Title: Tuesday, August 24, 2004 HIA Review Committee
Date: 04/08/24
Time: 9:03 a.m.
[Mr. Jacobs in the chair]

The Chair: Good morning, ladies and gentlemen. I will call the committee to order.

Thank you all for attending today. It looks from our agenda like we will have a full day, a busy day, and it should be a very interesting day. You should have all received meeting materials on Wednesday, August 18. We'll be breaking for lunch around noon today. Lunch will be provided.

Before we move to ask for your approval of the revised agenda, which you should have in front of you, there have been a couple of changes on the agenda from what you received earlier. I'm going to ask Karen to update us on the situation with our first presentation today from the Edmonton police force. We had considered the possibility of involving other police forces, and I understand that we will have another police force today. So, Karen, would you update the committee on that?

Mrs. Sawchuk: Thank you, Mr. Chairman. Maybe just so we don't confuse everybody too badly, the change that was circulated this morning to everyone was item 3(b): the oral presentations list was brought current to yesterday. One additional number was added to the summaries of submissions, and that's number 67.

For the afternoon, as the chair mentioned, we had contacted the Edmonton Police Service. They did advise that they hadn't gotten together with the Calgary Police Service or the Lethbridge police service to put together a unified submission and that it wasn't something that there was any type of formal resolution from the chiefs of police on but that it was an item they had discussed over the years.

I guess that what happened was that after I contacted the Edmonton Police Service, they in turn spoke to one of their colleagues in Calgary. So the primary presentation this afternoon is going to be made by the Edmonton Police Service, but there is a staff person attending from the Calgary Police Service who will be here to respond to questions. She doesn't plan on making an actual presentation other than the submission that they had already made, and that submission is now included in the materials that were handed out to you this morning.

The only other changes on today's agenda were the additions of names of other parties attending for the oral presentations. Initially we just had company names and whoever it was who had made the submission. They'd since contacted our office to provide the names of who would actually be attending.

That's it, Mr. Chairman.

The Chair: Thank you, Karen.

Does anyone have questions on the revised agenda or the transition that took place? Okay.

Mr. Goudreau: Mr. Chairman, I was just going to move the agenda as revised.

The Chair: Okay. Thank you very much. You anticipated my next question.

So I have a motion to adopt the agenda. All in favour, please say aye.

Hon. Members: Aye.

The Chair: Opposed, please say no. Okay. It is adopted.

I was going to make one other comment also. I trust that everyone has their calendars with them today or could get them before we move to item 7 later today, which will probably be much later. We do need to schedule some more meetings, and we will discuss that further. I'm just reminding everyone to have their calendars if not already here.

All right. As you notice on the agenda, oral presentations start immediately after lunch. This morning we are going to continue with analysis of the submissions: today numbers 32 through 65 and number 67.

I'm going to ask Wendy – well, before I do that, I think we should get everyone's name on the record. So starting with committee members, maybe we could start with Ms Blakeman and come this way and ask all committee members to introduce themselves for the record. Then would others who are here on various assignments also introduce yourselves.

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

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

Mrs. Sawchuk: Karen Sawchuk, committee clerk.

Mrs. Dacyshyn: Corinne Dacyshyn, committee clerk.

Ms Sorensen: Rhonda Sorensen, communications, with the Clerk's office.

The Chair: Thank you very much. Welcome again to everyone.

Also, Karen has pointed out to me that we also needed to talk about item 3(a) and, before we start, an updated listing of submissions. You should have that. What tab is that under, Karen?

Mrs. Sawchuk: Mr. Chairman, 3(a) is the updated listing of submissions received, and it's just the final page. There were an additional 10 submissions from the last list that the committee was given. So that's it.

The Chair: Okay. So you have that for your information.

Mrs. Sawchuk: And then (b).

The Chair: Oh, yes. Summaries of submissions 32 through 65. You have those also, Karen, under item 3?

Mrs. Sawchuk: Mr. Chairman, if I could interrupt for one moment.

The Chair: Yes.

Mrs. Sawchuk: For item 3(b) we had the updated list for the oral presentations, and there was a change from the initial list that the committee had received. Petro-Canada has withdrawn its request to appear before the committee, and then we added on an additional two requests that came in at the end of the list. So that's the revised list that you got today.

The Chair: Okay. Thank you.

Questions?

All right. Wendy, let's go with submissions.

9:10

Ms Robillard: Okay. Just to recap what we're doing in the summaries of the submissions, 32 to 65 and 67, these are summaries of the actual submissions that were received. As much as possible the content in the document that you receive is verbatim.

What we're doing today is reviewing some of the key points, some of the key responses to the questions in the guideline. This is not analyzed at this point as when we started at the last meeting. We didn't have all of the submissions in to date, so we couldn't start that analysis. However, as the next step after today's meeting, we will be creating a summary of analysis chart. That chart will be created issue by issue. So we'll take the first question out of the guidelines, for instance, and provide all of the responses to that question, analyzed and with some further thought behind that in terms of some potential options that the committee might want to consider. At future meetings we will be going through the summary of analysis chart on an issue-by-issue basis. So to make that clear.

The Chair: Any questions from the committee?

Also, Wendy, I think any member of the committee who wanted a complete copy of the submission would have had that opportunity, and I think we do have copies today in case someone wants to look at a complete copy of the submission. Otherwise, you are summarizing the submissions.

Ms Robillard: Absolutely.

Further to that, there are two summary documents. We created a separate summary document called municipal responses because the municipalities were responding to one specific question at our direction. The remainder of the submissions are there in detail and summarize many more questions.

To speak first to the municipal responses. The document you have in front of you is three pages long. The first two pages were discussed at the last meeting, so I'll begin with the summary of submission 48, which is the county of Beaver.

The question that the municipalities are responding to is: "Should [ambulance] operators as defined in the Ambulance Services Act be included in the scope of the Act?" The county of Beaver council has no objection to the inclusion. The town of Whitecourt believes that ground ambulance operators should be included in the scope, the town of Cochrane agrees that they should be included in the scope, and the town of Canmore agrees that they should be included in the scope.

So I will proceed on, then, to the remainder of the submissions and, I'm sure, would invite comment or question. You'll see in the submissions as they're organized today that under each question there is a number before the response. That number is simply the number of the submission, and it's done for organization purposes, so when we pull the submissions together issue by issue, we'll be able to reference back to who said what. So you don't need to worry about those numbers, but that explains them.

Submission 32 is from the Alberta Mental Health Board. They responded to the question about whether any definitions in the act should be modified, and they've advised that the definition of "custodian" and "affiliate" need to both be clarified and expanded. They indicate that

> there is some confusion in these roles and the parameters of what may be shared . . . As an example, there have been instances in which mental health professionals from one regional health authority have interpreted [the act] to mean that they could not share information with mental health professionals from another . . . region regarding the programs, treatment and progress of an individual with mental illness who is transferring to that region, even with the individual's consent.

They've also recommended a definition for third party information. They indicate that it would be helpful to clarify what constitutes "third party information" through guidelines or definitions.

They also have a comment to make regarding the clarity of the application of the act. They indicate on wording in the act: "Purposes 'to manage the health system' would benefit from some guidelines or refer to the scope of that management function." They also believe that data matching could be more clearly defined.

In response to the question about the scope of the act and whether it should be changed given implementation of the electronic health record, the Mental Health Board recommends that the act "provide appropriate balance of the right to individual privacy and the need to share information critical to provision of necessary services."

In response to the question "Should the definition of health information be changed to include non-recorded information?" their response would be no. They say that it "would neither add value nor support professional practice guidelines."

In response to the question in regard to whether discretionary disclosures without consent are reasonable and appropriate, the Mental Health Board indicates that "many programs in mental health require partnership with providers outside of the healthcare system, and for cross-ministry integrated programs." So they're requesting that provision be made "for sharing health information for purposes of program planning, identification of needs and provision of services within integrated programs."

In relation to whether the research provisions in the act are reasonable and effective, they indicate that it would be useful for "guidelines for the composition of Research Ethics Boards [to] be adjusted to include individuals with expertise in mental health, aboriginal and other special populations."

The Chair: Questions?

As Wendy referred to earlier, they will be doing an analysis for your consideration. Comments that are made today by committee members will be considered and included in the analysis that's being done, so, you know, it is important to get your comments when you have some to make.

I see no questions, Wendy, so let's proceed.

Ms Robillard: Submission 33 is Aspen regional health authority. The first question they responded to is, "Are the purposes in the HIA appropriate?" Their response is yes.

"Are there any definitions that should be modified?" They recommend that "1(1)(a)(iv), an operator as defined in the Ambulance Services Act,' [should] now be included as an affiliate."

In regard to the scope of the act and whether it should be expanded to include other departments of the government of Alberta, local public bodies, or other entities, they comment that

> the scope [should] be expanded to include:
> – all regulated health professionals under the Health Professions Act; and
> – organizations whose primary function is to provide health services, irrespective of who or what pays for those services.

In response to the question about ambulance operators and whether they should be included in the scope of the act, their response is yes.

In terms of whether the scope of the act should be changed given the implementation of the EHR, Aspen comments that "as the Electronic Health Record evolves, the scope of the Act should [change] to include all providers who have (or will have) access to the [EHR]."

> Should health service provider information be included within the scope of the Act . . .
>
> Section 37 of the Health Information Act is appropriate in its

approach to health service provider information, but it may be more appropriate if it is stated in the Health Professions Act.

"Should personal health information contained in an employee . . . file be part of the scope of the Health Information Act?" The response is that "only those entities, whose primary role is defined as health services delivery, should be included."

"Should the scope of the [act] be extended to include WCB?" "Yes."

To be expanded to include Alberta Blue Cross? "Yes."

Should the definition of health information be changed to include non-recorded information?" They do not support this change. Primarily they see it as an access problem. If the definition is changed to capture nonrecorded information, the concern is how an individual would actually get access to that information.

"Is the process for obtaining access to records appropriate?" They suggest that there's a clarification needed "when a custodian determines the ability for a minor to make a request to access his/her health information."

"Are the exceptions to the individual's right to access their own information . . . appropriate?" They say yes. "Both the mandatory and discretionary exceptions are appropriate."

In response to the question in regard to the amount of fees they say:

> The fees set out in the [HIA] Regulation are clearer in depicting the actual cost when compared to the fees that have been set in [FOIP]. These amounts do not capture the actual costs and the Regional Health Authorities make up the shortfall. Whoever makes a request, should be charged the actual costs for processing the request. Some of the professional bodies (i.e. Colleges) have established their own fee structures for health information. We believe that these should all be consolidated and captured in the [HIA] Regulation.

"How should the [act] be amended to address the concept of custody or control of a custodian within the EHR?" They respond: "As previously stated, the Electronic Health Record is still in its infancy and before we can answer this question, a clear understanding must be made between custody and control of information in the [EHR]."

"Is the duty to collect health information directly from the individual except as authorized appropriate?" Yes.

9:20

"Should custodians be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide health care?" They say that at this point in time the legislation is appropriate the way it is currently stated and does not require a change.

> Is the requirement to inform individuals about collection practices effective . . .
>
> Although the Act is supportive of a custodian taking reasonable steps to inform the individual of the purpose and legal authority for the collection, it is difficult to inform individuals about collection practices in all cases. We question if this is becoming an administrative burden on Regional Health Authorities?

Around use of information, are the purposes currently listed in the act appropriate? The response is yes.

"If you recommended an expansion of the scope of the Act to include other entities, what purposes/set of responsibilities would you change?" They say that they "would not suggest any changes at this time."

On the question whether it's appropriate to use individual identifying health information without consent for the authorized purposes stated in the act, the response is yes.

"Overall, should the listings of authorized uses be expanded, restricted or modified?" The response is no.

> Are the elements of consent appropriate . . .
>
> Further clarification is needed around the appropriate elements of consent. Section 34(2)(b) states that "the purpose of which the health information may be disclosed" must be provided. Custodians do not have a need for this information and have no method of assuring that once disclosed the person receiving the information would use it only for those purposes. We also believe that section 34(2)(d) would be more appropriate for a collection process [as opposed to] a disclosure process.

In regard to the discretionary disclosures without consent and whether they're reasonable and appropriate, they indicate that, yes, they are. They "would like to ask for further clarification regarding Section 35(1)(m) when it speaks to 'imminent danger.'"

> Should the discretionary authority to disclose to police services without the individual's consent be extended to disclose basic registration information to police services for purpose of providing a warrant, subpoena or court date?

Aspen do not support this extension of disclosure. They feel that it

> would potentially discourage patients from seeking medical care. The current process for warrants, subpoenas and court orders is an appropriate process for police services to obtain personal and health information without consent.

Then in response to the proposed amendment referencing the triplicate prescription program, they were in favour of that amendment.

In response to the question about an informed/knowledgeable implied consent model for care and treatment and whether it's appropriate, they say that they do not support that model. They recommend that "immediate, active steps be taken to achieve a 'substantially similar' exemption for the Health Information Act from Industry Canada, (PIPEDA), in order to overcome a major current obstacle to such harmonization."

On the question about the research provisions in the act they feel that they are reasonable and effective.

In response to the question about the duties and obligations on custodians and whether they're appropriate or reasonable, they say that for the most part they are appropriate and reasonable. However, there are several areas that they've identified as being an administrative burden.

> First, disclosure notations represent a significant administrative burden for health care organizations . . . Second, compliance standards for dealing with contracted affiliates are another concern. For contracted service providers the level of accountability can easily outstrip the practical oversight and enforcement capacity of Health Regions.
>
> Third, obligations in relation to information security present another administrative challenge . . . Inconsistent messages from the Information and Privacy Commissioner's [office] and Alberta Health and Wellness on security standards and best practices [are causing problems]. Significant dollars have been diverted from patient care to assist Regional Health Authorities with their compliance with the legislation.

The Chair: We do have a question at this point.

Ms Blakeman: You still have one more page to go on this; don't you?

Ms Robillard: Yes.

Ms Blakeman: Please finish, and I'll ask them at the end. Sorry; I thought you were done.

Ms Robillard: On the commissioner's role, "Do you have any suggested changes to this part of the Act?" they recommend one change to section 83(3). The amendment "should include a clause

where the custodian impacted is provided with the name of the affiliate who makes disclosure to the Privacy Commissioners in accordance with 83(1)."

Under General Provisions, "Is the list of substitute decision-makers appropriate?" Yes.

"Are the offences and penalties appropriate?" Yes.

Do you have any suggested changes for the regulation? They suggest three minor amendments. Section 4 refers to the Child Welfare Act. They note that effective November 1, 2004, that piece of legislation will be known as the Child, Youth and Family Enhancement Act. Section 5(2)(e) refers to the Ambulance Services Act and the need to amend that accordingly. Section 6(2) refers to section 59, which was repealed in 2003, so "this section will need to be amended to reflect this change."

The Chair: The question you have, Ms Blakeman.

Ms Blakeman: Thank you. Two questions. I'm wondering which health professions would need to be captured, following through on question 33 from this particular presentation, where they're saying that the scope be expanded to include all regulated health professionals. My question is: who's not captured currently? You may want to bring a list to the next meeting.

Secondly, in question 13 they're concerned about the amount that it's costing them, the actual cost of fees that can be charged, and they seem to be indicating that what they can charge is nowhere near to what it costs them. Could we get some information on what they believe it does cost them?

Ms Robillard: We could ask the region to provide that, yes.

Ms Blakeman: Yes. Let's get it, and then we'll know. Thank you.

Ms Robillard: Certainly.

In terms of the regulated health professions the definition of custodian under the act today talks about custodians in relationship to organizations or who bill through the Alberta health care insurance plan. So health professionals who practise in independent practice, for example, would not be captured. Or if they work in an organization that is not a custodian. For example, they may work for a social service agency or something, so they wouldn't currently be caught by the act.

Ms Blakeman: Can I still get a list?

Ms Robillard: Yes. We can try and provide that.

Ms Blakeman: Thanks.

The Chair: Okay. Mr. Broda.

Mr. Broda: Yes. My question is also on question 13, the actual costs the regional health authorities have to pay. I see in there that some professional bodies have established their own fee structures for health information. Is it maybe advisable to see that everybody charges the same so there are no discrepancies? Once you know what it's going to cost, it's across the board for everyone.

Ms Robillard: Okay. If I can speak briefly to that issue. The fees that are defined in the regulations are fees that are charged when an individual makes an access request to access their own health information or when somebody acting on their behalf makes that application.

The fees that colleges set in this case I believe are referring to fees such as a transfer of a record from one physician office to another or the creation of a summary of a record to go from a physician, for instance, to an individual's lawyer. Those fees are not set by the Health Information Act. The College of Physicians and Surgeons does establish a fee structure that they recommend their members follow in relation to that. So they're outside the scope of the act at this point.

Ms Kryczka: Just based on a quick look at this submission, I think there are a few points here, one being the one that Mr. Broda just referred to, question 13. Also, looking at part 6 and their response, the second and third paragraphs, it just seems that they're making a statement, I think, on the burden of cost to the health region. I don't know. I haven't read it really carefully or other submissions, but I think that might be an overarching point, the cost to health regions.

Ms Robillard: Absolutely, and when we deal with the fees issue, we will certainly consider those issues and try and bring as much information forward as we can.

The Chair: For clarification, Wendy, would you tell me what a triplicate prescription program is?

Ms Robillard: Yes. The triplicate prescription program is a listing of specific medications that are monitored more closely, shall we say, than other prescriptions, and it's done in conjunction with the physicians and pharmacists. The prescription is recorded on a pad that actually has three copies, one of which goes to the AMA for their review and consideration. It's a controlled substance like narcotics.

9:30

The Chair: So not all prescriptions are done in triplicate.

Ms Robillard: No.

The Chair: So who decides which ones get done?

Ms Robillard: I'm not certain about who decides which medications get on that listing, but we'll follow up and check that for the next meeting.

The Chair: Thank you.

Ms Blakeman has a question.

Ms Blakeman: It has to do with whether the drug has a street value, because they're trying to control people getting multiple prescriptions and selling them on the street. So some of the other restrictions that go along with that triplicate program are that copies are sent to a monitoring body, which in this case is the AMA, who eventually will get along to track to see if one person got more than a reasonable amount of that particular drug. The prescription must also be filled that day. If it's not filled that day, it's null and void. So there are a number of criteria around it in order to protect who's getting the drugs and how they're using it.

The Chair: Okay. Thank you.

Ms Robillard: Just to clarify, it's the College of Physicians and Surgeons, I believe, who do the monitoring.

Dr. Pannu: The college monitors, but we need to know who

prepares the list and whether or not that list changes over time with new drugs coming on board and who makes the decisions on that one.

Ms Robillard: Yes, I'm certain it does change from time to time, and we'll endeavour to get that information.

Dr. Pannu: So the list will be made available to the committee?

Ms Robillard: A listing of the medication? Yes, we can do that, as well as the process for getting additional medications on the list or off the list, I guess.

The Chair: Okay. Could I ask all committee members to speak into the mikes as they speak.

Go ahead, Dr. Pannu.

Dr. Pannu: Okay. Good. My question is related to question 24 and the Aspen regional health authority, dealing with extension of personal disclosure provisions to the police. The Aspen regional health authority's position is quite clear; they're opposed to it.

We have 67 – or how many? – briefs up to this point.

Ms Robillard: We've summarized 65. I'm not sure; Karen can maybe tell us the exact number.

Mrs. Sawchuk: Submissions to date? Sixty-seven as of 4:30 yesterday.

Dr. Pannu: Right. Of the 65 that we have summarized, would you be able to recall how many of these take the position on this issue that the Aspen regional health authority has taken? I'm asking this question because this afternoon I think this important information will be useful for us to deal with.

Ms Robillard: I don't actually have a hard number for you. I do know that as we go through today, we will see many regions speak to this issue and many health professions as well. But, no, I don't have that number today.

Ms Miller: As part of the analysis, Dr. Pannu, we will be able to provide you that specific information, because we'll track that by that issue and show the range of opinion on that particular matter.

Dr. Pannu: I gather that that will be available at a later date.

Ms Miller: Yes.

Dr. Pannu: Not today?

Ms Miller: No.

Dr. Pannu: Not later today?

Ms Robillard: We might be able to get that information to you later today.

The Chair: Thank you. Any other questions?

Let's go to number 34.

Ms Robillard: Submission 34 is from the Pharmacists Association of Alberta, also known as RxA. They first responded to the purposes in the act, and they state that the purposes are appropriate and don't need to be changed. They point out section 2(a) to (c), which is of particular relevance in considering the scope of the act.

In terms of their input relative to the scope of the act, they support the expansion of the scope to include privately paid health service providers. They comment that the

> rules that promote the central objective (protect personal . . . information: promote individual control and choice, and enable efficient and effective information sharing for quality services and health system management) should be kept or added. Rules that fail to promote, or work against achieving the central objective, should be removed or not added.

They also submit that "HIA should be the umbrella legislation for all health care providers and organizations, whether those providers or organizations are paid from public or private sources."

Relative to health service provider information and whether it should be included in the scope of the act, they submit that the health service provider information does not belong within the scope of HIA. "If health service provider information is to remain within HIA, greater legislative clarity is required."

They comment that the central purpose of the legislation "is, and ought to be, to regulate the collection, use and disclosure of personal health information and other personal information that identifies the individual who receives health services." They further comment that no other jurisdiction in Canada has legislation regulating health information that includes health service provider information within its scope and that there is no clear and legitimate policy justification for including this information under HIA.

They also talked about the 2003 Information and Privacy Commissioner ruling that effectively requires the consent of health service providers for the disclosure of virtually every kind of information about them to a noncustodian. They comment that although the ruling is under judicial review, "if it is upheld, it will greatly expand the scope of protection" of health service provider information under the act "to an extent that, in our submission, is inconsistent with the legislative intent of Section 37."

They advised that failing to amend the provisions of the act

> will create a prohibitive administrative burden for pharmacists and other health information custodians . . .
>
> Requiring health services provider consent to disclosure of [health service provider information] will compromise current and future programs that are or will be of benefit to the health system, e.g. existing quality improvement, program review, health system management and research activities.

They have submitted alternatives or a combination of alternatives that should be considered including removal of "health services provider information" from the act, an amendment to the definitions section in HIA to specifically exclude work product type information from the definition, the removal of section 37(2) of the act, and the amendment of section 37(2) of the act "to impose a high standard of proof of harm to health services providers resulting from 'other information' being revealed."

I want to go on and talk about access and whether the HIA should be amended to address the concept of custody or control of a custodian within the EHR. They comment that

> the EHR environment presents many new and complex operational challenges and opportunities. Regardless of whether records are in paper or electronic format, the nature of the data they contain remains fundamentally the same.

They've suggested some principles that should be maintained including that

> – a record of personal health information is legally owned by the custodian that collects and documents the information,
>
> – the individual from or about whom the personal . . . information is collected has a legal right of access to the information, subject to very limited public interest exceptions,

– the collector of the information owes a fiduciary obligation to the information subject to protect the personal health information from being revealed to anyone else.

They go on to state that "the power to collect and share information electronically greatly increases the opportunities to share complete, objective information to improve patient safety and health system effectiveness and efficiency."

They go on and comment about the requirement to inform individuals about the collection practices. They feel that "adding a detailed explanation about health information lengthens transaction times and adds nothing of meaningful value for the patient." So they don't feel that it should be required.

In terms of the discretionary authority to disclose to police services without the individual's consent, they strongly support

> keeping and not changing the current rules, namely disclosure only with consent, a valid search warrant/subpoena, or the narrow exception under Section 35(1)(j) of [the act]. The well-established legal requirements around search warrants, supplemented by the narrow exception in Section 35(1)(j) of [the act], have proven to be practical, predictable and consistent with the legislative intent of [the act].

In regard to the triplicate prescription program, they support "in principle, whatever legislative changes are necessary to permit disclosure of appropriate information to third party payers" for payment purposes and to the triplicate prescription program.

9:40

A comment on an informed/knowledgeable implied consent model for care and treatment. They indicate that

> prescription dispensing transactions already are virtually always conducted through a form of an implied consent model involving the presentation of a prescription and of a payment card. – Moreover, it is critically important to pharmacies to be compliant with federal privacy legislation ("PIPEDA"), because of the frequency of information flow across provincial borders (for payment etc.). This is particularly so in an environment where the legal paramountcy of HIA vs. PIPEDA remains uncertain.

In terms of other comments, they support and "strongly urge efforts to achieve consistent rules for health information across Canada through legislative harmonization."

The Chair: Seeing no questions, perhaps we could go to submission 35.

Ms Robillard: This submission is from the Health Quality Council of Alberta, and they comment on the scope of the act and whether it should be expanded. The Health Quality Council indicates that

> without appropriate access to information [their] ability to evaluate, monitor and report to Albertans or the Minister on the performance, quality and safety of health system will be severely constrained. Therefore, [they] feel the scope of the act should be expanded to include the HQCA, as a custodian, in order to fulfill its mandate as outlined above.

They go on to comment, as well, about the research provisions, whether they're reasonable or effective. They indicate that

> it is not always clear which rules apply or how the rules should be interpreted. This has caused time delays and significant increased cost in completing [research] projects and consequently in reporting to the Minister and the public. There is also a concern the quality and accuracy of the reports could be compromised given the current data disclosure processes. We feel this could again be clarified and the process made more effective if the HQCA mandate was reflected within the scope and purpose of the Act as well as within the purposes/responsibilities of custodians.

Ms Blakeman: Can you give us any background as to why the Health Quality Council of Alberta wasn't included in the act in the first place?

Ms Robillard: Well, for one thing, the Health Quality Council of Alberta wasn't formed when the act was envisioned.

Ms Blakeman: Okay. That's a good reason.

Ms Robillard: Secondly, they were formed by ministerial order. They are affiliates of the minister and the Department of Health and Wellness.

Ms Blakeman: That's what I thought. They're essentially a Crown agency; aren't they? Well, an arm's-length government agency then.

Ms Robillard: Yeah. They're formed by a ministerial order.

Ms Blakeman: Okay. Thank you.

Ms Kryczka: I guess my comments are similar to that, because I am aware of when it was formed and how it started up. It was the health services utilization commission. I think they have done very good work in the last few years, increasingly so as their mandate has continued, and I think this is a very valid concern that they have.

Ms Blakeman: If they're an affiliate of the minister's office, can they not access the information using the blanket exemption that the minister and the minister's staff receive under this act?

Ms Robillard: Yes. There are two issues, I think, that relate specifically to the Health Quality Council of Alberta. One is their access to information to report on quality, performance, safety of the health system. Yes, you're right; those provisions apply to them as any affiliate of the ministry. So they have access to that information.

The second piece, which is important for the work they do, is the research provisions. They often work to put research questions out and to fund research. They don't necessarily do it directly, but they do fund some research. So the provisions in the act around research and the capacity of researchers to access information obviously, then, also impacts their ability to report.

Ms Blakeman: Thank you.

Mr. Broda: Further on this one. Seeing that the request is coming to be added to the Health Information Act here – and I think they should be – what happens in the future if, say, another organization would happen to be formed that would be in the health sector? Are there any provisions that could be added? They would first have to apply. But so that there wouldn't be any problems of having to review it again, what mechanism do we have in place?

Ms Robillard: Well, currently if these organizations are set up in relationship to the ministry, then the provisions in the act may already encompass them. If there's a new committee established under a ministerial order, then at that time there's a discussion and consideration made as to whether they are affiliates of the department or not. So depending on how they're formed, some of those rules kick in. There's also capacity under the regulation to name custodians under the act, so there's another avenue. Then I guess the third option, of course, is to amend the definition of custodian in the act to incorporate them.

Mr. Broda: Thanks.

Dr. Pannu: Well, I'm a little confused about the notion of the affiliate. The affiliate is entitled to have access to information; is it not?

Ms Robillard: Yes.

Dr. Pannu: If that is the case, then, why is the council making the request to be included among those with a right to access?

Ms Robillard: My best understanding of that would be that they currently have access to information through their affiliate status and that they're requesting to be specifically named as a custodian.

Dr. Pannu: But is there a problem for them to access information so long as they remain just affiliate and have this secondary right, as it were, to access? Do we know of any operational problems?

Ms Robillard: Not to my knowledge. I'm not aware of any problems.

Dr. Pannu: I'm trying to assess whether or not this request is redundant given that they already have a right to access.

The Chair: Thank you for the questions. Any others?
Ms Kryczka, do you have a question?

Ms Kryczka: I'm sorry. I don't have precise, immediate information either, but to respond to his concern about whether this is a valid request, I think that if you read through 35, they're quite specific that there is a problem for them and what their concerns are. Obviously, they have not been able to access information they need for research on a timely basis. Then it's quite specific, you know, the concerns that they've experienced.

Ms Robillard: The concerns about access to research: I think you're right that there are concerns there. The rules around research and the requirements for access to information for research apply equally to any custodian, any affiliate, or any external researcher.

Ms Kryczka: Exactly.

Ms Robillard: So being a custodian won't necessarily solve that problem.

The Chair: Thank you for the question. Does anybody have any other questions?
Wendy, we realize you're doing a lot of talking and appreciate the great effort you're making here.

Ms Miller: A further comment that might be getting at your concern. If the council were named as a custodian, they then would have the right to process research requests for the data that they held themselves. As they currently exist, which is an affiliate of Alberta Health and Wellness or on behalf of the ministry, the process requires the custodian to process the request in terms of determining least amount, highest level of anonymity, and need to know. So that may be what they're trying to achieve, although that's just my interpretation.

Ms Kryczka: Do we have an overarching process where if there is some need for more information for clarity, we can follow up and get it? We're sort of in the presumption field here.

Ms Miller: We can certainly follow up with them and ask for that clarity. That would be our responsibility.

The Chair: Thank you, Linda.
Wendy, are you ready to proceed?

Ms Robillard: Sure. The submission from the College of Physicians and Surgeons of Alberta. Their first comment is on the scope of the act and whether it should be expanded. Their recommendation is that

> the current restriction of the [Health Information Act] applying only to services that are "publicly paid" be removed, and replaced with the inclusion of all information that is collected or used by any regulated health professional.

A further recommendation is that "when the legal stature of Local Primary Care Initiatives . . . is clarified, consideration be given to including LPCIs in the definition of 'custodian' under [the Health Information Act]."

9:50

On the question about whether ambulance operators as defined in the Ambulance Services Act should be included in the scope, their response is: yes, they should be brought under the Health Information Act.

With regard to the health service provider information being included within the scope of the act, their recommendation is that

> health [service] provider information, when it is linked to identifiable health information, [should] be included in the definition of "health information" . . .
>
> While the patient is identifiable, the protection of that patient's privacy is the primary issue. But we further believe that when the identity of the patient is removed or anonymized, the issue of the privacy of the practitioner associated with their care moves to the fore, and should at that point be provided the protection of the [Health Information Act], or PIPA.
>
> We would hope that by so clarifying this issue, the problem of the sale for commercial purposes of health provider information associated with care information can be adequately dealt with.

Should personal health information contained in an employee file be part of the scope of the Act? Their recommendation is that "health information held by employers . . . not be brought under the [act]."

In terms of the scope of the act being extended to the Workers' Compensation Board, they say that "health information held by employers and by the WCB [should] not be brought under the [act]."

In terms of the definition of health information, whether it should be changed to include nonrecorded information, their recommendation is that "non-recorded information continue to be excluded from the parameters of the [act]."

Under individual's right to access, "Are the exceptions to the individual's right to access their own [health] . . . information appropriate?" their response is yes.

Should the HIA be amended to address the concept of custody or control of a custodian within the EHR, the electronic health record? Their recommendation is that "within the [Health Information Act] no special status be accorded, nor special rules created for, the electronic capture, storage, use or communication of health information." They believe that

> the Act should be clear enough in its principles to apply equally well to all media. As well, the rapidly developing nature of electronic technology makes obsolete equally rapidly those legislative provisions which are specific to a particular electronic medium or architecture.

Under the disclosure provisions their comment on the triplicate prescription program is that they recommend that the act "be

amended to provide clear authority for custodians to disclose health information to the Triplicate Prescription Program."

Around the genetic information and whether there should be stronger provisions to protect the confidentiality of it, their recommendation is that "genetic information about an individual be accorded the same status as other health information under HIA."

Under Duties and Powers of Custodians, whether the obligations of the custodian are appropriate and reasonable, their recommendation is that the Health Information Act "be amended to provide clear authority to the CPSA to disclose health information, as outlined in the CPSA bylaws, to custodians concerning individuals who are/have been in their care."

Under the commissioner's powers, "Do you have any suggested changes to this part of the Act," they recommend that the act "identify the OIPC as having the authority and responsibility to take custody or seize, and to administer, health records for which the custodian is unable or unprepared to do so."

They've had discussions with the Information and Privacy Commissioner's office on the issue of so-called orphaned files, those health information records for which the custodian may have died, moved or is otherwise unable to care for them, or records that have been entirely abandoned.

> In these situations, not only is the security of those records in potential jeopardy, but the right of access by the individuals who are the subject of those records is compromised: the individuals do not know where the records are, and/or who to approach for access to them.

They've made another recommendation, that "increased efforts be made for the harmonization of the various pieces of legislation which may affect the handling of health information." They speak specifically to the Health Information Act, the Personal Information Protection Act, FOIP, and the Personal Information Protection and Electronic Documents Act.

The Chair: Wendy, have other recommendations come forth similar to the one you just referenced, harmonization?

Ms Robillard: Harmonization? Yes.

The Chair: So that will be a clear indication of recommendations from many who submit?

Ms Robillard: Yes.

Mr. Goudreau: I'm just wondering: where do orphaned files end up?

Ms Robillard: It would probably scare you to know where some of them end up. Today we know of examples where offices have been abandoned, so whoever has the building, rents the office space, is left with the records. We've heard of instances where they've been left. A retired physician may have passed away and the records are stored in his garage and the family members don't know how to deal with them. So there are some examples.

Mr. Broda: Further to that, are there any provisions in place that you cannot destroy records for a certain number of years? I'm going to refer to the real estate industry, which I was in before. You have to keep them for seven years and get permission to destroy your files.

Ms Robillard: Yes, there are obligations through other pieces of legislation that require records to be retained. Probably, though, the length of time for most records – and this is a very general comment – would be in the neighbourhood of 10 years, I believe.

Dr. Pannu: After 10 years there is no requirement to seek permission to destroy them?

Ms Robillard: No.

Mr. Broda: Should we be looking at some provisions that would enforce some regulation – call them orphaned files or whatever – that whoever is in custody of them would have to automatically notify that they have existence of these records?

Ms Robillard: The issue comes up as well in the Privacy Commissioner's. So, yes, I'm sure that there will be some recommendation and discussion.

Ms Kryczka: I don't know if you want suggestions, but usually when you go to the doctor's office, they ask for next of kin or whom to contact. So I guess logically to me, if that happens and there's an orphaned file and there is a responsibility of the custodian to dispense of the file if they're closing the office down or whatever, would you not first of all contact the next of kin named on the file?

Ms Robillard: In this situation the person who has abandoned the records is actually the physician and not the family member themselves. So if your physician were to die, to move out of province, or to suddenly cease to practise and you no longer have access to the record, that's the issue here. It's not necessarily about the individual's ability to access them. They don't know whom to approach to get the access from because the custodian is no longer available.

Ms Kryczka: So there is no responsibility of people who have been working in the office to do that?

Ms Robillard: They may no longer have access to the records either. So if the office has been disbanded or if somebody leaves in the middle of the night, the employees may not have access either.

Ms Gallant: I would just comment that another example is that quite often if a business is seized due to failure to pay the rent, then records have been lost in that fashion as well. So then sometimes they fall perhaps to the trustee in bankruptcy. In the instance we were involved with, it just fell to the landlord. He had seized them for the purposes of nonpayment of rent, kept them for a year in his basement, and then burned them.

So there are many examples of how Albertans lose their right of access because there is no current provision in this legislation for how to deal with orphaned records. And, yes, the commissioner speaks to the same issue in his submission and also requests that something be done but perhaps not necessarily what's been recommended by the college and arguably so in that it's difficult for an oversight body to not only administer the act but also to oversee it. But we can speak to that when we get to our submission.

The Chair: Thank you. Well, we have some interesting challenges before us.

Number 37.

Ms Robillard: This is from the Alberta College of Pharmacists. The first question they respond to is whether health service provider information should be included within the scope of the act. Their recommendation is to "eliminate section 37(2)(a) of the [Health Information Act]."

They comment that

> the expansive protection given to health service provider information under section 37(2)(a) of the [act] will also prevent health professionals from sharing information:
> – with clients or patients, about the professional services offered by another health service provider . . . [or]
> – among health professionals, about the professional services offered.

10:00

"Are the elements of consent appropriate?" Their recommendation is to "allow verbal and, where appropriate, deemed consents to the collecting, use and disclosure of information." They comment that

> a detailed written consent may be appropriate in a limited number of circumstances in the health care system; in the vast majority of cases, the requirements are simply "overkill." . . .
>
> Changing the consent requirements in the [act], leaving more room for reasonableness and professional judgment, will greatly assist in reducing the endemic administrative burden under the [act].

In regard to the discretionary authority to disclose to police services without consent and whether that should be extended to disclose basic registration information, their recommendation is:

> Specifically authorize 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 offence under the Criminal Code, Controlled Drug and Substances Act, Narcotic Control Regulations or Food and Drug Act has been committed or is being attempted . . .
>
> The Alberta College of Pharmacists recommends adding a new ground for disclosure in sections 35 and 37 of the [act] that will allow a custodian to provide individually identifying diagnostic treatment and care information, health service provider information and registration information to a police service if the custodian has reasonable grounds for believing that the information reveals or tends to reveal that an offence under the Criminal Code, Controlled Drug and Substances Act, Narcotic Control Regulations or Food and Drug Act has been committed or is being attempted.
>
> The College is concerned that the disclosure only "of basic registration information to police services for the purpose of providing a warrant, subpoena or court order" will be woefully inadequate to address the issue of the illegal diversion of narcotics and other drugs of abuse through forgeries and double doctoring . . . If the HIA continues to narrowly restrict disclosure in circumstances of forgery and double doctoring, the HIA will continue to serve as a shield for those who divert narcotics for abuse and trafficking.

On the triplicate prescription program their recommendation is to specifically authorize "disclosure, without consent, of individually identifying health information to the Triplicate Prescription Program."

In terms of other recommendation, they feel that that there's a significant administrative burden imposed on pharmacists is an area of concern.

> The solution is to allow greater flexibility in the collection, use and disclosure of individually identifying health information by custodians through the principle of reasonableness and verbal and implied consents . . .
>
> [They] rationalize the HIA and PIPA and take the steps necessary to ensure substantial equivalence under PIPEDA so that pharmacists and other health service providers are governed under a uniform set of rules for all information that they collect, use and disclosure in their professional practices.
>
> Under the [act], common sense and sensitivity to individual circumstances are replaced by a complex set of legal rules that are difficult to apply.

The Chair: Seeing no questions, let's go to 38.

Ms Robillard: Submission 38 is from Capital health authority. They comment first on the purposes of the act, and they state that the purposes are appropriate. Specifically, in relation to the inclusion of an additional purpose and whether that would be acceptable, their response is: no, leave things as they are.

In terms of definitions that should be modified, they have some recommendations.

> The current definition of "diagnostic, treatment and care information" could be broadened to cover socio-economic and other personal information about families gathered during the provision of health services, and to explicitly include genetic information or inheritable characteristics as does the FOIP Act.
>
> The impact of the current situation is that collection of family information is partially covered by HIA and partially covered by FOIP, and the rules for [the] protection, use and disclosure of this information, as well as access to it, are governed by each Act.

They also recommend that the definition of health service

> include all health services irrespective of who pays for them. This can be achieved by amending section 1(1)(m) so that it reads "health service means a service that is provided to an individual for any of the following purposes."

In terms of amending the scope of the act, Capital Health believes that "the Act should apply to health information in the custody or control of both public and private sector health service providers." Capital Health sees no benefit to extending the act to cover AADAC, PDD boards or other public bodies where health information is already protected under FOIP.

> The term "custodian" [should] include all members of a regulated health profession as defined in the Health Professions Act when they are not affiliates of a custodian. It should also include organizations employing such professionals to provide a health service, such as laboratories, diagnostic imaging centers and private surgical facilities.

On the question of ambulance services and whether they should be covered by the scope of the act, they say yes.

"Should the scope of the Act be changed given the implementation of the Electronic Health Record?" Capital Health recommends "broadening the scope of the Act to include all regulated health professionals," and that "would ensure that access is available to all [service providers] within the circle of care." However, they "wish to retain the ability to control how health care providers are able to access information provided by Capital Health through the [electronic health record] and, if necessary, limit the use that can be made of this information."

"Should health service provider information be included within the scope of the Act?"

> Even without these rules, any disclosure of health services provider information would be governed by FOIP and sufficient protection exists to prevent any harm coming to our employees. It would seem that removing these provisions would not weaken protection of this information and would simplify administration of employee records, but Capital Health has no specific recommendations on this matter.

"Should personal health information contained in [an] employee health file be part of the scope of the [act]?" They say no. They advise that "current provision presents administrative difficulties for human resource departments in health care bodies which have to differentiate between health information and other personal information in [employee] records." They recommend that "the definition "diagnostic, treatment and care information" . . . be amended to explicitly exclude employee health information except where the employee is a patient or client of the custodian employing them."

In relation to the scope of the act and whether it should be extended to WCB, they say no. They see "no reason to expand HIA

to include WCB" and believe "such an expansion might have the potential to diminish the privacy of individuals."

Relative to the Alberta Blue Cross, they have no recommendation "although it would seem administratively more attractive for that organization to be covered by HIA than partially covered . . . (as an affiliate), perhaps partially covered by FOIP . . . and partially covered by federal privacy legislation."

"Should the definition of health information be changed to include non-recorded information?" They believe

> the current provisions relating to non-recorded health information are adequate and appropriate . . . One possible way to provide additional protection for [nonrecorded] information might be to broaden Section 107 (2) of the Act so that use or disclosure of non-recorded information in contravention of the Act is also an offence.

Are the processes for individuals obtaining access to the records appropriate? Their recommendation is that

> routine access to information . . . be more clearly encouraged by making section 17 of [the act] as explicit as section 3(a) of the FOIP Act and stating that the procedures are in addition to and do not replace existing procedures. This would make access under the Act a method of last resort rather than one of first resort.

"Are the exceptions to the individual's right to access their own information . . . appropriate?" Their recommendation is that

> Section 11(2)(a) of [the act] be amended to allow for disclosure of any information supplied by an individual about a third party subject to the discretionary exceptions contained in section 11(1). This may not be necessary if our earlier recommendation to redefine "diagnostic, treatment and care information" is accepted.

Are the amount of fees set out appropriate? They recommend that

> the fee structure should be reviewed annually to ensure [that the] fees continue to reflect the costs of processing requests.
>
> HIA has added substantial administrative costs for the processing and reviewing of requests for health information. [Capital Health's] workload has increased substantially since 2001 and has doubled since assuming responsibility for mental health services . . .
>
> There is an increasing subsidy from operating costs to process these requests and we can only see this continuing to increase in the future as more people become familiar with [the act] and as Albertans' awareness of privacy issues increases.

Should the act be amended to address the concept of custody or control of a custodian within the EHR?

> Capital Health recommends that HIA makes it explicit that the onus for protection of identifying health information obtained from [the] electronic health record rests with the custodian who accesses that information.

They support the view that "access by an individual to that individual's EHR information or information about disclosure from the EHR should be coordinated by the health region with custody of that information."

10:10

"Is the duty to collect health information directly from the individual except as authorized appropriate?" Yes, no changes required.

"Should custodians be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide health care?" They state that "there are circumstances when [the] collection of family health history can only be done indirectly with and without consent. These include situations where the individuals concerned are dead or have moved away." They recommend that section 22(2)(e)(i) be reworded in line with the wording in the consultation guide "to make it clear that indirect collection of medical, genetic and other family information is permitted in order to provide a health service to an individual."

In regard to the requirement to inform individuals about collection practices and whether it's effective, they say yes. They go on to say that they've managed that through posters and plaques.

"Are the purposes as currently listed in the Act appropriate for existing custodians?" That's the use purposes, and they say yes.

Is it appropriate to use individual identifying health information without consent for the authorized purposes?

> Capital Health believes that custodians should be accountable for how they use health information that has been disclosed to them and that the disclosing custodian has the right to indicate when making such disclosure whether or not [the] use is restricted.

They indicate that "Albertans are strongly in favour of use of electronic health records for care and treatment but are much less likely to approve of their use for supplementary purposes."

"Are the elements of consent appropriate?" They indicate that the elements of consent have "increased the administrative burden on custodians," but they believe that's necessary for transparency purposes. They state that "the concept of verbal consent would create both operational and legal difficulties in that there would be no record of consent having been given and it could create adversarial situations that are irresolvable." Their recommendation is that "the Government of Alberta . . . provide an education program to ensure that the requirements for consent are understood and complied with by the private sector."

> Are the discretionary disclosures without consent . . . as listed in the Act reasonable and appropriate?
>
> Capital Health believes that the privacy loss to an individual would be minimal if hospitals and continuing care centres were able to disclose the presence and location of an individual within those facilities, subject to the individual having a veto on that disclosure.
>
> Section 35(1)(b) provides for disclosure without consent to any person for providing continuing treatment and care. Capital Health has experienced operational difficulties in interpreting this section in that many of our patients and clients need assistance that is not "medical" in nature. This includes help in finding adequate shelter, food and financial assistance. Capital Health would like to see this term better defined in order to assist us in helping our clients.

So they recommend "a definition of 'continuing treatment and care' that includes the provision of shelter and financial assistance."

They also support

> expanding section 35(1) to permit disclosure of limited diagnostic, treatment and care information to third party insurers and other governments for the purpose of obtaining payment from them for health services. However, we also believe that third party carriers have an obligation to clearly advise their clients that such information will be collected in order to pay claims.
>
> Should the discretionary authority to disclose to police services without the individual's consent, be extended to disclose basic registration information . . . for purpose of providing a warrant, subpoena or court date?
>
> Capital Health supports the redefinition of "police service" to ensure that it includes both the RCMP and First Nations police services.
>
> Capital Health has encountered difficulties with police services in terms of disclosure, especially when there have been non-life threatening situations involving individual or public safety and security. However, HIA seems to have created the right balance between protecting individual privacy and the duty of the police to protect and preserve the peace. We note that 86% of Albertans surveyed by the [Information and Privacy Commissioner's office] in 2003 stated that consent should be required before disclosure of health information to law enforcement officers.

On the triplicate prescription program they agree with "the policy position outlined in the Consultation Guide that there is already adequate authority under HIA whereby health information can be disclosed for the purposes of this program." They see no need for explicit authority.

> Granting explicit authority for one purpose can only lead to requests for explicit authority for other purposes authorized or required by legislation . . . It might be better for a listing of such requirements or authorities to be provided in the Guidelines and Procedures Manual or in some other guidance document provided by the Government of Alberta so that custodians have a ready point of reference when asked for health information.

"Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information?" They recommend "explicit inclusion of genetic information in the definition of 'diagnostic, treatment and care information.'"

"Is an informed/knowledgeable implied consent model for care and treatment appropriate?" They agree with the statement that consent should be based on knowledge.

Would there be operational and service delivery implications? Capital Health believes that "all custodians should inform individuals of this likely disclosure at the time of initial contact." Again, they talk about doing so through print resources.

Are the research provisions in the act reasonable and effective?

> The research rules contained in [the act] have the potential to place heavy burdens both on researchers and custodians. At times this has been challenging for the research ethics boards and custodian, and has caused some delays in the conduct of research. However, the current system of balancing privacy against the need to have access to health information seems to be working.

"Are the duties and obligations on the custodian appropriate and reasonable?" They support "the need to have clear agreements in place both with other custodians and non-custodians when handling individually identifying health information." However, "because all custodians have the same obligations under [the act], we do not see the need to have an additional Information Manager agreement between custodians; rather we feel an agreement as outlined above would suffice."

They recommend that "section 42 be removed entirely or limit the purpose and authority to the disclosure of records containing identifying diagnostic, treatment and care information." They would also

> support a regulation that defines the scope and content of Information Manager Agreements as envisaged in section 66(2) of the Act, or removal of the provision. Information Manager Agreements [should not] be required between custodians.

On the list of substitute decision-makers they comment that section 35 should "be amended to allow for broader disclosure to family members recognized through policy and procedure in order to assist in making decisions on continuing treatment and care."

"Are the offences and penalties appropriate?" Yes.

On the regulations. Any suggestions for improvements? Capital Health would support a regulation dealing with the transfer, storage, or destruction of records so that they can be compliant with HIA. "As stated above . . . we would also support a regulation that defines the scope and content of Information Manager Agreements."

Mr. Snelgrove: I wonder if you could obtain for me the survey they quoted as the 2003, suggesting that 86 per cent of Albertans would agree that consent be required. Unless they did the survey in the Remand Centre, I think that the question must have been extremely leading. I would like a copy of that if I could.

Ms Gallant: It was the survey that we did through our office, so if you'd like, I can provide the entire survey to the committee. Sure.

The Chair: Thank you.

Other questions or comments? Well, perhaps we can do another one before we take a break if your voice is still okay, Wendy.

Ms Robillard: Absolutely.

Submission 39 is from the Independent Insurance Brokers Association of Alberta. They comment on the question about personal health information in an employee file and whether it should be part of the scope of the act, and their response is no.

The Chair: I suggest that we take a 15-minute break, if that meets with the committee's approval. We will reconvene at 25 to 11.

[The committee adjourned from 10:19 a.m. to 10:35 a.m.]

The Chair: We will call the committee back to order.

Before I ask Wendy to proceed with the next submission, I have had an issue raised by Ms Blakeman, and I will ask her if she would like to raise that question at this point.

Ms Blakeman: I'm asking the staff that's here if they're able to give me some information around the disclosure to the minister or the department that's available under section 46 in the act. I'm wondering if this has ever been made use of, and if so, can we get some information? Obviously, not identifying information about the circumstances in which it came about. I suppose there's also the possibility that it's never been used or requested, but if I could get the research done on that, I'd appreciate it.

The Chair: Any comments on that? Wendy, Roseanne, anybody?

Ms Gallant: Well, the one comment I would make is that under this particular section the minister, if contemplating disclosure under this particular section, has the obligation to submit a privacy impact assessment to the commissioner, and to date there has not been one submitted under this section. So if that's helpful to you.

Ms Robillard: I can also speak to this. No, to date the minister or department have not used section 46. However, we are contemplating using that provision in the near future. It does, as Roseanne says, require that a privacy impact assessment be completed, and I believe we are in the process of doing that. In the case that we're working towards right now is a quality assurance, quality improvement initiative around medication, lab reports, et cetera. So it will require, if the PIA goes forward, custodians, regional health authorities, and those people who operate labs to provide some information to the department so we can look at a quality improvement, quality assurance initiative. I believe it's relative to a specific drug and perhaps even to a specific illness or diagnosis. However, I don't have that level of detail.

Ms Blakeman: Would it have individually identifying information attached to it?

Ms Robillard: It would have to be individual in the first instance to get it to the department so that the information can be analyzed. The analysis itself I assume can be done based on aggregated information, but somebody within the ministry would have to anonymize or aggregate that information so the analysis could be done by another person.

Ms Blakeman: Thank you.

The Chair: Okay. Let's go with submission 40 then, please, Wendy.

I also perhaps should just comment that we are going to suggest that if we don't get through the order of the submissions that have

reference to the presentations this afternoon – for example, the ones on the police force – we will go out of order and cover those so that we have covered those before we receive the oral presentations. We'll watch the clock, and Wendy is mindful of that. So if we go out of order, that will be one of the reasons.

Ms Robillard: Submission 40 is from the office of the Information and Privacy Commissioner. The first section that they commented on was the definitions section, and they recommend that "the definition of a custodian should be amended to include corporate entities such as medical clinics, medi-centres, Local Primary Care Initiatives ('LPCI's)."

The second issue that they comment on is the issue of orphaned records. These records arise when a custodian is no longer a custodian. The examples they provide are when a health service provider such as a doctor sells a medical practice, goes into bankruptcy, retires out of the jurisdiction, ceases to practise, loses mental capacity, or passes away.

These events may occur suddenly and without warning. The result of this is that individuals lose their rights and protections under the act.

> Individuals may not be able to locate their health records and consequently can no longer exercise rights such as access, correction or amendment. The privacy of the health information may not be sufficiently protected.
>
> The additional difficulty is that when a custodian is no longer a custodian as defined in [the act] . . . the traditional sanctions no longer apply. The entities that usually exercise oversight functions such as health professional colleges and the Commissioner have no continuing authority over the provider and hence no continuing jurisdiction over the health information . . .
>
> I recommend that the definition of a custodian be amended under HIA to ensure that continuing responsibility for health information rests with a custodian who ceases to practice (and hence with their estate through their legal or personal representative).
>
> Individual rights and HIA custodian obligations for health service providers such as physicians currently only arise when the provider is paid by the [Alberta health care insurance plan]. Health service providers such as physicians have multiple relationships with individuals and health facilities. The same provider may be paid in various ways; for example as an employee, a contractor, via hospital or facility privileges or via joint appointments at health and academic institutions.
>
> The [Health Information Act] approach is becoming increasingly problematic with the intertwining of private and public partnerships in the financing and delivery of health services. The application of health legislation in other Canadian jurisdictions such as in Manitoba, Saskatchewan and Ontario does not turn on payment.

So the commissioner recommends amending the definition of a health service so as not to limit services paid for by the department.

Should the scope of the act be expanded to include other departments of the government, local public bodies, or to any other entity that has health information? The commissioner comments:

> Government departments have invested almost a decade of intensive effort to implement and fine tune the FOIP regime in their facilities. I see no compelling reason to impose the additional administrative burden of HIA on those public bodies.

So the recommendation is to

> maintain status quo for application to additional Government Departments and Local Public Bodies.
>
> Although HIA creates the authority to designate custodians by regulation, this designation goes to the scope of the Act . . . To the extent possible, decisions of this significance should be entrenched as a matter of statute rather than regulation as entities could [easily] be . . . added or omitted by regulation without any requirement for public consultation.
>
> Although I am not making any specific recommendations about particular entities, in my view the committee should consider whether the [Alberta Health and Wellness] entities that have been designated as custodians under the . . . regulation for three years should now be included in the list of custodians under the Act . . .
>
> The provincial rights and protections for health information that Albertans have gained under [the Health Information Act] in the public sector by and large do not yet exist in the private sector. In my opinion, this issue should be addressed during this legislative review.

10:45

> Are the discretionary disclosures without consent . . . as listed in the Act reasonable and appropriate . . .
>
> Section 35(1)(q) of [the act] authorizes a custodian to transfer health records to a successor as a result of the custodian ceasing to be a custodian and when the successor is a custodian. This provision appears to [preclude] a custodian from transferring health records to a non-custodian and when a custodian is continuing to be a custodian.
>
> In situations where a custodian is ceasing to practice, there might not be another custodian interested in taking over custody and control of the health records. This is particularly the case due to the administrative burden involved and the current shortage of some types of health providers such as general practitioners in Alberta. A logical solution for a custodian who is ceasing to practice or for the estate of a deceased custodian might be to transfer the health records to a non-custodian such as a professional record storage company. Section 35(1)(q) appears to preclude [those] arrangements . . .
>
> In my view, [the act] should be amended to enable the custodian to transfer records and should not be restricted to situations where that custodian is ceasing to be a custodian.

Where the custodian is transferring records to a noncustodian, they should be required "at minimum to impose HIA obligations upon the recipient."

> Should the [act] be amended to include stronger provisions to protect the confidentiality of genetic information . . .
>
> The definition of "diagnostic, treatment and care information" . . . does not expressly include genetic information.
>
> The sensitivity of this information is obvious . . .
>
> The issue of genetic information arose in the last legislative review of the FOIP Act in Alberta. As a result of the recommendations made by that review committee, the definition of "personal information" was amended to include the individual's fingerprints, other biometric information, blood type, genetic information and inheritable characteristics.
>
> In my view, the definition of "diagnostic, treatment and care information" should be amended to include genetic information in HIA. The HIA definition should explicitly include genetic information to ensure that the same rules exist for access, correction and amendment as well as for the protection of privacy as for other types of health information.
>
> Are the research provisions in the act reasonable and effective?
>
> When approving a research proposal, HIA requires ethics committees to prepare a response outlined in the Act and to send a copy of the response to the Commissioner . . . [The act] is silent about the authority of the Commissioner to publish this type of information. It is unclear whether or not I am authorized to publish research approvals in a . . . registry on the Website.
>
> In my view, it is in the interests of openness and accountability to initiate a research registry on our Website for research approvals that have been granted by the designated ethics committees.

So they recommend amending the provision to create explicit authority for the commissioner to publish a summary of approved research projects.

Part 7, dealing with the commissioner.

> Do you have any suggested changes to this part of the Act?
>
> General powers and duties for the Commissioner include an explicit power of investigation including independent investigation to ensure compliance with [the act].
>
> It could be argued that the Commissioner already has the authority under HIA to conduct audits by virtue of these provisions. However, none of these powers explicitly authorize the Commissioner to conduct audits or to compel the information needed to complete the audit . . .
>
> An explicit legislative auditing power for the Commissioner is a powerful tool to ensure that custodians are safeguarding the privacy of health information. However, the exercise of this power may be contentious.

The commissioner recommends establishing "an explicit auditing power that expressly authorizes the Commissioner to conduct audits."

In terms of other issues

> the second FOIP review specifically recommended that consideration be given to harmonization of the FOIP and HIA during the three-year review of HIA. Consideration of any such amendments must keep in mind the fundamental differences between the two pieces of legislation.

The Chair: Dave Broda.

Mr. Broda: Yes. Thank you, Chair. A question, again, under orphaned records. The comment was made that when the custodian is no longer a custodian, files could be taken into a storage place who are really not custodians other than storage people. Is there a possibility of creating something that would protect that information? I'm going to give an example. If you don't have a will, you have a Public Trustee that looks after the children. So in those cases if the custodian does not have anywhere to revert his files to another custodian, then maybe a mechanism such as a public trustee steps in and takes charge of those files.

I'd also like to know what statistics have said. We didn't have any of these acts before. What happened in the cases of the information that has been collected? Has it ever been sold? What really happened to it? Has it been really that disastrous? I'd like to know if there are any statistics showing what transpired, if there is such information. But now that we are making people more aware, people are more cognizant of what's happening. I don't know whether a public trustee type of situation could seize those files that don't have other custodians to look after those files.

Ms Robillard: I don't know that we actually have any statistics about how frequently this happens. Obviously, it only comes to our attention or to the commissioner's attention where this is some kind of a problem. There are probably lots of situations that, shall we say, resolve themselves, however that might be, that don't come to anyone's attention. So I'm not sure that we would have that information.

Secondly, on the concept of potentially creating some kind of an oversight body to manage those records, I think the possibility exists. One of the issues, no doubt, will be: who operates that oversight agency, and who's accountable for the costs in terms of maintaining the records and, also, dealing with access requests, et cetera? Whatever that organization might be, it would likely have to be a custodian or an affiliate in some capacity and would have obligations upon it.

Mr. Broda: Further to that, you know, the fees or the costs that would be incurred, everybody pays a fee to an association. If you took 2 per cent or 1 per cent of a fee that would go towards an orphaned record fund when you're in practice, that would be in a reserve that somebody could look after. As you indicated, you don't know how many incidents there are. Maybe there are only 10 a year, but that gives that individual or that organization the authority to dispose of those records rather than having somebody holding them in their basement to burn them a year later.

The Chair: Thank you for the question.

Roseanne, did you have a comment?

Ms Gallant: No. Thanks. I'm going to withhold my comment at this time.

The Chair: All right. So noted.

Hector Goudreau.

Mr. Goudreau: Thank you, Mr. Chairman. Maybe to add to the confusion or the discussion – I'm not sure – we had an incident in Fairview where one doctor was in fact murdered and disappeared, and the police in their wisdom actually went in and seized the files. I received numerous phone calls from family members indicating: how do we access our own files? Some of them had taken tests and were awaiting results. Those results were in the doctor's files. Then they wanted to maintain their medical treatments and had no way of accessing them. To this date I'm not sure where those files are.

The Chair: Thank you for the observation.

Other comments or questions?

Okay. Let's go to submission 41.

Ms Robillard: This submission is by the Edmonton Chamber of Commerce, and they spoke specifically to question 7, "Should personal health information contained in an employee health file be part of the scope" of the act? They say no.

Submission 42, the Alberta Association of Registered Nurses. They speak first to the purposes in the act. They state that the purposes are appropriate. They feel that "a patient's right to privacy and confidentiality takes precedence over the 'need to know' of individuals not involved in the direct care of the patient with exceptions as required by law."

Will the inclusion of additional purposes be acceptable? Their response is no.

Should the scope of the act be expanded to include other departments of the government, local public bodies, or any entity that has health information? Their response:

> One of the most important objectives for policy-makers should be to attempt to rationalize the legislative regime so that, to the extent possible, organizations are only covered by one piece of privacy legislation. Either an omnibus piece of privacy legislation could be created or initiatives could be taken by the provincial and federal governments to harmonize existing legislation to eliminate overlaps and conflicts.

They feel that extending the scope of the act would only increase the duplication that currently exists.

> If all public and private health care agencies are not included as custodians under [the act] there will be gaps in the information collected and lack of ability to compare data across sites, setting and time.
>
> Including public bodies covered by FOIP would increase the duplication that currently exists and cause more overlap of legislative provision.

10:55

"Should operators as defined in the Ambulance Services Act be included in the scope?" Yes.

> Should the scope of the Act be changed given the implementation of the Electronic Health Record . . .
>
> The policies, procedures and practices to achieve privacy protection for health information should not be different for an electronic health record than with a patient record where an authorized health professional can access the record.

"Should personal health information contained in an employee . . . file be part of the scope of the [act]?" They talk about this in relation to occupational health and safety, and they indicate that the

> Occupational Health and Safety legislation provides guidance in these kinds of situations and the AARN does not think that personal health information contained in employee health files should be part of the scope of [the act].

"Should the definition of health information be changed to include non-recorded information?" They would not support the definition of health information changing. "Non-recorded events increase the potential for discrepancy and errors in information due to differences in an individual's recollection and interpretation of the events."

> How should [the act] be amended to address the concept of custody or control of a custodian within the EHR?
>
> In the development of an EHR there will be guidelines and policies that address access to an individual's own health information, as well as policies and processes for security and privacy. Although the process for authorization and authentication may differ with access to health information in an electronic format versus access to written documentation from a patient record, the concept of custody or control should be the same and would not need to be specifically addressed.

Should custodians be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide care? "Nurses recognize that individuals have the right to make informed decisions and this includes the right to refuse or withdraw consent for care or treatment." But they also indicate that the collection of information is one component of their process and provision of care.

"Are the elements of consent appropriate?" The AARN feels that the elements of the consent are too detailed. They do not agree with verbal consent, but they suggest that the following elements should be in a written consent: indication of who is to receive the information, effective dates of the consent to disclose information, and description of the information to be disclosed.

"Are the discretionary disclosures without consent . . . as listed in the Act reasonable and appropriate?" They say yes and that they shouldn't be restricted. They go on to talk about an overlap and a conflict between the HIA and the Health Professions Act. The Health Information Act

> requires health professional bodies to destroy individually identifying diagnostic, treatment and care information obtained from a custodian at the earliest opportunity after a final decision has been made in the professional conduct process.

Section 121 of the Health Professions Act, on the other hand, requires the body to retain this information for 10 years. So their concern is that those two conflict. They suggest that

> the simplest method to address these potential areas of conflict is to amend the [Health Information Act] by deleting the current section 35(4) and adding a provision providing that a custodian may disclose individually identifying diagnostic, treatment, and care information to a health professional body for the purpose of an investigation, a discipline proceeding, a practice review or an inspection where such a disclosure is authorized by or under any Act governing the health professional body.
>
> Should the discretionary authority to disclose to police services without the individual's consent, be extended to disclose basic registration information . . . for [the] purpose of providing a warrant, subpoena, or court date . . .
>
> RNs must respect the legal and ethical requirements to keep client . . . information confidential. Under certain specific situations, breaching confidentiality may be necessary.
>
> Should the [act] be amended to include stronger provisions to protect the confidentiality of genetic information . . .
>
> Genetic information should be no more or less confidential than other health information. It is important that an informed consent is obtained prior to obtaining . . . genetic information to ensure that the purpose for collecting and [disclosing] the information is explicit.

Is an informed/knowledgeable implied consent model for treatment and care appropriate? "Privacy of health information is a priority value held by individuals and an informed written consent should be required." It should contain the following elements:

- be in writing;
- be signed and dated by the client and witness; and,
- describe the particular information to be disclosed, the purpose for the disclosure, and effective dates of the consent to disclose the information, and who is to receive the information.

Mr. Lougheed: Under 24 there, "Under certain specific situations, breaching confidentiality may be necessary," in the document submitted, was there any elaboration?

Ms Robillard: I don't believe so.

The Chair: Thank you, Rob.

Dr. Pannu, did you have a question?

Dr. Pannu: Yes, Mr. Chair. Concerning question 3, expansion of the act "to include other departments of the Government," et cetera, the question of duplication is raised I guess rather explicitly in this brief. What's your view of this problem? Is this likely to become a major problem if the act is extended to include others?

Ms Robillard: Yes. We spoke about this at the last meeting, the concept of duplication, in fact triplication in some cases. It is an issue for some organizations, without a doubt.

Dr. Pannu: Okay.

The Chair: Other questions or comments?

Okay. Proceed.

Ms Robillard: Submission 43 is from the Canadian Association of Chain Drug Stores. They first comment on definitions. They indicate that "the definition of a custodian under the Act should be amended to include all the health professionals such as allergists, nurses and technicians in diagnostic labs."

In terms of expanding the scope of the act, they fully support the act "being expanded to include all publicly and privately funded health services providers."

In relation to the scope of the act, given the implementation of the electronic health record, they

> strongly recommend that any provision related to standards for electronic health records or custodians using electronic means to collect, use and disclose personal health information, should be harmonized with the federal privacy legislation.
>
> Should health service provider information be included within the scope of the Act?
>
> Recommendation that the legislation be amended to remove health service provider information (HSPI) from the scope of the Act.
>
> . . . the protection of personal or professional information about providers is outside of the purposes outlined in section 2 of the [act].

> Rather than providing accessibility to a provider's information for purposes related to providing health care to patients, the HIA actually prevents this information from being accessible to most stakeholders . . .
>
> Information about the prescribing activity of identifiable physicians can be used to improve systems for drug warnings and recalls.
>
> For these and other reasons, in many Canadian jurisdictions, the trend is toward not including health services provider information in privacy legislation.

With regard to the triplicate prescription program, they support that amendment.

In terms of "other," they comment:

- Improved health care, from the perspective of an individual's treatment and universal access to quality services, should be the fundamental outcome and guiding principle underlying health information legislation;
- sharing of health information among health care providers to improve patient outcomes should be encouraged and should form the basis on which the legislation is founded; and
- effective regulations in this area must: strike a balance between protecting privacy and making sure that health information is available when needed for health care purposes; be sufficiently flexible to account for unique privacy needs and [concerns]; clearly establish accountability; and be based on accurate, complete and up-to-date information.

The Chair: Questions?

Let's go to number 44.

11:05

Ms Robillard: Calgary health region. They comment on the purposes of the act. Are they appropriate? "Yes."

Are there any definitions that should be modified?" They have a number of recommendations here: the definition of affiliate.

> There are significant differences between the types of affiliates and it may not be appropriate to impose the same duties and obligations on Custodians with respect to all of [them]. The Region recommends the Committee consider whether the definition of affiliate should be split into three separate definitions: (1) a definition encompassing employees, volunteers and other members of the workforce over whom Custodians have direct control, (2) a definition encompassing business partners, vendors and agents over whom Custodians have indirect, contractual control and (3) a definition encompassing physicians and their interaction with other Custodians (e.g. health regions). These new definitions would enable the Committee to more precisely define a Custodian's obligations with respect to its affiliates.

They also say that the committee "should consider expanding the definition of affiliate with respect to physicians." Under the current definition only physicians with hospital admitting privileges are covered. The "narrow definition of physician affiliate is therefore capturing a smaller and smaller percentage of physicians within health regions, which may not be appropriate in the current health care environment."

In terms of the definition of custodian,

> the Region strongly recommends that the definition of "custodian" be expanded to capture any individual or organization whose primary purpose is the delivery of health care services to individuals and whose activities are regulated by the Health Professions Act. The Region suggests that the definition of "custodian" should be based on function, not funding.

The definition of diagnostic, treatment, and care information:

> . . . and includes any other health-related information collected when a health service is provided to the individual" instead of: "and includes any other information about an individual that is collected when a health service is provided to the individual.

In regard to the scope and the application of the scope to the government of Alberta and local public bodies, they say that, no, it should not apply.

> Should operators as defined in the Ambulance Services Act be included in the scope?
>
> Yes. However, [they note] that such operators will fall under the Act when their governance and funding becomes the responsibility of the Region as expected in the near future. Therefore, it may not be necessary to amend the Act to include operators.
>
> Should the scope of the act be changed given the implementation of the Electronic Health Record?
>
> Restricting the application of the Act to health service providers that provide publicly funded health services creates administratively challenging requirements in the context of the Electronic Health Record.
>
> Should health service provider information be included within the scope of the Act?
>
> The Region supports the inclusion of health service provider information within the scope of the Act, but suggests that Custodians should be allowed to share this information with other Custodians for the purposes listed in [section] 27(1) and (2) of the Act without the provider's consent. The current provisions regarding disclosure of health service provider information are very strict, which can hinder a Custodian's quality assurance and improvement activities, and potentially even affect patient safety. However, the Region supports including provider information in the scope of the Act as it is important to clearly differentiate health service provider information in its custody from other employee information . . . in light of quality assurance activities and section 9 of the Alberta Evidence Act.
>
> Should personal health information contained in an employee health file be part of the scope? "No."
>
> Should the scope . . . be extended to include [the Workers' Compensation Board]? "No."
>
> Should [Alberta Blue Cross] be subject to the HIA? "No."
>
> Should the definition of health information be changed to include non-recorded information?
>
> No. It would be virtually impossible to grant access rights to non-recorded information . . . Expanding the Act to include non-recorded information will create significant administrative burdens without a corresponding benefit.
>
> Is the process for obtaining access to [health] records appropriate? "Yes."
>
> Are the exceptions to the individual's right to access their own information . . . appropriate? "Yes."
>
> Is the amount of fees set out in [the act] . . . appropriate?
>
> Yes. This issue should be revisited to determine if the schedule continues to be appropriate in the future when information will be retrieved and reproduced from electronic databases, as actual costs may be relatively higher or lower. The Region also recommends that the fee schedule be periodically assessed to ensure it continues to accurately reflect the costs of producing records.
>
> How should [the act] be amended to address the concept of custody or control of a custodian within the EHR?
>
> The Region regularly fields concerns from the general public regarding unrestricted and almost universal access to their health information in the EHR environment. The current provisions of the Act do not always allay their fears. The Region is concerned that public support for EHR initiatives may wane if issues regarding the custody and control over collection, use and access of information are not clearly specified.
>
> The Region recommends that this Committee and all stakeholders carefully consider the general public concern with the notion of "big brother" databases when contemplating how to define "control" in the EHR environment . . .
>
> The Region suggests that Custodians rather than Alberta Health and Wellness retain custody and control of health information collected or generated by the Custodian.
>
> The Region recommends that the Committee consider which

Custodian is responsible for providing access to specific records within the EHR environment . . . The Region recommends that Custodians only be responsible for providing access to records collected or created by the Custodian.

The Region recommends that the definition of "record" be amended to more accurately reflect the EHR environment.

Collection of Health Information. Is the duty to collect health information directly from the individual . . . appropriate?

The Region recommends that the Act be clarified to remove the requirement that Custodians must collect health information directly from the individual. In an electronic environment, health information must often be accessed quickly from a multitude of data sources.

Should custodians be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide [a health service]?

Yes, they should be permitted to do so.

Collecting family information without express consent of the family members for the purpose of providing a health service to the individual results in better patient care without significantly harming patient privacy.

Is the requirement to inform individuals about collection practices effective?

The Act should be amended to specify how Custodians may inform individuals about their collection practices . . . The Region suggests that methods other than a general notice are typically not effective and can create operational difficulties to implement . . .

The Region suggests that the Committee consider amending the Act to allow Custodians to fulfill its duty to adequately inform individuals by posting a notice.

Use of Health Information. Are the purposes as currently listed in the Act appropriate? "Yes."

If you recommended an expansion of scope of the Act . . . what purposes/set of responsibilities would you change to reflect that?

The Region recommends that the Act be expanded to include all health care service providers regardless of the source of funding.

Is it appropriate to use [individual] identifying health information without consent for . . . authorized purposes?

Yes. [The region] strongly recommends that the committee retain this framework. Using information without consent in the limited situations specified in the Act promotes efficiency and a higher standard of patient care without negatively affecting patient privacy.

Overall, should the listings of authorized uses be expanded, restricted, or modified?

The Region recommends that the authorized uses listed in the Act be expanded to include the ability to raise money to fund operations. Allowing Custodians to conduct these donation-related activities would be beneficial to Custodians, help fund needed programs and improve overall patient care delivered by the Custodian. Information used and disclosed for this purpose should be limited to have a minimal effect on patient privacy.

Are the elements of consent appropriate?

Yes . . . The Region recommends eliminating the requirement to make the individual aware of the risks and benefits of why their health care information is needed. It is very difficult to capture all risks and benefits of disclosing or refusing to disclose information.

Are the discretionary disclosures without consent . . . reasonable and appropriate?

Yes. Specifically, the Region suggests section 35(1)(b) be replaced as follows: "to any person who requires the information for the purpose of providing care to the individual." Specifically, the Region recommends the following language be added as a new section 35(1)(r) of the Act, "for the purpose of directly responding to a complaint or allegation against the Custodian made by an individual in a public forum, provided that the Custodian may disclose only the minimum information about the individual as necessary to respond to the allegation" . . . The Region notes that in these situations, the individual has chosen to disclose health information related to the allegation in a public forum and therefore does not have a reasonable expectation of privacy for such health information. The Region is concerned that a Custodian's inability to appropriately respond to allegations results in decreased public confidence and trust in the public healthcare system.

Should the discretionary authority to disclose to police services . . . be extended?

No. [The] Region notes that police do not necessarily require access to registration information, or even a specific patient name, in order to obtain a warrant. The Region believes that the past three years have demonstrated that the current discretionary provisions regarding disclosure sufficiently balance patient trust and privacy with a reasonable level of law enforcement access to health information without consent.

With regard to the triplicate prescription program, the region "supports a limited and specific provision to disclose" to that program.

The Region further recommends that the committee consider requiring that these non-custodial regulatory bodies agree in writing to not disclose the information to any other person except as authorized by or under their governing statute/regulation, similar to the existing provisions under section 35(4) of the Act.

Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information?

The Region believes that this is a complex issue that requires careful consideration and extensive consultation. The Region strongly suggests including a clear, precise definition of "genetic information" to ensure there is minimal confusion regarding what information would be subject to this higher standard.

11:15

Is an informed/knowledgeable implied consent model for care and treatment appropriate?

The Region generally supports the Committee's efforts to make the Act substantially similar with PIPEDA, in order to minimize the overlapping privacy laws affecting Custodians. However, the Region is very concerned that the informed consent model proposed by the Committee could become impossible to administer if individuals have the ability to withdraw their implied consent for discretionary uses and disclosures of their information by Custodians.

The Region agrees that by seeking care, and having an opportunity to review the notice, the individual is knowledgeable about possible uses and disclosures of their information. By continuing to seek treatment, the individual has implicitly consented to the use and disclosure of their health information for the purposes identified in the notice.

Custodians such as the Region will be put in an impossible situation if the individual is able to withdraw consent for the discretionary uses and disclosures of information set forth in the Act (e.g. for providing health services and internal management). Withdrawal of individual consent to collect, use and disclose information for these core functions would directly contradict the Region's mandate.

Additionally, some information and administrative systems used by Custodians may not have the technical capability to track and honour an individual's withdrawn consent in all situations, making it extremely difficult for Custodians to always comply with the individual's request.

The Region recognizes this is a difficult issue, and recommends that the implied consent model be explored in greater detail, but with the provision that an individual may not withdraw consent for the existing uses and disclosures specified in the Act. The Region is hopeful that a modified informed consent model of the Act as described herein will be found substantially similar to PIPEDA.

Are the research provisions in the Act reasonable [and] effective? "Yes."

Duties and powers of custodians Are the duties and obligations on the custodian appropriate and reasonable?

Yes. Section 58(1) provides that Custodians must only collect,

use and disclose the minimum amount of information essential to carry out its intended purpose. The Region suggests amending this section so that it does not apply when the collection, use or disclosure is for the purposes of providing health services.

60(1)(b) provides that Custodians must protect the confidentiality of health information when stored or used in a jurisdiction outside of Alberta. The Region recommends deleting § 60(1)(b) and its accompanying regulation. [They] are redundant and Custodians already have a clear obligation to protect health information regardless of where it is geographically stored or used . . .

60(1)(d) provides that a Custodian must "ensure" compliance with the Act by its affiliates. The Region recommends modifying § 60(1)(d) to remove the word, "ensure" and replace it with "promote" or similar language. It is appropriate for Custodians to "ensure" compliance by affiliates who are employees, but is less reasonable to ensure compliance by physician affiliates or contracted third parties . . . [Section] 66 of the Act describes relationships with information managers. The Region recommends amending [this section] to explicitly provide that it only applies to information managers that are not Custodians. The Region believes that Custodians should not be required to enter into an agreement when the information manager is another Custodian. Entering into information management agreements with other Custodians subject to the Act is unnecessary and administratively burdensome.

Commissioner. Do you have any suggested changes?

The Region believes that the Act should be amended to allow for some discretion on the part of the Commissioner in deciding to initiate a formal review/mediation in response to a request. Such an amendment would allow Custodians to utilize an interim informal process to determine whether it would be more expeditious to resolve an issue between a Custodian and an applicant. An applicant would still retain the right to request a formal review if the parties could not reach a satisfactory resolution.

General Provisions. Is the list of substitute decision makers appropriate? "Yes."

Are the offences and penalties appropriate?

Yes . . . the Region believes that Custodians should have the ability to use limited registration information for fundraising purposes and this should not be an offence under the Act.

The Region recommends clarifying § 107 of the Act to specify when a fine will be imposed for a violation of the Act. In an electronic environment, one inappropriate action by the Custodian could result in a huge number of individual breaches under the Act. It is not clear whether the $50,000 fine can be imposed for each individual breach, or whether the fine is only applied to the action that resulted in the breach.

The Region recommends clarifying the Act to set a reasonable cap on the aggregate amount of civil fines that may be imposed on a Custodian [in a] year.

The Region recommends clarifying whether the penalties set forth in the Act can only be imposed on Custodians, or whether the Commissioner has the authority to directly impose fines on individuals employed by the Custodian.

Do you have any suggestions for improvements [for the] Regulation?

The Region believes that section 8(4) of the Regulations should be deleted.

The Chair: Are there questions? Comments?

Dr. Pannu: I want to start with perhaps part 6, question 29. "Are the duties and obligations on the custodian appropriate and reasonable?" If not, provide rationale.

It says that, yes, they're appropriate. Then "the Region suggests amending this section so that it does not apply when the collection, use or disclosure is for the purposes of providing health services." I'm not sure what's the point, because 58(1) "provides that Custodians must only collect, use and disclose the minimum amount of information essential to carry out its intended purpose." And intended purpose would be something other than health services? That second sentence brings in the issue of providing health services, and in the first sentence it simply stops with "intended purpose." Is that something different than the provision of health services?

Ms Robillard: That would be one intended purpose. A custodian may collect, I presume, for other purposes.

Dr. Pannu: Is that already provided for in the act?

Ms Robillard: Yes.

Dr. Pannu: For research, that is? Would that be one of the other intended purposes?

Ms Robillard: Not typically specifically for research purposes. However, custodians have obligations, regional health authorities in particular, so they may need to collect information to meet those obligations. It may not be simply limited to the provision of a health service. They could do a survey, for instance, in terms of how people feel access to health services is in the region. So it would have to be a purpose that's linked to what they're responsible to do, and should anybody question their collection, then they would need to justify it based on the purpose.

Dr. Pannu: Thank you.

My second question is about making some changes to the act to allow the use, including perhaps sale, of patient information for fundraising purposes.

Ms Robillard: I believe what they're saying – in the act currently there's a section that speaks to the fact that you can only use information that you have for fundraising purposes if you have the consent of the individual. I believe this health region is suggesting that if an individual has accessed their region, they should be able to use their registration information for fundraising purposes without consent; that's what I would take that to mean.

Dr. Pannu: So it's the removal of the condition of consent?

Ms Robillard: That's what I would understand.

Dr. Pannu: Is that, then, the same point that I guess earlier on was made? I just want to seek clarification again.

Ms Robillard: That was raised twice in this submission, once around the use of the information and once around penalties and fines, I believe.

Dr. Pannu: Right. Okay. Thanks.

The Chair: Thank you, Dr. Pannu.

Any other questions, comments?

Before we proceed, could we just have some additional information that Mrs. Sawchuk has found in response to Mr. Lougheed's question earlier, which we perhaps could read into the record. Mrs. Sawchuk, if you would like to do that.

Mrs. Sawchuk: Thank you, Mr. Chairman. It refers back to submission 42, the registered nurses. Mr. Lougheed had asked

whether there was a specific instance where they referred to where they would disclose information, and there is one little bit in their presentation here. It says:

> Health care professionals respect the legal obligation to disclose patient health information in order to promote individual or public health and safety. Any exception that currently exists is clear (for example, public health provisions for specific infectious disease risks or knowledge of possible child abuse).

11:25

The Chair: Any further questions?

Mr. Lougheed: No. Thank you.

The Chair: Right. Thank you, Mrs. Sawchuk.
Let's go to number 45 then.

Ms Robillard: This is from the Provincial Diversion Program Advisory Committee. They speak to two issues, the first being the scope of the act and expansion of the scope. They recommend expanding the definition of custodian.

> The inclusion of Alberta Justice and Attorney General and Alberta Solicitor General since they are integral to ensuring safety and security of the individual and the community in which he/she resides. Professionals within the justice and corrections systems may have specific "health-related information" about the individual that could assist in the development of plan of care and treatment, if required.

The second issue that they spoke on is around the use listings and whether the authorized uses should be expanded, restricted, or modified. They indicate that the Alberta Mental Health Board

> should be retained as having the designation of Custodian and should have its role extended to reflect its function as a user of health information, in that it requires access to mental health information from a number of sources, including the regional health authorities, in its planning of provincial mental health strategies. The AMHB has a key role in provincial collaboration, coordination and support to the mental health system.
>
> If the Review Committee supports the request for inclusion of a statement regarding "integrated programs" we recommend that there be an additional statement within Section 27(1)(g) to indicate that a cross-ministerial initiative that has met the criteria for an "integrated program" would be considered a Custodian and would be able to utilize individually identifying health information for "internal management purposes."

The Chair: We have questions.
Ms Blakeman first.

Ms Blakeman: I'm sorry. I cut you off again, didn't I?

Ms Robillard: Sorry. I thought that was only a one-page submission, Laurie. There are two. One more issue.

It's around discretionary disclosures without consent as listed in the act, whether they're reasonable or not. So they go on to speak further about the integrated program issue.

> In order to ensure that both individual and public safety and the individual's care and support are addressed, sharing of health information is critical, especially that information relating to an individual's mental health.
>
> Even with a signed consent form, situations have arisen in which health care professionals have been hesitant to provide information regarding the Diversion participant's progress, or, even information regarding whether [the] individual has followed through on a referral.

They talk about the section in the FOIP Act that speaks about integrated programs and indicate that the

> personal information may be disclosed "if the disclosure is necessary for the delivery of a common or integrated program or service and for the performance of the duties of the officer or employee or member to whom the information is disclosed." A similar category related to integrated programs would be appropriate for cross-ministerial mental health and justice programs such as Diversion.

The Chair: Okay. Question.

Ms Blakeman: Thank you. My understanding, then, under their part 1 is that they are recommending that the Minister of Justice and Attorney General and the Alberta Solicitor General and both of their departments be added and be able to enjoy all of the exemptions that are listed in the act under sections 39, 40, and 46.

Ms Robillard: They seem to be saying that they should be included in the act. If they would go as far as you have suggested: perhaps.

Ms Blakeman: Wow. Thank you.

The Chair: Any comments, Heather?

Ms Veale: I have not had any role in the preparation of this submission, so I couldn't comment further.

The Chair: Right.
Ms Kryczka, did you have a comment, question?

Ms Kryczka: Well, I just wanted to make it really clear in my mind. The Provincial Diversion Program Advisory Committee: can you be very specific about what "diversion program" means? You know, it's referred to, especially in the last paragraph, but I don't want to guess what it would be and would rather have it specifically explained.

Ms Robillard: We'll see if we can track information down about who's on the committee, but specifically I believe it's a cross-ministry committee that deal with diversion of mental health clients from the police justice system when their issues are more appropriately related to their health as opposed to commission of an offence or some other thing. They're diverting patients to appropriate care, which may not be through the courts or jails.

Ms Kryczka: So it's a combination of mental health, Albertans, when they come across problems with the law?

Ms Robillard: Yes. I can give you a little bit of background about them. A small working group was set up from the Provincial Diversion Program Advisory Committee. The committee is comprised of representatives from a number of ministries and reports to the Mental Health and Justice Partnering Deputies Committee.

The Chair: Roseanne.

Ms Gallant: Yeah. I was just going to mention that also within that submission it says: in order to divert eligible individuals from the criminal justice system, sharing of appropriate health information is essential. It says: within the diversion program individuals with mental illness may be considered for diversion at a number of diversion points, beginning with first contact with law enforcement to the Crown Prosecutor's office as well as for the remand centres.

Then at the end of the submission they indicate who submitted it. So it's on behalf of the Alberta Mental Health Board, the Solicitor General, a law firm, and then the Alberta Mental Health Board diversion co-ordinator, if that's helpful.

Ms Kryczka: Yes, it is. Thank you.

The Chair: Thank you very much.
Mr. Goudreau, do you have a question or comment?

Mr. Goudreau: Well, I think Karen's question was very, very similar to mine. I was trying to understand their submissions by trying to determine who these people were, and certainly that helps. Thank you.

The Chair: Thank you for the questions.
Number 46, Calgary police force.

Ms Robillard: Yes. The Calgary police force spoke to one issue, and that's the discretionary authority to disclose to police services without consent. They submit that "the discretionary authority to disclose to the police services without the individual's consent should be extended to disclose basic registration information to police services for the purpose of providing a warrant, subpoena or court order." They say that the registration information is vital to their ability to obtain the warrant.

> It is imperative that there be an amendment to the provincial legislation, specifically allowing the release of patient information to a law enforcement agency for the purpose of assisting in the investigation of criminal or provincial offence and protecting the health care professional from any criminal or civil liability for the release of such information in good faith. Alternatively, an amendment to the Regulation allowing for the disclosure of registration information to a law enforcement agency for the purpose of conducting an investigation would go a long way to maintaining our ability to obtain warrants and satisfying our duties under the Criminal Code of Canada. It is suggested that the HIA is amended such that it is more in line with the Freedom of Information and Protection of Privacy Act for the purposes of law enforcement.
>
> It has been our experience that the Health Information Act has compromised this cooperative relationship and is interfering with police duties and authority as outlined in the Police Act and the Criminal Code of Canada.

Dr. Pannu: On the very last part of the statement there in the summary, do they provide in the brief itself some specific instances how this act may have compromised the ability of police services to do the job that they do?

Ms Robillard: I don't recall.

Mr. Lukaszuk: In response to Dr. Pannu's question, the Edmonton police department has provided quite a collection of descriptions of instances where their work may have been hindered.

The Chair: Also, they will be presenting to us at 1 o'clock this afternoon, so certainly committee members would have the opportunity to ask questions to the police force.

Dr. Pannu: Does the Solicitor General's department have any information on this survey, a compilation of reported cases where police have in fact got in touch with the Solicitor General's department or the Attorney General's department – let me add another department here – indicating cases where they have had this difficulty arising from the coming into being of HIA?

Ms Robillard: I wouldn't be knowledgeable about that if there were.

Dr. Pannu: Is this something that's worth inquiring about, requesting information on?

Ms Robillard: Yes, we can certainly inquire about that. I can speak to information – and I don't have that with me today – that police services have provided to us around accessing health information. So we do have some information about that that they've reported directly to our department. Yes.

Dr. Pannu: Good. I'd still like to have that. Yeah.

11:35

Ms Robillard: In relation to the Calgary Police Service's submission, no, I don't see any specific examples noted. It's short.

The Chair: Wendy, perhaps we could do 47. Also, keep in mind that we probably should do 51 before we adjourn for lunch. Would that not have relevance to the oral presentation?

Ms Robillard: So we'll do 47, then 51?

The Chair: I'm just mindful of the clock, so if we could do at least those two before lunch. If we have time for more, we will. So maybe we could go to 47, then 51.

Ms Robillard: Okay. Absolutely.

So 47 is a submission from the Alberta Medical Association, and they speak to whether the purposes in the act are appropriate. The AMA says:

> The commitment to putting patient privacy first is too important to be relegated to Part 6 under Duties and Powers of Custodians. The commitment to operate upon principles of least amount of information and the highest degree of anonymity would become more powerful and contribute far more to the protection of privacy if moved to a preamble in Part 1 . . .
>
> Physicians fully accept that the use of individual patient information is a fundamental component of the overall provision of direct health [care] services. Additionally, we accept the use of aggregate patient information as a fundamental component of the management of health services and the health care system.

In terms of modification of definitions, they have a number of recommendations. To add a definition to "access," they suggest access as "the ability to acquire or possess health information in any format."

> In [the act] the word often refers to access by an individual (or authorized representative) to the individual's own health information.
>
> If this is the definition that is meant to apply, such a distinction should be spelled out and the word should not be used elsewhere in any other meaning.

The definition of an affiliate needs clarification.

> The breadth of this definition has caused concern in parties contracting with physicians. . . . Is any person who has a contract with a custodian thus an affiliate? Is every information manager an affiliate by this definition?

Confidentiality. They want a definition added. Physicians would support the definition, "the idea that health information needs to be protected and that custodians are obligated to protect it and keep it safe."

They also provide the CMA privacy code definition of confidenti-

ality and confidential, which means that "health information that is confided by a patient is kept secret and not disclosed or made accessible to others unless authorized by patient consent."

They suggest that we modify the current definition of custodian. "This should be modified to designate health service providers that are recognized under the Health Professions Act."

They want to add a definition of disclosure to add clarity to many subsequent portions of the act. "It is difficult to differentiate between 'disclosure' and 'use'."

They want to modify the definition of nonidentifying. They say that

> the test by which information is considered "non-identifiable" is too low a threshold. "Readily ascertained" could easily connote a low threshold of review.
>
> The definition of non-identifying information should guarantee that the use of such information without consent would not result in the patient being identified.

They want to add a definition of privacy. They support a definition that says: "our rights as individuals to determine when, how and to what extent information about us is shared."

Further, they talk about the CMA privacy code, which states that privacy is "a patient's right to determine with whom he or she will share information and to know of and exercise control over use, disclosure and access concerning any information collected about him or her."

They suggest adding a definition of security based on the CMA privacy code.

> [It] means reasonable precautions, including physician . . .

"Physical," I presume that should be.

> . . . and technical protocols, to protect health information from unauthorized collection, use, disclosure and access and to ensure that the integrity of the information is properly safeguarded. A breach of security occurs whenever health information is collected, used, disclosed or accessed other than as authorized, or its integrity compromised.

On the scope of the act, "the AMA supports expansion of the scope of HIA to cover all bodies, public or private, that collect, use or disclose [individually] identifying health information," and they support ambulance services being covered by the act.

In relation to the scope of the act and the electronic health record, they say:

> Unquestionably, EHR will deliver timely, necessary information. It will improve care, enhance efficiency and improve the health care system. With equal certainty, however, it threatens to remove the clinician's traditional and essential ability to protect information in his/her custody – unless HIA is amended to prevent such a dangerous trend.
>
> In the long history of medicine, certain principles have applied to the relationship between physicians, patients and the health information they exchange. These principles have served patients and health care well and, as we move into the electronic world of the future, they must not be lost or diluted.

They go on to talk about some issues which they believe are fundamental to information-sharing principles, the first being consent and disclosure. They say:

> Consent and disclosure in the EHR environment are the weak point in the "informed/knowledgeable implied consent model" proposed in the *Consultation Guide*. The model is acceptable – and reflects current practice – in direct care situations. It will work for collection and use in non-direct care situations. It will not work for disclosure for non-direct patient care situations unless the patient is allowed to consent and revoke consent.
>
> . . . Patients must be able to consent when their information is taken from EHR for non-direct care purposes.
>
> Finally, under HIA the patient must be able to revoke consent at any time.

On tracking access they say:

> A detailed audit log is required to ensure the appropriate information is available for the patient and the professional when needed to deliver continuing care. This audit log should show that the purpose for which information has been accessed through EHR are consistent with those authorized under Section 27.
>
> We recognize that creating such an audit mechanism is a complex task.

Respect for rights over need to know:

> A patient's right to privacy and confidentiality takes precedence over the "need to know" of individuals not involved in the direct care of that patient (with a few exceptions as required by law).
>
> This position is in direct opposition to many sections of HIA and is particularly important in the EHR environment.

No secret data repositories. "HIA should contain a prohibition against creating any repositories that cannot be audited and reported back to the individual or the physician responsible for his/her care."

Accuracy:

> We recommend that the Act should reflect that physicians can only ensure the accuracy of information that they record themselves. Physicians cannot be held responsible for information that they or their affiliates do not directly [collect] . . .
>
> Where patients cannot trust that the information remains confidential, where they cannot believe that their privacy comes first, there can be only two outcomes. First, that patients will fail to provide physicians with the information needed to appropriately diagnose and treat illness and disease. The second outcome, accordingly, will be substandard care and a failure of Alberta's health care system to deliver the quality its citizens expect and deserve.
>
> HIA must be amended so that the pursuit of information does not become more important than the protection of its confidentiality.
>
> Should health service provider information be included within the scope of the Act . . .
>
> Yes, [it] should be included . . . It should be subject to the same rigour as other health information under the Act. Express consent should be required before [disclosing] to third parties.
>
> Should personal health information contained in an employee health file be part of the scope of the Health Information Act . . . Yes.
>
> Should the scope of the HIA be extended to include [the Workers' Compensation Board] . . . Yes.

Should Alberta Blue Cross be subject to the act? "Yes."

"Is the process for obtaining access to records appropriate?" "Yes."

> . . . Some clarity should be provided within HIA with respect to the ability to serve as authorized representatives under the Section 104(1) provisions. Some members of the legal community are inappropriately using these provisions to take advantage of the lower HIA-regulated fees for an individual's access, instead of the professional medical-legal fees agreed to in negotiation between the AMA, the College of Physicians and Surgeons of Alberta (CPSA) and the Law Society of Alberta.

"Are the exceptions to the individual's right to access their own information . . . appropriate?" "Yes."

11:45

Are the fees set out appropriate?

> Fees for access and providing copies of records must not be so high as to prohibit patients' access on a purely financial basis. They must, though, be sufficient to appropriately remunerate physicians and office staff for the time and effort required to assist the applicant with his/her access request.
>
> . . . The fee should be raised to a level commensurate with other fees regulated or set by government. At minimum, the addition of some discretionary fees that might be applied in the case of complex charts would help to make the proposition fair for busy physicians and staff.

Is the duty to collect health information directly from the individual except as authorized appropriate . . .

[Clearly] these provisions appear to be acceptable, that clause 22(2)(d) should be clarified. What does reasonably practicable mean?

Should custodians be permitted to collect information about the individual's family health history without the consent . . . where necessary to provide health care to the individual . . .

Collection and use of family or genetic history is frequently essential for treatment and care and should be permitted. Restriction should occur, however, in the context of disclosure (for non-care purposes) and consent must be required. The same rule should apply to private insurance companies assembling family or genetic histories for actuarial purposes.

"Is the requirement to inform individuals about collection practices effective or does it create any operational difficulties?" "Yes," it's effective.

Are the purposes around use listed in the act appropriate?

Section 27(2) allows certain custodians further authority to use such information for: (a) planning and resource allocation, (b) health system management, (c) public health surveillance, and (d) health policy development.

Physicians believe there are very few circumstances . . . in which the Minister, a regional health authority [and/or] board would require individually identifying [health] information to manage the health system or develop public policy.

Section 27(2) should be removed, or amended to restrict such use of information to non-identifying information. In those few instances where the use of individually identifying information may be justified, the approval of the information and privacy commissioner must be a prerequisite.

If you recommended an expansion of the scope, what purposes or responsibilities would you change?

If private entities are added to the scope of [the act], as the AMA recommends, this will create circumstances where certain custodians or affiliates will be working within HIA in both public and private sectors.

A specific purpose/mandate should be included in expanded HIA for any new custodian whose practice will involve both public and private sectors.

Is it appropriate to use [individually] identifying health information without consent for the authorized purposes stated in the Act?

The opportunities to disclose without consent are too numerous, especially when the viewer is a regional health authority or government civil servant with no involvement in direct care.

For any situations beyond direct treatment and care, the patient's explicit consent must be required.

Exceptions to this rule should be the work of health professional regulatory bodies, third-party carriers for purposes of payment for health services provided and CMPA . . .

Canadian . . . Excuse me. Do you remember what that stands for, Heather?

Ms Gallant: Medical protective . . .

Ms Robillard: Protective association? Thank you.

. . . for medical-legal purposes. Disclosure without consent to third parties must not include disclosure of health services provider information for commercial purposes, [for example] disclosure of prescribing data to pharmaceutical firms or other commercial applications.

Overall, should the listings of authorized uses be expanded, restricted or modified . . .

Other than our Question 18 commentary [regarding] Section 27(2), and Question 20 regarding associated consent requirements, the current list of purposes can stand.

We also offer a comment with respect to existing processes under Section 27(d) and conduction [of] research. It would be useful to standardize the rules for disclosure of health information for projects reviewed by these ethics bodies.

Where there is disagreement between research ethics boards regarding proposals of mutual participation, HIA could establish a process to resolve such questions before granting approval for research to proceed.

Most importantly, the rules for disclosure of health information for purposes of research must be consistent throughout the province.

"Are the elements of consent appropriate?"

Yes. The AMA is satisfied with the current components of consent . . .

For non-direct-care situations, consent must be written, with the permitted exceptions as noted of regulatory bodies, third-party carriers . . . and CMPA . . .

Section 42(1) requires that a custodian that discloses individually identifying diagnostic, treatment and care information must inform the recipient in writing of the purpose of the disclosure and the authority under which the disclosure is made.

This provision appears to be redundant . . . It seems unnecessary, therefore, to subsequently notify the individual who originally applied for the disclosure about the reason and authority for the disclosure.

Section 42 should be deleted. At a minimum, it should be amended to directly reference non-direct-care situations since the practice of notification in direct care is impossible.

"Are the discretionary disclosures without consent . . . reasonable and appropriate?" For the most part, yes.

We recommend, however, that clause 35(1)(l) be modified. It allows discretionary disclosure to an officer of the Legislature, specifically, the Auditor General, the Ombudsman, the Chief Electoral Officer, the Ethics Commissioner and the Information and Privacy Commissioner. We fail to see why the Chief Electoral Officer should be included in this list.

"Should the discretionary authority to disclose to police services without the individual's consent be extended?"

Disclosure by the custodian to police without consent for purpose of providing a warrant, subpoena or court order would be acceptable on the conditions that (i) the prime directive applies as part of the preamble to HIA (ii) that the disclosure is discretionary and (iii) that the physician also has the discretion to consider any expressed wishes of the patient.

The CMA Code of Ethics and the longstanding physician practice will dictate that responsibility to the patient comes before responsibility to society.

The triplicate prescription program. They support the amendment. "Any such amendment, however, must be unequivocally focused on TPP alone."

"Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information?" "Yes. Express, written consent from the individual to whom the genetic information applies must be provided before it can be disclosed for non-direct-care purposes."

"Is an informed/knowledgeable implied consent model for care and treatment appropriate?" "This model is workable for collection and use. Given the environment of EHR, difficulty arises in the area of disclosure in terms of the 'operational and service delivery implications'."

Are research provisions reasonable and effective? "A standardized approach . . . should be reinforced through HIA."

Are the duties and powers on the custodian appropriate and reasonable?

Section 61 gives custodians the duty to ensure accuracy of health information. We recommend that the Act should reflect that physicians can only ensure the accuracy of information that they record themselves . . . This becomes a major issue in the EHR environment . . .

Section 64's duty to conduct a privacy impact assessment . . . is a substantial administrative task.

. . . The PIA process should be streamlined.

In regard to the commissioner, "any suggested changes?"

> Section 82 deals with duty to comply with an order . . . Clause 82(2) stipulates, "A custodian must not take any steps to comply with a commissioner's order until the period for bringing an application for judicial review under subsection (3) ends." Subsection (3) states that 45 days is the limit to apply for a judicial review, yet [subsection] (4) goes on to provide that "despite subsection (3), the court may, on application made either before or after the expiry of the period referred to in subsection (3), extend that period if it considers it appropriate to do so."
>
> The AMA believes that the ability to stay an order pending appeal is open to abuse. It seems ludicrous that once the OIPC has identified that a breach of the Act has occurred, the offender can indefinitely continue with a breach, without penalty, as the matter winds through the courts. There is no incentive for the offender to speed things up.
>
> The current structure of Section 82 severely restricts the OIPC's ability to deal with an issue or sanction a breach of the Act. It should be repealed or amended.

"Is the list of substitute decision makers appropriate?"

> On a related note . . . some clarity should be provided within [the act] with respect to the ability to serve as authorized representatives under the Section 104(1) provisions. Some members of the legal community are inappropriately using these provisions to take advantage of the lower . . . fees for an individual's access.

"Are the offences and penalties appropriate?" "Since we are unaware of any instances where these penalties have been imposed . . . the AMA will not comment."

Any suggestions for improvements on the regulations?

> The current base fee of $25 [for an access request] is unreasonable in today's environment and this makes little sense given the sensitive nature of the information being handled. The fee should be raised to a level commensurate with other fees regulated or set by government. At minimum, the addition of some discretionary fees that might be applied in the case of complex charts would [also] help to make the proposition fair for . . . physicians and staff.
>
> We noted that the regulations have not yet been updated and still make reference to the repealed Section 59, consent for disclosure by electronic means.

The Chair: Thank you, Wendy.

We have a question.

Mr. Goudreau: I'm referring to section 5. On page 59 they talk about "no secret data repositories." By bringing it up, are they indicating that those things exist?

Ms Robillard: I would assume that they're implying that they exist.

Mr. Goudreau: We had an incident where a family was requesting information on their father, who was in long-term care, and it seems that before they were able to get the file, the file was purged. By the time the family got the file, there was really nothing there that was useful for them. I'm just wondering where that information ended up and whether we need to address that.

The Chair: Tough questions, Hector.

11:55

Ms Robillard: Are you saying information from a purged file?

Mr. Goudreau: Well, the provider indicated that before we turn the file over to you as family members who had the authority from the father to get that information – it ended up that they felt they were receiving only part of the file. The reason for requesting it was that they were wondering how come the father went from long-term care to a hospital situation very rapidly and what kind of treatment the father had received, and they could not get that type of information. They are saying: where did the information go?

Ms Gallant: Well, I would just comment that in the instance you're describing, it sounds more like they made an access request to the father's health information. Therefore, the custodian, in providing access to the authorized individual, which could be the family member, then chose to sever parts of the record. They should only be severing, of course, under the limited and specific exceptions under the HIA. I don't know if they did or they didn't because I don't have access to the example.

To me that would perhaps differ from what is being proposed here, that there be no secret data repositories. This sounds more like electronic databases that they're referring to and perhaps are suggesting exist. That would be my take on it too. I'm not sure. They don't give any examples in their submission?

Mr. Goudreau: That's right. It's scary.

The Chair: Okay. Ms Kryczka, you have a question?

Ms Kryczka: Yes. Well, more of a comment. This is part 1, number 2 on page 56, how they address definitions. I think it's important. I've seen other work in government where we have not got clarity in defining certain words and terms: types of housing, types of seniors' housing, different levels of care, et cetera. We don't have clear enough definitions, and they're not used consistently. I just think that the work they have done here is very good. I know that definitions have been referred to in the other submissions, but they do a good job here.

The Chair: Thank you, Karen.

Ms Blakeman.

Ms Blakeman: Thank you. Could we ask that the staff go back to the AMA and ask them for clarification on their statement about secret depositories and see if we can get either specific or anecdotal information from them? It's piqued everyone's interest, but they can't leave us dangling like that.

The Chair: Thank you.

I would like to ask the indulgence of the committee that we do 51 even though we are at your lunchtime. Could we quickly do 51 then, Wendy?

Ms Robillard: We can try to do it quickly.

Value Drug Mart. They speak to whether Alberta Blue Cross should be subject to the scope of the act. Their response is that if they're considered a custodian and no other amendments are made to the legislation, then they "would be provided with an unfair business advantage to provide insurance services in Alberta." So that's their response there.

In terms of disclosure of health information around the triplicate prescription program they currently state that "custodians cannot disclose personal health information to adjudicators or prescription drug plans without first obtaining written consent." They talk about how difficult that obligation is, so they're recommending that this type of disclosure be enabled.

"Are the offences and penalties appropriate?"

> The HIA also states that it is an offence to use individually identifiable health information to market any service for a commercial purpose. For continuity of care, follow up with patients is a critical

> aspect of improving the health and wellness . . . If a pharmacy calls a patient to remind them that their heart medication needs to be refilled, the pharmacy could be considered using individually identifiable health information to obtain a fee associated with dispensing a refill of a prescription. However, if the patient is not reminded to obtain a refill of their medication, they may suffer from a heart attack. If a physician calls a patient to remind them that they have to make an appointment for follow-up, they are doing this for continuity of care, but the physician also experiences financial gain (commercial gain) from the results of this process – another office visit and associated fee. It would be prudent for the HIA to provide a clearer definition to where the line of continuity of care as opposed to commercial activity is. Otherwise, health care professionals will reduce their provision of follow-up, monitoring and preventative health services.

The Chair: Are there questions, comments? Seeing none, thank you very much, Wendy.

When we resume with submissions, we'll start with 49. We will now break for lunch. I would remind committee members that at 1 o'clock we will hear from the Edmonton police force, the first of our oral presentations.

Thank you.

[The committee adjourned from 12:01 p.m. to 1 p.m.]

The Chair: We will call the committee back to order. I welcome everyone back.

As you all know, this afternoon we will receive the first of the public presentations that we are scheduled to hear as a committee of about 13. We're very pleased to welcome the three ladies from the Edmonton and Calgary police services to give you a presentation this afternoon and to answer your questions.

So what I'm going to do is ask the committee members if they would please introduce themselves, and then I'm going to ask Ms Ning Ramos to introduce herself and her colleagues. So maybe starting with Thomas, could we go around to committee members first, and then other members, if you would please introduce yourselves.

[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 Miller, Ms Robillard, Ms Swanson, and Ms Veale]

Ms Sorensen: Rhonda Sorensen, communications with the Clerk's office.

Mrs. Dacyshyn: Corinne Dacyshyn, committee clerk.

Mrs. Sawchuk: Karen Sawchuk, committee clerk.

The Chair: Ms Ramos, we welcome you again and would invite you to make the introductions of your colleagues and then proceed with your presentation.

Ms Ramos: Thank you, Mr. Chairman. I will start with introductions. My name is Ning Ramos, and I'm a legal adviser and FOIP co-ordinator with the Edmonton Police Service. To my right is Sergeant Darlene Savoie, who is a legal adviser with the Edmonton Police Service. To my left is Ms Hina Thaker, who is a legal adviser and FOIP co-ordinator with the Calgary Police Service.

Before we start with the presentation, I just wanted to thank the committee on behalf of both the Edmonton Police Service and the Calgary Police Service for inviting us to present and make further submissions as well as for the opportunity to answer any questions you may have. As you'll be well aware, disclosure to law enforcement under the Health Information Act is an issue that has a significant impact on our members and their ability to conduct their duties.

Prior to starting with the presentation, I wanted just to make some opening remarks about what amendment or addition we're seeking under the Health Information Act. What we're looking at is a limited provision wherein disclosure can be made by health service providers to law enforcement bodies with respect to registration information such as defined under the Health Information Act, which would be name, address, telephone number, that sort of information. As well, we'd be seeking to a limited extent access to health services provider information, meaning the name of the custodian holding a certain record, address, telephone number, that sort of information. We're certainly not seeking to have disclosure made to law enforcement agencies pertaining to diagnostic or treatment care information without the proper warrant or order. Certainly, I can go on to explain that further on in the presentation.

What I thought I'd start with is just very briefly going over where the powers of the law enforcement agencies come from. They come from common law. As well, we have the Police Act for municipal bodies, municipal law enforcement authorities. As you can see, that arises from section 38 of the Police Act, which lists our authority, duties and jurisdiction of police officers. Just to provide a brief background – I'm not sure how many of the committee members are aware of that act and that we do have legislated duties – here is a list of some of them.

What I wanted to spend the bulk of the presentation on was just to give you an overview of other law enforcement disclosure provisions that are already provided for under other statutes, under other legislation, that give us the ability to get the name, address, telephone number, basic contact information, without having the use of a warrant, without having to use a court order, and without having to show immediate harm or life-threatening circumstances.

Before we go into that, you'll see that the theme in each of the pieces of legislation I'll be discussing uses the definition of law enforcement, so I thought I would start there by presenting to the committee what the definition of law enforcement means under the FOIP Act, the Freedom of Information and Protection of Privacy Act.

This definition pretty much is carried through in the other acts that I'll be talking about, and as you can see, it's a little broader than what is provided for in the everyday term of what people would think law enforcement would be. This includes policing, criminal intelligence operations. It also includes administrative investigations, including the complaint giving rise to the investigation. It also includes proceedings that lead or could lead to a penalty or sanction, including any other body which that might be transferred to to carry on with the penalty or sanction or to hear the rest of that investigation.

Under the FOIP Act you see the disclosure for personal information. Now, we're talking about without consent disclosures, where the police come and they ask for just contact information for the individual to be able to start the investigation or to be able to lay an information to obtain a warrant. I will go through what is needed in order to get a warrant, just as background for the committee.

So here you can see that a public body may disclose personal information without consent to another public body, a law enforcement agency in Canada, to assist an investigation. Again, the law

enforcement definition that we took a look at earlier is carried through there with a view to a law enforcement proceeding or from which one is likely to result.

As of January 1, 2004, this year, we got some provincial legislation that came in called the Personal Information Protection Act. The short form of it is called PIPA. That deals with private bodies, so private businesses and how they use, collect, and disclose information. Now they have to be responsible for that as well. The disclosure without consent provision to law enforcement is found under section 20, and again you see that it mimics the FOIP Act in that it says, "The disclosure of the information is to a public body or a law enforcement agency in Canada to assist . . . undertaken with a view to a law enforcement proceeding" or, again, from which one can result. That's provincial legislation.

It also gives a further provision that disclosure of information can be done without consent if it "is reasonable for the purposes of an investigation or a legal proceeding."

We also have the Personal Information Protection and Electronic Documents Act, PIPEDA, which is the federal legislation. Again we're looking at disclosure without knowledge or consent. It's found in section 7(3), and it goes on. Clause 4.3 of schedule 1 just deals with consent issues. So if somebody gives you consent to get their information, then you can pretty much get their information to the extent that they've consented to. Whatever they say you can have, you can have. Again you see that the disclosure is requested for the purpose of enforcing any law of Canada, a province, a foreign jurisdiction carrying out an investigation relating to the enforcement of a law, and away it goes. So it does mimic the FOIP provision pretty closely, and that's what we would be seeking as an amendment.

Again, I'd like to just remind the committee that we're seeking a very limited amendment to registration information, which to my understanding does not contain any health information, and as well to health services provider information only to the extent that we can find where the records are, know who the custodian is, find the telephone number so that when we go on – and you'll see the conditions for swearing out an information for a warrant – we can tell a Justice of the Peace or a judge this so that they know we're not on a fishing expedition, that, you know, we know where the records are and we do have reasonable and probable grounds to know that they're there.

Now, we take a look at the Health Information Act, and at this point there's nothing for law enforcement that I can see in the act where we would get registration information or health services provider information without fitting under this. This is how it's been implemented in cases where we have sought to get information from health care service providers. They said that you've got to fit into 35(1)(j).

So we've run into situations where it's a life-threatening injury, which gives rise to them being able to contact law enforcement agencies and give us some information. But at that point the concern has been that if that person sustaining a life-threatening injury says, "Please don't release my information," or in whatever fashion does not give their consent, we still wouldn't have the ability to get that information, and we wouldn't have the ability to investigate any crime-related facets of that injury.

1:10

The other thing, too, is that there may be crime-related injuries that are happening and that our health care providers may be suspicious of, but it doesn't give them an ability to contact police and just have us become aware of that because they're not life-threatening injuries. But they could be crime related. Motor vehicle accidents are a good example. We have injured parties, our police officers attend the scene, and at that point they determine, you know, that either the parties need medical attention right away or they're incapacitated to the point that we couldn't start our investigation without having them looked after. So we call for EMS transport. The ambulance comes, takes them to the hospital. We do our investigation of the scene and then proceed afterwards to the hospital.

At that point, included in our original submissions, you can see that we've had some trouble even locating the patient after the fact. Even though we're the ones that sent them there and responded to the accident, we're not given the information of where they're taken to. Perhaps we don't even know their names at that point because they aren't able to give it to us or that's not the primary concern. The primary concern is getting them the medical attention that they need. And I know that Ms Thaker, my colleague from the Calgary Police Service, has had similar instances with their service as well.

The other way they've told us that we could try and get information is if a custodian believes on reasonable grounds that the disclosure will avert or minimize an imminent danger to the health or safety of a person. Well, if we don't have any information to begin with, we're not able to really fulfill the prerequisites of this condition. It's also at that point difficult for us to get a warrant or a court order because we have really very limited information that we could lay for the affidavit to get the warrant. I'll go on to discuss that as well.

I have tried to get information by using the section saying: if there's any enactment or other statute that may provide for you to be able to get this information. I've tried to use the Police Act, as you can see, as broadly construed as that is, to say: "Look; these are our legislated duties. The law says that this is what we have to do, as well as the common law." I've been told: "That's too broad. We're not going to release that information to you." So either way, we've tried to be creative, and we've really had, you know, certain difficulties in trying to get that information.

The interesting thing though – and this has been kind of a source of a chuckle for myself – is that under section 36 there is a provision for a custodian to give out identifying registration information, which is what we're seeking the amendment for, to collect a debt owed to the government of Alberta or to a custodian, a health care provider. So the act does recognize that some information, though health information, is accorded special status in case law. That's true. There is some recognition under the Health Information Act that this information can be given out, and it would not be an unreasonable breach of Albertans' privacy as provided for in the act already.

So it's interesting that as law enforcement bodies with a legislated duty under the Police Act, we're not able to get information to enforce the laws of Canada, especially our Criminal Code laws, which, you know, lead to our peace, order, and good government, so to speak. But here it is: if we were to collect a debt, we'd get it. Our position, respectfully, would be that if Albertans consent to their information being given out without their consent to collect a debt to the government of Alberta or to a custodian, certainly they would be all right with it if it were given to a law enforcement agency to follow up on their motor vehicle accident so that they can have a report for their insurer or to enforce the Criminal Code laws of Canada that keep us safe at night, so to speak.

Before I get into the warrant issues, I also wanted to point out – and this may be a little bit of a newer aspect than in my original submissions – that the Edmonton Police Service and other municipal law enforcement agencies fall under the provisions of the Freedom of Information and Protection of Privacy Act, which means that we

have legal obligations in and of ourselves. So if the concern is that we give out health information and the cat is out of the bag, so to speak, because now we have it, under section 17 of the FOIP Act we can't give out any of that health information. It's said to be an unreasonable invasion of a third party's privacy, so we wouldn't be able to give that information out anyway. We're under the same duty as in the Health Information Act to only use that information for law enforcement purposes, only for the purpose consistent with how we collected it. So that's another safeguard that's in place.

The last thing I kind of wanted to close with – two things, actually – is just to show you and give the committee a feeling for what the prerequisites are to obtain a standard search warrant, which is the other way to get information from health service providers. As you can see, we need to develop reasonable and probable grounds. So we have to have some reason to believe that this information will be there and that it's probable that that information will be there. Then we need a description of items to be seized, and we need enough detail to tie them back to an alleged offence that we're investigating and to identify the purpose of that search. We also need to specify alleged offences, identity of the victim, the person accused of committing the crime, the manner in which the alleged offence was committed, and then specify a building, receptacle, or place to be searched.

That's why I would ask for the limited health care services provider information, so that if the records aren't actually held at a hospital but held by a custodian – another doctor's office that's a custodian under the Health Information Act – we'd be able to get at least the address or the name and then be able to swear that information to get the warrant.

So as you can see, without minimal information, at the very least the registration information, our hands would be pretty well tied unless we can show imminent harm of some sort. That's been the position of the service to date. It's been difficult to get information without showing that. That's been the standard that we've had.

I just wanted to close by reiterating that the law enforcement agencies and the health care providers have a mutual goal. We certainly don't want to be getting diagnostic or treatment care information without the proper warrant, without the proper court order simply because it doesn't do anything for us. It gives rise to Charter scrutiny, evidentiary issues, and that certainly wouldn't forward our enforcement of the laws. It wouldn't forward gaining convictions on the charges that we lay, and it certainly wouldn't do a lot to show how much accountability and integrity law enforcement agencies use to perform their duties.

So those are the balance of my submissions. I think at this point I'm just going to open it up for questions to the committee. I guess I'm supposed to go around to the back, so I'll just get up and do that.

The Chair: Well, thank you very much, Ms Ramos, for the presentation and to your colleagues for also coming. A very interesting presentation and certainly in language that was easily understood, so we thank you very much for it.

There may be questions from the committee, so we will now open the floor to questions. Mr. Lukaszuk, we would recognize you first.

Mr. Lukaszuk: Thank you, Mr. Chairman. Thank you, Ms Ramos, for that presentation. Prior to your arrival, I read thoroughly the Edmonton Police Service's submission and the attached documents showing some instances where law enforcement officers have been running into difficulties in their encounters with medical services providers. I also read the Calgary submission.

I must tell you that when I first learned of the fact that you have those difficulties, I was rather surprised and perhaps even appalled, and some of that was discussed in our last meeting. Without a doubt in my mind I believe that you should have access to this kind of information for purposes of investigating criminal offences, but at the same time I recognize the balance that needs to be struck for the protection of privacy.

So my question to you would be: would your needs be satisfied if we were to amend the Health Information Act by introducing a clause to it that would resemble that of section 40(1)(a) of the Freedom of Information and Protection of Privacy Act?

1:20

Ms Ramos: Thank you, Mr. Chairman. To the hon. member's question, yes, I would say that that would be very helpful in just getting registration information and partially some health services information if that amendment were made.

Mr. Lukaszuk: By way of supplement. Then you would be able to use that information to secure a warrant or subpoena and then acquire any additional medical information that may be pertinent to your investigation. Is my understanding correct?

Ms Ramos: Yes. Certainly that would be our intention.

Mr. Lukaszuk: Thank you.

The Chair: Thank you, Thomas.

Other questions? Yes, Ms Blakeman.

Ms Blakeman: Thank you for taking the time to come today. I appreciate that very much. I'm reading through the additional documentation that was provided in your submission and the examples that are attached. Can you help me link these together?

You seem to be asking for the ability to approach health providers – staff in a hospital, for example – for registration information, which is personal information, like their home address, their phone number, and their location, which could be a location in the hospital, and that this is needed in order to satisfy the requirements of the Criminal Code. To do their job, in other words; right? But when I'm looking at the examples that you have given me, there are a couple of missing persons ones, which I'm assuming is not under the Criminal Code.

Ms Ramos: No.

Ms Blakeman: I'm not a police officer, so I could be wrong there.

There's one where they were looking to execute a warrant, and there was a lack of co-operation there. There are a couple of other ones where what's described is, "Well, it would have been a bad situation, but in the end we were given the information, so it was all okay." So nothing happened there. A couple of them would now be satisfied by Bill 205, which is being able to check for the blood product. Again, another couple where they got the information, but, "Boy, it would have been bad if they hadn't."

So I can't find anything in your examples that actually supports your statement that you can't get this information and that you're unable to complete the requirements of the Criminal Code. So help me.

Ms Ramos: Certainly. I think the law enforcement agencies are able to investigate things above and beyond the Criminal Code. We have a broader scope that way. Certainly the enforcement of the laws of Canada is the scope of the duties of a police officer.

Some of the submissions were part of an earlier submission from when the Health Information Act was first enacted, and they're mixed up with a couple of examples that have happened after the

fact, more recently. Our main concern is the consistency. Sometimes we get the information; sometimes we don't get it. As you can see with the first example there with the missing senior citizen, you have one hospital that will assist us and another hospital that won't.

I think our respectful submission would be: if there were an express provision in the act stating that they could give out this information, we wouldn't have to go through that. Many times in investigations time is of the essence, and that's a very important factor when we're collecting evidence and we're trying to find people, when we're trying to do that sort of thing. So that's what we're wanting the express provision for. It is already recognized under section 36 of the act that this registration information is given out to collect debt. So why not to enforce the laws of Canada? Certainly that's as important.

I'm wondering if my two other colleagues might have anything they'd like to add further to this.

Ms Thaker: If I may. In response to your question, I can provide you with numerous examples where it didn't work out in the end, where limitation periods ran out because there's only a set amount of time that an officer is able to lay an assault charge, for example. It's six months from the date of the incident. They can't access the video cassette or a witness statement because they can't find out who the individual was that was assaulted. They know they're in the hospital, but they don't know who they are. They are unable to speak to them, get a statement which would allow for a charge to be laid. Without that, they can't lay a charge, so the offender walks away. Because they're prevented from, in a specific scenario, accessing a video cassette from an ambulance bay where the assault took place, we're unable to say without a doubt that this person actually committed the assault.

The Chair: Supplementary, Ms Blakeman.

Ms Blakeman: Yeah. I'd love to have those examples because, as I say, what I have here doesn't support what you're saying.

Now, the police already have powers, extensive powers like the hot pursuit, which allows them to do things when they're in hot pursuit that they can't do otherwise. You've been granted some freedoms through FOIP, through PIPA, through PIPEDA. You're granted it here in life-threatening situations. So I'm struggling to find that balance. You already have a number of powers here that I'm assuming you're exercising regularly.

Help me to understand why the envelope needs to be pushed even further to capture these others: non life threatening, non hot pursuit, and not covered by the three other pieces of legislation. I'm feeling that there's not a balance happening here in protecting individuals' privacy versus extensive powers that the police already have.

Ms Ramos: Thank you for that question. I think the way that we're looking at this is that it's not a further pushing of the envelope. What we're looking for is information such as name, address, telephone number, which, as I hope my presentation showed, other legislation is already recognizing. So if other legislation is striking a balance, much like the Health Information Act is trying to do, and they're allowing disclosure without consent provisions for name, address, telephone number, that sort of information, there is a balance there already.

With respect to hot pursuits and all of those, respectfully, that has nothing to do with our ability to get information. The tools which a law enforcement agency has to get information are privacy law legislation under which there may be law enforcement exceptions. PIPA, PIPEDA, and FOIP are passed laws; they are laws in Canada. They do strike the balance with respect to privacy. We do get names, telephone numbers, addresses that way. The other thing is by court order or by warrant, and as you can see, we have to meet specific prerequisites to swear an affidavit before we can be given those. That is the way we get information. With respect to the other powers, that has nothing to do with our ability to get information.

Ms Blakeman: When you're getting the information from other places, are you getting it from health providers? Is the information from health providers?

Sergeant Savoie: If we can just take one step back. I think that the problem, as well, is that we're not getting the information in the first instance. We rely on the public to call us and tell us that criminal activity has occurred.

I'm sure a lot of you have heard about the gang violence that many of us as Edmontonians are exposed to these days. In the past, before HIA, if someone came into the hospital with an injury, the staff would call us and say: "A criminal activity has obviously occurred. You need to come out and investigate this." But because of HIA the staff are feeling handcuffed. They no longer can call us and tell us that criminal activity has occurred in many instances. The criminals themselves, obviously, aren't calling us. The victims aren't calling us because they're part of the criminal activity. So we're not even getting this information in the first instance because of this legislation. The staff at the hospitals are telling us: we can't call you in the first instance any more because this legislation is handcuffing us.

An example would be that perhaps there has been a shooting, a gang-related shooting. The victim is at the hospital, and it's not life threatening, and he doesn't want the police called. The staff can no longer call us and say: okay; this has just occurred. HIA is handcuffing us, so we're not even getting the information in many cases in the first instance. That's why we don't have any anecdotal information on that, because of course we weren't called out in the first instance. We often hear about this after the fact, perhaps from family or friends that we have who work in hospitals and tell us this sort of information. So if we're not called in the first instance, again, there's nothing the Edmonton Police Service can do.

The Chair: Mr. Lukaszuk, do you have a question, comment?

Mr. Lukaszuk: Both. I think as a side margin we should keep in mind: whose privacy are we are attempting to protect over here, and why are they not disclosing it voluntarily in the first place?

My question to any one of you would be: how are we dealing with situations where you have children checked into hospital with injuries which could have resulted from a criminal activity? They can't consent. Very often the parent won't because the parent, chances are, is the perpetrator. Now, if it's not life threatening, the doctor won't call you. Do you ever find out about those cases? I imagine there must be quite a few of those.

Ms Ramos: We do find out about those cases because of the Child Welfare Act. It compels them to report those incidents.

I think my colleague from the Calgary Police Service has an example with respect to your question.

1:30

Ms Thaker: We have a specific one where Child and Family Services has contacted CPS to then go and investigate, and the two constables that attended at the hospital were told: "We can't tell you anything. It's a child; they can't consent. The parents aren't here." They refused to provide the parents' information to the constables,

so they couldn't contact the parents, and it was basically a stakeout, waiting for the parents to show up so that they could speak to them.

We have another scenario with protection of persons in care, where they have an obligation under their legislation to turn over investigations that they feel are criminal in nature to the police to continue an investigation. They turn it over to us, and we can't view anything dealing with the person who is supposed to be protected.

So the one organization that feels they're doing the best thing for them by turning it over to the Calgary Police Service essentially is harming them because our hands are tied. We can't go and find out why the person was at the hospital. They won't even say, "Yes, they were here," let alone "This is why they were here, and this is what they were complaining about."

Sergeant Savoie: Again, we're relying on hospital staff to make the determination: is it criminal in nature? Are they best positioned to make that determination? You know, if we erred on the side of caution and had police get involved who have some training in that area to then make that determination – it just makes a lot more sense.

The Chair: Thank you.

Ms Kryczka: Well, I mainly want to say that I'm very impressed with what you're telling us. I think it's very important information for us to know as we review this act, very critical. What you're telling us in terms of your hands being tied really concerns me.

I heard a point made: your main concern is with lack of consistency in acquiring information where time is of the essence. That's the message I've written down. I mean, we can talk all around this for a long time, but the lack of consistency, many roadblocks?

Ms Ramos: Yes, that's what we're finding.

Ms Kryczka: Thank you very much.

The Chair: Thanks, Karen.

Mr. Goudreau.

Mr. Goudreau: Thank you, Mr. Chairman. I've got three points that I want to bring up. It appears – and I'm not sure if I'm getting a consistent message. On one side I'm hearing that you can eventually access the information that you require.

Ms Ramos: Not in every instance.

Mr. Goudreau: Okay.

Then the other side is the timeliness of the availability of that information. An issue at times is to get the information on time so you can react favourably.

Ms Ramos: Yes.

Mr. Goudreau: Okay. Yeah.

This morning we had a quick discussion about the instance where patients may be discouraged from getting medical treatment because of a fear that the information will be provided to law enforcement agencies. In the long run, if we're looking at the health and health issues of particular individuals – have you run across that particular situation, where people refused to get health services because of what may happen to their records and information?

Ms Thaker: We haven't had an experience where people have reported not going to get assistance. We do know that there are scenarios where people show up at clinics and tell security at the clinics: don't tell police I'm here. Or they flout the fact that they have outstanding warrants, and there's nothing that can be done to get them. Like, they can go in and say, "Oh, yeah, I've got 10 outstanding warrants, but you guys have to help me." That's basically their attitude.

The point that you're making in terms of individuals not seeking help because they are afraid their information will be released are generally people that – we need to strike a balance – are the ones that are using the hospitals and the clinics as a safe haven to hide from police. They know that they'll get the assistance they need. They'll no longer have a bullet in their arm, and they won't get picked up for it or won't be questioned about it, and that won't reveal the activities that they're involved in.

Ms Ramos: The other point I wanted to mention is that it's reasonableness. It's reasonableness of invasion. We live in a society where we have limits and we have laws that are enforced, and they're reasonable infringements on our freedoms. When you take a look at whether you should disclose a name, address, or telephone number to a police service, that service itself has obligations under privacy legislation. It's not so much that the information is out there now for anybody to use. We have our own obligations which people who feel that their privacy has been breached can enforce against us. We would then be accountable for it.

So it's not necessarily that they give us the information, that the cat is out of the bag. That's many times what I've told health care providers in presentations about what we do and how we treat their information.

Sergeant Savoie: Remember that victims and people who are not involved in criminal activity are the ones that are going to consent to the hospital staff releasing this information. We're talking about in most cases the criminal element.

Mr. Goudreau: Thank you very much for those comments.

I guess my third point was that we talk about the Edmonton Police Service and maybe the RCMP and the Calgary Police Service. What about other individuals providing security, like special constables? There are quite a number of people out there that provide some form of legal enforcement in the province.

Ms Thaker: For Calgary specifically there are the Calgary Transit peace officers, who are considered peace officers under the Police Act. However, we have a wonderful working relationship with them where generally they're not doing the ongoing investigation. I have a specific example of an individual that was mugged at the train station basically, and it was the transit officers that responded to the call, but because it's a criminal investigation, it will be turned over to the Calgary Police Service. So we work in conjunction.

Private security falls under a different, a whole other scope, and they actually have better access than we do, because essentially the title "police officer" is what triggers the act.

The Chair: Thank you, Hector.

Dr. Pannu.

Dr. Pannu: Thank you, Mr. Chairman. I have a question that perhaps can be answered by our resource people here. On what date and year did the Health Information Act get proclaimed and come into force?

Ms Robillard: April 25, 2001.

Dr. Pannu: In 2001.

Now, my question is for Ms Ramos. Ms Ramos, I was looking at the brief, which is quite extensive. I want to thank you for providing us with some information on specific instances of difficulties that police encountered in getting the information that in its judgment was necessary to proceed further with the investigation or lay charges. Clearly, the instances that have been provided here predate the coming into effect of the Health Information Act. Why do you think that what information you have given us gives us some compelling reasons first of all to believe that these are related to this new piece of legislation that this committee is asked to review? Secondly, could you perhaps give us some examples of how the HIA specifically has made your job more difficult?

Ms Ramos: Well, thank you for those comments. I think it goes back to the submission. As Sergeant Darlene Savoie said, in the first instance the Health Information Act does make health care providers more hesitant in helping us or reporting things at first instance. That's one reason.

The other thing with respect to the submissions is that we've simply tried to collect anecdotes that give you a feeling of what the challenges are that our members are facing. We did do a call for more recent ones. I believe the Calgary Police Service can provide that for you. Generally, law enforcement agencies experience that as well.

There are some recent ones that I have included here. The missing senior was a recent one, wherein they tried to locate that individual and were told by one hospital that they couldn't release that information we were seeking and another hospital assisted us, which ended up in our finding that individual.

1:40

The other recent example is a warrant as well. There was a warrant that was presented to a health services provider, I believe a records manager of that organization. At that point the records manager said to our member: no; I'm going to pick and choose what documents you get because of the Health Information Act. At that point they had to call the legal adviser's office to think of a more creative way – you know, we still want to maintain a healthy relationship with the health care providers – to explain to them that a warrant is a court order, that our judiciary has already taken a look at the issues surrounding giving that order, and that they are required to follow it. So that is a recent example. I know the Calgary Police Service has more recent examples than we do.

It's just simply a matter of our members reporting the incidents to us. I know we get phone calls about that, as well, where the Health Information Act is cited and where members say: they're not giving us information because of that.

Sergeant Savoie: I think it's probably purely coincidental that the dates are prior to the coming into effect of HIA.

As you can all well imagine, one of the least favourite parts of a police officer's job is paperwork, so trying to get them to put pen to paper on some of these issues has been very difficult. We have lots of anecdotal information where they call in or walk into the office and say: I've had these issues, these problems. But trying to get them to put pen to paper sometimes is a little bit more difficult. However, if that would help, we could ask once again and impress upon them the importance of having this in a paper format.

Dr. Pannu: Well, I appreciate the responses, the answers to my questions.

Yeah, there are two cases here. One is the missing senior case, and the other case is I think the warrant being served, where you had difficulties, I guess, in the current year, 2004. You've got those two examples here, and thank you for providing us with that information.

However, we hear – I think the matter was raised by one of the members of this committee before – from health care professionals and we heard from regional health authorities in their formal briefs to us that the Health Information Act does indeed strike a proper balance between the need to protect the privacy of individuals when they are in need of medical help and providing that information to the doctors and nurses, our hospitals, and the needs of enforcement of Canada's laws, including the Criminal Code.

So we are getting very conflicting messages from different parts of the public. What would you have to say to the Aspen regional health authority, for example – we were briefed on it this morning – which says that the proper balance is struck in the Health Information Act, and to many other professional organizations who say that there are other pieces of legislation that exist which do provide considerable leeway to police forces in doing their job and that the protection of medical private information in particular is critical for the ability of medical professionals to do their job and provide the services that, in their judgment, their patients need? Other laws do provide some access, some means to law enforcement agencies, so why would you want this act, which speaks specifically to protection of information related to medical reasons, to be made available to you?

The Chair: Thank you, Dr. Pannu.

We are rapidly running out of time. I have one more question. While we'll allow you to respond to that, it seems to me you've answered that question quite well. But, certainly, we'll allow an additional comment, Ms Ramos.

Ms Ramos: I guess I just wish to reiterate that the amendment that we're seeking is not with respect to medical treatment/care information but with respect to registration information, which has no health information attached to it, likewise with health services provider information – name, address, telephone number – also not relating to any personal health information.

The acts, which are law in Canada, PIPA, PIPEDA, and the FOIP Act, already provide disclosure without consent to law enforcement agencies, and in that respect we're looking at consistency that way. We are not seeking to get medical, diagnostic, or treatment/care information without the consent of a person. It certainly would serve us no purpose. It wouldn't meet our evidentiary obligations as a law enforcement agency.

The Chair: Thank you.

Mr. Lukaszuk, we'll allow you one last brief question.

Mr. Lukaszuk: I'll try. In response to Dr. Pannu's comments, I'm not sure if we're getting that much of a conflicting testimony here. I notice the college of physicians and the College of Pharmacists advocating on behalf of police, wanting them to have access to that. So one health region objects; many others advocate.

My question to you would be this. Even though you may have had some difficulties obtaining information from care providers prior to the proclamation of the Health Information Act, is it your submission that the review of this act at this point gives us an opportunity to standardize your access to that information in the province irrelevant of whether you had problems pre- or post proclamation of this act?

Ms Ramos: Yes, that's correct.

Mr. Lukaszuk: Thank you.

The Chair: Thank you very much to the committee for your questions. Ms Ramos, Sergeant Savoie, and Ms Thaker, thank you very much for coming, for a very good presentation. You've been very helpful, and the committee, I think, has some interesting debate in front of it regarding some of the issues that have been raised. Again, on behalf of the committee, we thank you very much, especially Ms Thaker for coming from Calgary to share this time with your colleagues. Thank you.

We'll take a couple minutes to get everything cleared, and then we'll start with the next presentation.

1:50

Thank you very much. I see that the committee is basically in their places again, so we will commence with the second presentation this afternoon: from Value Drug Mart Associates, Mr. Jody Shkrobot, who is the manager of pharmacy services and professional affairs. He is accompanied by Alan Hodgins, CEO. So we welcome you gentlemen here, and I think Jody is going to make the presentation. Prior to starting with Jody's introductory comments and presentation, I will ask the committee, legislative members, and other members, to please introduce themselves.

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

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

Mrs. Dacyshyn: Corinne Dacyshyn, committee clerk.

Mrs. Sawchuk: Karen Sawchuk, committee clerk.

The Chair: Thank you very much.

Jody.

Mr. Shkrobot: Thank you, Mr. Chairman. I'd like to say thank you to the committee for the opportunity to speak to some of the comments or recommendations that we had previously circulated to the committee as a result of the review of this very important piece of legislation, the Health Information Act.

I hope that I will be able to come to you today both as a pharmacist, a health care practitioner who's actively practising pharmacy within the province of Alberta, as well as a representative of a variety of different community pharmacists that operate under the banner programs Value Drug Mart, Apple Drugs, and Rxellence professional dispensaries, that I work with in my role as manager of pharmacy services and professional affairs.

I've provided the committee with a briefing document that summarizes some of the recommendations and issues that I hope to bring forth today to supplement and further emphasize the comments that I previously provided to the committee in written word. Essentially, I want to give you guys a little bit of introduction in terms of where I am coming from and where our organization stands on certain issues as well as bring up about six different points on how the Health Information Act has made some significant changes to how pharmacy services are able to be delivered to Albertans and how the health and safety as well as some of the administrative barriers that have now been placed on health care practitioners have kind of caused some issues that have required us to make some changes in how we operate and provide services to Albertans.

So just a little bit of background first of Value Drug Mart. We are an association of independent community pharmacies. We operate under three different banner programs. Each is individually owned and operated, but we do have a common, collective objective, obviously: providing pharmacist services to citizens of Alberta. We have 45 Value Drug Mart locations, 17 Apple Drugs locations, and five Rxellence professional dispensaries, all essentially doing the same type of business in terms of providing health services to Albertans. We employ approximately 200 community pharmacists within these locations, and there are 67 within Alberta. We do also operate pharmacies within Saskatchewan and British Columbia, but the majority of them are within the Alberta jurisdiction.

I guess the first point I would like to start with is the confusion of how health care practitioners are having to deal with certain legislation, in particular the privacy legislation. Traditionally, health care practitioners have dealt with a code of ethics that has always held the confidentiality of patient information of utmost importance to the standards of both our regulatory authorities as well as to the public's general self-interest. Now with the advent of the Health Information Act, the Personal Information Protection Act, and with the federal legislation PIPEDA we have sometimes conflicting pieces of legislation that make a web of privacy legislation difficult for some practitioners who are essentially delivering health care services to their patients and clients.

Instead, we have to kind of shift our focus to a little bit more of a lawyer mentality when dealing with some of the legislation as far as how these issues are addressed on any specific situation. It's not unlikely for a pharmacist in any one situation to have to deal with all three pieces of legislation and try to understand and see how all the issues relate to the specific circumstance that they're dealing with.

So one of the hopes that we have in bringing these issues forward to this committee is that we can have some clear, consistent rules that apply to all jurisdictions and all health care practitioners as well as other industries or organizations that deal with health information, that the rules are consistent throughout so that there is no confusion both to the public as well as to the health practitioners that are dealing with the issues.

Probably one of the first issues that came up as a result of the Health Information Act is the adjudication of prescription drug claims that occurs on a very regular basis throughout pharmacies in Alberta. Alberta pharmacies fill approximately 30 million prescriptions each year in Alberta, of which we expect that probably about 50 per cent of these claims are actually transmitted through an electronic adjudication system to a third party adjudicator who is acting on behalf of an insurance company to provide drug payment coverage for citizens.

The problem with the situation is that this information is sent electronically, and pharmacists are currently not collecting written consent as is required under the Health Information Act. So we are disclosing to a noncustodian, whether it be Alberta Blue Cross for some private-paying plans or to some multinational company such as BCE Emergis or Green Shield that deals with the adjudication of drug claims.

If pharmacists did go to the approach of collecting written consent for this process, based on participation in some pilot studies that were done revolving around section 59, we discovered that the prescription claims process itself would take approximately seven minutes longer than what is currently anticipated in terms of providing drug distribution services to a patient. This approximately doubles the time required for a pharmacist to fill a prescription if they had to collect written consent each and every time a prescription was presented to them. Pharmacists face the same issues as other

health care practitioners within Alberta, within Canada, and worldwide as far as shortages of pharmacists, so this is a situation where we really don't have the resources to be able to handle the written consent requirements of the Health Information Act.

Under the consent requirements there are a few other issues that come up because of the stipulations and regulations that HIA presents. In section 34(2)(c) the pharmacy traditionally sends this information, again, electronically to a third party adjudicator. We do not know the name of the person that accesses this information. It is simply an organization that is working on behalf of the insurance company. So, obviously, we cannot comply with that section of the Health Information Act.

We do not know the risks associated with the disclosure. We are not able to effectively communicate that to our patients because once the information leaves the pharmacy, it goes across Alberta's borders to other organizations. We really have no control of the information, so we cannot adequately inform the public in terms of the risks of disclosing this type of information. So even if we were collecting written consent, again, there would be some problems in terms of identifying these issues.

With any disclosure, if modifications were made to the Health Information Act to allow insurance companies to receive this information because it's probably for the good of the patient – essentially, what happens with the adjudication is that instead of the patient having to submit their receipt on a manual basis and then getting reimbursement after the fact, the pharmacy is transmitting this information for them so that the patient doesn't have to pay their prescription drug costs up front. They can get their portion of their insurance paid immediately, and the pharmacy is paid directly by the adjudicator for this purpose. If this occurs without consent, notation is still required in the pharmacy records. Again, under section 41(1)(a) it is a requirement that the pharmacy or the custodian know the name of the individual that this information was being sent to for the same reason as consent being an issue.

The notification requirements also under HIA require that the custodian, or the pharmacist in this case, must notify the recipient of the information in writing of the purpose and the authority that the information is being disclosed to them. For this purpose, because this adjudication is occurring by electronic means, it is not possible for the pharmacy to send this written notification to the adjudicator who is receiving the information. So with or without consent this aspect of compliance with HIA is really not possible.

So the solution that we as pharmacists are hoping, looking for, is for this committee to make recommendations revolving around the insurance industry issue. If things stay the same in the Health Information Act – and currently we have a letter from the minister of health indicating that he understands that this issue is a systemic problem and understands that there needs to be a remedy in terms of amendments to the Health Information Act. If things stay as is, pharmacies in Alberta will no longer be able to transmit insurance claims for their patients and for Alberta citizens, which again represents probably about half the prescriptions that pharmacies are filling in the province. If that practice is what is still wanted within the Health Information Act, we need to remove some of the barriers in terms of the legislation to allow the electronic claim submission, so either allow implied or deemed consent.

2:00

Patients presenting with an insurance plan usually understand that their insurance company or adjudicator is receiving this information, but the pharmacy is not privy to the information that the insurance company provides in terms of their collection of consent process. Because the Health Information Act puts the responsibility in the hands of the custodian, we are ultimately responsible for ensuring that, and as the legislation is currently written and as our dealings with the industry go forward, we are not comfortable that we know exactly how the risks and the ramifications of sending this information occur.

I apologize. I am not a lawyer in the aspect of interpretation between names of organizations and names of persons, but there has been some interpretation saying that the Health Information Act really doesn't allow disclosure to an organization as a group. So we would require changes to the legislation to allow organizations to be considered an individual person.

We would also request that there would be removal of the notification requirements. Again, the transmission of data through a modem, either via a telephone line or through an Internet service provider, doesn't facilitate the requirements of notifying the individual receiving the information of the purpose and intent.

The Health Information Act has created some constraints on the delivery of health services for pharmacists administering this to their patients and clients. Essentially, because pharmacies are really the only health care practitioner that involves the issuance or the sale of a product in addition to the service component of it, it is a quite common occurrence for the patient to not be the individual picking up the prescription.

This causes some complications because of the Health Information Act, because the question in terms of getting a patient to take their medication properly usually requires some verbal consultation with the client. If it's a patient caregiver that is attending, the pharmacist is put in the position of trying to determine if this person is entitled to get and receive some information regarding the prescription and how to use the prescription medication wisely. So there are questions if the verbal consultation that is necessary for a pharmacist to do to a patient or a patient caregiver is even legally possible under the Health Information Act.

There are some other administrative requirements that also create issues because of the fact that it's not necessarily the patient picking up the prescription; specifically, as I mentioned previously, the notation as per section 41(1). The storage in this notation creates some issues as well. Pharmacies under the Food and Drugs Act must maintain prescription records for two years after the last date of the prescription being filled. Under the Health Information Act the notation of who the information is disclosed to without consent must be stored for 10 years. This is creating some havoc in pharmacies in terms of what information needs to be kept where.

Also, the notification as per section 42(1) creates an issue as well. Each time someone other than the patient picks up a prescription from a pharmacy, the pharmacy must provide them with a sheet of paper that essentially says what the authority and obligation are that the pharmacy is releasing the information to them under. In a day of electronic technology and in light of other privacy information that is out there, we would suggest that this be something that could be administered to a patient or a patient agent upon their request rather than having to occur at every single occurrence.

Section 107(2)(f) poses an issue for pharmacies because we are not necessarily a publicly paid health care practitioner, and as governments look towards other alternatives for the provision of health services, this will probably ring true to other health practitioners within the province. It's basically saying:

> No person shall knowingly . . .
>
> (f) use individually identifying health information to market any service for a commercial purpose or to solicit money unless the individual who is the subject of the health information has specifically consented to its use for that purpose.

Pharmacies traditionally will provide more than just medication distribution services. We offer wellness initiatives that might

include diabetes screening, cholesterol screening for clients that we feel are at risk for developing these diseases. Obviously, we have the public's best interests at heart when we're offering these services, more so than looking for financial gain to recruit patients to participate in these types of services.

Also, in order for medications to work, obviously we have to make sure that our patients are using the medications. So some pharmacies have instituted services such as refill reminders to remind Mrs. Jones that she needs to take her blood pressure medication, and then she should probably be due for a refill to have her medication used. This could be seen as being a financial gain for the pharmacy by having the patient coming in for a refill of their medication. Obviously, there's a dichotomy in terms of the continuity of care and the monitoring of therapy that the pharmacist has to do as opposed to the commercial gain.

This, obviously, doesn't affect just pharmacists. This could be related the same way to a laboratory. It could be related the same way to a physician wanting to call back a patient to do a further assessment for them. They might not receive monetary gain in terms of the patient directly buying a product or service from them, but instead they're being reimbursed for another office visit or a follow-up consultation with a patient. So there should be some more clarification or some discretion offered to health care practitioners when the use is of obvious benefit for the patient involved.

I bring up another issue on health service provider information. There's been a little bit of controversy around this issue as far as releasing information of health services providers. The problem that we see within pharmacy comes down to, again, adjudication and payment of claims. Under the Income Tax Act a prescription claim is an eligible medical expense if it is prescribed by a medical practitioner who is operating under the authority of provincial legislation in terms of ability to prescribe a medication. Right now on all the prescription receipts the physician's name or the prescriber's name is going to appear on that receipt.

The ruling that was offered by the Privacy Commissioner that the health service provider information should not be issued without the health service provider's consent to releasing the information – prescription receipts could no longer contain the prescriber information, which also means that an insurance adjudication of these claims, which also require a prescriber ID number, cannot occur. There are also issues around the triplicate prescription program, which is looking to help curtail or monitor medications that could be at risk for abuse.

It also creates some issues around continuity of care. If I need to have a physician's authority to disclose their name to a specialist who is looking to find out what physicians are involved with their treatment and care, it would obviously cause problems for the patient as far as that continuity of care.

When I look at that piece of the legislation or that section of the legislation, I see that the health service provider information is actually protected more so than the patient's own information. There could be a situation where a pharmacist made an error in dispensing a medication, and as the custodian is obligated to ensure that they have the consent of that health practitioner before they can release the information, a patient could technically ask to see the record and find out which pharmacist was involved in that situation.

The pharmacist who made the error on the actual dispensing of the medication could be responsible and could obviously receive undue financial harm. Therefore, they could say that they do not want their information on the situation released to the patient. So now the patient would be forced to go through some other legal proceedings in order to collect that information. It just doesn't seem to be the most ideal situation when dealing with this type of circumstance.

I know that you've already had some presentation from the Edmonton Police Service as well about the issue of releasing information to peace officers. I can speak from personal experience and I can also speak from experience that has been relayed from pharmacists in the community that certainly the issue about drug diversion is becoming more of a concern on the health practitioner front.

There are many cases, and probably the most common way that medications or prescriptions are forged is by making modifications to existing medications: adding a zero so that instead of the person receiving 50 tablets of morphine, they end up having a prescription for 500 pills of morphine. The problem is that that is still valid health information. It is a valid prescription. Yet the forgery itself would prevent the pharmacist from wanting to report that to a peace officer, because not too many police services will want to go out and get a subpoena and warrant to collect that information without knowing the name of the patient involved and what the actual situation involved was. So we ask that you would maybe recommend some modifications to allow the custodian to have additional discretion in terms of dealing with disclosure to police officers, again, when looking at the public's best interests.

My last point comes down and reiterates my first point in terms of the amount of different privacy legislation that affects health care practitioners. A great deal of responsibility has now been placed on custodians, and while regional health authorities probably have the resources to deal with and ensure that individuals who are receiving health information are using that health information appropriately, when it comes to pharmacists and small practitioners, it's been very difficult for us to deal with multinational companies such as insurance companies and adjudicators when trying to comply with the Health Information Act.

2:10

I can bring up a couple of circumstances that I've dealt with with our own pharmacies where a national insurance coverage came in and did an audit on a pharmacy. Under the Health Information Act the auditors are entitled to receive that information as long as they sign a disclosure agreement allowing the health practitioner or the custodian to be able to track that information and know what that information is being used for and know that it is destroyed appropriately. The auditor in that national insurance company had explained to the pharmacist and the pharmacy owner that if they did not release the information immediately as requested, they would shut down the pharmacy's ability to transmit any further claims to the insurance company, essentially rendering that pharmacist's business closed for the day because they wouldn't be able to proceed in doing the day-to-day functions that pharmacists are supposed to be doing.

So we would hope that the committee might be able to provide some assistance for custodians that are having problems dealing with issues that are outside of Alberta's borders, where other jurisdictions don't necessarily apply, whether it be the government itself or the office of the Information and Privacy Commissioner, to provide assistance for pharmacists and other health practitioners in dealing with these issues.

In summary, we're looking to have some universal privacy legislation, to have, where possible, national legislation so that the rules are the same in every province regardless of what is happening and the rules are the same for every organization that is handling health information. We need to have a decision regarding the adjudication of prescription drug claims, whether it's in the public's interest to allow it or not allow it. If it is allowed, then to make sure that we have the administrative changes that will allow that and facilitate that process to occur and, hopefully, remove some of the

administrative burdens so that they can get pharmacists and other health practitioners back to the job of administering health care and delivering health care to Albertans.

We hope to allow for provision for the use of health information when it's in the patient's best interests – this, again, gets back to section 107 in terms of the financial gain that health practitioners could receive from using the information in an inappropriate manner – to remove protection that is currently placed on the health service provider information because of a whole number of issues that were raised previously, and to provide some protection to custodians that are reporting suspected criminal activity. Finally, anything that the government might be able to do to assist custodians in the implementation of the Health Information Act for those custodians that are having difficulty in dealing with certain issues and circumstances.

With that, I would like to conclude. Mr. Chairman, with your permission, I would like to ask if there are any questions that I might be able to answer.

The Chair: Thank you very much, Mr. Shkrobot, for a very interesting presentation, which I know is going to elicit some questions from the committee.

Ms Blakeman, I think you have a question, but I guess I have one before you. Ms Kryczka, we'll give you the first question.

Ms Kryczka: Thank you. Eye contact helps.

Just a comment and then a question. Thank you for your very practical, grassroots-based information. It's great to hear that. I just have a little question. When you talked about someone other than the patient, say, that picks up the prescription – or, you know, a lot of them are being delivered now too – do you see that problem increasing in the future with an aging population?

Mr. Shkrobot: It will certainly be an issue that will occur on a much more repeated basis just in light of the aging population. So regardless of the circumstances, whether it be a delivery of a prescription or having another caregiver, the pharmacist is essentially put in the situation of trying to determine if this person is entitled to receive the information.

We also run into the problem about relaying information about the proper use of that medication. Right now we know that probably approximately 50 per cent of medications that are being used by individuals are not being used appropriately. That will compound the issue. If you get an aging population that might not be getting the information that they need to properly use their medication, it just compounds it again. As the population ages, these services will be required significantly more, so we need to have some sort of resolution to this type of issue.

Ms Kryczka: Right. Thank you.

Ms Blakeman: This is actually directed towards the staff. Can you tell me where in the act it's telling us that they're required to get written permission from the person every time a prescription is filled? Did I misunderstand? Yes, I did.

Mr. Shkrobot: It's not really required every single time. Obviously, there needs to be some sort of consent registry that the health practitioner could go back on. Unfortunately, within the community pharmacy environment the technology to enable that – again, the pharmacists don't have the leverage to allow and facilitate that process to occur. The consent could be requested once and collected and collated, but within our current information technology abilities we wouldn't be able to ensure that the patient had not revoked their consent at that point in time. So the easiest way to implement those practices would be to collect consent on a regular basis or on a prescription-by-prescription basis.

Ms Blakeman: I guess that's what I'm not understanding. You know, for the reminder thing why can't you get permission when the prescription is filled the first time that you will phone them as a service and remind them of when the refill is required? I'm not understanding why you can't do that.

Mr. Shkrobot: It's not that we necessarily cannot do it; it's the workload that would be involved to maintain that. That is becoming more of the issue for the pharmacists. If the consent process itself doubles the time that it takes to fill a prescription, with 30 million prescriptions occurring in Alberta each year – and, granted, after you've gone through the first year, you'd probably collect the majority of the consents from your client or patient base – we would not have the manpower to be able to facilitate and allow that to happen without essentially crippling the medication distribution side of the system.

Ms Blakeman: I can understand how onerous it is if it's seven minutes extra for each prescription, but if it's done once for each prescription which is then filled whenever, a year's worth, I'm not understanding why seven minutes is onerous, I guess.

Mr. Shkrobot: It's the seven minutes, and also it comes to the fact that it might not be the patient that is presenting with the prescription. If somebody is in a long-term care facility and we're getting their prescription, we still need to have their written informed consent for that. How else can we obtain the written informed consent, and now do you delay the actual filling of the prescription as a result of it, with the patient not receiving the care that they require?

The Chair: Mr. Goudreau.

Mr. Goudreau: Thank you very much, Mr. Chairman. Thank you for your presentation. As you've identified, pharmacists are providing more and more services, such as cholesterol and diabetes screening, maybe some blood testing and whatnot. Do you foresee being involved in the future to a greater extent in more provisions of health care services that would impact with the Health Information Act or vice versa?

Mr. Shkrobot: Certainly, as a pharmacist I hope to see pharmacists playing a larger role in terms of the delivery of health services. I feel that for a lot of what pharmacists have been doing, we're really an untapped health resource for the health care system and can fill in some gaps that currently exist.

Obviously, because pharmacists are pretty much the only health practitioner outside of probably physiotherapists that are on the private side, I guess, of the reimbursement structure, we've been dealing with this issue probably before other health practitioners will have to. So we certainly want to make sure that we can provide these services where possible, whether they're screening or medication management or even additional primary health care initiatives. But, obviously, some of the issues as far as dealing with the Health Information Act have to be resolved for us to make that more effective.

Some pharmacists have said: well, why don't we just remove pharmacy out of the Health Information Act completely? I would say that that's probably not what we want. We want to be sharing

the information, whether it's through the Pharmaceutical Information Network or Wellnet. We need to have that information to be effective at our jobs.

Again, when it comes back to the consent issue, we can certainly do that, but if we're stuck in the situation of having to deal with the consent, that's going to take us away from our ability to provide and fill in the gaps of other health services that we want to be providing and that we feel we'll be effective at providing for Albertans.

2:20

The Chair: Supplementary, Mr. Goudreau.

Mr. Goudreau: It's a little different, Mr. Chairman, if I may. You've identified some conflicts between the Health Information Act, PIPA, and PIPEDA, yet you didn't, you know, point out those conflicts. You indicated that they exist. Do you want to elaborate?

Mr. Shkrobot: Certainly. Obviously, it's going to vary from pharmacy to pharmacy. There's the pharmacy aspect of the medication or the pharmacist service side of things. A lot of pharmacies also exist, and they operate commercial enterprises. We're front store sales, so you'll be selling your gum and your chocolate bars as well as other health implements. It might not be exclusively health-related services. We have to fall under PIPA in terms of the release and use and disclosure and storage of that information. So pharmacists have been asked to kind of comply with different aspects of things, which we've done for the most part. Understanding that the majority of pharmacies are small businesses, having to have policy and procedure manuals has been an onerous task for a lot of them, but obviously we have been trying to comply with those types of things.

The problem that we come up with is that when it comes to the health information, does PIPEDA apply or does the Health Information Act apply? Obviously, for pharmacies within Alberta we have to comply with the Health Information Act, but the majority of our information, when it's sent through a third party adjudicator, is sent outside Alberta's borders. Now PIPEDA is applying to that information, which allows to have deemed or verbal consent as far as the disclosure of that information. So we're dealing with what do we have to kind of handle, and that's just one example of the circumstances of where and what legislation is applying to the disclosure of that information. Needless to say, again, pharmacists are not the legal entities to be able to interpret this. We have to try to do this in the middle of providing our health services to our patients.

The Chair: Thank you.

Mr. Lougheed: Thanks for the presentation. Well done. In your comments there's something that I just wanted to have you clarify for me for interests outside of this act, probably. You made a comment that a prescription was presented for 50 tablets, and it was modified by, I presume, the person presenting it to 500. You said that it was still a valid prescription. Something like modifying a prescription doesn't invalidate it?

Mr. Shkrobot: It would. I guess the clarification on that is that it's no longer a valid prescription because it has been modified. However, the information that is contained on that prescription has been somewhat questionable. We've received comment from the Alberta College of Pharmacists that that was a legitimate prescription. It is legitimate health information. The modification makes the prescription invalid, but it is still health information, and the registration information that's on that prescription would technically be protected under the Health Information Act. I'm sure that is probably subject to legal interpretation, but that is what the Alberta College of Pharmacists has been telling its membership as far as being wary on the disclosure of that information until you have confirmed.

There could be other circumstances where the prescription might have had one drug that was modified and there was more than one medication on the prescription. So the pharmacy would not be able to release that record itself to the police officers in terms of reporting it because, again, the registration information would still be protected under the Health Information Act.

Mr. Lougheed: Just to follow up a little more, what do you do when you get a prescription like this?

Mr. Shkrobot: This is where there's probably a discrepancy in terms of other health practitioners that are out there in terms of whether or not they feel that it's something that they have to report. Certainly, I would expect no pharmacist would fill the prescription and would probably refer the patient back to their physician for follow-up in trying to deal with this issue. But I do know that there have been some pharmacists within my group that have run into these situations, and instead of traditionally reporting it to the police, they have tried to deal with it internally and not release that information for fear of ramifications of the Health Information Act and the fact that: would this be something that would get turned over in court on any criminal charges against that individual that was presenting the forged prescription? So it's certainly a mixed bag in terms of responses from it.

The Chair: Thank you.

Dr. Pannu: Thank you for a rather detailed and complex presentation. Certainly, you have been successful in drawing attention to the difficulties and the burdens that implementation of HIA on pharmacies creates, I think, for pharmacists and businesses that provide prescription services.

My question to you relates to some interesting observations that you made with respect to the electronic adjudication, which involves, as you suggested, multinational companies, some of them insurance companies and whatever have you, and the ability of pharmacists to respect the obligations that this HIA generates for you for protection of patient information and their prescriptions when you have to transmit it to these multinational corporations, which may in fact have headquarters outside of Canada, not just Alberta but outside of Canada. Would you like to elaborate on that? Are they not still obliged to respect the legal requirements that are embodied in HIA with respect to protection of this information?

Mr. Shkrobot: Certainly. This is subject to I guess my own personal observations from my dealings with some of the adjudicators dealing with this specific issue. The adjudicators have a contract with the pharmacy to provide these services to the pharmacy. The patients are not the adjudicators' clients. It's an insurance company that essentially is a client of the adjudicator. So, first of all, the adjudicator is outside of Alberta's jurisdictions, so the only way the adjudicator would have to comply with the Health Information Act is through the custodians' requirements to ensure that that information that is disclosed to them is complying with HIA.

The Pharmacists Association of Alberta, who is our advocacy organization, has tried to deal with these third party adjudicators to

get them to make modifications to their contracts to provide the provisions that would give the custodian either the ability to make sure that the information is not being used inappropriately or disclosed inappropriately and have some ramifications that would put the onus on the adjudicators to ensure that they're using that health information according to the Health Information Act. But, essentially, from the individuals that I have spoken with at RxA, the adjudicators say: it's not within our jurisdiction; we don't have to make any changes to our contracts. So it again goes back to the hands of the pharmacists. They were unable to make an ascertained change, which is why I've been asking for help either from the government or from the Privacy Commissioner to help facilitate, I guess, the contractual agreements to allow pharmacists to have the control and keep the control of that health information we feel that our patients expect.

Dr. Pannu: Excuse, Mr. Chairman, my ignorance, but the role of the adjudicator is something new for me. What exactly do adjudicators do? They obviously are third party between the pharmacists on the one hand and the insurance companies on the other?

Mr. Shkrobot: Yes.

Dr. Pannu: So what do they exactly do?

Mr. Shkrobot: Essentially, the adjudicators will allow the claims transmission to occur. What happens is the pharmacy will transmit certain information data through a modem or Internet service provider to the adjudicator who then gets that information, ensures that the client is indeed a client of the insurance carrier, will find out the information in terms of drug prices, what the dispensing fee for the pharmacy is, and then will transmit information back to the pharmacy to inform the pharmacy how much the patient will have to pay as part of their insurance plan. That adjudicator basically administers all those plans and has the infrastructure in place to allow for that electronic transmission of the data. They will of course issue the cheque to the pharmacy for the portion that the pharmacy is entitled to be reimbursed. The adjudicator will then go back to the insurance company and provide the insurance company with the information they need and will charge them for what the plan participants are, I guess, being funded for in terms of the administration of the program itself. So it's a third party in between the insurance program.

One of my concerns is that the adjudicator doesn't have any obligations to the patient. They do have obligations to the insurance company, which hopefully through federal legislation is certainly going to be acceptable. But once that information is sent to the adjudicator, the pharmacist really has no control over the information or what is handled with it, if data matching is occurring, if it is being sold to other industry or whatever the case may be. It's unfortunate that we are kind of put in that situation, but again without knowing the insides of that industry, I'm not sure what happens with that information.

The Chair: Dr. Pannu, one final.

2:30

Dr. Pannu: Yeah. I just want to conclude very quickly, Mr. Chairman. Thank you for the opportunity. Another instance of the adjudicators' role. I'm not sure whether any of them have their headquarters in Canada at all or whether they are mostly outside of Canada.

Mr. Shkrobot: As far as the information that's transmitted via modem, they do go to Canadian jurisdictions. With the exception of Alberta Blue Cross they are all outside of Alberta's borders.

Dr. Pannu: But in my mind it does raise questions, Mr. Chairman, about the debate that we had the other day, you know, on the PATRIOT Act and the inability of corporations which may provide services in Canada but are located in the U.S. not to be able to refuse disclosure of information regardless of our acts. I think we were confronted last week with information on the fact that B.C. is reviewing the implications of the PATRIOT Act to the ability of the government here and in B.C. in particular to enforce the act, and I think a similar problem would arise in this case too.

The Chair: So noted.

Mr. Shkrobot, Mr. Hodgins, thank you very much for a very good presentation. You've certainly enlightened the committee on some of your concerns and made some good recommendations. We thank you very much on behalf of the committee for taking the time to come and present to us. Again, thank you very much.

I would suggest to the committee that we take a 10-, 12-minute break at this point before we proceed with our deliberations.

[The committee adjourned from 2:31 p.m. to 2:46 p.m.]

The Chair: Okay. We will call the committee back to order.

We have approximately one hour and 15 minutes left, and we're going to probably keep you until 4 o'clock today. So we're going to ask Wendy to take one hour, the next hour, on submissions. If she isn't able to get finished with all the submissions today, we can probably find a few minutes on tomorrow's agenda to do that. We want to save 15 minutes at the end of the meeting for a couple of items under Other and also calendaring for our next meetings and a critical path document which we will share with you.

So, Wendy, could we start? I think we're on number 49; is that correct?

Ms Robillard: That's my recollection. The Canadian Mental Health Association.

The Chair: That's right.

Ms Robillard: So the Canadian Mental Health Association comments on definitions. They suggest that "the test for non-identifying information is too low and does not provide patients with adequate comfort that their . . . information will be used in a way that respects their privacy rights in the information." They're recommending that the HIA adopt a narrower definition of "non-identifying" information.

They also further state that

> certain information may be especially sensitive, either inherently so, or because of its potential for embarrassing or discriminatory use. This might include information about sexually transmitted diseases, mental illnesses, abortion and a range of other types of health care services.

So they suggest that

> the "lock box" provision contained in the earlier Health Information Protection Act ought to be restored so that a patient may inform their health care provider that they wish to place sensitive information "in" it and be secure in the knowledge that the information will not be disclosed without their consent.

Under Disclosure of Health Information, "Are the discretionary disclosures without consent . . . listed in the Act reasonable and appropriate?" They suggest that

> one possible change might be that, at a minimum, a patient ought

> to be notified whenever identifying information is to be disclosed under the [Health Information Act]. This way, the patient could challenge the disclosure through the Information and Privacy Commissioner, before the disclosure actually occurred. The CMHA recommends that changes to the [act] go further, however, and limit or eliminate some of the possible disclosures without consent altogether.

Under the duties and powers of custodians and whether the obligations are appropriate and reasonable, they indicate that "stricter controls on data matching ought to be implemented and they ought to recognize the threat that data-matching, especially in the digital age, presents to the privacy of personal . . . information."

In terms of other notes, they say that

> it will be important, for example, that a pan-Canadian frame . . .

Presumably a framework.

> . . . clearly articulate an obligation on the releasing jurisdiction to provide confirmation that the patient has consented to the release of his or her medical information beyond the originating jurisdiction . . . This legislative review process should not be considered complete until further information concerning the pan-Canadian framework is made available to all stakeholders and potential respondents to the review, and their feedback on issues of interface between HIA and the framework has been received and considered.

They also go on to comment that HIA allows for breaches in confidentiality of information between patients and practitioners to occur with little or no justification. They also believe that the legislation is likely unconstitutional.

Mr. Broda: I have a question here. Basically, every time it's referred to as the patient having consented, is there a reference to a guardian? A patient himself may not be able to grant that consent. There's no reference to a guardian. Has that been looked at?

Ms Robillard: Yes. I don't think most people refer to that, but it would be implied. There is a provision in the legislation that allows for other people to act on their behalf. Yes, that would be implied.

The Chair: Are there other questions or comments?

Number 50.

Ms Robillard: This submission is from the College of Physical Therapists of Alberta. They comment on the purposes in the act, and they say: yes, they're appropriate. They comment on the inclusion of the additional purposes, and they indicate that, yes, that would be acceptable to them. As to definitions, they indicate that there's no requirement for modification.

They then go on to talk about the expansion of the scope of the act. They say that in fact the scope of the act should be expanded. It should include

> any entities that are not within the public sector of healthcare but who have health information about an individual within their custody or under their control. The Act should also be expanded to include other departments of the Government of Alberta and local public bodies if they have jurisdiction over any health information.
>
> With regard to the question about the ambulance operators they say: yes, they should be included in the scope.

In relation to whether the scope of the act should be changed given implementation of the electronic health record, they say:

> For the [electronic health record] to be effective, the scope of the [act] must be extended to include all health entities engaged in providing healthcare – regardless of their source of funding. The key issue with the implementation of the EHR and privacy protection is that of access. The HIA will need to include strict guidelines as to who can access an individual's EHR and why. As with any electronic information system, the security of information is of utmost importance. Guidelines as to the security systems/programs required when using this database are essential.

With regard to the inclusion of health service provider information in the scope of the act, they say that it's appropriately included.

Whether personal health information contained in an employee file should be part of the scope of the act, they say yes.

Should the scope of the act be extended to the Workers' Compensation Board and Alberta Blue Cross? Yes on both counts.

> Should the definition of health information be changed to include non-recorded information . . .
>
> The definition of health information should not be changed to include non-recorded information. The logistics of attempting to administrate such information are difficult to fathom and unnecessary as the current system of having the confidentiality of this non-recorded health information protected by professional practice guidelines is sufficient.

Regarding the individual's right to access, is the process appropriate? Yes.

"Are the exceptions to the individual's right to access their own information . . . appropriate?" Yes.

Are the amount of fees set out appropriate? Yes.

> The amount of fees is appropriate. However, the health service provider needs to be compensated for the time they take to review the individual's health information request, to assess if all the information may be released, to write out relevant abbreviations so that the information is understandable to the applicant, etc. The government, and health service providers in the private sector, should set an agreed-upon rate for this task and the HIA should include a provision whereby health service providers may bill for the time they spend responding to an individual's request for their health information.

"How should the [act] be amended to address the concept of custody or control of a custodian within the EHR?" They comment that

> there are two levels of custody with the EHR:
>
> (1) that of the entire database that stores the personal files containing the health information; and
>
> (2) the information supplied by the custodians who provided healthcare to the individual that resulted in the various reports that make up the [electronic health record.

2:55

They go on to comment that

> if the government can be said to have custody of the entire EHR system, they are ultimately responsible for its security. If they wish to access their entire record, they can make an application to the health service provider who provided the service. A copy of this request [could] also be sent to the custodian of the database (the Alberta government) so that if they are tracking access to records, they are aware that this is a legitimate transaction and access to information.

Going on to the collection of health information. "15. Is the duty to collect health information directly from the individual except as authorized appropriate?" They state that

> the only legitimate circumstance that is not specifically outlined is that of collection of information from parents or guardians of minor children on their behalf, which may be covered by section 22(2)(d) of the Act. If this is the case, there are no other circumstances for indirect collection and the collection of health information directly from the individual except as authorized is appropriate.

Should custodians be permitted to collect information about an individual's family health history without consent? They say, "In order to provide appropriate, safe and optimal care, it is necessary that custodians be able to collect [this] information about an individual's family history." They should be able to collect this information without the relative's consent.

> Is the requirement to inform individuals about collection practices effective . . .

> If informing individuals about the custodian's collection practices can be said to be accomplished by simply having a poster prominently displayed that describes these practices, then doing so would not create significant operational difficulties. If an individual cannot read/understand, [then] problems will be encountered.

With regard to use and whether the current purposes for using information are appropriate, they say: yes, they are.

If you recommended an expansion of the scope of the act to include other entities, what purposes or responsibilities would you change to reflect that? They indicate that

> the purposes outlined in section 2 . . . are appropriate and sufficient . . . With regards [to] health information in the employee health file, there needs to be clear guidelines as to who can access this information and for what purpose.

Is it appropriate to use health information without consent for the authorized purposes? Yes.

Should the listing of authorized purposes be expanded, restricted, or modified? They say that it's sufficient.

In terms of disclosure, "Are the elements of consent appropriate?" They state that

> individuals should be allowed to provide verbal consent to the custodian to disclose their health information. The custodian can obtain this consent verbally and document the details of the verbal consent for disclosure.

Then they go on to say:

> The potential complication of verbal consent is that the individual could contest that they provided this consent . . . To avoid this situation the custodian could either:
> (1) provide the individual with a generic verbal consent form for the individual to initial . . . or
> (2) request that a witness be present to confirm that verbal consent was given.

"Should the discretionary authority to disclose to police services without . . . consent be extended to disclose basic registration information?" They state that

> the disclosure of limited, basic information (information on the residency or location of an individual) for the purpose of delivering a warrant, subpoena or court order . . . is appropriate. If a subpoena indicates that a custodian needs to disclose an individual's personal health number . . . then this may be provided without the individual's consent. It is inappropriate to allow access to an individual's PHN unless it is in the individual's best interest to do so . . . [The] PHN should be fiercely protected, especially in light of the information that may be retrieved within the EHR.

On the triplicate prescription program they agreed with that extension.

"Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information?" They say yes, and they go on to give some examples of what should be considered.

In terms of informed/knowledgeable implied consent model they say that that is appropriate for the health care system. "Concern once again is that the individual is able to read/understand and access [the] information" required.

What would the operational service delivery implications of that model be?

> The government may need to consider television or radio advertisements to convey this message and set up a 1-800 number or establish a relationship with provincial Healthlink programs to answer questions [in] relation to the collection/use and disclosure of health information.

Are the research provisions reasonable and effective? Their response is yes.

In terms of the substitute decision-makers they suggest that

> there is one other case to consider: [where] injured, incapacitated adults who have no personal directives or powers of attorney, who are not under the Mental Health Act but due to their medical condition cannot provide written authority to another person . . . Can there be provisions made/developed for people in this situation?

They state that the offences and penalties are appropriate.

They have comment in the regulation with regard to section 59, disclosure by electronic means, and wonder: "Are there provisions that an individual can refuse that their health information be disclosed electronically and request [it] in a written format and sent by regular mail or courier instead?"

Dr. Pannu: Mr. Chairman, of the 50-odd summaries that we have heard so far, this is one of the very few which advocates the expansion of the scope of HIA to include WCB and ABC, Alberta Blue Cross. Wendy, would you recall any reasons that are given in support of this position that the group has taken?

Ms Robillard: Sorry; I don't recall that.

Dr. Pannu: Yeah. It would be useful to I think have that.

The Chair: I'm sure that in the analysis that will probably come out, Wendy.

Ms Robillard: Absolutely.

Mr. Goudreau: On section 13 again – and it's only a concern that I have – one of the comments that they put there is "to assess if all the information may be released." It seems to me, you know, that if somebody is asking for their information, then all the information should be released. It goes back, again, to a need for purging information and whether some of that information should not be made available to the individual client or patient. I guess I'm concerned about that statement.

Ms Robillard: Section 11 of the act talks about both mandatory and discretionary exceptions. Discretionary exceptions are ones that the custodian may choose to apply if they're appropriate, but mandatory exceptions they must apply. That would include if there was health information about another individual in the record. So they may have a need to consider those exceptions if they apply; it's not optional.

Mr. Goudreau: Thank you.

The Chair: Thank you for the questions. Are there other questions or comments?

Having done submission 51, may we go to submission 52.

Ms Robillard: This submission was put together by the University of Calgary and the University of Alberta.

They talk about the purposes of the act, and they say that the purposes are appropriate. They don't recommend inclusion of the additional purposes. They don't find them necessary.

In terms of the definitions they say that both

> the terms "affiliate" and "custodian" need to be defined more clearly to deal with the complexities of a system that allows a physician to serve in various capacities – from independent contractor to employee of a private or public organization.

They also talk about the term "research ethics committee," which is used in the legislation, and say that it is inconsistent with terminology currently used in Canada and suggest that it should be changed to "research ethics board" in keeping with standard usage.

In terms of the scope of the act, the universities recommend expanding the scope of the act "to include a University with respect to health clinics, owned and/or operated by the University, whose primary purpose is the provision of health service to patients."

In terms of operators as defined in the Ambulance Services Act, they feel that, yes, the scope should be extended. "Anyone who has direct access to patient information should come under the . . . Act."

In terms of the scope of the act, whether it should be changed given implementation of the electronic health record, "no changes are necessary with respect to the principles in the Act but the medium in which the record will be kept will require different 'metrics' to ensure and measure compliance with the Act."

In relation to health service provider information included within the scope of the act, they feel that, no, that information should not be included in the act. They feel that the FOIP Act is "the appropriate authority for access to information" and that "the focus of the HIA should remain patient information."

The issue about personal health information contained in an employee file included in the scope: no, they think that that should not be included. "Employment law and case law already provide adequate protection of health information on behalf of the employee."

Should the scope of the act be extended to include Workers' Compensation Board and Alberta Blue Cross? "Yes. Anyone who has . . . access to patient information should come under the . . . Act." So there should be a consistency in how it's applied.

"Should the definition of health information be changed to include non-recorded information?" No. They say that it would not be possible to track or ensure compliance with that change.

3:05

In terms of the individual's right to access information, "Is the [current] process for obtaining access to records appropriate?" "Yes."

"Are the exceptions to the individual's right to access their own information . . . appropriate?" They've not experienced problems with any of those sections.

Are the amount of fees set out appropriate? "Yes."

> How should the HIA be amended to address the concept of custody or control of a custodian within the [electronic health record]?
>
> There should be no change to the principles or standards set by the original legislation – only operational anomalies should be addressed and metrics for compliance articulated.
>
> Is the duty to collect health information directly from the individual except as authorized appropriate . . .
>
> For the most part, it is sufficient to collect health information directly from the individual the information is about. However, there are legitimate circumstances in which it is highly appropriate for the health care professional to collect information from other, typically related, individuals. For example, the mother of an anorexic, the spouse of an alcoholic, [et cetera]. This information can be very valuable in the treatment of the patient and it is in his or her best interests that the doctor have access to that information.
>
> It is our view that s. 22(2)(c), which states that a physician may collect information from someone other than the individual the information is about where he or she believes that collection from the subject would prejudice the interests of the individual or the purposes of the collection, does not adequately cover the situation described above.

Should custodians be permitted to collect information about the individual's family health history without consent to provide care to the individual? "Yes."

Relative to the use provisions in the act, if you recommended an expansion of the scope of the act, what purposes or responsibilities would you change? There is no need to change anything.

"Is it appropriate to use identifying health information without consent for the authorized purposes . . . in the Act?" "Yes."

> Overall, should the listings of authorized uses be expanded, restricted or modified . . .
>
> The Act is currently too restrictive and needs a better balance between the public good and an individual's right to privacy.

Are the elements of consent appropriate . . .

> Verbal consent should be permitted when written consent is impractical or the matter is emergent.

They give a situation where a student accessing a service within one of their health clinics subsequently leaves the geographic area and asks for their information to be shared, that it's difficult to obtain the consent by phone or fax. So they believe that where it's in the individual's best interest, they should be able to disclose that.

> Are the discretionary disclosures without consent . . . as listed in the Act reasonable and appropriate . . . "Yes."
>
> Should the discretionary authority to disclose to police services without the individual's consent be extended to disclose basic registration information . . .
>
> Yes. Police should have access to registration information for the purposes of identifying and locating a suspect and/or witness if disclosure will avert or minimize an imminent danger to the health or safety of any person.
>
> Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information . . .
>
> No. There needs to be some flexibility with respect to genetic information and its use by front line caregivers. In the end, if the provisions in the Act are strong enough to protect the confidentiality of general health information, they will be strong enough for genetic information.

Is an informed/knowledgeable implied consent model appropriate for Alberta's health system? Yes, but it needs to be enabled through legislation.

What would the implications of that consent model be?

> Two pieces in particular are critical if an informed/knowledgeable implied consent model is to work. First of all, there needs to be a hierarchy of substitute decision makers – a ranked list of people who are considered competent to act on another individual's behalf when that individual lacks capacity or is incapable of making treatment decisions. Second, the health practitioner needs protection from liability for administering or withholding treatment based on consent that the health practitioner believed, on reasonable grounds and in good faith, to be sufficient and legal.
>
> Are the research provisions in the Act reasonable [and] effective . . .
>
> There needs to be a process whereby surrogate approval can be sought so that those who lack capacity can participate in research studies.

The Chair: Do we have comments or questions?

Let's go to number 53.

Ms Robillard: This submission is by the Alberta Cancer Board. They comment first on definitions. They suggest that

> it is unclear whether epidemiological information collected by a custodian, as part of a research project is diagnostic treatment and care information and therefore satisfies the definition of health information under the current . . . Act. Clarification is required.

They also comment that "the definition of health service provider appears circular and does not provide clarity in a meaningful way." So they are requesting a revised definition.

Also, they say:

> The definition of health services provider limits the use under [section 27(1)(e)] for education [purposes]. As well there are students in the health care environment who are not and will not be health care providers. It is recommended that this Section be changed to say "providing for education."

The definition of descendant as mentioned in Section 35(1)(o) "is required."

The definition of personal representative under Section 104(1)(d) "is required."

> The definition for non-identifying information needs to be expanded so that it is clear which data elements constitute a means of direct or indirect identification or by which methods information may be transformed legally from individually identifying to non-identifying.

In terms of how the act should be amended to address the concept of custody or control of a custodian within the EHR, they say that there is a clarification of custodial responsibilities required.

> – There needs to be limitations as to what health information will now and in the future be included in the Provincial [EHR].
>
> – We are not in favor of each custodian having custodial responsibilities for patient access and disclosures for all the health information available in the Provincial Electronic Health Record.
>
> – A custodian should be limited to providing access and granting disclosures to that information in the Provincial Electronic Health Record which he has collected or [accessed] to provide care.
>
> – The implementation of custodian responsibilities for the Provincial [EHR] must not create administrative burdens for the custodian.
>
> – A fee schedule for access and disclosures from the Provincial [EHR] is required.

In terms of use, should the listings of authorized uses be expanded, restricted, or modified? They are looking at an expansion of authorized uses.

> 22(2)(e)(i) Frequently geneticists request health information of one individual to provide health care services to another individual. This section limits the collection to providing a health service to the individual who is the subject of the information.
>
> 27 Whether a custodian may use the health information of one person to treat another individual with a like condition is not clear. Clarification is required.
>
> 27(1)(e) The definition of health services provider limits the use under this section for education. As well there are students in the health care environment who are not and will not be health care providers. . . .
>
> Sections 54, 35(1)(a) and 27(1)(d): It is unclear when one custodian discloses individually identifiable health information to another custodian for research purposes . . . whether the disclosing custodian requires a research agreement as noted in Section 54.

Are the discretionary disclosures without consent listed in the act reasonable and appropriate? They say that for improved clarity, consider grouping sections concerning disclosure to quality assurance committees. They've noted the sections that they addressed.

Relative to disclosures for treatment and care the Cancer Board

> recognizes the need for Alberta to pass legislation which is substantially similar to national requirements (PIPEDA). However to require processes for either explicit consent of the patient in the form of a signed document for disclosures for care and treatment or for implied consent, registration of denial of select disclosures and notation of any overriding authority contrary to that denial when invoked, would impede the timely, effective delivery of appropriate care and treatment [and] burden the custodians with a cumbersome and likely ineffective process and fail to meet the needs and wishes of patients. The current [act] provides no requirement for consent, either implicit or explicit. We would support continuation of the [act] in this regard.

3:15

In terms of research provisions

> it is recognized that a research agreement is a necessary and important precaution to the protection of health information. It is recommended that the [act] identify the researcher who signs such an agreement as having similar custodial responsibilities in the area of administrative, technical and physical safeguards for the protection of health information as the original custodian. In particular when the researcher appoints students to assist in the research project, it would be the researcher who must manage that relationship as an 'affiliate'. The researcher who signed the research agreement should be accountable under the [act] for any breaches.

Further, in terms of disclosures for research purposes

> the provincially designated ethics committees generally are ill equipped to undertake this responsibility. In addition, the custodian tends to require a specific and detailed accounting of the safeguards to be implemented by the researcher. It is recommended that this be deleted as a responsibility of the provincially designated ethics committees and clarified as a responsibility of the custodian.

They talk about consents that the researchers use, and they say:

> There tends to be confusion among researchers about the need for individual consents in that one consent is sometimes required to provide the custodian with the authority to disclose the individual's health information to the researcher and sometimes, in addition to that consent, another consent is required to indicate that the individual is willing to participate in the study. It would clarify the differences if two . . . terms were used to describe the two different 'consents', the one which authorizes the custodian to disclose the information to the researcher could be called Authorization . . . and the other, which demonstrates agreement to participate . . . could continue to be called consent.

They say:

> It is necessary to state explicitly which data elements constitute a means of direct or indirect identification of individuals which, if removed, would render a health information database de-identifiable, or by which [means] individually identifiable information may be transformed legally to be non-identifying.

They go on to talk about the increase in automated health information.

> It becomes possible and feasible to create de-identifiable databases which will meet the needs of some researchers. This Section of the Act appears to support the need to return or dispose of the . . . information provided to the researcher by the custodian.

They go on to recommend that if nonidentifying health information is provided, it should not have to be disposed or returned.

They go on to state that under section 72 "it is not clear whether a research project which involves data matching requires a PIA." So they're seeking clarification.

In terms of the regulations they're talking about the fee schedule, and they indicate that "a fee schedule for CDs is required" and that the actual cost of computer tape is greater than the $55 identified. So the fee schedule needs to be changed to reflect actual costs.

Section 8(4) of the reg. "It is not clear whether Section 8(4) is meant to address disclosures of individually identifying health information or both non-identifying and identifying . . . Clarification is required."

They go on in Other to say, "A retention schedule for health information and audit logs is required."

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

Okay. May we proceed to 54?

Ms Robillard: Submission 54, the Alberta Shock Trauma Air Rescue Society, STARS. They're commenting on the definitions, the definition of custodian and affiliate. They say:

> Health care providers find themselves possibly categorized as affiliates and custodians and can also be affiliates to different custodians, adding complexity to the access, privacy impact assessment and administrative costs required by organizations to meet the requirements.

So they want "additional clarity to [the] terms 'affiliate' and 'custodian' and the respective scope of each."

Around the issue about operators as defined in the Ambulance Services Act. Yes. They think that including those operators "under the scope of the Act is a natural transition with the devolution of ground and air ambulance services to the . . . regions."

> Should health service provider information be included within the scope of the Act . . .
>
> [It] should be released only with consent, although this consent may be implied for most purpose(s) . . . If the policy intent is protection of the health service provider information against use for purpose(s) other than the purpose(s) for which it was provided . . . it is recommended that the provision for protection be strengthened.

Should personal health information contained in an employee file be part of the scope of the act? They say that

> the retention of health information within the personnel file is related to human resource management and not the direct provision of health care and treatment. Any . . . information within the personnel file is currently bound by the privacy and access requirements of the PIPA or PIPEDA.

Are the fees appropriate?

> Affiliates can be and are required to process access requests on behalf of custodians. Clarity on the disposition of the fee collected from the patient is recommended as both the custodian and affiliate incur costs for . . . retrieval, preparation and review.

Disclosure to police services. They say:

> Clarity is requested on the mechanism and process for rapid disclosure of patient registration information to the police in life-threatening circumstances when time may be of the essence, both in protecting the information of the individual patient of whom the information is about, or others whose lives may be threatened by circumstances.

The Chair: Seeing no questions – how did we get to 55, 56, 57 so fast? – go to 58.

Ms Robillard: Thank you. East Central health spoke to the protection of the confidentiality of genetic information, and they support the inclusion of stronger provisions to protect that. "Provisions should be made in the [act] to provide special considerations [also] for the retention, use and disclosure of genetic information."

Under Other they talk about the disclosure of psychological raw testing and raw data scores. They are of the belief that "raw test scores resulting from psychological testing should not be disclosed to other health service providers or non-clinicians who are unqualified to interpret them." They go on to state that "the College of Alberta Psychologists has developed professional guidelines for the control of [these] tests." They believe the guidelines "should be taken into consideration and that HIA be amended to make stronger provisions to protect . . . psychological raw testing scores."

Further, East Central health references a submission that's upcoming from the health boards of Alberta Council of Chairs and simply want to state that they support that submission and so have not reiterated those concerns.

The Chair: Number 59.

Ms Robillard: This submission is from the Faculty of Medicine at the University of Calgary. They have spoken to the research provisions in the act, and the same recommendation applies both to the research provisions and to the substitute decision-maker. So the issue relates to surrogate consent for research, and we've heard that in a previous submission as well. So when an individual who is not competent to make health care decisions yet qualifies for a research study with a number of well recognized safeguards, they allow participation of that individual in the study, but the actdoes not currently permit the person who gives consent for someone else to be in a study to give consent for the researcher to access the health records. So they've been advised that "the Research Ethics Board may waive consent, allowing research to look at health records without permission," but they believe that "appropriately qualified surrogates, with all the safeguards that are in place, should be [allowed] to give consent for health records to be accessed."

The Chair: Let's go to 60.

Ms Robillard: This submission is by the health boards of Alberta. This is a subset of the Provincial Health Authorities of Alberta. They've brought together a group of organizations, regions, and I believe the Cancer Board to respond to the act from a regional perspective, a custodian perspective.

The first issue they addressed was the expansion of the scope of the act. They feel that "restricting the application of HIA to health service providers that provide publicly funded health services does not correspond to evolving patterns of health information flows," and they say that they should extend the application of the act to "all health information, irrespective of who pays for the health service, and irrespective of who is in possession or control of that information."

3:25

That's one option, but they submit that that option is too broad an expansion of the act and would create administrative burdens "that are disproportionate to the benefit that might reasonably be gained from such a change." So they recommend "a more moderate expansion of [the] scope." They suggest that it should

> regulate the collection, use and disclosure of identifying health information in the possession or control of organizations that have as their primary function the provision of health services, irrespective of who pays for those services.

They go on to comment that

> certain [types] of health services providers carry on independent community practices. Where the primary purpose of such practices is to provide health services, HIA should apply, whether the service is paid for privately or publicly. A definition of "health services organization" should include . . . independent health service providers.

The health authorities support inclusion of ambulance operators in the act.

> Should the scope of the act be changed given the implementation of the [EHR] . . .
>
> Health authorities strongly support adapting the scope of HIA so that it clearly encompasses health services organizations that will contribute to or have access to the provincial [EHR].

They submit that "regulation by HIA should be a mandatory condition of admission to the provincial [EHR] environment." They go on to say:

> At an operational level, the provincial [EHR] has the potential to raise numerous complex issues. However, at its current stage of development, health authorities feel that any more detailed comments would be speculative.

In terms of the potential of expanding the scope of the act to include the Workers' Compensation Board and Alberta Blue Cross, in principle they "support regulation of information in the custody or control of these organizations in a manner consistent with organizations whose primary purpose is the provision of health services." However, the inclusion of these organizations within the scope is not supported because these organizations "do not comply with the 'primary purpose' principle," they are "already regulated by different statutes that have information privacy provisions [in them]," and "there may be legitimate operational implications for those organizations that would make inclusion impractical." They also recommend that "promoting harmonization of HIA with . . . applicable legislation may be a more constructive approach."

> Is the process for obtaining access to records appropriate . . .
>
> In relation to procedures for access, health authorities support the current HIA model in the great majority of cases. However, a [disproportionate] amount of resources are aborted by a very few, repetitive and/or frivolous requests for access. The Committee should consider a procedure for dealing with demonstrably illegitimate access requests, either summarily or with a requirement that requesting parties be financially accountable.

Are the fees appropriate? In relation to fees they "support the current model but submit that it should build in sufficient flexibility to permit health authorities to get reasonable cost recovery accounting for cost inflationary pressures." The legislation "sets a high bar in terms of the obligations [that custodians] owe to the communities and citizens they serve." With the limited resources they are "continuously challenged" in allocation and the public is often critical if they perceive allocation of resources is directed toward nondirect care services.

"Are the elements of consent appropriate?" Yes. "Section 34 is an effective model for express consent for disclosure of health information." They do not support "the introduction of an implied consent model."

Are discretionary disclosures without consent reasonable and appropriate? They support the current model but "wish to emphasize the importance of retaining the current model in relation to disclosure to law enforcement services." Health authorities support the specific exceptions to the consent requirement in 35.

Should the discretionary authority to disclose to police without the individual's consent be extended? They support, as I've said earlier, the current model.

> The rules for responding to law enforcement requests are well established and well understood by police officers and by health service providers: disclosure with consent, by warrant or as specifically permitted by Section 35 . . . The general rule requiring consent or a search warrant protects individual privacy without unreasonably obstructing police investigations. Section 35(1)(j) carves out an adequate and properly balanced statutory exception to the rule. Health Regions strongly support the retention of this section 35 exception as . . . written.

The regions support the triplicate prescription program, the amendment to support that.

> Is an informed/knowledgeable implied consent model . . . appropriate . . .
>
> [It] would give custodians greater discretion but health authorities would prefer the predictability of an express consent with specific exceptions model. The current HIA model provides protection of individual privacy equal or superior to an implied consent model, so concerns about substantial similarity with PIPEDA should not be an obstacle to retaining the current model.
>
> Are the duties and obligations [of custodians] appropriate . . .
>
> [The] health authorities support the list of custodian duties . . . under section 60 . . . but submit that a review of the application of these duties should be undertaken by the OIPC in consultation with front-line managers and providers as to how these principles have been pursued in practice.
>
> A primary concern of health authorities is the scope of their accountability . . . for the collection, use and disclosure of information by independent third parties whose only connection to and control by health authorities is through contracts.
>
> Consideration should be given to amending the Act to the effect that custodians would be required to have a good faith or reasonable effort to protect health information provided to affiliates, but that custodians would not be held liable for the actions of affiliates in a contractual relationship.
>
> Sections 60 and 62 effectively make custodians guarantors of the actions of their affiliates.

In terms of the commissioner's role and any suggested changes the role of the OIPC in accepting privacy impact assessments should be addressed.

> This detailed review often results in a project being well underway before feedback is received. The OIPC will not "accept" the PIA until all their requirements are met, a process that equates more to an "approval" [of] the PIA . . . It should be noted that health authorities support the notion of PIAs as a good internal operational tool but question the process of acceptance by the OIPC. If the OIPC maintains a role in accepting [privacy impact assessments] it is strongly urged that the process be streamlined and made much more efficient . . .
>
> Are the offences and penalties appropriate . . .
>
> While Section 105 provides some legal protection (immunity from civil lawsuit for good faith actions), similar legal protection does not apply to penalties imposed by the Information and Privacy Commissioner.

In terms of other issues, with regard to retention rules

> health authorities submit that the Committee should investigate the progress of these efforts [to establish retention rules] to date and consider whether there are some core principles that could be incorporated in HIA by regulation.
>
> [They] urge the Committee to promote the harmonization of HIA with other information, access and privacy legislation in five . . . dimensions.

They're looking at legislation that regulates other Alberta organizations that interact with the regions, so FOIP is one example; looking at legislation that regulates individual health services practitioners, so the Health Professions Act; at the Regional Health Authorities Act; at health information access and privacy legislation in other provinces; and at PIPEDA.

The Chair: Are there any questions? Comments?

Well, you're doing a great job, Wendy. Sixty-one.

Ms Robillard: Okay; 61, the Canadian Medical Protective Association. The first question they responded to is whether custodians should be permitted to collect information about the individual's family health history without the consent of the family members for the provision of care. The short answer is: yes, they support that provision.

In terms of disclosure of health information, "Are the elements of consent appropriate?" They say that there are still some

> difficulties in interpreting and applying the various provisions of the [act]. For example, the requisite elements of a consent to disclose individually identifying health information enumerated in subsection 34(2) are quite onerous. The "informed consent" requirements . . . are particularly troubling in this regard as informed consent in this context must include an acknowledgement that the individual has been made aware of the reasons why the health information is needed and the risks and benefits to the individual of consenting or refusing to consent. This would appear to apply even where the disclosure request [was] initiated by the patient . . . In circumstances such as these, it is questionable whether a physician who is not initiating the disclosure has sufficient information to advise the patient of the reasons why the health information is needed by the third party, not to mention the risks and benefits of consenting or refusing to consent . . . The onerous nature of subsection 34(2) is compounded by the requirement that patient consent in these circumstances must always be obtained in writing or electronically.
>
> Are the discretionary disclosures without consent . . . as listed in the Act reasonable and appropriate?

They say that "legislation of this nature [must] be drafted in such a way that it does not unnecessarily impede physicians from contacting organizations like the CMPA in order to obtain necessary risk management and legal advice." They say that "clear exceptions that would permit physicians to communicate with the CMPA about

medical-legal issues with respect to both day-to-day practice and existing or anticipated legal proceedings are extremely important."

3:35

They are satisfied that the existing exceptions in HIA likely cover off the circumstances noted above.

> However, in the interests of greater clarity and to avoid a "privacy chill", the CMPA submits that the HIA should be amended to expressly recognize the important role risk management advice plays, not just for physicians, but for the health system as a whole.

They submit that

> it would therefore be appropriate for the [act] to be amended to specifically authorize the disclosure of diagnostic, treatment and care information without consent if the disclosure is required for the purpose of obtaining risk management advice.

They go on to specifically identify how that could be incorporated in sections 35(1) and 41 as noted.

They also submit that there should be an amendment

> to expressly permit the disclosure of individually identifying diagnostic, treatment and care information without the consent of the individual for the purpose of anticipated proceedings in which the custodian is likely to become a party. This could easily be accomplished [by] the following amendment:
>
> 35 (1) A custodian may disclose individually identifying diagnostic, treatment and care information without the consent of the individual . . .
>
> (h) for the purpose of a court proceeding or anticipated proceeding or a proceeding or anticipated proceeding before a quasi-judicial body to which the custodian is a party or reasonably anticipates becoming a party.

In relation to the informed/knowledgeable applied consent model they submit that

> such an amendment is unnecessary, as consent to transfer patient information to other custodians for this purpose is already implied under the common law . . . Legislating implied consent requirements could also limit physicians' ability to discharge their legal and ethical duties to consult and refer patients in appropriate cases.
>
> The requirement to make and maintain a notation of all disclosures made without consent pursuant to the [exemptions] found in section 35 can . . . be onerous in practice.

In terms of the duties and obligations of the custodian, whether they are reasonable and appropriate, the "additional administrative requirement may contribute towards a reluctance to refer and consult with colleagues," so they're concerned about that. As well, again the notation requirements under section 41.

Finally, on another issue they say that

> it is clear that greater uncertainty regarding the interpretation and application of the [act] has arisen since the introduction of . . . PIPA. Unfortunately, the paramountcy provisions found in both the HIA . . . and the PIPA . . . contribute to the confusion in this regard. The CMPA submits that it would be helpful if the Alberta government undertook to provide further clarification of the intersection between these two pieces of privacy legislation. We note that this issue is one of particular concern to occupational physicians who practice in the private sector.

Mr. Goudreau: I need a little bit more information about the Canadian Medical Protective Association. Is it a legal body or an insurance body? I'm making assumptions that they provide legal counsel to physicians.

Ms Robillard: Noela, would you be willing to tackle that one?

Ms Inions: I could. The CMPA, Canadian Medical Protective Association, is not actually an insurer although they do provide coverage for all their members. They are created by a statute, and they do represent, by and large, most physicians across Canada in defending them in malpractice litigation and a number of legal and quasi-legal proceedings.

Mr. Goudreau: So they're both insurance and legal.

Ms Inions: They are not technically an insurer – they say they're not an insurer. They're, for example, not caught by the Insurance Act and that sort of thing. They are basically funded by fees paid by the physicians across Canada, and they represent them in all kinds of proceedings brought against physicians and would do something like this and participate in inquiries before office and that sort of thing in the policy issues.

Mr. Goudreau: Thank you.

The Chair: Thank you.

Dr. Pannu: What is the relationship between it and the CMA if any?

Ms Inions: The Canadian Medical Association? There's no specific relationship. They each provide different types of services to physicians. A physician may choose to belong, I think, to the CMA, but if they're practising, they would be probably – it's not to say that there aren't other insurers. There is the British Medical Association as well, that insures some of the European physicians or physicians from that area. So not all physicians practising in Canada are insured through CMPA.

The Chair: Thank you.

May I suggest that we conclude with number 62 for today, and then we'll finish the agenda.

Ms Robillard: Okay. Number 62 is a submission from an individual Albertan, and this individual is expressing concern regarding the electronic health records and the confusion surrounding the intent of the Health Information Act in relation to the electronic health records. This Albertan's daughter

> was dismissed [from a program of education] after successfully completing her first year in a health related field because she was accessing patient records for the purpose of educating herself in preparation for her second year in clinical studies. It was indicated to her that she could review the physical patient charts to better understand the treatment protocols and tumor classifications, so it was her thought that she could also review electronic patient records in the same manner.

So this individual is asking that the OIPC be asked to "intervene or rule on cases where there appears to be a miscarriage of justice with regards to any government Act, and in particular, one which is relatively new and has no prior precedents to set standards for."

The Chair: Questions?

I'm still confused, Karen. Which one is the government one?

Mrs. Sawchuk: The government submission is number 67, and we just handed out the summary this morning as well as the actual submission for tomorrow, Mr. Chairman, so all the members should have that one. But the summary was also handed out this morning.

The Chair: Perhaps we should review that one as our final one today, Wendy.

Ms Miller: Could I suggest, Mr. Chairman, that – in tomorrow's submission Mr. Todd Herron, the assistant deputy minister of health, will be here in person and speak to it in an executive fashion – at that

time between Wendy and I we could assist in further detailed discussion of the submission. Otherwise I think you might end up doing it twice.

The Chair: That sounds good. Thank you very much.

Okay. Let's go back to the agenda. I should perhaps note to the members of the committee that we did at a recent meeting extend deadlines for submissions until September 10, so there still could be a few more submissions which we will have to review as we go forward.

Under Other Business, Mrs. Sawchuk, would you discuss the item of the survey and the other item you have there.

Mrs. Sawchuk: Mr. Chairman, we had a very quick response from Roseanne Gallant from the OIPC to a question from Mr. Snelgrove this morning referring to the OIPC stakeholder survey in 2003, and this is the highlights report. It's in response to the question this morning that related back to the Capital health authority submission. We'll just make copies available for the members.

The other thing is from Noela Inions, also from OIPC, an addendum to the Information and Privacy Commissioner's submission. They will be appearing before the committee tomorrow afternoon. We'll just make sure that the members have this so that they can go over it.

That's it under Other Business, Mr. Chairman.

3:45

The Chair: Thank you.

Does anyone else have anything under Other?

As we get into scheduling, you will note that we are scheduled again tomorrow at 9 a.m. Catarina Versaevel will be here to present us on the unification, the harmonization of this act and the PIPEDA. Then we will be doing five public presentations tomorrow also, commencing at I think 11:20, finishing up after lunch.

How many committee members will not be able to be here tomorrow? Okay. Thank you. So noted.

Linda, would you please explain to the committee the critical path planning, and could we hand those out. You will receive a copy of this. When they're out, Linda, if you would take the committee through this before we do our final item, which is calendering for the next couple of months.

Ms Miller: Sure. What we did in support of the committee and your work was draw together some assumptions that we felt likely was your intent and, based on those assumptions, draw up a revised schedule of activities, planning, and options for the committee to discuss. I believe they're handed out now, and I'd like to go over the assumptions first. Just to reiterate, these are assumptions we've made on your behalf. If we are incorrect, please indicate as such to us.

We're anticipating that you want to conclude your work by October 22. Given the initial critical path, that was tabled with this committee some weeks ago, I just point out that we have had that critical path shortened by some seven months and that we really now have a six-week working timeline between the date of the last submission that could be tabled to the committee, that being September 10, to when a final report would be due. So, clearly, that has a lot of work implications for us back at the office and in support of the committee here in your meeting sessions.

We understand that you want to meet your full mandate and that completion of only partial mandate issues is not acceptable to you. We also understand that this revised schedule may have a significant impact on the pan-Canadian work. However, we probably will get more clarity from Catarina Versaevel tomorrow on that particular issue.

So what we're proposing in terms of trying to address these assumptions is that item 5 is where there is ready consensus or agreement that the committee consider taking a moderate approach in terms of making the necessary changes to the Health Information Act. However, where there is not general agreement, the committee may choose to not change the legislation at this time, but that particular issue would have to be then left to a later review date.

As commented earlier, we will work on summary analysis charts. What those charts will reflect is grouping all of the comments by each question, indicate to you in that chart where there is a range of opinion or agreement or not on a particular question, and provide some options to you to consider based on the inputs of the various stakeholders.

We will endeavour wherever possible to circulate one week in advance. However, there may be times when we're just not able to turn that around as quickly as we'd all like. So just to kind of give a bit of a notice on that issue. Unfortunately, the revised schedule does not allow for a second round of consultation, assuming that you want to conclude your work by the October 22 date.

I believe you've already received a planning options calendar, colour coded. The yellow indicates, of course, established meeting dates, the blue indicating some proposed meeting dates that we need to target in order to achieve the final report to be tabled by the 20th, and the grey indicates, obviously, when we'll be able to have for discussion at a meeting the updated summary analysis charts as indicated on the monthly calendar in front of you. Again, these are assumptions that we've made on your behalf. If we are incorrect, please indicate to us.

The Chair: Thank you, Linda. I'm going to suggest that we are trying to table our report to the Clerk, which we must do to achieve any validity with our report. If we don't get our report tabled with the Clerk before the writ is dropped, then our report is sort of lost. So the goal I'm suggesting and hoping that you will support is that we do our best to get our report tabled to the Clerk by October 20. It was suggested the 22nd, but, you know, we're just talking about a couple of days.

Questions on anything that Linda said?

Ms Blakeman: Well, one of the meeting dates that's proposed here in order to meet your goal of the 20th is on Monday the 18th, which is the municipal elections.

The Chair: We'll go into dates, Ms Blakeman. We'll talk about that. A good point. Thank you.

Going back to September 13, are there other questions, comments? We already accounted for September 13 and 14, so that should be on your calendars.

You will notice that on September 21 it's proposed that the analysis chart updated summary will be circulated.

Mr. Goudreau: Does that mean there's a formal meeting?

The Chair: No. That means that you will receive it. We feel that we should leave some time there for committee members to look it over before we convene the next meeting. So we've actually proposed for your consideration meetings on the 27th and 28th of September.

Ms Kryczka: The week before the 7th of September we receive the

draft summary analysis chart. You've got: September 7, circulate first draft summary analysis.

The Chair: Okay. Would you clarify that?

Ms Robillard: Yes. It would be our intention that we would have a document ready to circulate to the committee members prior to the September meeting that starts pulling this information together. It's not quite a week before because of the stat holiday.

The Chair: Then the next one would be circulated on the 21st?

Ms Robillard: Yes. We'll update it.

The Chair: An updated one?

Ms Robillard: Yes. So we'll have done more work, more thinking, and have more information.

The Chair: Dr. Pannu.

Dr. Pannu: Thank you, Mr. Chairman. I may be late in making an observation that I'm going to make on the proposed schedule, but with your permission I'd like to do this.

The Chair: Sure.

Dr. Pannu: There's an assumption, of course, that's driving this that it must be completed by October 20, that if not, the work of the committee will be lost. I really question that, you know. The committee is doing lots of work. We have invited Albertans of all kinds and organizations to do their work, and we'll certainly be recording that work in the form of some sort of a draft or some document up to the time the writ is dropped. If we are unable and for good reasons believe that we can't really do a good job in this very short period ahead of us, between now and the 20th of October, I think we should simply pass on the information to the next Legislature and the committee that will be struck, and they will start with the work that this committee has done and worked hard on putting together and then go from there.

We already have in a sense acknowledged that the report of the committee will be incomplete in the sense that only those recommendations on which we have a general consensus – I don't know how you define it – are the ones which will be included in this report and that the ones on which we have further work to do before we develop a consensus will be left over to be addressed by the next committee. So we are acknowledging that the committee report will be an incomplete report.

I am frankly asking this question in good faith, whether there is really a set of reasons to rush through this. We're also dispensing with the second round of consultations, which we thought would be appropriate to do. It's a very important piece of legislation.

Thirdly, I commiserate with the resource people. You know, we might drive them crazy before they finish their work.

3:55

So for all these reasons, I am submitting, Mr. Chairman, for your consideration, for the consideration of the committee the possibility that we do as much work, work in all earnestness to do this work but not necessarily rush to complete the report until we have gone through the second round of consultations and given ourselves time to seriously reflect on what recommendations we want to make. Work will not be lost. I think we will simply be handing over a fair bit of hard work that we have done to the committee of the next Legislature if the election is called, as we expect it to be called I guess somewhere around October 25.

The Chair: Thank you, Dr. Pannu.

Before I make my own comments about that, I'm going to call on the committee members who want to speak. Mr. Lukaszuk and then Ms Kryczka.

Mr. Lukaszuk: Thank you, Mr. Chairman. Those are definitely interesting comments coming from Dr. Pannu. It would be a shame if work would simply just disappear into thin air. But I'm wondering: there must be some legislative, legal ramifications and legal parameters within which this committee operates. I would seek legal counsel, because my understanding is that indeed, however we may not want it to happen, this committee does actually disappear. There is no provision for passing of work from one legislative session on to another. That's one point.

The second point is that I'm wondering if it would be possible for a new committee, with a different constitution of members, to be able just to pick up and carry on having not had the ability to hear the presentations and do that kind of work. You know, we would be presumptive in assuming that the new committee would be constituted of the same members.

The Chair: Thank you, Thomas.

Ms Kryczka: Well, I think we had this full discussion actually.

The Chair: We did. I'm not sure Dr. Pannu was here.

Dr. Pannu: I probably was not at that meeting.

Ms Kryczka: Oh, I'm sorry. I'm going to start again. I wasn't sure whether I was supposed to speak or someone else was.

The Chair: No. You have the floor.

Ms Kryczka: Okay. Thank you. I think that we went over this same topic and made certain decisions two, three months ago regarding time frame, et cetera.

What I wanted to add is that when I came here yesterday, realizing how many submissions we've had – and you look at the list of organizations and institutions that have spent I think a lot of time preparing these submissions – and, in addition to that, the number of presentations and people making efforts to be here, I think we have a responsibility to complete the task with the committee as it is.

The other thing that I want to say, though, is that there's a lot of work to be done behind the scenes. Not the committee members, the MLAs; it's the support staff that have all the really heavy work to do to get us ready for the next meetings. If they feel they can do it, I think we can do it.

The Chair: Thank you. I tend to agree.

Okay. You know, certainly, as chair of the committee I have had these thoughts and recognize the challenge we have before us, especially the challenge that's before our support staff, who are the ones that do the analysis and the work. They realize the challenge also. I am of the opinion that we as a committee should do our level best to table a report. If we don't get it tabled, we don't get it tabled, but I believe we can do it. The staff have committed to make the effort to do it. They will have to work extra time, weekends and so on and so forth. Certainly, they have my total appreciation for their willingness to do that.

Regarding the number 5 that Linda referred to within timelines provided and take a moderate approach, I think that's there just to help us get through some tough items. If we can't absolutely get everything done, then we could take that approach to sort of enable us to table a report. I'm a person that always looks at the glass as being half full instead of half empty or whatever, so I'm going to be positive about this and believe that it's possible that the committee can resolve the issues. Certainly, number 5 is there, which Linda has very well described. But if we can't, then we have that option to fall back on.

So I'm now going to ask Karen to briefly comment on the responsibility or the logistics, and we could bring Louise in here too. We've spoken to Louise today about this report and the necessity to get it tabled before the writ is dropped.

Mrs. Sawchuk: Thank you, Mr. Chairman. It just refers to the paper that the Clerk Assistant and Clerk of Committees had done for the committee right at the outset stating that when the election writ is dropped, the committee dissolves. There's no status to it any longer as well as to the work that it's completed. It's sort of in limbo and never-never land because it doesn't belong to anything. It wasn't adopted by a committee. It doesn't have any status as far as staff members are concerned.

We could hope that a new committee would be struck and that they would be prepared to take whatever work this committee had done, but there's absolutely no way of ensuring that. So, you know, the paper that was done by Louise Kamuchik back on May 31 is still valid. We just, you know, seem to have a bit more information with respect to dates now.

For the committee's mandate there really isn't anything unusual about it. It's a standard type of wording that they've used for the majority of select special committees that are struck. In part – I mean, there are a number of provisions here – it says that

> the Committee must submit its report, including any proposed amendments to the act, within one year after commencing its review . . .
>
> When its work has been completed, the Committee must report to the Assembly if it is then sitting. During a period when the Assembly is adjourned, the committee may release its report by depositing a copy with the Clerk and forwarding a copy to each member of the Assembly.

Provided this committee gets the report done and deposits it with the Clerk, even if the election writ is dropped the next day, it still has status. It will eventually get tabled in the Assembly. The provision we have to worry about is getting it into the Clerk's hands in time.

That's it, Mr. Chairman.

The Chair: Thank you.

Mrs. Sawchuk: I'm sorry. I should qualify that by saying: if the committee chooses to go through with the revised timeline.

Ms Blakeman: Well, nice to see Dr. Pannu agreeing with the comments that were raised earlier by the Member for Edmonton-Gold Bar and myself. I think it is a challenge before the committee that we do risk rushing this. I understand the chairperson's optimism in believing that we can get through it in time. I still think we have to ensure that the work that we do is of a quality that we can put it forward inside the timelines.

Unfortunately, Dr. Pannu, this is one of the ways in which having a smaller opposition and a huge number of majority members reflected on the committee really plays against us. We did have a discussion earlier, and I believe there was a vote on it earlier, and we were not the winners of that vote. So it has been discussed at length, and the committee members seem quite clear that they want to progress with it.

The Chair: Thank you. You know, I certainly understand the comments that were made earlier and the concerns that some members of the committee have expressed, but I'm just going to ask that we as a committee do our best, try our best to get this report tabled. Certainly, we don't want to submit an inferior report, but we'll do our best to do the best we can. So I would just ask for your co-operation to the best of your ability to go forth now. We did have the debate, as you've pointed out, Ms Blakeman, and we did vote, and the majority was to go ahead.

I see on the calendar that we've actually proposed five meetings after the September 14 meeting, those being September 27, 28, and October 7, 18, and 19.

4:05

Ms Robillard: If I may, just to note about the 18th or 19th, we think we need one day there. Hopefully, we'll be down to a second draft or a final draft.

The Chair: Well, that's very good because the 19th is off. We cannot meet on the 19th. Several members of the committee have a caucus meeting that day.

An Hon. Member: Why can't we meet on the 18th?

The Chair: Because it's the municipal elections. [interjections] Well, we want to table it on the 20th.

Okay; we want to vote on the 18th, so maybe we could vote in the advance poll for municipal elections. What other reasons would we have to not be able to meet on the 18th?

Ms Blakeman: Well, I don't know about others, but I'm not available that day.

The Chair: Okay. All right.

Ms Kryczka: I am not either, but could you not e-mail me what you're doing on the 14th? I'll be out of town. I'll be a long ways away, but you could e-mail me on the 14th – couldn't you? – and I can give you written comments.

The Chair: Well, certainly we could do that. There's still at least one member that can't come on the 18th.

Dr. Pannu: Mr. Chairman, I think that it's not bad but it's undesirable as it is that we're rushing through it for finalizing the report. Two members have already indicated that they won't be here on the 18th. I may be a third one. We have two more working days in that week, so I wonder why we can't accommodate, especially at this crucial stage.

The Chair: Yeah, I'm amenable to that. We could meet on the 20th and then, hopefully, finish our work and table the report. Could we have agreement or consensus for October 20?

Mr. Goudreau: Rather than the 18th of October?

The Chair: That's right. Thank you, Hector.

Mr. Goudreau: Sure.

Ms Miller: We'll need at least a day between the last meeting and tabling of the final report, though, so that would mean that the final report . . .

The Chair: So what you're saying is that we wouldn't be able to table it on the 20th if we don't meet till the 20th.

Ms Miller: Right.

The Chair: But we could still table it by the 21st or 22nd.

Ms Miller: We'll do our level best, yes.

The Chair: Okay. I'm still amenable to suggestions from the committee.

Ms Kryczka: Well, I mean, why do we have to be at government caucus on the 19th if it's so important to get this done?

Dr. Pannu: To say good-bye, I guess.

Ms Kryczka: Possibly.

Mr. Lougheed: How about seeing how many could make it on the 18th?

The Chair: Okay. I have at least two who can't make it on the 18th. You said that you couldn't make it, Dr. Pannu?

Dr. Pannu: No.

The Chair: And, of course, Karen. So there are three.

Ms Kryczka: I can see if I can change my travel plans.

Ms Blakeman: So we're looking at the 19th now?

The Chair: No, we're talking about the 18th, I think. You did say the 18th; didn't you, Rob?

Mr. Lougheed: Yeah. I'm certainly good for the 18th. I don't see any problem there.

The Chair: Well, I can see how the vote's going to go. We have three members that can't come on the 18th, and the rest have indicated they can.

Ms Kryczka: Well, I still make my offer. I'll either be back here or I can have it e-mailed, and I can make comments, any comments. But I think that at that point there will be minimal changes. That's my prediction anyway.

Mr. Goudreau: Mr. Chairman, I really don't have any compelling reasons not to look at the 20th for a meeting date and the 21st to table our final report.

The Chair: It's just a challenge for staff to get it tabled.

Ms Miller: We need one day to do the printing. Well, I guess we could look at a meeting on the 20th, but the tabling of the report could not be until the 21st. I mean, we couldn't table the report and have a meeting on the same day.

Mr. Goudreau: No, no. What I'm suggesting is that we meet on the 20th with the tabling on the 21st.

Ms Miller: We can work to that endeavour, yes. Printing may be an issue.

The Chair: Did we not talk about printing this morning?

Mrs. Sawchuk: Yes, Mr. Chairman, we did. We'll find a way to physically get it printed. It's not just printing a copy. We have to ensure that we have one copy for every member in the Legislative Assembly Office, and we have to get it to them to meet the requirements and to table it with the Clerk and the Speaker. So physically we need a bit of time. We can't get around that. We have to be able to copy it, and that'll be after the members have passed the motion to approve it. If there are any corrections, those have to be made, too, before we can print it.

The Chair: Mr. Broda.

Mr. Broda: Yes. I think we should give them time, and the 20th seems like it's red-flagged here. I can't see why we couldn't have the 18th and 19th, either/or. We don't need both days. If we could check and see who cannot be at caucus that day, we should continue. Maybe it won't be a full day; we can still attend caucus.

The Chair: Thank you.

Mr. Lougheed: I propose we keep the 18th with the potential for the 19th or 20th, I think, if a second day is needed. Let's go with the 18th, and the 20th would be, certainly, our sort of cleanup day. I'd prefer to clean up on the 18th if that's possible.

Ms Kryczka: Well, I like Dave's suggestion. Why can't we plan on meeting on the 19th, say from 12 o'clock to 6 o'clock? We need six hours, and I can tell you that with our caucus the heaviest work is going to be done in the morning, and we've been there. We might even be finished by noon.

The Chair: How many committee members could make it on the 19th? Those who are involved in the caucus meeting: just don't use that as an excuse. Okay? So other than that, how many committee members could come on the 19th?

Dr. Pannu, you can't come on the 19th?

Dr. Pannu: I am not sure, Mr. Chairman.

The Chair: Certainly, I would like to see all members of the committee have a chance to vote on the final report. I think that's, you know, an important consideration.

Okay. I would like to check a couple of things about caucus on the 19th, and Karen's comments may well be that half a day will do for caucus. I would like to just discuss this with our whip. So could we just leave the final decision on this, whether it's the 18th, 19th, or 20th, until tomorrow or as soon as possible? Could we agree on all other dates, the 27th, 28th, and the 7th, and we'll try to get some more information on the 18th, 19th, or 20th? Can we leave it at that?

Mr. Goudreau: Mr. Chairman, some of us have commitments fairly early in the evening on the 7th in Red Deer. The 7th is okay as long as we can finalize by fourish.

The Chair: If we finish at 4 o'clock, does that get you there?

Mr. Goudreau: Yeah.

The Chair: Could I have a motion to confirm the dates of the 27th, the 28th, and the 7th with a note that we get out by 4 o'clock at least and with the option of the 18th, 19th, or 20th to be decided tomorrow?

Mr. Goudreau: Mr. Chairman, I'll move that.

The Chair: Thank you, Hector. By a show of hands, all in favour? Opposed? Okay. Carried.

All right. I would accept a motion to adjourn.

Mr. Broda: So moved.

The Chair: All in favour? Opposed? Okay. We are adjourned.

[The committee adjourned at 4:15 p.m.]