expanded to include other government departments, public bodies, and local public bodies as defined under FOIP? Other government departments, AADAC, and the WCB feel that privacy is adequately covered under FOIP and that expanding the scope of HIA to these bodies would add an extra burden.

The second area of consideration is: should the scope be expanded to other entities that are not custodians but have health information under their custody and control? These would include privately funded service providers, supplementary health insurers, and employers.

Again, expanding the scope supports a more complete profile within an electronic health record, but it can be argued that PIPA and PIPEDA already cover these areas from a privacy legislation perspective. There's also a concern that this will also add an extra administrative burden. The primary purpose for these bodies having this information is not care and treatment, so it could be argued that the Health Information Act shouldn't apply. Health Information Act rules were designed to work within a controlled arena. If the scope were expanded beyond the controlled arena, "consideration would need to be given to which rules would apply outside the controlled arena."

2:35

The third area of consideration is ambulance attendants and operators. They're currently covered by the confidentiality regulation in the Ambulance Services Act. In spring 2004 a decision was taken to transfer ground ambulance to regional health authorities effective in fiscal year '05-06.

So we're asking, as the first item, that the committee "consider the implications of extending the scope of the Act to any additional bodies to determine in which cases there is potential significant benefit or other justification for inclusion."

The second substantive area has to do with electronic health records, and there are two recommendations that I'll be bringing forward. The first one has to do with explicit authorization to disclose health information into databases accessible by multiple custodians. Now, we have on record a handful of patients who have withdrawn consent. The committee should bear in mind that custodians are required to sign information manager agreements. Manitoba's FIA legislation, a personal health information act, is explicit on this point and does allow disclosure without consent. Networked database systems support screening programs and allow the system to manage long-term and short-term disease trends. Custodians must adhere to the principles of highest degree of anonymity and in a limited manner. Once information is disclosed to an electronically networked system, the custodian is not in a position to make individual evaluations of disclosures to other custodians.

So we'd like the committee to

> consider whether there is a need for more transparent and explicit rules in the Act regarding:
> - disclosure without consent to an electronic health record or other networked health database established by the government or another custodian for a purpose authorized by the Act, and
> - subsequent access by providers or other authorized persons.

The second electronic health record issue has to do with whether it's necessary to uniquely identify every health provider that will need access to the provincial EHR. Currently consent is required to disclose provider information. Unique provider IDs are required for authentication and authorization to the electronic health record. This is the requirement to know, "Are you who you really say you are?" and "Are you allowed to do what you're trying to do?" and to do electronic referrals, to disclose diagnostic, treatment, and care information. A unique provider identifier should be viewed, in our opinion, in the same light as business card information. So the committee is asked to "consider changes to enable custodians to collect, use and disclose a unique health service provider identification number for system-wide use without consent."

The next nine recommendations have to do with disclosure without consent. The first issue has to do with disclosure to third party insurers for the purposes of payment. Under the Health Information Act consent is required. Pharmacists routinely ignore this requirement in order to adjudicate claims. No other workable consent mechanism has yet been identified. Pharmacies have advised that HIA should not require a change to their current practice, and the minister has advised RxA that this issue will be reviewed during the three-year review. The Office of the Information and Privacy Commissioner is aware of this issue. We're asking

the committee to "consider providing authority to disclose health information without consent to third party insurers for the purpose of payment."

The next consent issue is regarding disclosing information to the police who are investigating fraud. Consent is required to disclose to the police. Custodians can share information among themselves if fraud, abuse of health services, or another offence is suspected. Health information can be disclosed under subpoena, warrant, or court order if the police are aware of the situation. The catch-22 is that the police need to be made aware of the problem to get the warrant. The provider can't make the police aware because they can't disclose the information without consent without a warrant. Put another way, the provider would need the consent of the suspect to aid the investigation. We're asking that the committee "consider enabling the disclosure of health information without consent to police for the purpose of investigating potential fraud in the publicly funded health care system."

The next statement has to do with disclosure of information to other federal, provincial, or territorial health departments. Disclosure is required for reimbursements for services to out-of-province and First Nations patients. CIHI, the Canadian Institute for Health Information, maintains a database of these service events to support research and policy development. Clear authority to disclose is required for jurisdictions to receive information needed to manage their health systems. We're asking the committee to "consider enabling disclosures without consent to provincial, territorial and federal health departments about services provided to persons under their jurisdiction."

The next item regarding consent is disclosure to other Alberta government departments. The Health Information Act does not enable disclosure of individually identifying health information without consent to other government departments. Other departments have requested such information for determining or verifying the eligibility of an individual to receive health services for their internal management purposes including planning, policy development, monitoring, audit, evaluation, reporting, or obtaining or processing payment for health services. We're asking that the committee "consider whether [the Health Information Act] should enable the disclosure of health information without consent to other Alberta government departments."

The next disclosure issue has to do with explicit authorization to disclose provider information to the College of Physicians and Surgeons to manage the triplicate prescription program. Current practice is for physicians and pharmacists to disclose this information to the college.

The act allows custodians to disclose health service provider information without consent where allowed under an enactment. Under the Interpretation Act an enactment includes a bylaw or a resolution. The CPSA and the Alberta College of Pharmacists have chosen the mechanism of a bylaw and resolution respectively for TPP disclosures. An amendment would clarify this authority but could set a precedent for naming other programs explicitly in the legislation. We therefore ask that the committee "consider whether disclosure of health information without consent to the College of Physicians and Surgeons of Alberta . . . for the purpose of managing or operating the Triplicate Prescription Program should be explicitly authorized."

The next item around consent has to do with health provider information being disclosed for research purposes. The Health Information Act policy intent was to focus on patients' health information. Provider information is dealt with in other statutes. No authority exists in other statutes to disclose provider information for research. Alberta Health and Wellness has little identifiable information about providers outside of that in billing records. Researchers have requested access to provider information. If the definition of health information for research purposes were to include provider information, it would be afforded the same protection as patient information. We ask that the committee "consider whether health service provider information should be included in the definition of 'health information' for disclosure for research purposes."

The next consent issue has to do with disclosure processes that are too onerous for research purposes. At their discretion custodians may disclose identifying patient information to researchers if the researcher has had the request approved by an ethics committee named under the Health Information Act regulations. The Health Information Act, sections 57 and 58, require custodians to consider the highest level of anonymity and the least amount of information. Alberta Health and Wellness experience has shown that often through data manipulation the needs of the researcher and the Health Information Act can both be met. We ask that the committee

> consider whether custodians in general, or [Alberta Health and Wellness] as custodian of administrative databases, should continue to be required to disclose the least amount of information at the highest level of anonymity necessary for research purposes when an ethics committee has approved the research proposal and recommended that consent is not required.

The next consent issue has to do with section 37(2), and the meaning of the phrase "would reveal other information" in relation to disclosure of health service provider information is not defined. "Other" has been interpreted to include limiting disclosure of first name if it would indicate gender or last name if it could indicate nationality. We're asking that the committee "consider whether a definition of 'other information' is required in relation to the limitations on disclosure of health service provider information."

2:45

The next consent issue has to do with disclosure for managing common integrated programs or services. Consent is currently required, although some exceptions do exist; for example, in cases where there's imminent danger, mental capacity issues, or the custodian believes that it is in the patient's best interest. FOIP allows disclosure without consent to deliver common integrated programs. A parallel provision in HIA would enhance the delivery of cross-ministry programs such as the family violence initiative. Parameters to administer such a provision would be required: a formal framework for defining the services, clearly defined membership, clearly defined lead organization, the requirement that all member organizations be subject to provincial privacy legislation, rules for sharing information that are consistent with the Health Information Act policy intent.

We ask that the committee "consider whether [the Health Information Act] should be amended to allow the disclosure of health information without consent for the purpose of delivering common or integrated programs and services in conjunction with other government departments, local public bodies [and] other entities bound by provincial privacy legislation."

The next substantive issue has to do with maintaining certain disclosure information. There's one recommendation in this area, and it has to do with notation requirements that are impractical for electronic information systems. The Health Information Act custodians maintain records of, among other things, the purpose of the disclosure without consent. The duty appears to apply to single records even if it is disclosed as part of a batch of records. This is onerous for disclosures for research purposes. Electronic audit trails can track individual record disclosures but don't track the purpose.

The Health Information Act enables a person to see the record of

disclosure of their information. Provided that there is a notation of the purpose of the batch disclosure and there is an electronic audit trail of disclosures, then there should not be a need to create a notation individually for each record. So we ask that the committee "consider removing the requirement for notation of the purpose of disclosure without consent when the disclosure is part of an electronic batch process with an automated auditing capability."

The next area of substantive concern is duties and powers of custodians, and there is one recommendation with three areas of consideration. The first area of consideration is clarifying the definition of an information manager, the second is clarifying the relationship of an information manager as a special type of affiliate, and the third is clarifying the duties and powers of custodians who are also information managers.

Now, the first item, around defining what an information manager is. There is a contradiction between the wording in section 66(1) and section 66(2). The use of the word "and" in section 66(1) suggests that the person or body must perform all of the services listed in order to be an information manager. However, the intent, as evidenced by the wording in section 66(2), was that an information manager may be a person or body who performs any or all of the services described in section 66(1). The current understanding of the term is likely more narrow than section 66(2) but broader than section 66(1) and requires clarification if the information manager concept is retained.

The next area of consideration is information manager and affiliates. Custodians can contract for information management activities to outside entities. Information managers then become a specific type of affiliate. Unlike with other affiliates, an information manager agreement is required for the custodian to disclose information without consent. Some custodians question whether an information manager is indeed an affiliate.

The third area of consideration has to do with the powers and duties of a custodian who is also an information manager. The Health Information Act contemplated custodians and information managers as separate roles. There are cases where these roles overlap. The Health Information Act does not set out the duties or limit the powers of custodians who are simultaneously information managers.

So we ask that the committee

> consider the continuing need for provisions specific to information managers, and clarify:
> - The definition of information manager
> - The information manager as a type of affiliate that operates under a specific agreement
> - The duties and limits on powers of a custodian in relation to information held by the custodian in its role as an information manager.

The next substantive area is just under General Provisions, and there's just one recommendation here. People appointed by the court as next friend or guardian ad litem may not be able to exercise the rights of an individual under the act. Section 104 of the act does contemplate the exercising of rights by other persons. It is not clear whether this would apply to next friends or guardians ad litem, so we request that the committee "obtain a legal opinion, and if appropriate based on the legal opinion, consider an amendment to the provision to enable a 'next friend' or 'guardian ad litem' to exercise the rights of an individual under the Act."

The next eight recommendations are quick housekeeping items, and I'll move through those fairly fast. We want to recommend that "business title" be included in the definition of health service provider information; that professional registration numbers be included as part of the definition of health service provider information; a recommendation to "update the definition of custodian to reference section 17(1)(a) of the Regional Health Authorities Act"; a recommendation to "correct an inconsistency with the Health Professions Act by amending the [Health Information Act] to authorize professional bodies to retain health information used in investigation and conduct of hearings for ten years," and this is just to align a timing issue; to "authorize the disclosure of health information without consent to First Nations police services in section 35(1)(j) for the purpose of investigating an offence involving a life-threatening injury to [an] individual."

The next recommendation is to "enable the disclosure of health service provider business title and registration number to any person for any purpose without consent" as this information is generally publicly available.

The next recommendation is to "delete section 1(2) of the Health Information Regulation, which refers to section 59 of the [Health Information Act]," which was repealed in 2003.

The final recommendation is to "delete reference in section 2 of the Health Information Regulation to the Billing Practice Advisory Committee and replace it with 'a committee of an organization referred to in section 18(4) of the Alberta Health Care Insurance Act.'"

That summarizes the presentation.

The Chair: Thank you, Mr. Herron, for your presentation today. You made some excellent points, and we appreciate that. We do have some questions from the committee. I will recognize first Ms Blakeman.

Ms Blakeman: Thank you, and thank you very much for your presentation.

I do have some questions. The first one is around scope. Referring to page 7 of your presentation – let me make sure I'm right on that this time; yes, the Alberta government submission to the Select Special Health Information Act Review Committee – you enter into a discussion around the Freedom of Information and Protection of Privacy Act. The question that arises for me is: is the health information not in just as much need of protection in one department as in another? It appears to me that you're saying: well, we'll protect the information when it's under one group, but then when it moves to this wider group, it doesn't get the protection. Is the information not in need of the same kind of protection no matter where it is?

Mr. Herron: Well, the issue, I guess, is which privacy legislation should be doing the protecting, which rules should oversee it. There are rules under both acts to protect the information.

Linda, I don't know if you have more details under FOIP.

Ms Miller: Yeah. The concern that the other government departments have expressed to Alberta Health, because it was our responsibility to collect their issues as part of the government submission, is that they already have protection rules under their respective legislation, and it would reflect further duplication or, as it was earlier commented, triplication in some cases if that extension of HIA applied to them as well.

Ms Blakeman: Do I take that as a reassurance, then, that the health information is protected under other government departments through other pieces of legislation?

2:55

Ms Miller: That would be the perspective of the other government departments, yes.

Ms Blakeman: Okay.

The Chair: A supplementary, Ms Blakeman.

Ms Blakeman: Thank you. Referring to section 3 on page 9 – this is around disclosure without consent. Sorry; I misdirected you. Actually, on page 4 in your executive summary you list a number of areas where you're asking that we consider providing authority to disclose information, and I'm wondering what the department has done to look at the consequences of having your suggestions implemented. Have you done a business case or risk analysis or some discussion of what consequences might flow from the changes that you're suggesting here?

Ms Miller: We've certainly tracked these issues since the legislation was proclaimed, so we've been aware of them for some time. No, I cannot say that we've done an actual business case on each of the particular items. For example, enabling disclosure without consent to other provincial, territorial, and federal health departments has been a long-standing practice. As an example, British Columbia residents come to Alberta for services. Naturally and understandably the Ministry of Health Services in B.C. wants to be aware of that information, so based on long-standing practices, we've continued to give them information of their particular residents. However, today in the legislation as it's currently drafted, there is no wording in the statute to support that particular activity, but based on long-standing practice, that does continue to exist.

So there are issues like that. I could go through each one of them if you would wish. In terms of timing?

Ms Blakeman: Well, I'm just wondering. If you have the information, maybe you can just provide it to the committee, and we can read it on our own.

Ms Miller: Certainly. I can certainly do that: the rationale for why we've made the recommendation. Absolutely.

Ms Blakeman: That's what I'm looking for. Thanks.

The Chair: Thank you.

Mr. Broda.

Mr. Broda: Yes. Thanks for your presentation. My question was very similar to Laurie's. Under recommendation 12, about the other provincial departments, it does say: that are bound by provincial privacy legislation already. So I think it's a good recommendation to do. I think that when you receive the consent by the individual – I don't know what the consent document states, but I think that if it's identified that your information will go to other departments that are already protected under privacy legislation, it would suffice to allow that information to flow. Just a comment.

The Chair: Thank you.

Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. I'm not sure if you had the ability to listen to the presentation prior to yours, but the Canadian Mental Health Association has taken a very strong position on the issue of the minister's – and that's the minister of health, I imagine – ability to solicit or obtain from a custodian identifying information without the consent of the patient. It is the association's position, as stated, that it's a situation that's ripe for potential abuse or misuse. What is your position on this? Should the minister have access to that kind of information?

Mr. Herron: The minister himself?

Mr. Lukaszuk: The minister himself or herself, yes.

Ms Miller: If I could comment. We often get challenged with that question: the ministry of health on behalf of the minister of health. The ministry requires identifiable information in order, fundamentally, to do linkage across data sets so that we can do policy. To anonymize the data, you first have to have it identifiable so that you can link data that's collected, say, in the acute care system with data that's collected in the long-term care system with data that's collected in the ambulatory care system. Because those systems collect information somewhat differently, you need it identifiable so that you can match it across those different domains, and then you anonymize it so that policy can be done.

What the ministry does do is track and monitor very closely anybody that has access to identifiable information within the ministry, and it is only provided to those individuals who have a need to know; that means based on their current job description. There are very few people within the ministry of health today who have access to identifiable information, although our databases are identifiable. So that is the primary reason why we need identifiable information.

Also, to respond to research requests. If not all, nearly all research requests require us to be able to link data from those various domains that I've just talked about. In our assessment of ensuring that we're only releasing data at the highest level of anonymity possible, we often are required to do that linkage, and we can only do it if it's identifiable. Then we deidentify it before we hand it over to the researcher. So that is the second reason why we require identifiable information.

The third reason, I would argue, is that if we did not receive the information at the identifiable level, the information would have limited purposes. It can only be used in the nature for which it was very explicitly collected and could not support other types of questions, because you could not manipulate the data, as you would need to in any kind of systematic policy analysis or management work. So that would be my argument on behalf of the ministry of why we need identifiable data.

The Chair: Thank you, Linda.

On this point, Wendy.

Ms Robillard: If I could add some other information. Section 46 in the Health Information Act is the section that deals with this primarily, and it says: "The Minister or the Department may request another custodian to disclose . . . information." It does require the department to do a privacy impact assessment statement before the information is disclosed. The Privacy Commissioner would have opportunity to vet that and to provide comment, and it would then be available for public record before the disclosure would take place.

As well, as we discussed yesterday at the request of Ms Blakeman, we have actually not used that section of the act yet. However, we do contemplate doing that in the near future. Again, it's a requirement to collect data at an individual level so that we can link it with other data, deidentify it, and then give it to somebody to do some analysis around a specific medication and treatment program.

The Chair: Thank you.

Ms Blakeman, I think you have additional questions.

Ms Blakeman: I didn't expect you to come back that fast. Okay.

In the paragraph at the top of page 9 – and this is the end of your

discussion on electronic health records. I understand that it's difficult, once you get into electronic health records, to say: "The buck stops here. Somebody, you're responsible." If they can't be, it's now gone out into cyberspace. Nonetheless, do you agree or disagree that responsibility has to be assigned somewhere, and if not here, then where?

Mr. Herron: I agree that responsibility does have to be assigned. It just may not be the disclosing custodian that can control where it goes to at the next point.

Ms Blakeman: Then where?

Mr. Herron: I'm not sure I understand.

Ms Blakeman: Well, if this isn't where the buck stops, if this isn't who holds the responsibility, who are you saying should hold the responsibility?

Mr. Herron: Well, the information manager, I guess. I'm just thinking now in the context of Wellnet and where this information resides. Under the current policy framework, prescription information, for example, is disclosed to the pharmacy information network. It's available in these databases, and any provider with appropriate authorization can go in and pull down that information. We haven't made it a requirement that there be a point-to-point linkage between the prescribing provider and the next provider who's pulling down that information. Right now it's just sitting in not an open database but a secure database. We're relying right now on professional governing bodies of professions to oversee the practices of their own providers and professional members. What we do is track any accesses to that type of data. That's the limit of where it's at right now.

3:05

Ms Blakeman: Okay. Well, on more or less the same topic, then, somebody I think coined the phrase "leakage" in one of the earlier meetings, which is that once the control of the information starts to get further away, how do we control the leakage out of the system entirely? What work has the department done on that? I mean, that's one step further from what we've just been discussing.

Mr. Herron: Well, in terms of security, we've designed security right into the Wellnet and the EHR, so we've made significant provisions for the strong authentication of users, making sure that the roles are clearly defined, and those policies are coded into the software that we've implemented.

Ms Miller: If I could add to that. Back to your earlier question in terms of where does the buck stop, the person accessing the electronic health record is held accountable to access that record in accordance with the rules of the Health Information Act. We only provide access to the electronic health record for those that are caught within the umbrella of the Health Information Act. They also have to sign information manager agreements, which refer to what we call an information protocol, which highly detail all the rules of access, use, and disclosure in much more detail than you would find in a piece of legislation. Those rules have been determined based on all of the stakeholder groups that participate today in the Health Information Act, that being the pharmacists, the doctors, and the health authorities themselves. So they must access, use, and disclose that data that's available in the EHR in accordance with those roles as well as, obviously, in accordance with the act itself.

The Chair: Thank you.

Ms Blakeman, I realize you have some more questions. I have no one else on my list. I would allow you. Could you sum them all up into maybe one or two questions because we are down to about three, four minutes left?

Ms Blakeman: On the spur of the moment?

One of the questions I have, then, appears as a result of the discussion on page 13, recommendation 10. If you're considering that custodians in general – there's a discussion here about the requirement about releasing "least amount of information at the highest level of anonymity necessary for research purposes" because an ethics committee is already looking at it. But the ethics committee is looking at it with the understanding that on the other side of that, balancing that, is the requirement in the legislation of "least amount of information at the highest level of anonymity." If you remove that from the legislation but you still have the ethics committee operational, you've upset the balance. You would now require that some additional criteria be placed upon the shoulders of the ethics committee, or you'd have to reinstitute the highest level of anonymity and least level of information; would you not?

Mr. Herron: You've articulated the problem very well. The essence of the issue is that we're getting – maybe complaints isn't the right word – a lot of concerns raised by researchers that getting access to data is extremely onerous. They're not getting it in a timely enough manner to answer the questions. So we just raised this issue without sort of a recommendation on either side of the fence at this stage to say that this is a concern that is coming up from the research community: that they need to get more timely, more complete access to more data.

Ms Blakeman: Okay. Last question then: has there been an analysis on whether the triplicate prescription program really works? There's a lot of angst around that in what people have been presenting to us and what's in here. Has there been analysis on whether that triplicate prescription program actually works? It was lumpy to begin with and very far behind. By the time the information got analyzed, it was 14 months later, which was a little late to catch the guy on the street selling the pills. So has that resolved itself?

Ms Miller: I really cannot answer that. That would be a good question to redirect to the College of Physicians and Surgeons. They would really be the best persons to answer that question.

Ms Blakeman: Because they administer it?

Ms Miller: They administer it.

Ms Blakeman: Okay. Thanks.

The Chair: All right. Thank you to the committee for the questions.

Mr. Herron, Linda, Wendy, thank you very much for the answers and especially for coming in today and making the presentation to us. A very good presentation and very interesting, which should be helpful to the committee as they go forward. So, again, on behalf of the committee I thank you for your time and effort today. Thank you very much.

The committee will take a break and reconvene in five minutes, please.

[The committee adjourned from 3:11 p.m. to 3:19 p.m.]

The Chair: All right. We will call the committee back to order, and as suggested this morning, we would give Wendy a few minutes to finish the submissions. She's on 63, and I've asked her to go as reasonably fast as possible, still doing the job of course. So, Wendy, we'll ask you to proceed, please.

Ms Robillard: Okay. Submission 63 is by the Canadian Institute for Health Information. The first question they responded to is the question of the scope of the act, and to put their comments in perspective, they identify their role in health information within Alberta as set out in an information management agreement through section 66. So they're an information manager on behalf of the department. They go on to say that the definition of an information manager does not specifically restrict the work that they are doing now but that "the description in the Act is not particularly transparent as to the breadth of [their] functions." Their mandate "includes some of the functions of a custodian under the HIA." They support research. They analyze and support planning and allocation of resources, quality improvement, and evaluation.

They comment, as well, that there are a number of other organizations which do similar work, one of which is the Alberta Health Quality Council. They have asked the committee to "consider specifically recognizing such organizations in the legislation." They suggest an amendment to

> make it clear that custodians can provide limited personal health information to specially designated entities, such as CIHI. The purposes for these disclosures could be stated in the Act and could include analysis of the health system. Limitations on the uses and disclosures permitted for such entities could also be stipulated to assure control over the flow of personal health information. CIHI believes that amendments recognizing the disclosure of limited personal health information to such entities, for identified purposes, would provide greater transparency than the current provisions of the Act.

They also go on to talk about the individual's right to access their own information and whether the exceptions are appropriate. They indicate that: "CIHI is secondary collector of personal health information that other Alberta public bodies have collected. It holds information in an electronic format for statistical purposes," not as part of the EHR and not "for the purpose of making decisions regarding the provision of benefits to, or treatment of that individual."

They do not have a direct relationship, in fact, with the individual. Nor do they "hold sufficient direct identifiers, such as full name and address, to authenticate an individual." Therefore, they could not be certain that they would be able to provide access to correct an individual's information. They indicate that the "accepted best practice for organizations involved in secondary collection is to refer individuals back to the original data provider in order to access their information." That's part of their privacy policy.

They go on to speak about collection practices, and they just indicate there that they would "welcome the public being advised through posters and other material" through custodians here that "health information is shared with CIHI, under agreement, for statistical and analytical purposes."

In terms of the use of information the question is: "If you recommended an expansion of scope of the Act to include other entities, what purposes/set of responsibilities would you change?" They say that if the act is "revised to recognize entities authorized to perform statistical compilation or analysis, [they] would recommend that consideration be given to the importance of data matching for statistical analysis purposes."

They go on to respond to the question in regard to discretionary disclosures without consent and whether they're reasonable and appropriate. They go on to highlight the issue that we just heard of from Alberta Health and Wellness. When a patient is treated outside of their home jurisdiction, "CIHI receives the discharge abstract for that patient," and other provinces go to them to request that information to be provided. They indicate that that information should continue to flow to the province where that individual resides. They would like the legislation to be amended to facilitate that.

They had two other points that they wanted to identify. They have "key interests with evolving health information privacy legislation," first off that "the legislation be transparent as to the role of designated bodies" such as themselves, that the "route of authority enabling the flow of defined data sets to occur for those purposes" be identified, and that the "processes required for researchers to access and use health information" be transparent, and finally, that " the principles embodied in the legislation be as consistent across jurisdictions in Canada as is possible."

The Chair: Are there questions or comments?

Number 64.

Ms Robillard: This submission is by the Alberta Long Term Care Association, and they've addressed a number of questions. First, in terms of the scope the Long Term Care Association is of the view that "health information that is shared electronically between organizations in the public or private sector or that is shared across jurisdictions should be subject to the same set of privacy rules." So they would like the legislation harmonized so "the same privacy rules apply."

They say that HIA could make this apply to both private and public sectors. One approach would be to "amend the definition of health service Section 1(1)(m) so that phrase 'and is directly or indirectly and fully or partially paid for by the Department' is removed." They indicate that the definition of a custodian would also require amendment, so "the qualifier of health services providers being 'paid under the Alberta Health Care Insurance Plan' should be removed."

3:25

To go on and talk about health service provider information and whether it should be included in the scope of the act, they say "yes," however with clearer limitations.

In regard to the personal health information contained in an employee file, whether that should be within the scope of the act, they say "yes," and the rationale is "that health care providers face a common set of rules with respect to [that] information."

In regard to extending the scope to WCB and Alberta Blue Cross, they say "yes, from the standpoint of administrative efficiency" it should apply.

They responded to the question as to whether the definition of health information should be changed to include nonrecorded information. They say "no," primarily based on administrative burden.

In terms of the process for obtaining access to records, they indicate that there is a need "for family members to be able to act on behalf of residents who lack mental capacity."

In terms of the exceptions to an individual's right to access their own information, they say "yes," that those exceptions are appropriate, but they would also like custodians to "have the power to disregard requests deemed unreasonable, frivolous or vexatious." They indicate that "in the event of dispute custodians should be required to notify the individual that they could ask the OIPC for a review" of that situation.

They comment on the fees in the regulation and whether they're

appropriate. They indicate that "custodians may only charge fees for services provided under Part II of the Act," which is the access and correction piece. However, in their view, they think that "there are instances where it would be appropriate to charge for [other] disclosures." And primarily, again, the issue around disclosure to lawyers for legal purposes. When an individual has consented, that's not the same as an access request, so it's confusing as to whether the fees can or cannot be applied.

They also feel that "custodians should have the power to charge fees for the disclosure in some instances," especially where the "information sought is large," so they're looking to "recuperate costs."

They feel that "the basic fee should be increased to $50 or the regulations changed so that custodians can ask for a deposit in an amount determined by the organization." They indicate that they handle "relatively large charts." They are also "more likely to get requests for information from charts that have already been archived," and in some cases the retrieval cost to get the record out of archives "may exceed $25."

They also go on to state that another issue associated with costs is that in some cases producing a copy is not the only cost that they need to recover. The costs for them of processing a payment or developing an estimate sometimes are large enough that it makes no sense to charge the $25 fee, that they've already expended more than that effort, so they often bear the costs of producing the copies alone.

In terms of how the HIA should be amended to address the concept of custody or control within the EHR, they talk about the "collective custody or control of health information by multiple custodians participating in an EHR" and the fact that it would "probably not work unless the group of custodians also had the power to enforce HIA compliance over affiliates of other custodians." They go on to state that that's obviously "not feasible because it could result in affiliates being disciplined by someone other than their employer."

They suggest that the "distributed custody or control of health information might work if the EHR possesses appropriate auditing capabilities," the technology to track who accessed, viewed, printed, edited, or deleted information, and that "auditing capabilities should therefore be a prerequisite to custodian participation in an EHR."

Another issue they identify is "who will be responsible for maintaining safeguards that protect the EHR from outside attackers," or hackers, and that "it may not be practical to allocate responsibility to multiple custodians." They suggest that perhaps this should be imposed "on the EHR vendor or on the largest of the participating custodians."

In terms of the duty to collect health information directly and whether that's appropriate, they say "yes."

"Should custodians be permitted to collect information about the individual's family health history without the consent of the family members" for treatment and care? And they say no. "A consent requirement would create an administrative barrier to the delivery of care; family history of a disease can be useful, and [is] sometimes critical, in making clinical decisions."

In terms of whether the requirement to inform individuals about collection practices is effective, they say "yes." However, they indicate that the process which is used by other custodians, that of notification through posters and notices, is not consistent with the philosophy of the long-term care centre, which is a home environment, and so they use other ways of doing that.

In terms of the purposes in the act for the use of health information, whether they're appropriate, they indicate that it would be helpful if the HIA also provided a list of prohibited uses, and they suggest prohibitions for "using genetic code information to determine eligibility for health insurance," using health information for that purpose as well, "using health information for marketing products or services," or "to discriminate against prospective or current employees.

On the question of whether they recommend an expansion of the scope of the act, what additional purposes or responsibilities they would change, they indicate that "the set of authorized purposes in Section 27 could be expanded to reflect the mandates of those additional custodians. Alternatively, a generic 'best interests' [approach] could be included."

Around the elements of consent and whether they're appropriate, they say: "For the most part consent for disclosure should be obtained in writing; verbal consent should be limited to circumstances where the disclosure is needed quickly, i.e., to expedite an investigation." They comment that "when verbal consent is obtained . . . [it] should be kept within the individual's health record," and the individual should have the right to access that verbal consent. They also indicate that "it is critical in the context of long term care that consent not be required when the disclosure is in the best interests of an individual who lacks mental capacity."

In terms of the discretionary disclosures without consent and whether they're appropriate, they indicate that the act

> doesn't permit the disclosure of individually identifying health information to municipal, provincial, or federal government departments without the consent of the individual . . . Government departments often need this information to determine eligibility for benefits or services, to distribute those benefits or services and to confirm that those benefits or services were received.

They cite organizations such as Veterans Affairs, Alberta Seniors, Human Resources and Employment, Edmonton's transportation and streets department for the DATS service, and the emergency response department. So they have suggested adding a clause that deals with that under 35(1), and they've specified subsections there as well.

In terms of disclosure to police of registration information without consent, they don't support that. They feel that the

> privacy of an individual should be protected in the interest of providing care and treatment. For example, some individuals who fear the police would not be willing to provide identification information to health service providers,

and that could compromise their medical history being available for treatment.

In terms of the triplicate prescription program, they agree with the recommendation. They go on to state, however, that "if the police have access to the information then their use of that information should be limited to investigations where there are reasonable grounds for believing criminal activity is occurring."

"Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information?" "Yes." They feel, however, that "the issue is not the information so much as the purposes for which it will be used or disclosed." So that's their concern.

In terms of informed/knowledgeable implied consent, they feel that

> in principle, expanding the consent requirement is a good idea; in practice this would create barriers to the sharing of information for care and treatment purposes.

They also said that

> in the absence of new funding, resources would need to be diverted from care and treatment to privacy compliance. Resource constraints make it difficult to take any steps towards making individuals and families knowledgeable about their rights and how their health information will be used, disclosed and protected.

In terms of the provisions around research, they would like the definition of research restricted so that "certain kinds of investiga-

tions, and their related requirement under the [act] to obtain ethics review, are excluded." They go on to talk about investigations that don't require the use of individual-level data or those enabling program evaluation or quality improvement. They also suggest that the size or number of ethics boards should be increased but not their scope. They indicate that there is a backlog of proposals that need review. They would also like to "permit custodians to obtain advance consent for disclosure for all research purposes. This would be administratively easier than obtaining consent for each research proposal where [it] is required."

In terms of the duties and obligations on the custodian, they feel that "custodians generally have too many obligations under HIA. Individually these obligations appear reasonable but taken together they are quite a burden." They particularly cite sections 22(3), 41, and 42 as offering "minimal benefits to the individual while imposing a significant burden on custodians. At a minimum, section 42 should be amended to exclude where the disclosure is to the individual the information is about."

3:35

In terms of the commissioner's powers they indicate that

> a Commissioner has no power to impose penalties on individuals who make complaints that he/she considers frivolous or vexatious. A small penalty may serve as a useful disincentive; the Commissioner could therefore direct his/her efforts towards more worthwhile reviews.

In terms of general provisions and the substitute decision-makers, they note that many of the residents "who lack capacity do not have family members who are formally authorized by law to act on their behalf" and that an individual who is willing to act informally would not satisfy the current requirements under the act. So they feel that it should be expanded to capture those individuals. They also state that

> it is not practical for custodians to insist that family members obtain, for example, guardianship, prior to making decisions about the management of health information. The cost and effort required to complete such an application process, together with the time [for court applications, et cetera] represent a significant hurdle for some families.

So they go on to suggest two amendments: one, where a spokesperson can be appointed by a party of family members; the second,

> in situations where there are no family members who come forward but there are people with whom the individual has a close personal relationship . . . we recommend adding . . . a further clause [authorizing] . . . a spokesperson who is appointed by a party of persons with whom the individual has a close personal relationship.

And they go on to spell out how that might be envisioned in the legislation.

In terms of the offences and penalties, they feel that they are appropriate.

In terms of the regulation, they raise the issue about health records and the fact that "provider organizations are subject to different retention periods." They would like to see that harmonized in the reg, and they would like, also, to have guidelines on what information should be retained. They also indicate that "the regulations could include a list of technical, physical or administrative security principles," but they recommend against "the identification of specific security safeguards since they would rapidly become outdated."

Finally, they feel that "the regulations could also reference the Electronic Transactions Act."

The Chair: Are there comments or questions from the committee?

Submission 65.

Ms Robillard: Submission 65, a submission from Syncrude Canada. Syncrude commented on the scope of the act and whether it should be expanded, particularly in the definition of "any other entity" that would include private-sector employees. They feel that that would not be necessary. They indicate that PIPA would provide necessary protection of that information. However, they say that "if a decision is made for private companies to be covered by the Act, we would like an opportunity to provide feedback at that point," that they "have not been able to fully assess the implications" to date.

The second issue they commented on was personal health information contained in an employee file and whether that should be part of the scope of the act. Again, they submit "not," that PIPA would provide protection. They further state that if PIPA does not provide adequate protection, perhaps that legislation should be amended to meet any requirements.

The Chair: Thank you, Wendy. Are there questions or comments from the committee on 65?

Well, I believe that concludes the submissions to date. We could get a few more, of course, as we go forward, but thank you very much, Wendy, Linda, and Evelyn for your hard work in getting those summarized and presented to us. We do appreciate it.

That brings us down to Other Business on our agenda today. The only other item I have is to finalize dates for the completion of our work. Yesterday we got down to agreeing to September 27, 28, and October 7 and had some problems trying to find a date between October 18 and 19. So after consulting with the members of the committee who do the work – that didn't come out well – those who do the paperwork and do the analysis, I'm going to propose to the committee that we go back instead of forward and look at October 15 for our final day to approve the final draft report.

Mr. Lukaszuk: October 15?

The Chair: Friday, October 15.

Ms Blakeman: From 9 to 4?

The Chair: Just a second.

That doesn't work for you?

Ms Kryczka: It doesn't. I'm away that week.

The Chair: You're away that week? Okay. I'm sorry; we might have to do the e-mail thing.

Ms Kryczka: I'm happy to do the e-mail thing.

The Chair: Most of our work, I think, will be on the 7th. Will you be here on the 7th?

Ms Kryczka: Yes.

The Chair: Okay. Then on the 15th, whenever they submit the final draft, we'll be just dealing with the items that the committee had problems with on the 7th. So it may not even take a full day to do that. I am proposing that we meet in the morning at 9 o'clock. If we are finished by noon, that's great.

Could I have a motion from a member of the committee for October 15, then? Thomas Lukaszuk. The motion is that we meet on October 15.

Mr. Lukaszuk: From 9 a.m. until the work is completed.

The Chair: Thank you very much.

Mr. Broda: It could go till the 18th; right?

Mr. Lukaszuk: That's right.

The Chair: No. It has to end on October 15.
Okay. All in favour, please say aye.

Hon. Members: Aye.

The Chair: Opposed, please say no. Good. Done.
Any other items? Yes, Mr. Lukaszuk.

Mr. Lukaszuk: Just to confirm, Mr. Chairman: we booked September 27, 28, October 7, and October 15.

The Chair: That's correct.

Mr. Lukaszuk: Perfect.

The Chair: As well as September 13 and 14, which we already had booked.

An Hon. Member: The 7th; yes?

The Chair: That's right.

Mrs. Sawchuk: It's on your calendar.

An Hon. Member: It's on this calendar?

Mrs. Sawchuk: Do you need another copy, Laurie?

Ms Blakeman: No, I've got it here somewhere.

Mr. Lukaszuk: October 18, 19 still?

The Chair: There's no meeting. We're finished on the 15th.

Mr. Lukaszuk: Perfect.

Ms Kryczka: And on the 20th there's no meeting; it's just the formality.

The Chair: Okay. Would a member of the committee like to just comment? Karen or Linda or Wendy, when the committee gets finished on the 15th, what will be your process, then, to get it tabled? Who wants to respond to that?
Karen.

Mrs. Sawchuk: Mr. Chairman, it's going to be probably both offices working together because what will be required once the committee adopts the final report is for our office and Health and Wellness to get the actual report printed, enough copies to meet the requirements whereby we have to deposit copies with the Clerk and ensure that there's a copy sent to each MLA.

That's what we'll look after right at the beginning. We'll do that. If we can manage to do it in the morning on Monday, October 18, that's exactly what we'll do. Then as staff we'll ensure that copies go out to the stakeholders and, you know, all other agencies that were involved later on during that week. We just have to make sure that we meet our requirements to have it recognized.

The Chair: So your target would be October 18 to have that done?

Mrs. Sawchuk: Yes.

Mr. Broda: Move to adjourn.

The Chair: Okay. I have a motion to adjourn. All agreed?

Hon. Members: Agreed.

The Chair: Opposed? Carried. We're done. Thanks to the committee for your hard work today. Thank you very much.

[The committee adjourned at 3:44 p.m.]