Title: Tuesday, September 14, 2004 HIA Review Committee
Date: 04/09/14
Time: 9:04 a.m.
[Mr. Jacobs in the chair]

The Chair: I would call the committee to order. We're a little bit after 9 o'clock. I'd like to welcome you here this morning. Thank you for attending again today. It looks like we have an interesting day. We have some discussion on the preliminary summary analysis this morning and three presentations this afternoon. Of course, as usual, lunch will be at noon in the next room.

Before we deal with the agenda, I would just like to indicate to the committee for the record that Dr. Pannu has tabled with me this morning a document from the office of the Information and Privacy Commissioner, Response to Bill 40, the Health Information Act. It's a document that was discussed yesterday, and I think Dr. Pannu referred to it yesterday in his discussions.

Ms Inions has briefly seen the document and had some comments to me earlier. I wonder if she would like to make those comments to the committee at this point.

Ms Inions: Yes. Thank you, Mr. Chairman. The document is entitled Response to Bill 40, the Health Information Act, and I'm trying to recall whether this was actually posted on the commissioner's web site or not. This was a document that I located yesterday but was unresponsive to Dr. Pannu's reason for requesting the document in that, as I recall, he was looking for something that provided a rationale for including health service provider information in the Health Information Act. I've taken a couple quick looks through the act and didn't find any discussion of that issue.

In any event, this is the document that he was thinking of, so for that purpose it's being tabled with the committee.

The Chair: Thank you very much. I'm sure you will read it again and see if there is something you missed.

Dr. Pannu, did you have any comment at this point?

Dr. Pannu: No. I haven't had a chance to take a fresh look at the document.

I undertook yesterday here that I'd look for it. We found it, and it's brought forward for the attention of the committee.

The Chair: Thank you very much. So it is tabled with the committee, and if anyone else would like a copy, we can certainly make that available to you. Perhaps at our next meeting, if there is something relevant here, we could put it on the agenda for discussion. Okay?

You have a revised agenda in front of you, I believe. So is there any discussion or other items that you would like to add to the agenda this morning?

Mr. Broda: I move that we accept it.

The Chair: I have a motion to adopt. All in favour, please say yes. Opposed, please say no. So adopted.

Okay. Wendy, are you starting this analysis? Evelyn is going to start. Okay.

Oh, sorry. I was looking left instead of right.

An Hon. Member: You don't want to be doing that.

Dr. Pannu: You were looking left, Mr. Chairman?

The Chair: To the clouds, to the trees.

Ms Blakeman: To the wonderful constituency of Edmonton-Centre.

The Chair: Yes.

Ms Blakeman: I just wanted to put on record my thanks. Someone's done some homework overnight and come up with some documents on mandatory reporting of gunshot wounds, that they've given to me. I don't know if anyone else got them, but thank you very much.

The Chair: I think that was yesterday afternoon, just after you left, Ms Blakeman.

Ms Blakeman: Yesterday afternoon, then, just after I left. Excellent. Thank you for the work.

The Chair: Thank you.

Ms Swanson: I'm going to lead off, and I just wanted to make sure that I'm speaking into the mike.

I'm going to give a little bit of background before we go into the actual review of the long charts that were circulated yesterday afternoon. What we're proposing to do today is run through, in particular, the summary of stakeholder input on each of the questions that were asked in the consultation guide.

What we hope to achieve over the course of the day is to priorize some of the issues that you will want to be considering in further detail over the course of the next month or so and to also identify those issues on which you feel that you have sufficient input at this point in time to perhaps reach some preliminary conclusions. During the day as we go through each of the questions, what we'd like to do is get some feedback from you about additional information or research that you think is required.

Our next step will be to actually prepare some analysis of the issues. We've not done this. This is strictly an analysis of what the stakeholders said, but there's more background research to be done on many of these issues before conclusions are drawn. In some cases you might find that there is enough information here to make some preliminary conclusions.

The Chair: So, Evelyn, on that point, then, if the committee was basically achieving consensus on some of these issues today, we could actually put those forward in a preliminary draft to be considered in the draft?

Ms Swanson: Sure.

The Chair: So one of the things that we might look to today is to identify issues that there is general consensus on. Then for the others that there is not consensus on, we'd have to do some more analysis and some more background and more discussion.

Ms Swanson: That's right.

The Chair: Very good.

Ms Swanson: Another point. The pan-Canadian framework was mentioned yesterday. At the next meeting, I believe around the 27th, we will bring back a document, possibly this document, with additional relevant input from the consultation that was going on in parallel on the pan-Canadian framework. So, for example, one of the key questions is around informed knowledgeable consent. What we're proposing to do today is set aside three or four questions that deal with that topic because that is a key issue in the pan-Canadian framework. So you'll be able to look at the input from the consultation paper plus the input from the pan-Canadian framework consultation at the same time, if that's seen as appropriate.

9:10

The Chair: Any comments from the committee?

Ms Swanson: Rather than going through it twice and trying to integrate it later on.

The Chair: I think it's a great idea.

Ms Swanson: Okay. All right. I think that those are the initial points I wanted to make about what we want to achieve today, and if that's acceptable, I'll just proceed then.

The Chair: Okay. Let's just see if there are any questions to this point on the plan. Good.

Ms Swanson: First of all, I wanted to give you a little bit of context about who responded to the consultation. We've categorized all the responses. We have 72 responses to date. This document includes 68. We received four late on Friday afternoon. We weren't able to get them into the typed text, but Wendy went through them last night, and we're going to just mention them verbally in the relevant part, and we'll catch up in the typing later on, after the meeting. So we have 72 responses in total.

Fifteen of those are from municipal governments. We have six from health authorities including the health boards of Alberta, which represents all of the health boards, the regional health boards and the Alberta Cancer Board. We had seven from professional colleges or associations representing four professions. Actually, now that's eight. Yes, that would be eight because we got the Occupational Health and Safety nurses on Friday. We have nine health service providers including groups like the Alberta Long Term Care Association, STARS ambulance, for example. So those are examples of health service provider organizations.

We had 10 private-sector responses including the chambers of commerce of Calgary and Edmonton plus large private employers. We had five from the insurance sector plus the WCB. We had three from the police, two submissions from universities. The universities of Calgary and Alberta submitted a joint submission, and we had one additional from the University of Calgary medical bioethics.

We had four from what we're calling the health information and research sector. You heard from CIHI yesterday, and we've included AFMR and CIHR and one other organization that responded in that category.

We had two advocacy groups, the Canadian Mental Health Association and the Consumers' Association, and we had three individuals plus one representative of a religious group who is speaking this afternoon.

The government of Alberta submitted one submission, and then there was a submission from the Health Facilities Review Committee on Friday afternoon, so we'll count those as government of Alberta, and the office of the Information and Privacy Commissioner.

That should add up to 72. We'll include a summary like this in writing for you at your next meeting.

Okay. So if there are no questions on that, then I'm going to go into the document. You'll see that we have titled it a working draft in progress, and that's because we will add in any of the late responses. I wanted to note that we have summarized the stakeholder input. We've reworded for brevity. Although we tried to retain the original wording as much as possible, we very much condensed it. So if you need original wording, we'll have to go back to the letters. Also, we will mention the late submissions. We've incorporated them, and we will mention them. With that, I'm going to move into the first question.

The first question was: "Are the purposes in the [Health Information Act] appropriate? If not, please explain why and make suggestions for improvement."

Well, we received 10 comments now from nine organizations and one individual, because we received a comment from Canadian Blood Services. The general consensus is that the purposes in the HIA are appropriate as written, but there were two suggestions for changes. The AMA suggested a preamble to part 1 giving primacy to the principles of least amount of information and highest degree of anonymity because they feel that this is very central to what the act should be about. Canadian Blood Services suggested that we amend the purpose to acknowledge public health as a legitimate use of health information.

The Chair: We have a question.

Mr. Snelgrove: The question I would have is on 1(a). The AMA says: yeah, we should put this on. On 1(b) they say: no, don't change it. So I think the compelling reason is to just leave it alone, although Canadian Blood Services do make a good point.

Ms Swanson: Yeah, 1(b) is a slightly different question. It's specifically about whether or not it would be acceptable to add transparency and accountability as purposes. So in 1(b), then, we received seven comments from seven organizations, and the general consensus was: no, don't include transparency and accountability as purposes because that's not what the act is about; the act is about privacy. They feel that it would be confusing to add those additional purposes of transparency and accountability.

There was one professional association and college that did agree to the inclusion, but they didn't clearly state a rationale for their thinking.

So that's 1(a) and 1(b) now.

The Chair: Okay.

Mr. Snelgrove, any further comment?

Mr. Snelgrove: I think that by saying to expand it on their end and then not to expand it on the other end – they are the same thing, limiting one with a preamble or not including it in the second one. The purpose, when you read it, is pretty complete. I would suggest that they might make a point, but we should be able to go to the next and say: it's fine.

The Chair: So you're suggesting that we just leave the purpose as is.

Mr. Snelgrove: The purpose, yes.

Ms Blakeman: No, I think this requires further discussion. If we're at a point where you're asking the committee to okay this and put it forward as a recommendation of the committee that we would accept what Mr. Snelgrove has just suggested, I would strongly argue against that. I think there is room for discussion. We also have this group appearing before us today, and it's an opportunity for Mr. Snelgrove to question them more closely if he has issues with it.

The Chair: I guess, Evelyn, we're not going to put them forward to the final draft unless we have consensus or agreement. I see we already have some discussion on this item.

I guess you would welcome any comments. Mr. Snelgrove and Ms Blakeman have certainly made valid points. Anyone else?

Ms Kryczka: Well, I guess I would refer you to, for instance – and this is a good for instance – where you have a total of 10 comments, such as in 1(a), and there's only one of the 10 that makes a different statement than the other nine. It's not exactly a majority; right? Obviously, we're still going to have a discussion around it even if it's only one submission that is different than what the other nine are saying.

9:20

Ms Swanson: Yes. It will be up to the committee to decide whether or not it wishes to have further discussion. One point out of 10 may be a very valid point that you really want to take into consideration and do further analysis on.

Ms Kryczka: Obviously, we would look at: who was it? Which organization made that statement?

Ms Swanson: That would be one consideration.

Ms Kryczka: Okay. I just wanted to put that on the table at the beginning of this exercise, I guess.

The Chair: Thank you, Ms Kryczka.

Dr. Pannu: Mr. Chairman, more on sort of procedure than anything else. I think it would be perhaps appropriate for us to flag in the summary those comments that require further discussion before making sort of ultimate or penultimate judgments on whether or not to include them. Let's go through this. It's a fairly extensive list of recommendations and suggestions. We should ask ourselves, if we have reservations about some of these, which ones require further discussion and then return to them for a serious discussion of those which you have identified as ones that merit such attention.

The Chair: Thank you very much. I think that is the intent, and certainly this one is now flagged. However, I do appreciate the comments that committee members have made, because it does give us some inkling, some indication of some of the concerns that are with the committee. I certainly don't want committee members to feel like they shouldn't make comments, because we would welcome your comments.

Anyone else on this one? It is flagged; we will do further discussion.

Seeing no further questions, Evelyn, I guess we can proceed.

Ms Swanson: Okay. Question 2 is: "Are there any definitions that should be modified? If so . . . provide the rationale . . . and any suggested wording." Now, on this one we did receive quite a number of suggestions about definition of the term "custodian." We've dealt with all of those in the section of questions specifically about custodians. There were also a few comments about genetic information, and we've dealt with those in the context of the question around genetic information. So they will all be included, but they're just not included in this particular set of questions.

We've tried to group some of the suggestions for definition changes, and here we have the Capital and Calgary RHAs suggesting changes to the definition of diagnostic treatment and care information, both of them suggesting an expansion to include other information collected when providing health services to an individual. This would include information, for example, about the family, about other third parties, or information about provision of shelter and financial assistance. So they are suggesting an expansion to the definition of the term here.

In addition, there were some suggestions around nonidentifying health information. Three organizations mentioned it. Two suggested that the definition should be a little more narrow, and the third asked for some clarification around which data elements make information nonidentifiable.

Then there were many individual suggestions that were made, suggestions to clarify. These included third party information, data matching, inclusion or exclusion of epidemiological information gathered through research, whether it should be part of diagnostic treatment and care information and health service provider information. There were also suggestions to add definitions, including "manage the health system," which is one of the uses of health information, access, confidentiality, disclosure, privacy, security, and descendant and personal representative.

Other suggestions were to expand the affiliate definition to capture physicians without admitting privileges – right now they're captured as affiliates to an RHA if they are employees – and to include corporate entities such as medical clinics in the custodian definition and to update the reference to custodians in the definitions. We've referenced a section of the RHA Act which has been changed.

The Chair: Are there questions? I have a question on process, and perhaps Wendy or Linda would like to address this one. As we go forward here and as we make this preliminary analysis today and find that there are many items we don't have consensus on, is it the intent of Health to bring forth some recommendations which would cover the comments, take into account the comments we've received, the comments of the committee? As a starting point for future discussions will you be bringing forth some recommendations from your department that would include the items and the questions that have been raised?

Ms Robillard: In the further analysis that the department will do, yes, we'll look at all of the submissions, what people have suggested. We'll do further analysis, and we'll develop some options in terms of those issues.

As far as bringing recommendations forward, we can certainly try to do that where that makes sense, yes.

The Chair: Well, sure. What I'm getting at is that we need some point to start the discussion from so that we have some basis to get started on to reach decisions.

Ms Robillard: It would be our intent to do that for the next meeting.

The Chair: Okay.

Further to this, Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. I'll take this opportunity to say good morning to everyone as well.

I'm not entirely certain, then, what the purpose of the exercise is that we're undertaking right now, if we're going to go point by point and vote on particular changes in the next meeting and today we will not be making any binding decisions. We all have those forms available to us. We can read them whenever we choose, at our own time. Is it the point to just go over the form and identify what submissions we had?

The Chair: Well, Mr. Lukaszuk, one of the intents here is to find out first of all if we have consensus on any of the recommendations. If we do, then those recommendations would go forth in the preliminary draft. The second purpose is to allow the committee members the opportunity to again respond to the items. Further to that, I will ask Linda or Wendy if you want to add reasons for this exercise.

Ms Miller: Just a further comment. I think that earlier on the request of the committee was to summarize how many perspectives were given on a particular issue, because you were, previous to this, just getting them one off at a time. So the intent at this stage is to group where the responses were on a particular question and thus show the diversity or similarity in opinion on that particular question or others. That was fundamentally the whole purpose of this exercise.

The Chair: All right. Can we proceed on that basis, Mr. Lukaszuk?

Mr. Lukaszuk: Definitely. It sounds reasonable.

The Chair: Any other comments?

I realize, you know, that it seems like we are sometimes talking about the same thing two or three times, but it is important, and we need to make sure we understand what we're doing and what's been said.

Ms Kryczka: I just want to say that I think it's an important first step, because if we don't go through this first step, we may find ourselves coming back because we've missed this first step.

The Chair: Thank you. I agree, but I also need to say at this point that we don't have unlimited time here. This committee has agreed to a final meeting of October 15, when the plan is to do the final draft. So everybody is under a little bit of pressure here, especially Wendy and Linda and Evelyn, who have done yeoman's work to bring us to this point. I'm sure that they have spent countless extra hours doing this, and as chair of the committee I express appreciation for that because I realize what you're doing. Thanks again.

Okay. I'll have more comments.

Ms Blakeman and then Dr. Pannu.

9:30

Ms Blakeman: Thank you, Mr. Chairman. My memory might be faltering, but did we actually have a vote, that the committee agreed and the vote was carried that October 15 was the date that everybody was happy with?

The Chair: Yes, we did.

Ms Blakeman: Okay. And were dissenting votes recorded?

The Chair: Check *Hansard*. Check the minutes. It's got to be there.

Ms Blakeman: Okay. And dissenting votes were recorded?

The Chair: We didn't have recorded votes. Does anyone remember specifically on that one? We'll check that for you, Ms Blakeman, and if something further needs to be done, we'll do it.

Ms Blakeman: Thank you.

Dr. Pannu: My comment is related to what has just been said by Ms Blakeman. I think it would be perhaps more appropriate to say that the majority decision of the committee was to have October 15.

The Chair: Okay. I stand corrected.

Dr. Pannu: I expressed very serious reservations about the schedule, and I think I want to be on the record saying that.

The Chair: Very good. I will be more careful with my selection of words. I always operated on the premise that when a committee makes a decision, those who didn't agree support the decision. I stand corrected.

So, Evelyn, are you ready to proceed?

Ms Swanson: I'll move on to question 3 because at this stage I think it's premature to do much of anything with the definitions.

The Chair: One moment.

Dr. Pannu: Mr. Chairman, back to the substance of what this committee is doing, question 2, to which we received the responses, I think is an important one because it deals with definitions, and that speaks to the heart of what is in the legislation. So this will require careful scrutiny, I think, by our resource people and to come back with some sort of options, as we use the term, to see which of the definitions indeed require expansion or contraction or whatever.

The Chair: Thank you very much. Good comment.

Ms Swanson: Okay. Question 3 has to do with the extension of the scope of the act, asking whether or not "departments of the Government of Alberta, local public bodies as defined in [FOIP], and any other entity that is not a custodian [but] has health information . . . in its custody or under its control," whether or not any of these organizations should be included under the act.

Before I run through the summaries, I wanted to point out what it means to be named a custodian under the Health Information Act. You'll recall that the Information and Privacy Commissioner mentioned, when he was describing the act, that the custodians are the people who are part of the inner circle under the Health Information Act, and once a body is named a custodian, that party is able to share individually identifiable health information with other custodians without the consent of the person. So it is very much an inner circle for purposes of the act, and one of the considerations is whether the party that you're considering should be part of the inner circle and have access to health information without consent from other custodians.

We received 22 responses: one individual and 21 organizations. With respect to the inclusion of government departments, local public bodies, and other public bodies, the city of Edmonton, OIPC, health boards of Alberta, Capital health, Calgary health region, and government departments do not support inclusion because these are adequately covered by FOIP. That's the position taken by those bodies. However, the inclusion of these public bodies and government departments is supported by the College of Physical Therapists and the AMA. Both of those groups suggest including all public and private bodies that collect, use, or disclose identifying health information.

The universities, the U of A and the U of C, in their joint submission supported inclusion of the universities as custodians where they own or operate health clinics with the primary purpose of health service provision. So they have taken a slightly different view on a subset.

The health authorities and four health professions participating in the consultation so far – nurses, pharmacists, physical therapists, and physicians – health service providers, and the office of the Information and Privacy Commissioner all support inclusion of all health professionals regulated under the Health Professions Act as well as organizations with the primary purpose of providing health services. So there does seem to be quite a lot of support for inclusion of health professionals as well as organizations with the primary purpose of providing health services. These organizations suggest the removal of the reference to services fully or partly paid for by the department as a requirement to be included under the act. They think that it should apply whether it's paid privately or publicly.

The Consumers' Association did not state a position about extension to other government departments and local bodies, but they did note that there are implications of extending the circle of information-sharing outside the public health plan funding and to private insurers.

Regarding the insurance sector, we did receive input from two insurance organizations who said that they were opposed because they are not publicly funded and they are not health service providers. They provide insurance benefits. They are already subject to PIPA and PIPEDA. However, the AMA and the ALTCA, the Alberta Long Term Care Association, would include Alberta Blue Cross, which is an insurer. The individual would include insurers.

Two health information and research organizations made comments about their specific inclusion in the act. The Health Quality Council of Alberta suggested that it would like to be a custodian, and you heard the CIHI presentation yesterday about not being recognized as a custodian but, rather, as a specific organization with very limited purpose for receiving health information.

The Chair: Okay. Dr. Pannu, do you have a question or comment?

Dr. Pannu: Yes, just a question to Evelyn about the summary of the position of the Consumers' Association. What they say there is somewhat ambiguous. They draw implications, as you suggest here, but are they supportive?

Ms Swanson: They didn't state a position at all in their letter, but they're making a presentation I believe this afternoon, and I think their intention was to state their position when they make their presentation. They were just alerting us that these are the topics they think are important and want to address.

The Chair: Thank you.
Mr. Broda.

Mr. Broda: Yes. Thank you. I would tend to agree that we see forward-thinking to include all of them.

My question is on the insurance companies that are saying that they're private, that they're not public bodies. When an individual gets insurance and you have to go for a medical, they keep your record. That is why I'm saying that they should be included, because they have records on you as an individual. So how would they sell that record to somebody else to say, "Dave Broda has cancer" or "Dave Broda has heart problems"? They have that information, so they should be included in the privacy, I would suggest.

9:40

Ms Swanson: There are different ways to include organizations under the Health Information Act. Certainly, one is to make them custodians and then allow for information sharing without consent among those custodians, or you can choose to regulate certain sectors that you don't think should be party to those disclosures. You can still regulate them and include them under HIA but not as custodians. You could say that you want certain provisions to apply to insurance companies that hold health information in their records, if that's what you want to do. So you have some choices there.

Ms Robillard: The other thing, of course, which we can do a further analysis on is: how is that information protected today under the rules that the insurance companies follow? Insurance companies have been around for a very long time, and they have had health information for about as long as they've been around, I assume. How have they been protecting that to date? Has there been a risk? Is there a reason to bring them into HIA? I'm not sure that we have identified any of that to date.

The Chair: Mr. Broda, did you have additional questions?

Mr. Broda: No. That's fine. Just a point to be made.

The Chair: Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. With respect to the insurance industry, particularly in the life and motor vehicle categories, I'm rather surprised that they weren't asking to become custodians because they are in possession of extensive medical records. You know, the form that you fill out to obtain life insurance, that's minor in comparison to what they avail themselves with upon the settlement of a personal injury claim by way of undertakings. In tort proceedings they literally obtain your entire medical history in hard copy from all the doctors you've ever seen in your life, and that remains in their custody.

Now, if they were to become custodians, then underwriters, different insurance companies could freely share that information with each other without the consent of an individual. So the initial form that one files to obtain life insurance has very limited medical information, but most Albertans have had some form of motor vehicle accident or personal injury by way of a slip and fall, and that information then would be freely flowing between all the insurance companies.

So (a) I'm surprised that they didn't ask for it; (b) I would have a great deal of difficulty to make them custodians.

The Chair: Any response to Mr. Lukaszuk's comment?

Ms Miller: Mr. Lukaszuk's remarks are exactly accurate.

Ms Inions: There's no question that insurers and groups like them have extensive health information and that they provide a variety of services. They don't just provide insurance services, but they might actually provide the health service in assessing whether you qualify for the insurance, what the rating is, how they set the premiums. They might be an adjudicator in a claim. They may have all kinds of different roles. The same company might hold your mortgage. For example, AMA does that in Alberta, a mortgage company as well as an insurer. So they provide different functions.

The other thing that Evelyn has alluded to in considering where they ought to fall, if at all in HIA, is the entitlements of a custodian. Do you want them? Are they appropriately in that controlled arena? Are they appropriately going to access the information of other custodians? So that's a real question. I think that especially groups like this do raise that question. Ought there to be a third category, or ought there to be a category for entities that are more or less recipients of information? So it just raises all these questions. They're certainly not the same thing as your community physician, the same category, yet they may be gathering information from that individual, or they might in fact have that person on staff, wearing different hats, as a physician.

Dr. Pannu: I think the comments just made are extremely important for us to note. There may be a need for a third category. You know, the case of insurance companies draws attention to that gap, perhaps, in our current legislation. Insurance companies do have extensive medical information. The question is twofold. What is the current protection provided to each one of us whose information is in the hands of insurance companies?

The second is: to what uses can such information be put? Protection is one thing, but once the information is there, the potential is always there for it to be used for purposes far beyond what you can imagine it was collected for. So I think it's important for the committee to pay attention to this issue.

The Chair: Thank you.

Mr. Lukaszuk: Mr. Chairman, under the current scope of the act can one insurance company transfer medical information to another insurance company without the consent of the individual?

The Chair: Go ahead.

Ms Inions: If you're looking at me, I'm not sure I know the answer. Essentially, they're not caught by the act. They're not a custodian under the act unless they become an affiliate by way of some contract or obligation imposed by a custodian in the course of disclosing that information. Then the question is: what other provisions apply? There are certainly not HIA rules applying, but the question is: does PIPEDA apply? Does PIPA apply? You might have totally different regimes that apply. I don't know if there are any government-run insurance schemes, but possibly even FOIP could be triggered.

The Chair: Wendy, do you have additional comment?

Ms Robillard: Yes. I'd just like to draw attention to the current scope of the act. The current scope of the act is written to include primarily the publicly funded health system. If we are going to change who is a custodian, that will no doubt require a significant rework of the legislation. I would assume that if we would consider including insurers in any way, shape, or form, that would require a detailed look at the legislation and probably a rewrite of the legislation.

So you could still have the concept of the controlled arena for those people who provide primarily health services, but you might have to rewrite other pieces of the act for those people who might have health information that would not necessarily give them full, open access to information of any custodian without consent. That's an option. We don't have to just include somebody in the scope and assume that all the rules that are there apply to them today.

The Chair: On this point, Noela. Yes, go ahead.

Ms Inions: Just a quick comment. One example to consider is Alberta Blue Cross, the public component of that insurance or benefit scheme. That's an example of an insurance function that's currently caught under the act. So it's a way to consider the appropriateness of this.

The Chair: Thank you.

Mr. Lukaszuk, followed by Ms Blakeman.

Mr. Lukaszuk: Thank you. The purpose of my question is to ascertain that insurance companies cannot transfer information from one company to another without the consent of the individual. So my question is: do we leave the act as is, or do we have to introduce a third category that would prevent them from transferring information from one company to another, or do we have to put them in the category of the custodians? Which vehicle has to be used in order to prevent any potential future transfers of that information between one company and another?

The Chair: Who knows the answer?

Ms Inions: The first thing is to look at the current regimes. Different insurers are going to fall under different rules. Some are going to fall under PIPA. Some will not. Some will fall under PIPEDA. So I am suggesting that you've got different sets of rules. The only way to ensure what you're saying is to, I guess, capture them under HIA, where you dictate the rules. Otherwise, they're going to fall under other regimes.

I guess the question, too, is enforceability and companies being caught by two or three different regimes, which is their problem, I guess, not yours as the makers of the legislation. But the first thing is to look at the different sets of rules. I'm going to suggest that they are probably caught by every privacy regime out there, including some that are in different provinces, some in different jurisdictions. Many are international insurers.

The Chair: Thank you.

Ms Blakeman: Well, I think the reality of the situation with this is that none of this needs to apply because what insurance companies are doing is getting blanket permission in advance. So they already have consent.

I've just gone through this. My insurance company sent me a document explaining that there are privacy laws, blah-blah, and they now need my permission, and failure to complete the document and return it may result in the cancellation of my policy. When you turn it over, there are basically boxes that say: if you don't want to release the following information, please tick the box.

9:50

It's a negative billing situation. You have to consciously say: not this kind of information. But when you go through it and look, by the end of it if you didn't tick anything off, you would be okaying and giving permission, written permission because you sign it and send it back, to release everything: motor vehicle information, billing information, financial information from your bank, health information. It basically covered all possible categories. I went through, and I was only going to release one or two categories to them.

So it's not a matter of whether or not we need to capture them. They're already participating in an advance blanket permission, and people are doing it because they don't understand why, for instance, you would have to give your driver's licence and motor vehicle information if what you're insuring is your house. People are tending to do it, so they've already got the permission, and it's out there.

The Chair: Thank you.

Mr. Lukaszuk: What Ms Blakeman says is unfortunate, but if people are doing it and are given the option to opt out whatever the consequences may be, then that's fine. But one thing I would want to prevent is us passing a piece of legislation that now permits them to freely transfer information from one underwriter to another, not having to go through that exercise of sending the form like the one that would have been sent to Ms Blakeman.

So if they send those forms and people consent to it and still decide to purchase that insurance policy or settle that personal injury claim, that I can live with because then it's individual consent. I do have a concern with us passing a piece of legislation that now consents on behalf of Albertans for them to do that.

The Chair: On this point, Linda, yes.

Ms Miller: Yeah. Just for clarity, the legislation as it stands today doesn't permit or not allow. They're just not caught in this piece of legislation. It just does not apply as it stands right now to that sector of the industry, if you will, so it does neither. You know, it's just not applicable.

The Chair: Thank you.

Mr. MacDonald.

Mr. MacDonald: Yes. Thank you, Mr. Chairman. Wendy, perhaps you could . . .

The Chair: Mr. MacDonald, is there any way we can get you to speak a little bit closer?

Mr. MacDonald: I'm sorry. I apologize, Mr. Chairman.

Wendy, is it possible that – for instance, we could use Blue Cross as an example – insurance companies are not caught in the interpretation of "affiliate" in regard to a custodian?

Ms Robillard: Very rarely would they be caught, and the one place I do know they're caught is Alberta Blue Cross insofar as they operate an insurance scheme on behalf of Alberta Health and Wellness. They're our affiliate, so they are caught, yes, for that portion of their business. They have lots of other business, including work that they do for Human Resources and Employment and private stuff, which is not caught by the act.

Mr. MacDonald: Thanks.

Dr. Pannu: My question is whether we can get a report on what ways PIPA and PIPEDA cover insurance companies handling health information for us so that we have an assessment of the need to pay attention to it. You know, if that information and the privacy of that information is appropriately protected by way of these other pieces of legislation, the question then arises: why duplicate that in our effort? So we need to have a clear assessment of PIPA- and PIPEDA-related legislation in place which may provide the protection for us with respect to the information on our health that insurance companies have.

The Chair: Thank you.

Wendy, do you want to respond to that?

Ms Robillard: Absolutely. As well as looking at PIPA and PIPEDA, we'd have to look at any legislation that currently binds those organizations. So there is legislation out there that deals with insurers. That's not the Health Information Act. Okay? I don't know today what that legislation says, but it would require a review of all of that legislation as well as any of the privacy legislation that might bind those organizations – it could be PIPA; it could be PIPEDA – and then do an analysis of that in relation to potentially capturing them as a custodian or something under HIA.

The Chair: Thank you.

One question in my mind, listening to your comments, is that I suspect many of us just don't realize what's happening to us when we fill out these forms and don't realize how much information we may be giving by implied consent or whatever. So that certainly raises some flags in my mind. You know, if people want them to have the information, fine, but I suspect many people just don't understand what they're doing, so they arbitrarily give permission without understanding what they're doing. So I think we need to try to achieve some balance here as we look at this discussion, which has been a very interesting discussion.

Ms Robillard: Just one last thing. I'd like to advise that this would be, I assume, a fairly massive undertaking in the time that we have, and remember how many issues you will refer back to us in the time that we have. So I'd just like to bring that to the committee's attention as well.

The Chair: Thank you very much, Wendy. Just what I needed to hear.

Okay. Can we go with number 4 now?

Ms Swanson: Sure. Question 4 was whether operators as defined in the Ambulance Services Act should be included in the scope of HIA. "If yes, what is the rationale?" We've received responses now from 29 stakeholders, including 15 municipal governments, including AUMA, three health service providers, five health authorities, three professional colleges, one insurer, and a joint university submission plus the government submission.

The vast majority of stakeholders are in agreement that ambulance services and ambulance operators should be within the scope of the act because these services are an integral part of the health system, there is a transfer of jurisdiction coming to the RHAs, it would improve information sharing and provide benefits to patients, there would be consistency across health service providers, and operators will be affiliates of the RHAs. One suggestion was that access to confidential health information would be useful for billing and other administrative purposes. There was only one stakeholder who felt it would not be appropriate.

The Chair: Can we talk about that one a little bit? Tell us what their reasons were.

Ms Swanson: This was a comment from one of the municipal governments that disagreed on the grounds that "the decision to transfer governance and funding to RHAs will not affect the Confidentiality Regulation under the Ambulance Services Act."

The Chair: This is one of the questions I was hoping we could sort of move forward on, by consensus, today. So there was basically a yes from the municipalities on this one, but there was the one no, which we've already identified.

Do any committee members have any other questions or comments?

Mr. Broda: I would say that we accept this one. I know that the county of Minburn is the one that opposed it.

The Chair: Yes.

Mr. Broda: However, I think maybe, as time evolves, more information will come to them where they will say: yes, we agree with it. So I think that the general consensus is that ambulance operators should be included.

The Chair: Okay. Without doing a formal vote, do we have consensus on this one so that we can indicate to the committee that we have consensus?

Hon. Members: Agreed.

The Chair: Okay. Hearing no objections, let's go to number 5.

Ms Swanson: Okay. Question 5 was whether the scope of the act should be changed given implementation of the electronic health record. If so, how and what would be the rationale?

We received 11 responses from nine organizations and two individuals. Ten suggested that additional entities be brought within scope in light of implementation of the EHR, including the suggestion that all entities with health information be within scope. That was one individual. Two suggested all providers who will have access to the electronic health record. Four suggested all entities with the primary purpose of health service provision regardless of funding source, and two suggested the addition of all regulated health professionals. The universities, consistent with their previous proposal, suggest that universities with health clinics be part of the electronic health record. The reasons are, first of all, to maximize use of the electronic health record, to promote information-sharing to improve patient care, to provide better information for quality, to provide privacy protection, to ensure security of information, and to have consistent rules governing public and private sectors.

10:00

Mr. Snelgrove: It seems like there are two issues: one, I guess, accepting the fact that there's going to be an electronic health record and that it should be controlled under this legislation, and then the question about how big the electronic record gets or who's entitled to use it. I don't think there's any question that we would all want the absolute same security, or better, for the electronic health record. Then as it expands, those people that would ever have access to it must fall under the act. But where that circle goes – it may grow in the future. I mean, I think we'd all agree that we have to have the electronic record under this act.

The Chair: Okay. Thank you.

Yes, Mr. Broda.

Mr. Broda: Yes. This question 5 refers back to 37(2)(a) and (b) of the act. I think there have been some very good presentations made why 37(2)(a) and (b) either be removed or amended somehow.

If you look at the number of yeses and noes in here, I guess they're maybe not quite clear as to which way to go, but I think this one here needs a little bit more work to see what we're going to do with that particular clause of the act.

The Chair: Thank you.

Any response to that?

Ms Swanson: I'd just point out that we do have a specific question on health service provider information, and I think it's coming up.

Mr. Broda: Oh, okay. Good.

Ms Blakeman: This is an area where I'm not feeling like I have enough information to understand the implications of this. I'm not sure as a committee member how to ask for more information or who else should be briefing us. I don't have a clear idea of where these electronic health records can go, but knowing that with an e-mail, for example, an e-mail can be sent to me and unbeknownst to the original . . . Mr. MacDonald sends me an e-mail. Unbeknownst to Mr. MacDonald, I now turn around and send the e-mail to Ms Robillard, who sends it on and on and on. We have no way of controlling electronic health record transfer, the transfer of information electronically, from the original person.

So I think there are a couple of issues here. One is that we want to protect it, but how do we protect it if once it starts to go, it's gone? I'm not feeling like I really understand this. I know one of the things that came up in the Legislature was having our X-rays read in India and then the information relayed back here. So we're now having electronic health records sent to other countries to be read by trained personnel, one assumes – one hopes – and then coming back again. Well, how far out does it get once it's over in India being looked at?

I don't think I have a really good idea of the implications of this, and I'm wondering if there's another way for us to get information about how this works and what the pitfalls really are. How do we know what the mistakes are? Then we can talk about how to start avoiding them. But I don't know what the pitfalls are, so I don't know how to recommend avoiding them.

The Chair: Thank you. Does anyone on the committee . . .?

Ms Miller: A little bit of an initial response. Currently we only provide access to the electronic health record to custodians as defined under the act, and that has proven to be a reasonable course of action to date, I believe.

Being a custodian has its privileges, as Evelyn has already outlined, but it also has a great deal of responsibility associated with that. So if you're named a custodian, you can be given access to the electronic health record. However, in addition to not only being named as a custodian under the act, you have to meet certain security standards, as defined by the ministry, that need to be in place. They are assessed periodically to see that these standards are being adhered to or at least that progress is being made. Those are conditions that we currently apply.

In terms of the issue of once it's really within the controlled arena and you've got access and you've met the security requirements in the first place, there are legal arrangements made. Anybody that has access in addition to all of that has to sign a legal agreement that says: if I later access any information from this electronic health record, even though I didn't get it originally from the point of source – it kind of went into a central database, if you will – and as another custodian coming in later to access that information, I must abide by the rules of this legislation as well as further rules that have been defined by what we call an information protocol that really specify in great detail more rules around access, use, and disclosure in accordance with the legislation but a lot more specific.

I would support that because of their specificity it is appropriate that those rules be in that kind of document under a legal arrangement rather than in legislation because we are in new territory here, and those rules developed by the applicable stakeholders that do have access are fluid from time to time just because of the new arrangements that we're talking about in this new EHR world.

The Chair: Thank you.

It also seems to me that there's so much here we don't know yet about electronic health records. We don't live in a perfect world. I suspect this is an area that will change very rapidly over the next one, two, three, four, and five years. I think this committee has to understand that we don't have a perfect world or perfect knowledge, and we will have to make some decisions from what we do know and what we do have.

We also know that this act is going to be reviewed again in a couple of years, three years or whatever the case may be, so it's going to be an act, particularly on this subject, that is going to probably change often. I certainly want us to have the best information we can, but I think there are limitations to achieving full knowledge here.

Ms Blakeman, I think you were again on this point, and then Mr. MacDonald.

Ms Blakeman: Yes. Thank you. I'm wondering. Right now with health information that is collected, there are a number of clauses in the bill that allow identifying information to be used for statistical or research purposes without consent. If we now have electronic health records that have identification attached to it, is it also subject to the same I think generous allowances for research and statistical use? Again, that X-ray is out there with somebody's name on it and can then be picked up and used for research beyond that. So now it's not just a number on a page, but it's actually a health record in a very tangible way.

Ms Robillard: So, yes, to speak to that. Information in the EHR today or in the future has the possibility of being used for statistical purposes. Remember that the overriding principles are: least amount of information, highest degree of anonymity, and need to know. A lot of the statistical analysis is done on the basis of aggregated information. It starts with knowing an individual, but once people know how many of something, that's what they do their work based on, not the knowing who. So it is a fine distinction, but it is there.

As well, research, yes. But, again, when information is used for research purposes, primarily it's disclosed from custodians to researchers, so those obligations apply to it still.

In today's world, in the electronic health record world, the issues of disclosure and use for statistical purposes are of major, major concern. As things stand today, that information is not used for those purposes; individual information is not used for those purposes. We have a data stewardship committee that is made up of members of professions and the public and ethicists, et cetera, and they are grappling with those issues today and trying to understand how they can apply rules in the EHR world that work and allow people to do the work that needs to come; i.e., they don't want to stop the research that might help us do better health care in the future. But they're very cognizant. They're discussing and debating and trying to come up with rules, as Linda stated, in the protocol that are specific to that environment, so there's a lot of acknowledgment in the community that that's very sensitive.

10:10

The Chair: Thank you.
Mr. MacDonald.

Mr. MacDonald: Yes. Thank you, Mr. Chairman. I'm led to believe that the implementation of the electronic health record system is going much more slowly than had been anticipated, and it seems to be quite cumbersome. If we were to follow the suggestions of Capital health and the Calgary regional health authority, for instance, would that speed up the participation rate, I should say, by Alberta physicians in the implementation of the electronic health record?

Ms Miller: In my opinion, no. You're correct; it is not happening as quickly as we would have all liked. There's a whole range of factors associated with that, but I don't believe the suggestions in this context would address those issues.

Mr. MacDonald: Okay. Thank you.

The Chair: Thank you.
Dr. Pannu.

Dr. Pannu: Thank you, Mr. Chairman. Wendy informed us that there is a committee that's currently looking at issues arising out of EHR, and since we have a key question – question 5 is about EHR, and we are reviewing this in part to deal with that issue – I'm wondering if, in fact, we should not have the benefit of a representative from this committee to come and talk to us about the issues that they have so far identified as important, problematic, requiring further attention. Frankly, I do feel quite uncomfortable about handling this particular issue. It requires both expert knowledge and a thorough understanding of the issues that arise out of centralizing our health records into electronic form because communication transmission issues become entirely different than if we had paper records.

So my suggestion, Mr. Chairman, is that we request this committee to help us with some information that they have already collected and perhaps some ideas that they may have to share with us.

The Chair: Linda or Wendy, do you want to respond to that?

Ms Miller: We did propose that to them, actually, and at this point we believe their response was that they were not ready yet to make recommendations to the committee because they're so early in their deliberations and are working through the issues themselves. However, we can still follow up if that's the committee's request.

The Chair: All right. It is requested, so let's see if we can follow it up.

Maybe we can go on to 6. Okay.

Mr. MacDonald: It wouldn't be possible to get a progress report, an update, please, on the implementation of the electronic health record?

An Hon. Member: It's irrelevant.

Mr. MacDonald: Oh, no, it's not irrelevant, particularly with the remarks of the chair earlier on how all this process is changing, and we are making legislation or legislative recommendations without all the information.

The Chair: I'm sure that we're going to follow through, if we can get any further help on this, as to a progress report.

Mr. Lukaszuk: Well, by the time we get to the last page of these recommendations, I imagine we'll have many other requests of our resource people to provide us with expert advice, which leaves us with very little spare time or resource capital to start going on fishing expeditions. I'm using the phrase "fishing expeditions" purposely because getting a progress report on the implementation of the electronic health record has nothing to do with the work that we do.

We may want to obtain expert advice from those who work on the electronic health record as to what changes need to be done in this act to either help them or assist them with their work, but it is none of this committee's business as to where they are in the stage of putting the record together as long as we develop legislation that is suitable to the work that they do. If this was a committee that deals with the infrastructure of the record, I could imagine why, but this is a simple request that has very little to do with the purpose of this committee.

The Chair: Thank you. I do not want to spend a lot of time debating this subject.

Noela Inions, would you like to comment here?

Ms Inions: Yes. Somewhere in between these two points of view I'd like to suggest that Wellnet does regular updates and does regular reports, and this information is available on the web site and is information that wouldn't require any work from anyone on the committee. So I'd suggest that as a readily available source that is providing regular updates on the progress of the implementation in the province.

The Chair: Okay. On this point, Ms Kryczka?

Ms Kryczka: Yes. I agree with what Mr. Lukaszuk just said. If we look at the question, the question is, "Should the scope of the Act be changed given the implementation?" I think we should just focus on what we need to do.

The Chair: Okay. Thank you. Ms Inions has suggested that we can avail ourselves of information that's out there and use it as appropriate.

So let's move on and go to number 6.

Dr. Pannu: Mr. Chairman, I just wanted to ask Wendy if there's a name for that committee so that I have it in my notes. I don't know what it's called.

Ms Robillard: The Electronic Health Record Data Stewardship Committee.

Dr. Pannu: Thank you.

The Chair: All right. Let's try to do number 6 before we take our morning break.

Ms Swanson: Question 6 is "Should health service provider information be included within the scope of the Act? If not, kindly provide the rationale." We had 19 responses, from 18 organizations and one individual. The groups that responded included five health professional colleges or associations, one insurer, three health authorities, one municipal government, four health service provider organizations, an advocacy group, and one from the private sector.

Two organizations commented but did not clearly state a position. Nine suggested that health service provider information should be included. One of these suggested that the provision might be more appropriate in the Health Professions Act, and another suggested amendment to allow sharing without consent with other custodians primarily for purposes of quality assurance, quality improvement, and patient safety. The rationale for inclusion is protection from being given or sold to a noncustodian for commercial purposes and privacy of the practitioner when patient identity is removed from the information.

Eight organizations, including one advocacy group, the U of A/U of C, one municipal government, and five pharmacy-related groups, recommend either removal of HIA protection or amendment to limit the protection or protection under FOIP instead of HIA. The rationale included no supportable policy rationale to protect the information; identifiable prescribing information being needed for patient safety programs, drug utilization trends, research, and control of drug costs; restriction of public access, which compromises care, accountability, and informed choice; inconsistency with HIA purposes; absence of protection in similar legislation elsewhere in Canada; and more appropriate inclusion under FOIP where organizations are already under FOIP.

Other issues raised include requests to clearly differentiate between health services provider information and other employee information held by a custodian under FOIP jurisdiction; to include business title and professional registration number in the definition if it is retained and to enable the disclosure of these items without consent; and to consider whether or not health services provider information should be available for research purposes. Right now it's not.

The Chair: Thank you, Evelyn. I do have at least one question. Mr. Broda.

Mr. Broda: Not so much a question, Chair, as a clarification. I guess I jumped ahead of myself. I was looking at question 6, to the previous one, when I brought up the comment about section 37(a) and (b) of the act. We've had numerous occasions to hear the importance or nonimportance of this particular section being in the act. I'm looking at the documentation here. I guess there are various opinions, but I think we had some pretty good arguments yesterday – I shouldn't say arguments but presentations – in regard to looking at section 37(2)(a) and either removing it or amending it. I just wanted to clarify that.

Thank you.

10:20

The Chair: Okay.

Any comment?

Mr. Snelgrove: Mr. Chairman, Dr. Pannu identified this problem early: that the definitions are what's going to make this down the road. That's where the work needs to be. There's no question this kind of information is going to be under the scope, but under what definition? Then the regulation around the definition of that particular entity will be there. So it's an open-ended question. Of course, it's going to be there. How are we going to define the different people that use this information? The sixty-four million dollar question gets back into the definitions or some additions to it. You know, I think you can just let this go with the understanding that when we get to the bread and butter, it's the definitions.

The Chair: Thank you.

Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. Mr. Chairman, when one reads the act and gets to section 37 and gets to this particular dilemma, "Should health service provider information be included?" speaking, you know, from my perspective, I found it a very unusual section to be in this act. It's almost a stand-alone section. It just doesn't flow with the purpose of the act as the name would describe.

I haven't had the chance, obviously, of reading the *Hansard*s of the committee that put the act in place in the first place and what the debates were in the House and what the spirit of the legislation was, but judging by the title of the act, judging by all the remaining clauses of the act, the act was designed purely to protect Albertans' health care information and to govern its flow from those who have to share this information, and all of a sudden this one section creeps in in the act protecting the service providers.

Now, hearing from those who presented, by and large most told us that either (a) it serves them no purpose whatsoever or (b) it hinders them. Very few identified it as a good section to have in the act. So I'm wondering: would the resource individuals shed any light on what the underlying reasoning was then, when the act was put into place, to include that section, being such a misfit?

Ms Miller: I'll just do some introductory. I just would like to stress to the committee that this is a very critical issue. I appreciate the appearance that it doesn't quite relate to the other pieces of the legislation. However, it is my recollection that this was a strong issue as represented by the various professions at that point in time, and I would encourage you to ask any professional group, such as the AMA, that will be presenting later on today, to address this question specifically.

It is my understanding – I'll back up a little bit. Even today we continually get reminded by all of the professional groups that we work with, particularly around the electronic health record and this ability, once you've let the information out, for further people to access it, that you don't really know who is going to access it. It is different than point-to-point communication.

Professions have a history of referring people based on trust: they know that provider; they like that provider's way of providing care. Professionals have this historical relationship built on trust, and this new electronic health record era changes that whole trust relationship, and for them it is new as well. I believe that when the legislation was initially enacted, that was one of the primary concerns, in terms of trying to maintain this relationship of trust, of how the information will be used once it's released from their particular custodianship.

But I do encourage you, as well, to ask professional groups for their opinion on this matter.

The Chair: On this point, Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. I'm looking forward to the presentation from the association. I'm not certain how it would prevent ongoing trust between care providers and how it would disturb their ability to still continue to refer. What I can see happening if that section was to be removed is that it would objectify the system of referrals, where the patient now would be able to also participate in making a consensual decision on which physician he's going to be referred to or which he chooses not to be referred to and wouldn't have to solely rely on the decision of his referring physician and information that he may or may not have but is not willing to disclose to the patient.

As I see it, it would basically allow a patient to participate on an informed basis as to where he is going to avail himself of medical care – being able to find out what the doctor's medical practices are, what his history of prescribing is, what his results are from surgeries, or whatnot – if that section was to be removed.

Ms Miller: I can certainly see both sides of the argument. I'm not in the position to defend the professions' perspective on it. I'm just recounting what they have told us time and time again. I think there is concern, but again I'm interpreting based on comments that I've heard previously that should the information not be protected, there is concern that there would be inappropriate monitoring of practices. They feel, I believe – and I'm generalizing here – that there are colleges and other bodies that have been established in the system to address those issues.

Again, I really would encourage that you ask the professions to speak to this issue. It has huge issues for them. Their perspective may have changed somewhat since the original drafting of the legislation.

The Chair: Thank you. An excellent point, and I'm sure the committee will.

Ms Kryczka: Well, my point isn't quite as important, but having listened to the previous discussion, under Stakeholder Position it looks like who stated positions yes or no, so obviously the pharmacists, people at the association, the college, et cetera. I look at the stakeholders who have said that they stated no. I find it interesting: the University of Calgary/University of Alberta, no. I mean, just looking at that information as you go across on the chart is rather interesting.

The Chair: Thank you for that comment.

Dr. Pannu: Mr. Chairman, I sympathize with our dilemma. Everyone is asking why this section should be there. The question was raised quite up front, explicitly, by the pharmacists' college of Alberta. IMS took the position that this has no place in it but that if it does want to retain it, then limit, define the other information more specifically. I notice that the AMA in their brief talk about the principle of least amount of information and highest degree of anonymity.

Once you have information on these things, then that information has the potential of being used for purposes for which it was not intended, and that's why, I guess, the principle of least information is important. We need to take a close look at the section and ask: what purposes will it serve? If the institutional memory is still there in the department, we need to know what rationale they used to include section 37 in the legislation before it is brought before the Legislature. We need to know that.

I was hoping that Bob Clark's analysis of it would have this information. I haven't taken a close look at it. We'll see if there is any reference to it there. But we do need to trace the rationale and then make our own judgment of whether or not that rationale is solid and sound. If we find that that particular part of the act is not necessary, not needed to advance the purposes of the act, then I think we may have to make a decision to say: well, it shouldn't be there. But there may be a compelling argument that comes from the department side, which we'll have to look at to see why it should be retained.

The Chair: Thank you. I take it as a yes that we will undertake that.

10:30

Ms Miller: We will definitely do a trace of the information and letters and points of view that we can find.

The Chair: And provide the committee with that information.

Ms Miller: Yes.

The Chair: Thank you.
Mr. MacDonald.

Mr. MacDonald: Mr. Chairman, thank you. Dr. Pannu was talking about institutional memory. My memory is very poor, and I'm wondering if you could please help me. In the year 2000, whenever this original act was drafted, what was the number of the bill that came before the Assembly? Was it 37?

Ms Inions: It was Bill 40.

Mr. MacDonald: Okay. Excellent. Thank you.

Ms Inions: We've just gone through the document again and see no reference to health services provider information or the rationale therefore.

The Chair: You're referring to the document that we tabled this morning?

Ms Inions: Yes, the response to Bill 40 prepared by Mr. Bob Clark, the Information and Privacy Commissioner.

The Chair: All right. Anyone else have a comment?

Okay. I suggest we take a 15-minute break and reconvene at 10:45.

[The committee adjourned from 10:31 a.m. to 10:47 a.m.]

The Chair: I would like to call the committee back to order.

Before we get into further analysis, I want to refer to *Hansard* of August 25, where we do have a motion. The chair asked for a motion from a member of the committee for October 15 as a final date, and the motion is that we meet on October 15. That motion carried. The discussion around the motion of setting October 15 as a final date was that because of the expected election in November, that would be about the last day we would have that we could still have certainty to get this committee's report tabled to the Clerk of the Assembly. If we don't get it tabled, then the work basically, you know, is not there; it's lost.

I was interested yesterday, as I visited with some of the presenters, that some of them made the comment that they realized that the committee had a huge challenge to get this done, but they certainly were hopeful and encouraging that we do the best we can and get as much done as we can. So that remains, I believe, certainly the goal of the chair and the goal of the committee to get a report tabled. I think it's safe to say that the staff, especially Health, have just been working really hard to meet this deadline, and it hasn't been easy.

If one looks back at the terms of reference of the committee – and I'm just going to refer to one paragraph right now – it says:

> This Committee will focus upon:
>
> - The Act and its supporting policy and administration to determine whether an appropriate balance has been achieved between protection of the individual's privacy and access to health information where appropriate to provide health services and to manage the health system.

Simply, given our constraints of time, we don't have time to go into all aspects that we may like to go into, such as a review of insurance legislation and other legislation. So as we proceed today, this morning and later this afternoon, could we focus on the areas that would be most important for us as a committee to address? We could make the act more functional and cover those areas of the act that really need to be covered.

I'm going to ask Linda or Wendy or both if they would like to expand on this a little bit as people who have to deal with the application of the act as it's presently constituted. You know, it is working pretty well, but there are probably areas of concern that they have that maybe they would share with us. So if we could keep in mind as we go forward that we need to identify areas that are of most concern. We don't have time to deal with the details on everything. If we could also keep in mind that we will be bringing back on the 27th and 28th options for the committee to look at, options which will cover the alternatives we have, and we can debate those options and make recommendations to the committee so that a preliminary draft can be completed by October 7. That's the time frame we've set, and I would encourage us as a committee to realize our constraints and do the best we can and move forward with the goal of getting a document tabled.

Linda or Wendy, do you want to just comment briefly on this subject?

Ms Miller: Yes. Thank you for the opportunity. I guess I would just draw the committee's attention back to the three primary issues as defined under the terms of reference in terms of the areas that need to be examined. One question, clearly, is the whole issue of scope. As I've commented earlier, the issue of scope is important from an electronic health record perspective and the sharing of information. However, within that question of scope, which is a complicated question in and of itself, and given the time frame that we have to work with, I think we need to look carefully at: if it should be expanded, what degree is comfortable at this point in time. As legislation gets reviewed the next time, that scope question will certainly come up again.

The second area that I'd draw your attention to is the whole issue of the electronic health record. As everyone is well aware, EHR is being implemented in the province of Alberta and is a critical issue for the sustainability of the health care system in areas where the act can improve the sharing of information for the purposes of electronic health record. I would encourage the committee to focus on those issues.

The third is the pan-Canadian harmonization issue, that you've heard Catarina Versaevel speak to considerably.

My recommendation would be to focus on those three areas primarily. That does not mean that there aren't other issues that are important. There are. However, the act works now reasonably well, in our opinion, and balancing the need for careful analysis prior to making anything as substantive as legislation changes is so critical that I would encourage you to perhaps consider deferring other issues to a later review when there is more time available.

The Chair: Thank you.

Leaving the committee the latitude to identify – you know, if there are a few other important issues, certainly they could be considered.

Wendy, do you have any other comments?

Ms Robillard: No. I was just going to make that comment. It would also be helpful for us. If the committee has other issues they would like us to focus on, we could do that. But, clearly, if every question that we put forward today results in further analysis and documentation, et cetera, et cetera, then we're simply going to be challenged with not being able to meet all of those questions. So that's part of what we're trying to grapple with.

The Chair: Thank you, Linda and Wendy.

Ms Blakeman, you had a question or a comment?

Ms Blakeman: I did. I appreciate the chairperson's interpretation of what they feel their role is. Given his choice of language in putting this forward, often I have to take issue.

The deadlines here are self-imposed. I as a member on this all-party committee constantly struggle with any limitations that are placed on us doing the best possible job, given the information. The choice was to do this consultation over the summer with very short time lines. We've heard mostly from professional groups. We've heard very little from citizens of Alberta, and I have real concerns that we do the best job possible here. I understand – I lost the vote on the final date of this – that the report will go forward, whether I like it or not. I'm nervous about starting to drop issues off to the side because we don't have time to deal with them.

10:55

I take the point raised by the staff that their time is limited; there are only so many hours in a day between now and October 15, and we can't be now going back to them and asking them to come up with reams of background information for us to understand. Nonetheless, those are the choices – and they are choices – that this committee report by the 15th. That was voted on, not by me, in this committee. So I have to challenge the language that the chair uses in assuming that, you know, everybody is on-board with that.

The Chair: Okay. I accept your challenge, but I'm not going to retract any words. The committee did discuss this at length. We've been over this issue two or three times. The committee made a decision. The committee will go forward, and we would certainly appreciate your support as we try to do the best job we can, Ms Blakeman. But your comments are noted.

I don't want to spend a lot of time on this because we're not going to have another vote here. We had a vote, and we're going to go forward.

Dr. Pannu: Mr. Chairman, everyone on this committee has been working as hard as elected officials are expected to. We're trying to work on it with as much earnestness as we can muster. I had concerns about the pressures of time. I tried to persuade the committee to not push ahead with such a tight timetable, that would bind our hands and put us in a position where we either have to ignore issues or dispense with the need to deal with issues in depth.

This is a committee of the Legislature, and we are given a very important task. I want to thank the resource personnel on the committee. It's not their job to insist on what needs to be done; it's our job. I thank them. I'm grateful for the enormous amount of work they have done. In fact, I said two or three weeks ago when we were setting these dates that there would be nervous breakdowns. You know, that's a possibility. You push the staff to the wall; what do you expect? They're either going to just not be in a position to feel well enough to do the job or they're going to say: well, look, these are the only things that we can do.

Now we are trying to find ways of cutting corners. I am concerned. This is a very important bill, three years in waiting. We have a legislative requirement that we return to this bill three years after it's been practised, implemented and find out from Albertans, from practitioners, clients of the system, stakeholders, about their views. And we've got some good responses. We've got 72 of them now, which is good. It gives us a start now to start really putting our hands on the real issues. That's the importance of this public feedback. It's wonderful that we've got at least these 72 submissions. Some were oral presentations, some still continuing this afternoon, and we are benefiting from hearing from people both by written word and by personal presentations.

My concern is that all of this work that we have asked people to do may not be exploited to the full by this committee, given our timetable. The election timetable is not something that I set. I decided to be on the committee as a member of the caucus because that's the portfolio I've been handling for the last several years. I thought I could make some valuable contribution perhaps – I won't be modest about it – and I want to learn from other members of the committee. Now we are pressed for time, and I find it dismaying, hearing from you and from whoever else is telling me that now we should put aside the work that we have done and rush ahead and prepare the report and sign on to it. I find it very difficult.

The Chair: That is not what I said. I simply said that we do have time constraints. It's no one's fault really. It's a reality. It's a reality that we have time constraints. So given the time constraints, we need to do the best we can. We'll identify as many issues as possible. We'll cover them as extensively as possible. We'll consider the submissions, which I think we've certainly done to this point. I think our staff have done an excellent job of analyzing and giving us the information. All Albertans had a chance to respond to this if they wanted to. Those who showed interest have responded. We have the responses. We'll do the best that we can. We just need the support of the committee as we go forward.

Ms Kryczka: Well, I am very frustrated in that I hear the same messages being repeated, and if that isn't a waste of time when we all know that we have time constraints – and I won't repeat it. I'm just saying that we have repeated messaging too much.

I think that even when we go around the table as we go forward, we should make a point, me included, that brevity is important. We have made the decision to get this done, so why do we keep going back and rehashing? To what end? Not unless you really want to impede progress. So I think we should just all get on board.

Now, I know that we should support the chair. I know he has stepped back. From time to time we're going to refocus. We can easily get off track here, but we have to refocus and use time the best we can and just move ahead and get the job done.

The Chair: Thank you, Ms Kryczka.

Let's go with number 7, please. [interjection] You're not on my list.

Mr. MacDonald: No, but I had my hand up, if you don't mind, Mr. Chair.

The Chair: Are you going to just talk about what we've already talked about?

Mr. MacDonald: Well, just for information for the committee I have my file from Bill 40. I retrieved it, and certainly there is a lot of interesting information in here. There is an editorial, undated, from the *Edmonton Journal* from that time period, and I'm going to ask, with permission, that this be photocopied. The headline is: Don't rush health information law. Now that we're reviewing this law, I think we should take our time and proceed and do it right.

Thank you.

The Chair: Yes. We will. Thank you.

Okay. Evelyn, will you please commence number 7?

Ms Swanson: Question 7 was: "Should personal health information contained in employee health files be part of the scope of the [act]? If yes, what is the rationale for doing so; if not, why not?"

We received 21 responses, including eight from the private sector. The eight private-sector organizations were in agreement with the majority of health sector organizations that personal health information contained in employee files should not be within the scope of the HIA. Reasons include adequate coverage by PIPA, PIPEDA and/or occupational health and safety legislation, employment law and case law; confusion, complexity of differentiating between health information and other personal information in the records; burden and cost of compliance processes; and collection for purposes other than health service delivery.

There were some organizations that felt that health information in employee files should be included. Those were four health sector organizations and an individual. Their rationale was that this information should be included to protect privacy and ensure confidentiality, consistent set of rules, and clarity for Albertans.

The Chair: Number 8.

Ms Swanson: Moving on to number 8, should the scope of the Health Information Act be extended to include WCB? If yes, what is your rationale?

We received 13 comments on this topic from 12 organizations and an individual. Six organizations, including the WCB, recommend the WCB not be included in the scope of the HIA. Alberta Health and Wellness supports the WCB position. The rationale includes adequate privacy protection and access under other legislation, including FOIP and the Workers Compensation Act; additional administrative burden, complications and cost to employers; health information collection for primary purposes of benefits administration and not for the primary purpose of health service delivery; and the potential to diminish worker privacy if the Workers' Compensation Board is made a custodian.

11:05

Five organizations and an individual took the opposite view of including WCB on the grounds of "clarity and understanding for Albertans, privacy protection, improved processes and health information management and less confusion and inconsistency in the treatment of health information."

Dr. Pannu: A good summary, Mr. Chairman. This is one question on which the people who have written to us seem to be quite divided. They are on one side or the other. That's the first comment I want to make.

Yesterday when the WCB made their presentation to us, the question of the Millard centre medical service providers came up. I didn't get satisfactory answers from the WCB representative with respect to why that part of the WCB – that is, the Millard centre medical services providers – should not be treated in the same way as others are under that section 37, provided we decide to retain that section. So I want to just flag that particular issue with respect to WCB and how its medical personnel should be treated.

The Chair: Does anyone want to respond to that?

Mr. Snelgrove: I would just ask members to consider that the WCB issues may have arisen over timeliness and ability to access plans and all the others, but it's never been one of lack of secrecy or privacy. They have done a very good job of maintaining that to the best of my knowledge. I've never had concerns from injured workers about their files being left on the streets. We've only heard about timeliness and access. If you're going to put more roadblocks on a system that is tough enough to administer now, you're going to expect that, which is the last thing that I think the injured worker wants.

The Chair: Thank you.
On this point, Dr. Pannu?

Dr. Pannu: Yes. All of us as MLAs deal on a regular basis, you know, with cases that come to us from our constituents who have problems with or have matters pending to be decided in their relations with the WCB. The number of complaints, by the way, has declined over the last two to three years. There were a lot more in the first four years of my first term.

The complaint that I heard, in addition to being maltreated and not being listened to and all of that stuff, was that their medical records are shared with private investigating agencies. The WCB, I guess, puts private investigators on to particular cases that they see as problematic. One of the complaints that I've heard is that those private investigating agencies have access to their medical records. So that is a matter of concern that's been communicated to me as an MLA by constituents who have come to my office seeking some redress to their concerns. I just wanted to share that information with you and the committee.

The Chair: Thank you.
Ms Blakeman.

Ms Blakeman: Thank you. Is anyone able to tell me whether the WCB is included under health information protection legislation anywhere else in Canada? I'm sort of thinking about the pan-Canadian harmonization, and if we choose to do something like this, would we be setting up something else that doesn't fit within the harmonization? Do we know if it's included anywhere else?

Ms Robillard: I can't recall specifically if the WCB is included elsewhere, but I know that the issue of including organizations like the WCB elsewhere is addressed in the pan-Canadian framework, and as I recall, it's not one of their fundamental issues. It's something that jurisdictions can decide on, but we'll verify that.

Ms Blakeman: So not a big deal.

Ms Robillard: That's my recollection.

Ms Miller: From a pan-Canadian perspective. In terms of remembering the pan-Canadian issue is more what needs to happen in harmony across the jurisdictions is the perspective that they're taking.

Ms Blakeman: What needs to happen as compared to other issues that can be chosen to be dealt with to greater or lesser extents by individual places.

Ms Miller: Yes.

Ms Blakeman: Okay. Thank you for that clarification.

The Chair: On this point, Ms Inions.

Ms Inions: Just one additional comment. One of the differences in HIA and other jurisdictions is that physicians and health providers generally are covered under the health information legislation in Saskatchewan, in Manitoba, in Ontario. So, for example, that would capture a physician working for the WCB as much as any other physician, whether Gimbel Eye Centre or the public sector. That is a fundamental difference in the scope of coverage that has an indirect effect on the WCB. So that physician examining a patient, creating a record is caught by virtue of that legislation in those other jurisdictions. The WCB itself is not listed, you know, as an entity covered, but the health service providers are clearly caught in all those jurisdictions.

Ms Blakeman: I'm sorry. I thought we'd been told that health service providers were not caught, that Alberta was the only place.

Ms Inions: Health service providers are caught as custodians or trustees in those other jurisdictions, but there isn't a separate category of information that's defined as health service provider information.

Ms Blakeman: With consent.

Ms Inions: Yes. Information about the health service provider is not specifically protected in other jurisdictions, but the information they generate in the form of health records – the medical reports, the observations, treatment, diagnoses – is a type of health information that's caught.

Ms Blakeman: Thank you.

The Chair: Thank you.

Ms Kryczka: I'm just wondering. When you look again at the columns and stakeholder positions and the names, their recommendations, it just seems to me that the key people, with the exception of the Alberta Medical Association, are saying no. Then the AMA has referred to questions 3 and 7, and I look at their rationale. It's somewhat reasonable, but they're far outnumbered. I just throw this out, not necessarily for discussion, just throw it out for the record. But is this an area, perhaps, that should be reviewed the next time the act is reviewed? I mean, to make a change now, it would be huge thing with the WCB. Call it whatever you want.

The Chair: I hesitate to put that to a vote.

Ms Kryczka: No. Don't. I'm just throwing out.

The Chair: Right. I understand. Any comment, Linda? No. Okay. So noted.

Let's go to number 9. This takes us to the end of the first document, and we only have five to go.

Ms Swanson: Number 9 is: should Alberta Blue Cross be subject to the Health Information Act for all health information as defined by the HIA in its custody or under its control? If yes, why? If not, why not?

We had responses from 11 stakeholders, including one individual and 10 organizations. Four of the organizations, including Alberta Blue Cross and the health boards of Alberta, indicated that ABC should not be included in the scope of HIA because, number one, there is adequate privacy protection under the Health Information Act, PIPEDA, or PIPA already, depending on the specific plan of the Alberta Blue Cross; number two, health information is not collected for health service delivery or health system management, but rather for administration of health and related benefit plans; number three, it would provide an unfair advantage to Alberta Blue Cross as an insurer to be included as a custodian; and number four, there is a potential loss of privacy through increased disclosures without consent. This says the WCB, but I believe it's to ABC.

There were five organizations and an individual who took the opposite view that ABC should be included because they felt that, number one, any supplemental health insurance company should be included; two, a consistency of access and privacy protection; and three, ease of information sharing.

One organization that did support inclusion noted that the goals of insurers are different, and that "some rules may need clarification if they are included." That refers back to the discussion earlier today.

One RHA made no recommendation.

11:15

Dr. Pannu: Mr. Chairman, I haven't made up my mind exactly on where to go on this. Although those who say yes to inclusion say that any supplemental health insurance company should be included, that reminds me of our last session of the Legislature, in which argument was made to treat ABC exactly as other supplementary insurance providers are dealt with. The term that was used was that a level playing field needed to be created, so ABC is now taxed as other supplementary health insurance companies are. If there is a validity to the argument of creating a level playing field, perhaps that principle should be invoked in considering whether or not ABC should be included, you know, as others might be.

The Chair: Okay. Thank you.

I guess I jumped a couple of pages, Evelyn, so we need to do 10 before we go to the next.

Ms Swanson: Number 10: "Should the definition of health information be changed to include non-recorded information?" If yes, why? If not, why not?

There were 13 comments from 12 organizations and one individual. The organizations were in agreement that the definition of health information should not include nonrecorded information. Half cited rationale related to practical problems granting access to nonrecorded information, problems with administrative burden, determining how such information was used/disclosed, legal problems if an applicant complains, proving or disproving the existence of such information including verifying or validating what was not recorded. The organizations viewed these problems as outweighing the potential benefits.

A third of the organizations indicated that such information was already sufficiently protected through professional practice guidelines and through the HIA provision requiring custodians to collect, use, or disclose only for the purpose for which it was provided to the custodian. An RHA suggested additional protection of nonrecorded information could be provided by making use/disclosure of such information in contravention of the act an offence.

The individual supported inclusion of nonrecorded health information. The rationale was that the same principle should be applied to health information as applies to the courts for nondocumentary evidence.

Mr. Lougheed: Shall we not revisit this one?

Mr. Broda: We have consensus here.

The Chair: Okay. Do we have consensus?

Hon. Members: Agreed.

The Chair: Okay. Hearing no objections, thank you.

I guess we'll go to the next page, part 2, question 11.

Ms Robillard: Okay. I'm going to deal with part 2 of the act. Part 2 deals with the individual's right to access their own health information. Question 11 is: "Is the process for obtaining access to records appropriate? If not, please explain and provide any suggestions for improvement."

We received comments from 10 organizations and one individual. Six organizations indicated the process for obtaining access to records is appropriate while four organizations and one individual suggested changes. Organizations indicate that they value the consistency the process provides. Fifty per cent of them support the 30-day timeline providing the initial request for information is clear. The health boards of Alberta suggested a provision to deal with demonstrably illegitimate requests. One health authority wants the provision for routine access to information to be better known by the public and recommends that routine access be as explicitly stated in the HIA as it is in FOIP.

Three organizations are requesting changes to section 104. This is the provision around who can act on behalf of an individual, also known as substitute decision-makers. This will be referred to question 31, so clarification of all of those comments have been referred to question 31 as well.

The comments from the individual reflect an interest in reasonable access and the ability to correct information. The advocacy group is concerned with fair treatment of individuals requesting access.

The Chair: Ms Blakeman, do you have a question? Yes.

Ms Blakeman: I'm wondering about the one that – there was only one that was concerned about vexatious applications to deal with demonstrably illegitimate requests?

Ms Swanson: In another question another stakeholder mentioned a similar concern. This was raised by both the health boards of Alberta and the Alberta Long Term Care Association. So two organizations raise it but in different contexts.

Ms Blakeman: Did they supply us with any statistical backup for that, that they've had X number of vexatious requests over a period of time?

Ms Swanson: No.

Ms Blakeman: Okay. Thank you.

Dr. Pannu: Any clue as to what these organizations and institutions considered demonstrably illegitimate requests? Any examples? I mean, that's fairly strong language, and in order for me to be persuaded, I'd like to see some examples. You know, what would be a demonstrably illegitimate request for information on one's own health record?

Ms Robillard: Given we're dealing with an individual accessing their own record or a substitute decision-maker accessing a record, presumably it would be multiple requests or repeated requests over time, I assume.

Ms Miller: We really don't know. I don't think they provided that detail.

Dr. Pannu: Okay. But we need to explore that.

The Chair: Mr. Broda.

Mr. Broda: Yeah. I have a question here. We have the health boards of Alberta saying that, yes, there have been a lot of frivolous requests for access, yet we have two health regions that say no. It doesn't seem to be consistent here.

Ms Inions: Just a comment. Again, it's impossible to know exactly what's being thought of here, but I can give you some examples of situations that have come to our office. We are aware of a situation that has resulted in numerous, numerous requests for almost the same information worded in a slightly different way. You know, I think that's almost a frivolous and vexatious category. I don't know what would be demonstrably illegitimate; I don't know what those words mean.

The other thought that came to mind is that there have been issues in relation to therapeutic abortion records particularly. Those requests generally are not responded to in that it's not the individual's own information they're seeking, but it might be organizations, lobby groups that are seeking information about individuals that have gotten such services. Again, that would be illegitimate from the sense that they wouldn't be entitled to that information; it's not their own information. But often those issues have gotten to our office in the form of an inquiry to that extent saying: we want that information.

So those might be some of the types of situations.

The Chair: Thank you.

Dr. Pannu: There's the notion of interest in reasonable access, and I also notice that the Consumers' Association of Canada, Alberta division, makes a reference to disturbing reports about how some providers use the HIA to increase expenses and make it difficult for someone to access their health records and information on treatment decisions. Now, is this what is meant by, say, unreasonable access, making it too expensive for people to access their own information? Would that sort of help us understand what is reasonable access?

Ms Robillard: Yes, I think you can assume that's part of reasonable access. If I recall, the individual who was requesting and who spoke to this issue, though, was speaking to her ability to access her health information, which we had a discussion previously about. It was around, I believe, some kind of a reaction to a medication, and she didn't want to have to wait 30 days to get that information. However, we've already had a discussion about how those types of exchanges of information are not limited to a 30-day time clock. Obviously, when you're having a discussion with your physician and they put you on some medication and you have an adverse reaction, the discussion about that adverse reaction should take place between the provider and the individual at that time, and it wouldn't require a formal request to access that information, which can take 30 days to respond to. So there are all kinds of information exchanged in the provision of care and treatment that don't take an access request or 30 days.

11:25

The Chair: Thank you.
Mr. MacDonald.

Mr. MacDonald: Yes, Mr. Chairman. Who owns the individual's health information? Is it the individual, or is it in some cases the provider?

Ms Robillard: Actually, the Health Information Act doesn't speak to who owns the information at all, and that would be an issue perhaps of common law. I might defer to Noela on that question, if you choose, Noela.

Ms Inions: Perhaps MacInerny is the Supreme Court of Canada decision that speaks mostly to that issue. It's never been fully settled. MacInerny says that the entity that compiles the record owns the property in the record. The hospital, the physician, owns the property, the physical record, but the individual is entitled to the information in the record, so they're entitled to a copy. They're entitled to reasonable access, with some exceptions; for example, if it would harm the individual and that kind of thing. Neither right is absolute. The proprietary right of the person compiling the record is not absolute and the individual accessing the information is not absolute, but the individual has a very, very strong right of access to the record.

It's been a perplexing issue. The whole business of ownership doesn't really suit health records. It just doesn't apply to it. Ownership is a bundle of rights. You can buy it; you can sell it. Now, if we say that the individual owns their information outright, that means that perhaps physicians are, you know, misappropriating information. Maybe they're guilty of theft because they have the individual's information sitting in their office. It leads to those absurdities. The concept of property like a house – you can sell the land or a house or cattle or whatever – doesn't work very well in the context of health information. If anything, I think it's truly a joint ownership between the individual and the entity compiling it in the way it works.

The Chair: An additional question on this point, Mr. MacDonald?

Mr. MacDonald: Just a clarification, please. So in the Supreme Court of Canada's decision in 1992, MacInerny versus MacDonald, I'm correct to assume that . . .

Mr. Broda: Was that you?

Mr. MacDonald: No. There are many.

. . . the patient is entitled to examine and copy all information in the medical file or in the medical records, but the physical records are owned by the physician. That's correct; right?

Ms Inions: Generally, that's correct. The information the individual is entitled to is the information that was used to provide treatment to the individual. So it's not all information, but any information relevant to the treatment of that individual. The court said that it's akin to a trust, but again they waffled and went back and forth, and they didn't clearly say exactly what the property right was or the ownership right was. If you read different parts of it, you can come up with different conclusions even in that Supreme Court of Canada decision, but there is a very strong right of access of the individual to the information about them in their record.

Mr. MacDonald: Okay. Thank you.

Dr. Pannu: I'm just quite intrigued by the Supreme Court decision. Would entitlement be a better word than ownership, as if it's a property or thing or something? We're talking about entitlement rights to access, to seek confidentiality or privacy protection. Those would be things that you associate with entitlement rather than possession, as with property.

Ms Inions: I think it's a more workable way to think of it. Whether you call them rights or entitlements, they are things that flow with the information.

The Chair: It seems to me we have belaboured this point. Are you on this point, Ms Blakeman, or do you have another question?

Ms Blakeman: It's on electronic health records. I can come back to it.

The Chair: Okay. Can we go to number 12, then, Wendy?

Ms Robillard: Question 12: "Are the exceptions to the individual's right to access their own information (both mandatory and discretionary) appropriate? If not, please explain and provide suggestions."

We received comments from 10 organizations. Most of them indicated that the exceptions to the individual's right to access their own health information are appropriate. One health service provider was supportive of existing exceptions but also recommended including a provision to allow custodians to disregard deemed unreasonable, frivolous, or vexatious requests and that in the event of a dispute, the individual could notify and request a review from the Privacy Commissioner.

Three organizations recommended changes. A health authority recommended an amendment to allow disclosure to the individual of any information provided by the individual about a third party – that would currently be withheld – subject to discretionary exceptions. The health information and research sector organizations recommend exempting from the access provisions personal health information a researcher uses solely for research purposes and information held by CIHI for statistical analysis.

The Chair: Okay. Seeing no questions, question 13.

Ms Robillard: Question 13 is a question about the amount of fees set out in the reg and whether that's appropriate or not.

A total of 13 comments were received from 12 organizations and one individual. The majority of the health authorities and health service providers stated the fees were not appropriate and should be raised to capture actual costs. Annual or periodic review of the fee schedule was suggested to reflect cost recovery. Further comments reflected a need to determine access costs for electronic health records and CDs. So looking at disclosures of new types of information.

One service provider stated that clarification is required on the disposition of an individual's fees within the affiliate and custodian environment, as both parties incur costs.

The individual, advocacy group, and insurance sector respondents stated the fees were not appropriate and should be lowered. Current fees are seen as a potential limit on the individual's rights based on ability to pay. Lower fees would heighten provider/payer accountability. The universities see current fees as appropriate.

The Chair: Mr. MacDonald, did you have a question on this? You don't? Good. Okay.

Dr. Pannu: I think the message that I get here is that there is widespread concern on both sides. The Consumers' Association of Canada is an advocacy organization. The point that it made in the previous question is reinforced here, I guess, by the responses that we received. On the other hand, health services provider organizations take a very different view because the question for them is the costs, additional costs to their operations. But we are dealing here with the access of individuals, the right of access of individuals to information, and anything that impedes that is something that should be a matter of concern to us as legislators.

The Chair: Thank you.

Mr. MacDonald.

Mr. MacDonald: Yes. Certainly, Mr. Chairman, I would like to remind all members of this committee of Justice McMahon's decision in regard to FOIP legislation and the use of fees. Fees should not be a barrier ever in the distribution or the release of information, and certainly fees should not be used to capture the actual costs. With respect, that's to do with FOIP, but certainly the Health Information Act, in my view, and the use of fees should not be any different, and I think we should pay heed to Justice

McMahon's decision from two years ago when we contemplate the amount of fees set under the Health Information Act. Fees should not be used as a barrier.

The Chair: Okay. So noted. When we come back with recommendations, there will be recommendations there, and the committee can debate the recommendations.

Mr. MacDonald: Thank you.

The Chair: Number 14.

Ms Robillard: "How should the HIA be amended to address the concept of custody or control of a custodian within the [electronic health record]?"

Eleven organizations commented. Five of the 11 organizations support no change in the act dealing with the concept of custody or control, and they provided a rationale: in principle, the same rules for collection, use, and disclosure should apply to all media; the changes needed are operational in nature; it is premature to consider changes today.

11:35

Three organizations suggested that custodians should retain custody and control of the health information they collect/generate in the EHR but not custody and control of the entire EHR. Calgary region recommended an amendment to enshrine local custody and control rather than custody and control by Alberta Health and Wellness. A professional association suggested the concept of two levels of custody: one for the entire database, and the other for the information provided by the custodians that make up the EHR. It indicated that if government has custody of the entire EHR system, it should be responsible for its security. These four organizations agreed that individual access should continue to be through the custodian who collected the information. Another health authority supports clarification of the custodial responsibilities.

The Calgary region supports amending the definition of a record to reflect the EHR environment so that custodians are able to determine the form in which health information is provided. Their concern is to avoid burdensome obligations like printing every screen shot that may contain health information in each application related to the EHR.

Capital supports the custodian with access being responsible for protection of the information. A health service provider supports the custodian who collects the information having fiduciary obligations to the person to protect the information.

The government of Alberta asks whether there is need for more transparent and explicit rules in the act regarding disclosure without consent to an EHR or other networked database established by government or another custodian for an authorized purpose and for subsequent access by providers or other authorized persons.

The government of Alberta requests consideration of a change to enable custodians to collect, use, and disclose without consent a unique health service provider identifier number for systemwide use.

The Chair: Okay. Again, I know the option will come forward in later discussion, so let's go to question 15.

Dr. Pannu: Mr. Chairman, I want to just underline the fact that it's an important issue, a very important issue, which merits I think close attention by the committee, although we would certainly welcome options that are put before us. It's a very important issue.

The Chair: So noted.

Ms Robillard: Part 3. We're now dealing with the collection of health information. The first question: "Is the duty to collect health information directly from the individual except as authorized appropriate? Or are there other legitimate circumstances for indirect collection?"

We've received now, including CBS, a total of nine comments from nine organizations. The general consensus is that the duty to collect health information directly from the individual except as authorized is appropriate. The existing rules appear to support custodian needs and individual rights.

CBS indicates that they would like to see indirect collection authorized for public health purposes. A health region and professional association/college did comment on a need to clarify the act by defining "reasonably practicable" in section 22(2)(d) and modifying the requirement on custodians to collect information directly from the individual for the purpose of providing health care services. The requirement of direct collection from the individual could be problematic in the electronic environment. In these cases, information entered by another custodian is accessed/collected from an electronic record rather than from the individual.

The Chair: Okay. I see no questions. Let's go to the next one.

Ms Robillard: Question 16.

> 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 to the individual? Or should privacy protection of the individual not allow this collection?

We received a total of 10 comments, one from an individual and nine from organizations. The general consensus is that collection of family history without consent is appropriate and essential to provide timely, efficient patient treatment and care.

A health authority suggested rewording for clarity, and they wanted the wording in the legislation to read much more like the consultation guide.

The AARN stated no position; however, did comment that collecting family history has potential to affect the extended family, and raises issues of obligation to inform family members who could be impacted by the collection.

The one opposing view was reflected by the individual's response, stating that family member consent should be required, and if not attainable, so be it. So, presumably, collect it anyway.

The Chair: Next.

Ms Robillard: Question 17: "Is the requirement to inform individuals about collection practices effective or does it create any operational difficulties?"

We received a total of 10 comments, one individual comment and nine from organizations. Fifty-five per cent of the organizations commented that the requirement to inform individuals about collection practices is effective. These organizations support the practice of posting notices explaining reasons for collection and giving direction for further information. However, 33 per cent of the organizations did indicate that public notices cannot be assumed to be effective ; e.g., not everyone will/can read and understand public notices.

Three organizations indicated that having to give notice to individuals in all cases is an administrative burden. If health care providers have to spend treatment time describing the custodian's collection practices to each individual, this will create significant operational difficulties. A health authority suggested that the act should specify how to inform individuals. They view methods other than a general notice as typically not effective and can create operational difficulties. The long-term care sector members have adopted the practice of notifying individuals within their admission agreements, since the use of posters does not align with their philosophy that a long-term care centre should provide a homelike environment.

Three organizations support an informed/knowledge based implied consent. Those will be referred to in question 27 as well. The comments from the individual support the patient's right to know what the custodian is doing with the information.

The Chair: Let's move to the next document and number 18.

Ms Robillard: We're now moving to part 4 of the act, which is Use of Health Information. The first question under use is whether the purposes currently listed in the act are appropriate for existing custodians and, if not, whether they could be improved.

Five organizations commented here. Four saw the current purposes as appropriate for existing custodians. Long-term care also supports the existing uses. However, it also suggested restrictions on use of genetic information to determine eligibility for health services, on use of health information for marketing products or services, and on use to discriminate against prospective or current employees.

The AMA does not support health authorities, boards, and Alberta Health and Wellness using individually identifying health information for planning, resource allocation, health system management, public health surveillance, and health policy development. They believe that identifying information is not required for these purposes, and where its use may be justified, approval by the OIPC should be required.

The Chair: Questions?

Dr. Pannu: In listening to what's been stated, I think the AMA's position seems to me to be quite appropriate here, that identifying information is not required for these purposes, and where its use may be justified, approval by the OIPC, the office of the Information and Privacy Commissioner. I think there's a good safety arrangement there, protection.

The Chair: Are you suggesting that we have consensus here, Dr. Pannu?

Dr. Pannu: I would like to explore it further with the AMA this afternoon – they're coming before us – before we go there.

The Chair: Okay. Very good.
Let's go to number 19.

Ms Robillard: Question 19: "If you recommended an expansion of scope of the Act to include other entities, what purposes/set of responsibilities would you change to reflect the mandates of additional custodians?"

Nine organizations commented. Four view the current purposes for use and responsibilities as suitable. Five recommended changes to reflect the mandates of additional custodians, and those include providing a specific purpose for new custodians practicing in both the public and private sectors, adding a "best interests" provision, changing to an informed/knowledgeable implied consent model, recognizing statistical analysis involving data matching for health system management and planning, and revising the purposes and language to more accurately reflect the nature and enabling applications of the act.

The Chair: Number 20.

Ms Robillard: "Is it appropriate to use identifying health information without consent for the authorized purposes stated in the Act?"

Five organizations and one individual commented. Two-thirds agreed with the use of individual identifying health information without consent for the authorized purposes stated in the act. The AMA recommends explicit consent be required for any purpose beyond direct treatment and care. The individual supports use with consent because use without consent is not consistent with the principles of privacy and confidentiality.

11:45

The Chair: Question 21.

Ms Robillard: "Overall, should the listings of authorized uses be expanded, restricted or modified in any way?" We heard from eight stakeholders including one individual and seven organizations. Two organizations favour no change. The AMA favours "restricting the authorized use to non-identifiable health information."

Four organizations and an individual suggest expanding the list of authorized uses for integrated programs, providing services to another individual, better balance between the public good and an individual's right to privacy, patient needs and the EHR, fundraising by the custodian, broaden the provision enabling disclosure for health service provider education to read simply "education purposes."

The Chair: Okay. Does that take us to part 5?

Ms Swanson: It does. We're proposing to skip over 22(a) and 22(b), which deal with consent, and deal with them in the context of the pan-Canadian framework at the next meeting.

The Chair: All right.

Ms Swanson: So we will deal with Question 23. "Are the discretionary disclosures without consent (subject to overriding principles) as listed in the Act reasonable and appropriate? Should these permitted disclosures be restricted in any way? Please explain."

Nineteen comments were received, 18 from organizations and one from an individual representing a religious group. Six organizations and one individual agree that the current discretionary disclosures without consent are reasonable and appropriate.

Several organizations made specific suggestions including enabling the following disclosures without consent: collaborative or integrated programs, suggested by the Mental Health Board, the provincial diversions program advisory committee, and the government of Alberta. The Canadian Medical Protective Association for medical/legal purposes. Health departments of provincial, territorial, and federal governments for out-of-province care data, suggested by CIHI and the government of Alberta. A municipal, provincial, or federal government department for payment of benefits or services, analysis, research, and policy development. The Alberta government asked the committee to consider this, and the ALTCA recommended it. Any person, the presence, and location in a health facility unless the patient expressly refuses, suggested by Capital health. A successor to include a custodian who remains a custodian but transfers records, this from the Privacy Commissioner. Any person to address a complaint or allegation made in a public forum, suggested by the Calgary health region. First Nations police services for investigating an offence. This was an oversight in the initial drafting, a suggested correction, in the government submission. Finally, clergy, a listing of all individuals in a health facility to enable pastoral visitation.

Then there were a number of other suggestions made, including changing the disclosure provision to any person who requires the information for the purpose of providing care to the individual, removing the ability to disclose to the Chief Electoral Officer without consent, restricting disclosure without consent to purposes related to direct care and treatment but allowing disclosures to professional regulatory bodies and third parties for processing payment, requiring the individual to be notified before disclosure without consent, prohibiting disclosure of psychological raw test and data scores except to those qualified to interpret them, and clarifying the meaning of imminent danger. The Canadian Blood Services thought the concept of imminent danger was too high a threshold, and there may be other legitimate circumstances where it may not be possible to obtain consent.

The Chair: Okay. Let's try 24.

Ms Robillard: Question 24:

> 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 [order]? If so, why and under what circumstances? If not, why not?

Nineteen comments were received, one from an individual and 18 from organizations. Eleven of the 18 organizations agreed with providing at least some discretionary authority, in certain circumstances, to disclose to police services.

Seven recommend no change. Four health authorities do not support extending the discretionary authority to disclose registration information to police. Their views are that this is not required to obtain a warrant, that the current process of court orders is appropriate, that the general rule requiring consent or a search warrant protects individual privacy without reasonably obstructing police investigations, and that the current provision in the act provides a right balance between protecting individual privacy and duty of the police to protect and preserve peace. One health authority is concerned that extending the disclosure may discourage patients from seeking medical care.

Six recommend disclosing basic registration information to police. In some cases stakeholders appeared to define "basic registration information" to include some diagnostic, treatment, and care information. When asked by the committee after his oral presentation, the Information and Privacy Commissioner supported the release of registration information or a subset of registration information that would allow the police to get a warrant but did not support general access by the police to department databases.

The Edmonton Police Service recommends disclosing basic registration information and health service provider information.

The remaining four have made specific recommendations:

- Disclose health information if the custodian has reasonable grounds . . .
- Under certain situations breaching confidentiality may be necessary . . .
- Disclose health information to assist in an investigation . . .
- Allow custodians discretionary authority to disclose health information . . .
- Enable disclosure of health information for investigating potential fraud in the publicly funded health care system.

Mr. Snelgrove: The Privacy Commissioner gave us information a month ago, or whenever, about the survey that stated 86 per cent. I'd asked them to give me a copy of that survey so that I can understand the context.

Ms Gallant: Yeah. I provided it to the committee.

Mr. Snelgrove: I'm sorry. I left . . .

Ms Gallant: Okay. I thought it was distributed, but I do have my own copy here today, so I can certainly share that with you if you like.

Mr. Snelgrove: Thank you. I'll get it at lunch. That would be great.

The Chair: Any other members need that? Okay.

Dr. Pannu: It's not been distributed, Mr. Chairman?

The Chair: I believe it has been distributed, but I think Mr. Snelgrove left earlier that day.

Could we try 25 and then go to lunch?

Ms Swanson: Question 25: "If you disagree with the proposed amendment to specifically reference the triplicate prescription program, please explain your rationale." Eleven organizations responded to the question.

Most support the triplicate prescription program being authorized explicitly with some caveats. The Pharmacists Association suggests a broader exception to include disclosure to other and noncustodians with quality improvement and other public interest objectives. The AMA and Calgary health region take the opposing view, saying that the provision should be very narrow and specifically focused.

The Calgary health region wants the provision limited to detect or prevent fraud and limit abuse. Capital health cautions that explicit authority may lead to further requests and suggests a listing in a manual as an alternative.

11:55

The Chair: We'll also do 25(a).

Ms Swanson: Yes. This is disclosure to third party carriers for purpose of payment. There was no question specifically asked in the document about this, but there was a statement about release to third party carriers.

Six responses commented. The organizations agreed to disclosure for payment purposes without consent or with deemed or verbal consent, but one individual disagreed to disclosure without consent.

The Chair: We have a question.

Dr. Pannu: Mr. Chairman, 25 and 25(a) raise some fundamental questions about the purposes of the act, the intent of the act being the protection of private information on health care. All I want to do is draw the attention of the committee to the fact that this question does draw attention to the possibility of using information for purposes other than strictly, you know, for the person from whom the information is collected for medical reasons. Nonmedical issues and considerations are coming in here, and we need to scrutinize these issues with much greater care than some other sections.

The Chair: Thank you.

Okay. I thank the committee and those involved with the information dissemination for your good work. I would remind you that we need to reconvene sharply at 1 o'clock because we have our first oral presentation at 1 o'clock. So having said that, I suggest that we adjourn for lunch.

Thank you.

[The committee adjourned from 11:56 a.m. to 12:59 p.m.]

The Chair: I am going to call the committee to order. Rabbi Ari Drelich apparently is trying to get parked, et cetera, and is going to be a couple of minutes late. So, Wendy, I wonder if we could do number 26 of the draft, and when the rabbi gets here, we'll finish off as appropriately as possible and take his submission.

Ms Robillard: Certainly.

Mrs. Dacyshyn: He just arrived.

The Chair: Good afternoon, Rabbi. We welcome you to our committee this afternoon.

Rabbi Drelich: Thank you.

The Chair: We're pleased to have Rabbi Ari Drelich here.

Rabbi, before we start, I'm going to ask the committee members to introduce themselves, and we'll start with our elected members and then go to the staff. We'll just go around the table, and then following their introductions, we will be pleased to hear your presentation.

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

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

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

Mrs. Dacyshyn: Corinne Dacyshyn, committee clerk.

The Chair: Thank you very much, everyone, and again welcome, Rabbi, to our committee. We have about 40 minutes, and we'd like you to save some time for questions. Other presenters have split that about half and half. We leave that to your discretion, but please go ahead.

Rabbi Drelich: Okay. First of all, good afternoon, ladies and gentlemen, and I'd like to take this opportunity to thank you all for allowing us the opportunity to be able to present what I feel is a very important matter.

Just a brief history of myself. I've been here in Edmonton for some 13 years. I'm part of a world-wide outreach organization within the Jewish community. Some of you may be familiar with the activities we do here. We put up a giant candle-lighting ceremony every year at the Legislature. The mayor and the Premier come, and it's really a very wonderful program.

Some of the many other things we do are we visit hospitals, seniors' centres, and so on, and we've been doing so for the past 13 years, as we were here that long. For the past 10 years, before FOIP became an issue, the freedom of information, et cetera, we were able to visit quite freely, pretty much I'd say 24/6. We rest on the Sabbath. If it was past the time that the office was open, I'd simply call security. They'd come; they'd open the door. I'd sign in, and I had access to the lists.

You have to appreciate that many people for one reason or another do not make it on the specific religion list. That is something that they may or may not be requested. Obviously, people sometimes are rushed to the hospital. For whatever myriad of reasons they do not make it on the specific religion list. As such, what I would do is scroll through the generic list and I'd pick out the names that I'm familiar with within the community and go and visit those people.

1:05

The positive feedback from visiting people from all segments of the Jewish community in my case has been very, very positive. I can't think of a single incident when people didn't appreciate a visit. They may have not been up to a visit. If they're in too much pain, there'll be a sign on the door, "Please see nurse," or they'll just wave you on that now is not the time, and so be it, but those have been very, very rare cases.

Actually, I should hasten to add that the interpretation of the privacy act is that it's been sort of across the board, a baby and bathwater type of situation where suddenly we've gone to the other extreme.

Now, I must hasten to add that in no way, shape, or form do I believe that we should not have a freedom of information and protection act. I think it's very good. I think people's information should be kept private, and only those individuals who have to have access to it, law enforcement or what have you, whatever area of society we're dealing with, should have it.

I have seen a stark difference in the last two or three years or so when the law has been actualized or, shall we say, interpreted insofar as people would say: "Rabbi, how come you didn't come and visit me? My grandmother has been in the hospital." I'd simply tell them that I just didn't know; please do not rely on my prophecy. The fact of the matter remains that we're severely curtailed in our ability to be able to, as we say, do what we do best, and that is to visit people.

Take the University, just for one example. You can only come between 9 and 4. I mean, this is just a compounded issue. You can come between 9 and 4 with the exception of 12 to 1, which is lunchtime, and even then you can only see the specific religion list and not know if anybody else is there from your faith group. A similar situation exists in the Alex, and it's a little more relaxed, if you will, in the Misericordia, where it's staffed a little bit longer, and that's, of course, Monday to Friday.

So what has happened is that in the interest of trying to protect people's freedoms, somehow along with that came the difficulty of being able to provide for people and to enhance their stay in the hospital, which is usually not a pleasant place to be, et cetera, et cetera. Therefore, what I would like to propose, suggest, shall we say, is a modification of the interpretation. I don't know, you know, who it's really up to to interpret the law. I had a meeting first with Mark Norris, who's our MLA, and that got bumped up to the minister of health, and it got bumped back to Mark Norris. Then it went to Capital health. Then we had a meeting with Brian Hlus and Karen Leibovici. So I really met pretty much the whole city council, all the MLAs, and I'm just about to meet the Prime Minister. In the meantime, we're sort of back to square one insofar as . . . [interjection] You think it will help? I'll try it.

What I would like to propose is that there should be some sort of a balance. Obviously, we're dealing here with select and controlled visits. Even though I'm coming from my perspective as a rabbi, I'm sure that I speak on behalf of many if not all clergy and their ability to freely visit their faith groups. You know, I've never come across a situation where somebody doesn't appreciate a visit, however so brief. Like I say, I've seen a difference from 10 years back, when we'd come and people were able to be visited freely. Now suddenly people are calling: "Didn't you know? I've been in the hospital for a week, so why didn't you come?" et cetera, et cetera.

You know, there's only so much you can blame on the government. The fact of the matter is that we're trying to reach out to people; we're trying to help people. Therefore, what I'd like to see is some sort of a balance where people's freedoms could be protected. This is what I've heard: if people's names are not on the religion list, they don't want to be there. I beg to differ. I think that it's simply that people, as I said, are sometimes rushed into the hospital and for whatever reason their name does not make it on the list, but that does not mean that they don't want a visit. If they don't want a visit, it's very easy. You can put a little sign on the door, "Speak to nurse," you know, "I'm not home; call later," whatever. There are many ways to sort of get around the situation, but generally speaking, it's always been appreciated.

We'd like to see it return to the former status quo with that balance of visiting, with the understanding that people are not going to be visited who don't want to be visited. You know, I'm not looking for extra work. I'm not going to start visiting all the other faiths unless I'm specifically requested, et cetera, but I think it's something that worked well. If the law is too much to a slant or its interpretation is too much to a slant, I think that ultimately some people are going to be adversely affected. So that's where we are.

The Chair: Thank you very much, Rabbi. I appreciate your comments. I certainly understand what you're saying. As a former clergyperson myself I certainly encountered that problem, so I do understand what you're saying.

We do have some questions for you. I'm going to start with Mr. Lukaszuk.

Mr. Lukaszuk: Thank you, Mr. Chairman. Rabbi, first of all, as an opening remark, when dealing with health care, good luck with the Prime Minister. He may make you feel good, but nothing will get resolved.

However, I appreciate the importance of what it is that you do when you visit hospitals. How do we accommodate those few – and I imagine it would be very few – from your faith group who simply don't want you to know that they are there because of the specific medical condition or the circumstances under which they find themselves?

Rabbi Drelich: I'd put a big sign on the hospital: Goldberg is not in. But a little bit more seriously, you know, there are 50,000 people a year in the United States that are killed in automobile accidents. I don't see a single group advocating the abolition of the automobile. Now, 50,000 people is a lot of people.

When we introduce a law, obviously we don't want to step on anybody's toes, but you have to look at the broad picture. What is going to be accomplished by this act? Yes, no person's privacy should be intruded upon, but for those select individuals, they have an easy option. Seriously speaking, they could put a sign on the door: no visitors.

It makes no difference if you know that they're in the hospital or you don't know. They don't want any visitors. It's as simple as all that. To take it the other way, then you're taking the 99 point whatever patient population that do appreciate a visit and do want a visit. So no one is saying that this person who doesn't want to be visited has to be visited. "Sorry; you can't visit that person." Place a sign on their door or something similar to that. They'll let the nurse know: only family or only clergy or what have you. Sometimes they don't want the family. They only want clergy.

Mr. Lukaszuk: Thank you, Rabbi.

Mr. Broda: Thank you, Rabbi, for your concern and presentation and humour. I come from a rural constituency where we have small hospitals in our regions. Maybe it's a little bit different. I don't know how the act applies, but we do have – and I'm sure the cities do as well – a pastoral group that is already interacting with the hospital facilities.

In my area, in Redwater specifically, I know that we've got about five clergy of different denominations. They belong to the pastoral group that interacts with the facility itself, with the Aspen health authority, or in this case now we're in Capital as well. You're in Capital. I don't find that with our clergy, the restrictions on them not being able to go. I'm sure you're able to go to the hospital as well or long-term care centres or lodges or whatever. But with the pastoral group it seems like it's an alternative. Each one does a Mass or, whatever denomination you have, a prayer vigil or whatever, and the patients in those facilities are usually invited. It's once a week, and everybody takes a turn to go in there. I don't know how that works in the city with Capital health. I just thought I'd question you on that part.

Rabbi Drelich: Well, obviously, in a smaller community, you know, it's like one happy family. News travels very quickly, and people interact very differently. When you are dealing with a larger city – and you have to appreciate that the statistics are that the average stay in the hospital is I believe five days. It could be less, of course, as well.

So you want to maximize your time when you're going to the hospital, especially if you're running all over the place. If you happen to be near the University, hop into the University. By the way, visiting hours are until 8 o'clock. You know, the doors shut at 4 o'clock, so you have a four-hour spread where you have no information available to you. Sunday is an excellent day to go visiting. Again, you have no information unless you know specifically that someone is there. So when you're dealing with a larger city environment, you have to be able to maximize your time. Information flows less freely than it does in a small community. In a small community you go to the general store and everyone knows . . .

1:15

Mr. Broda: That so and so is away, yeah.

Rabbi Drelich: Exactly. You don't have that in a large city, and therefore access and the controlled free flow of information is very important.

Again, we're not talking here about taking that information – we're talking here about a controlled group, a controlled environment, and perhaps there has to be a training session. You know, you don't just get your clergy card because you ask for it. You have to have a letter of recommendation, et cetera. And it's like that with any field. Alberta Registries knows my driving history; thank God, no one else does. So we're talking about controlled groups of people who are utilizing judiciously controlled information.

The Chair: Thank you.

Ms Blakeman.

Ms Blakeman: Thank you. Two questions, Rabbi. You've provided us with a copy of the letter from the Hon. Mark Norris back to yourself dated June 12, and I notice at the end of the letter that Minister Norris says, "I would encourage the clergy and their congregation to discuss alternative approaches with Capital Health." You've already mentioned that you met with Capital health, and I'm wondering what alternatives or assistance, aside from sending you to present to the committee, was in fact offered up by the representatives you met with from the Capital health region.

Rabbi Drelich: I come from New York, and people ask me how I like Edmonton. I say, "The weather is cold, and the people are very warm," which is true. But coming from New York, when you want to renew your licence or you want to do anything official, you call a number, they put you on hold, then they transfer you to another number, then they give you another telephone number, then they tell you to call back tomorrow, and it goes on and on and on.

In a similar vein, this is what has happened. It's gone from one area to one department. "Don't call us. We'll call you. We'll get back to you." And basically after all the series of meetings I said: "Go fight city hall. Forget about it. I'll wait and see what happens." As it happened, Brian Hlus called me. I welcomed him back from New Zealand because that's where I thought he was; I didn't hear from him in such a long time. I said: "Fine. You know, this opportunity has presented itself. Let's go for it." So here we are.

In other words, I'm trying to make light of what I think is really an important thing, but I take it as it comes. I wasn't going to go knocking on a bunch of doors and go to this one and that one because I saw when I started the process how it was going. I spoke with my MLA; it went to the minister. From the minister it came back to my MLA. From my MLA I was then transferred to Capital health. From Capital health I had a meeting with the aldermen and with Brian Hlus, and we've had a series of phone calls back and forth.

You know, I am busy, I do work for a living, and there's only so much time and effort I can put into any one particular project. I'm very pleased that I have this opportunity today – I mean, this is a godsend – to be able to present my case, and I hope, like I say, that we'll be able to come to some sort of a resolution with which everyone will be happy. But to answer your question more specifically, it was just that I don't know where to turn.

Ms Blakeman: Okay. Thank you for that. We're trying to determine if the act is adequate and balanced in the protection that it offers for people's personal health information. The scenario that you're painting for us would, in fact, I think require someone to essentially make additional effort to protect their personal health information, even the fact that they're in the hospital, never mind what they're in the hospital for, as Mr. Lukaszuk mentioned.

So they're told that their health information is protected, but "If you don't want to have a visit from your clergy representative, then you'd better tell us that in addition," if we follow through on what you've been recommending. You would be asking for individuals to make additional effort if they did not want to receive a visit in some way.

I'm wondering how many people this affects. You've said you already get access to the names on the list. How many times are you finding that someone is not on the list that you could have found if you would have been able to access it? Are we talking five people a month, five people a year, 50 people a year? What's the size of the issue?

Rabbi Drelich: Okay. Well, the Jewish community is a much smaller community than other faith groups. It's very hard to pinpoint and say an exact number. Of course, I visit the hospitals sporadically, and I can only tell you that I've received many phone calls. That represents a silent majority of people who don't bother to call and say: "Why don't you visit my grandma?" "Didn't you know that I was in the hospital?" These phone calls, these requests very rarely happened before the act was put into place. Again, I cannot give you exact numbers.

As far as your first issue is concerned, again in no way do I want to jeopardize anyone's specific right to complete privacy. I'm just proposing for that select and very select group who really do not want any visits that they can even put it on a master list, and next to their name could be NV or something, no visits, because the overwhelming majority of people do appreciate a visit.

You have to remember that a visit doesn't mean you just come bursting in. A visit means you come at the proper time. You knock on the door. "Who's there?" You say, "It's the rabbi." " Sorry, I'm not in," or whatever the case may be. They can always say, "I'm sorry; I'm not up to a visit," or not answer, so you just don't come in. You have to be invited in, but the person who's bedridden and in pain is not going to pick up the phone and say, "I'm in pain; please come and visit me." First of all, it's a lot of pride-swallowing for a person to ask for help, but we all know that as great as the medical cure is here – and it is number one; I've heard this from a lot of people – a hospital is not a fun place to be. It's very embarrassing, it's very hurtful for a person to suddenly find themselves going from being a productive individual to now, boom, being in the hospital and they're on machines and so on. When somebody comes, even if they can't communicate, it's the mere fact: "You've come. I'm important to you. Thank you."

Ms Blakeman: I understand what you're saying, and I know how important it is to people. Nonetheless, the health and information horse is out of the barn by the time you're knocking on that door because you know that they're there, and you likely know why they're there because you know what ward they're on. So their health information is already out there, even if they refuse a visit with you. Are you telling me that you feel that for the number of individuals who are not on the list, whom you have now gained information about, losing their control of their health information is worth it, is the balance to be achieved in order to capture those who would have liked the visit?

Rabbi Drelich: The fast answer to your question is yes. That's the fast answer to your question. The slow answer to your question is that anybody that's working in law enforcement has access to all kinds of private information about individuals, but society gives them that right. Anyone that works in the registries has access to all kinds of private information. Anyone that works in a bank, even if they're not my teller, has access to all my information at the click of a button, but society allows that because we're dealing with controlled and hopefully responsible individuals who are going to use or not use that information judicially.

So it is the unwritten understanding that someone that's a clergy, who's supposed to represent something and is there to help people, is not going to abuse the information that he has at his fingertips, the same way we don't want law enforcement agents abusing the information that they have, and they have all kinds of very sensitive information about all kinds of people, again at the click of a button. You go like that to any segment of society. There's a lot of information out there. It's impossible – we don't come with computer chips so that, you know, this information will only go to you. We have segments of society that have access to information, and providing that it's controlled and that information is used properly, it's to the benefit and betterment of society.

The Chair: Thank you.
Mr. MacDonald.

Mr. MacDonald: Yes. Rabbi, are there other clergy members from other faiths having the same difficulties that you are experiencing that you know of?

Rabbi Drelich: To be honest with you, I haven't done any polling or anything like that. I can only imagine so. I would presume to a lesser degree than within the Jewish committee simply because the Jewish community is much smaller. In our particular case I have the ability per capita ratio to pretty much visit, if I know, all the members of the Jewish community who are in the hospital at any given time. If you're dealing with other faith groups, because the numbers are so much larger, unless we're consequently dealing with a larger staff as well – but the spread is so great that they have enough, so to speak, to keep them going for a whole day just with the numbers that they have at their fingertips. But I cannot answer you specifically, because it may very well be that because of their additional staff and so on, there are people that are not being visited.

1:25

The bottom line remains the same. It's not the issue of how busy you keep yourself. The issue is that members of any particular faith group are not being able to be visited because of the fact that the information is not there for the clergy to have to visit them. Even if, let's say, you're dealing with the biggest faith group in Edmonton, whatever that may be, and the pastor is busy a whole day visiting patients, in the meantime that small segment that for one reason or another is not on his list don't get visited, so they're sort of left out in the cold, so to speak.

So it's not so much a matter of how busy you are or how many people you did see. We're worried about the people that are falling through the cracks and are not being visited. That's our concern.

The Chair: On this point could I have someone from FOIP or Alberta Health and Wellness clarify exactly, you know, the answer to that question? What is it in the legislation that precludes the rabbi or others from visiting their members?

Ms Robillard: I can try and address this question. The act protects the health information and establishes or authorizes certain specific limited disclosures without consent. We'd turn to sections like 35 that talk about where information can flow.

There is no provision currently that enables information to flow to clergy members, for instance of patient lists, so that they can visit people in the hospital. So the process which is noted in the letter from Mark Norris to the rabbi indicates that the hospital has built in a process which is a consent-based process.

The Chair: When did that happen, Wendy? Because I can well remember being a clergyperson, going to the hospital, visiting anybody I wanted on a Sunday evening at any given time.

Ms Robillard: This problem, similar to the issue with the police, probably came to the attention of regional health authorities around the time that the FOIP Act applied to them. That was the first time they had rules to apply that specified where they could or could not disclose information. So probably around that time, and I can't remember exactly when FOIP started to . . .

The Chair: Would that have been a result of complaints from the general public?

Ms Robillard: I think it was a result of education of the health service providers in terms of protection of privacy and access to information. HIA continued that, obviously.

The Chair: Okay. Thank you.
Mr. MacDonald, is that your question? Are you finished?

Mr. MacDonald: Yes. Thank you.

The Chair: Okay.
Mr. Snelgrove.

Mr. Snelgrove: Yeah. With few exceptions – except probably my father, who said, "Go home, Father; I'm not that sick" – I've never heard of anyone complaining about a visit.

It gets back to Broyce's suggestion. These things come and develop a life of their own. We make rules for carpenters, for example, that fall off the roof – not the ones that stay on – that they all have to live by. How to balance the rights that Laurie has kept espousing, the rights of those that want their privacy, with the greater good is a very difficult task, and I appreciate your frustration. I hope we're able to get a balance in here where we can make it easier for him because for the huge majority of people, having someone come to visit is probably as good a health therapy as we can get. But it is a very, very difficult task to skip carte blanche and go back.

The Chair: Thank you, Lloyd.
Let's see. Thomas.

Mr. Lukaszuk: Thank you. Well said, Broyce.

So now the trick that we have, Rabbi, is that – if I imagine being in a hospital, I think personally I would want to be approached, and I think, as you said, the majority of individuals would want to be approached. How do we now draft the law in such a manner that we still give the option, the safety valve for those who choose not to yet give you access to those who do?

You in your faith group – and there are a few others like it – are in the fortunate situation where even if those individuals don't find themselves on the religious list, you can probably figure out who members of your faith may be quite accurately based on last names, but that's not always the case. Particularly, I imagine that in the Christian community that may not be the case.

So just addressing access to the patient lists would perhaps resolve your particular problem, but there would be reverends and priests of the Christian denominations whose problem would not be resolved, because if you're a Smith, you could be Catholic, Anglican, Protestant, or whatnot.

So would you say that the problem perhaps lies not in the ability of clergy to access patient lists but that perhaps there should be an onus placed on hospitals, however inconvenient it may be to hospitals, that in addition to collecting registration information that includes, "Do you have any allergies?" and "Who is your family doctor?" it would be, if you choose to disclose: what is your religious affiliation, and do you care to have visits? Two additional questions on a registration program.

Rabbi Drelich: That is perhaps one way. Again, I was only presenting a proposal as to what may work to accommodate, and I reiterate what I said before: in no way do we want to exclude even that .1 per cent of people, who have a right to privacy. The issue is the greater picture over here in being able to serve society's needs, if you will, without infringing on the one individual. That may be one way. I don't know how well it's going to work. I've met many people, and I've said to them, "You know, I didn't know you were in the hospital, because you weren't on the list." They said: "Oh, I didn't know that. Nobody asked me, you know, if I wanted to be on the list."

We have to appreciate that nine out of 10 times when someone is coming into the hospital, they're in pain, and the faster they can get in, be registered, and be seen by a medical professional, the happier they are, and we don't want to ask them too many questions. We just have to go on the presumption of what, again, the average person in society is going to like.

Now, we have things on our driver's licence if you want to be an organ donor. Perhaps we can have a little something added to the paper there: "Do you want your information in strict confidence? Do you want that no one should know that you're here?" There could be something there for those that wish to make the exception to the rule, because that is an exception to the rule. The rule is that most people want and appreciate a visit. The exception is those that don't. There should be some sort of provision for people to bow out or what have you – no pun intended – to offer them their strict privacy.

Again, exactly how? Obviously, we're in a room full of intelligent people that have to deal with the juggling of the law, et cetera. I was just proposing one way, but it doesn't have to be limited to that.

The Chair: Okay. I have another question.

Mr. Lougheed: I think my question has really been answered in your response to Thomas and to others.

I appreciate your approach to this and your desire to serve your community. It's only the concern I would have for that, as you said, .1 per cent or probably even much less than that. It is something I think we'll have to wrestle with, but I appreciate your input to this because it also touches on some other issues that we've been presented with in this time of our discussion.

Thank you for your time.

Rabbi Drelich: You're welcome.

The Chair: Rabbi, we appreciate very much the visit you have made to us today. You have raised an interesting dilemma, an interesting challenge to the committee, but as you said, there are some people around here that should be able to figure it out, so I hope we can.

Again, on behalf of the committee thank you very much for bringing this problem to our attention and for your concern for people, especially people who need help and may be, unfortunately, in a hospital or in a situation where they need advice and counsel. So thank you for what you do and for bringing this problem forward. Thank you very much.

Rabbi Drelich: You're most welcome. Once again I'd like to thank all of you, ladies and gentlemen, for being here today and hearing me out and putting up with me, and I hope that we'll hear some positive results in the near future. I love dealing with the government, but it has its limits.

Thank you kindly.

The Chair: Thank you.

Committee, we will change presenters and resume as soon as possible afterwards.

[The committee adjourned from 1:35 p.m. to 1:37 p.m.]

The Chair: I would like to reconvene the committee and welcome Mr. Larry Phillips, president, and Ms Wendy Armstrong, board member, for the Consumers' Association of Canada, Alberta chapter, who are going to present to us this afternoon. We appreciate very much your taking the time to do that.

I would like to go around the table and ask the elected members of the committee and those who serve as advisers to introduce themselves.

[The following members introduced themselves: Ms Blakeman, Mr. Jacobs, Mr. Lougheed, Mr. Lukaszuk, Mr. MacDonald, and Dr. Pannu]

Mrs. Dacyshyn: Corinne Dacyshyn, committee clerk.

Ms Sorensen: Rhonda Sorensen, communications co-ordinator for the Clerk's office.

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

The Chair: Has everybody got their packages?

Ms Blakeman: Which package?

Ms Armstrong: We brought copies, and we're going to be referring to this.

The Chair: Are you going to use the screen? I'll move off to the side then.

Ms Armstrong: No, no, don't. We're not intensely going to use it.

Mr. Phillips: This was copied at great expense. The package is just to follow along through the presentation.

I'd like to start off, Mr. Chairman and committee members and our audience, with just a little bit about the Consumers' Association of Canada, Alberta, or as we like to call ourselves these days, the Alberta Consumers' Association, and to give you some context of why we're here. The purpose of the organization is to protect and promote consumer rights to health, safety, information, and fair and honest dealing in public and private markets in order to improve the standard of living for families.

Basically, that means that we're apolitical. We take a consumer perspective. We look at the situation and we see, you know, what the situation out there tells us, and that's how we form our opinions. We want to ensure that markets work to the benefit of citizens and the community. We have a belief that the wise use of personal and community resources benefits all, and a strong consumer voice providing information and education limits the need for expensive regulation, limits harm, and promotes fair and efficient markets. We look at the consumer as the end user of a good or service in public or private markets, and this term is used to acknowledge the differing perspectives and interests in relation to suppliers.

Just a brief history. We're a nonpartisan consumer rights and advocacy organization. It was founded in 1947 from a coalition of community groups. The purpose is to unite, inform, and educate in order to enhance an effective functioning of markets and balance the influence of industry. It was incorporated as a society in Alberta in 1968, and it's an affiliate of the national organization.

Just to address the purpose: to monitor marketplace practices. We've done that in health care with Taking Stock, which looked at the impact of the cuts in health care in the early '90s, and Canary in the Mine Shaft, where we looked at the history of private clinics in Alberta and came to the conclusion that the quickest service and the highest standard of care was provided in the public realm. We also did, just recently, Eldercare – on the Auction Block. Those are mainly going right to talking to people and seeing what the impact of the health system and health policy is on the individual.

We want to provide reliable information, skills, and strategies, and to that end we worked with the Alberta Medical Association in developing partners in care, which really hasn't gotten implemented. Basically, we wanted to develop a way to help doctors and patients communicate and record that communication to aid compliance and other issues.

Also, we're here to represent the consumer interest. That's why we're here.

Ms Armstrong: Our plan, hopefully, is to provide you with some information for about 20 minutes and then allow you to ask questions.

Certainly, our organization has a tremendous amount of corporate history in looking at a whole number of issues around privacy of personal information in many different kinds of sectors from banking services to insurance to marketing to one of our favourite areas of focus, where we've been relatively ineffective over the years, and that's the Alberta registries, that I believe one of your committee members has a great deal of interest in as well. We have also been intimately involved in issues relating to health restructuring and to the management of health information for many years here in Alberta.

One of the enormous challenges, I guess I would start off with, that your committee faces is that the problem is that legislation does not stand alone, in isolation from policy or practice or from the larger social context in which these activities occur. Indeed, what is happening in the commercial sector in society has as much influence on the success or failure of legislation dealing with public-sector activity as anything that you may choose to do.

Shifting public policy priorities in health care in both the federal and provincial governments also will have a big impact on the kinds of recommendations that your committee will have to bring forward. Even the dramatic and more dramatic changes to our health care system that are anticipated to come will have a profound effect on the implications of the legislation and any recommendations that you have.

The issues that we would like to highlight today are not new issues. Being able to count on the confidentiality of information in the hands of trusted health professionals, timely access to one's own health records and information about medical opinions, and access to information about hospitals, health plans, doctors, products, and professionals have been recurring themes for decades. These attributes are generally viewed as essential to ensuring the safety of patients and the safety of communities given the unique nature of the need for medical care – that is why we're called patients, not just because we have to be really patient waiting in those waiting rooms – and the need to limit the potential for exploitation and harm.

Now, I have an overhead on consumer rights and health care up there. However, we've also included in your package a Consumer Rights in Health Care document, which was originally developed nationally in 1973 and reratified in 1989.

So the fundamental issues that we're dealing with here today are not new. What is new is the breathtaking amount of ground that has been lost in less than a decade on these issues, the broken implied promises to Albertans, and the negative impact current system practices and proposed HIA amendments will have in reducing medical error, unnecessary expense, or improving patient and community safety.

1:45

Albertans have repeatedly expressed their growing discomfort with the loss of confidentiality and privacy related to their personal information, problems with accessing their own medical records, and frustration, repeated frustration with the lack of information, the lack of public or patient information about the health care system and about health care providers. Yet these concerns are repeatedly ignored. We know this because we have been writing letters and attending consultations for over a decade on these issues.

The problem that we have is that current provisions and proposed amendments to the Health Information Act allow for no real confidentiality, little control over the distribution and use of one's information, fewer opportunities for knowledge and scrutiny of what is happening to one in the medical realm, and less access to information about providers and the health care system.

So if you'll just go through your package, our first page is the Consumer Rights in Health Care. The second page lists some of the activities and initiatives that our association has been involved in relating particularly to the impact of computerization and automation of business and government in a changing social, economic, and public policy environment, because this has been a profound factor behind the very issues that you are struggling with today.

Now, I think what's really important and what I'd like you to turn to now is what we're calling the Consumer Reality Check: What Albertans Say. Albertans have repeatedly expressed their growing discomfort over the loss of privacy and the lack of access to information about the system. Even the willingness of Albertans to support initiatives such as the pharmacy database or electronic health records repositories is predicated on their ability to control access to this information. It's very instructive, and I hope the office of the Information and Privacy Commissioner has provided your committee with the results of their surveys in 2000 and 2003. I think it's important to recognize how they described privacy in their survey. "For the purpose of this survey privacy is considered as control over the distribution and use of one's personal information."

Well, let's see what Albertans had to say about the distribution and use of their personal information. In the 2003 survey respondents overwhelmingly agreed that it is more important to protect individual privacy in Alberta, 98 per cent, up from 78 per cent in 2000. Nearly three-quarters were concerned that the privacy of personal information is at risk in Alberta, an increase from 56 per cent recorded in 2000. In response to questions about the importance of keeping information safe, the highest ratings were financial data, personal mail, and health records. It's also interesting to reflect that the registration data portion in the Health Information Act may include financial data.

Now, in response to the identified current concerns in the year 2000 the provincial government brought in an amendment to the Health Information Act. It actually removed existing minimal requirements for even one-time consent for personal information being placed in an electronic health record for access by other parties without notification or consent. The press release from Alberta Health read, "Health Information Amendment Act protects patient confidentiality while providing needed access."

Now, in July 2003 the office of the Information and Privacy Commissioner also did a survey specifically around the issue of electronic records, which has been really a very strong initiative here in Alberta. What they found was that many Albertans expressed strong or moderate support for electronic health records, but the exercise of individual consent of who can obtain access to an individual health record was considered extremely important to Albertans. Eighty-nine per cent said that it was very important, and 8 per cent said that it was moderately important. Only 3 per cent said that it wasn't important. I guess the question we would raise: is anyone listening to Albertans?

The next issue that we'd like to deal with is the issue of and the confounding problems that are created by the inclusion of provider information in the act and the further problem that the privacy of provider information, of the professional information of providers of care, is actually provided more confidentiality and more privacy protection than the most intimate details of citizens' lives. We find this completely unacceptable. I'm delighted to see that the Alberta Medical Association folks are here because we are not interested in access to this information for witch-hunting on individual doctors. What we are interested in is having access to important information so that we can monitor what's happening in the system, so that public planners can do the kind of research that can be done in Manitoba, so patients can have access to very important information to make decisions as well. Certainly, any kind of provisions with regard to the nature of provider information should be dealt with in other acts and, indeed, are under such things, I'm given to understand, as the Evidence Act.

Let me give you an example of the kinds of problems that including provider information in this act have caused. We have had, actually, a number of reports of individuals who have had delays accessing their own medical records or charts because the institution or the family physician is unable to provide them with the specialist's report because it would reveal information about the third-party provider. I think it is so totally inappropriate to put the needs of the privacy protection or control about the personal information of citizens in the same act as information about suppliers in any marketplace. It is just really remarkable. It also confounds over and over again what you can do. We don't believe that consumers have the right or even want the detailed personal information about individual providers in the system, but we do think they want and they have a right to information about their professional practices.

I've included in here – and I'm going to have to move along – a letter that we wrote to Minister Mar around the issue of the prescribing data as well, which we believe has served as a bit of a red herring to some of the issues that are being addressed today, so I'd like to present that.

The next thing that we'd like to bring to your attention – and we won't have time to go into a lot of detail with it, but we would encourage you to read it in detail – is a list of patient stories that we have collected over time. This is the input that we as board members and at the association get with regard to what's happening to the real people out there, and we totally concur with the information provided by the rabbi who spoke to you previously in that we have gone overboard. Indeed, it is remarkable that almost anyone can have access to one's information except the very people we all count on to support and provide us comfort and advocacy at times of greatest need. In fact, a quote from Val Steeves, who was a privacy expert from Ottawa, sums it up.

> Somehow we have managed to take away the family and community supports that people so desperately need at the time they are ill – by refusing to provide information. Yet this deeply personal information is readily shared with complete strangers for reasons that are not always in someone's [best] interest.

The stories that we have documented here include the problems and the hassles and the costs that people have encountered when trying to get information: their own information, information about families. It's too detailed to go into, but if you want to skim through them, I think that it would be very enlightening.

We strongly recommend that any charges for the costs of access to one's own personal information be removed. I'll get into that when I go over the final recommendations.

The next issue that I think is terribly important is to be really clear about what research is and isn't and whether or not research should be included in the wide expanse of sharing and disclosure of information in the Health Information Act as it currently stands. In fact, I would really encourage the committee to ask the Alberta Health staff to look up the reasons why the U.S., which allowed, actually, quite widespread sharing of information for specific payment and care and treatment purposes, in 2003 under public pressure prevented widespread sharing of information for research purposes, particularly commercial research purposes. As a consequence, what's happened is that the whole commercial drug industry has moved big time into Canada, and we're actually threatened to become the guinea pigs of the world.

1:55

Now, I think that while there is much good research that can and needs to be done, it's important to remember the words of Bruce Phillips, the former federal Privacy Commissioner.

> Without someone to speak for individual rights, the mantra of "public interest" or perhaps the mantra of "greater efficiency" will inevitably win the day. Allowing health bureaucrats and researchers to represent the patients' interests risks putting Colonel Sanders in charge of the chicken coop.

I would like you to look at the next sheet that you have in your package. So just what is Alberta Health registration information that everyone including the police want to be able to access without notification or authorization for an expanded number of purposes? Most of us here tend to think that Alberta Health information is really pretty benign. It's, you know, your name, your address, your telephone number, perhaps your last billing date. I've taken the liberty of pulling this information from the Health Information Act regulations, and I think it's important that you all consider in your deliberations just what information is included in the Alberta Health Act registration information.

The next piece in your package deals with the issue of what is the real and potential harm from diagnostic labelling used for other purposes than treatment. This refers to an upcoming book called the *Bias in Psychiatric Diagnosis,* where the author points out that

> the public has a right to know that when they go to a therapist, they are almost certain to be given a psychiatric diagnosis, no matter how mild or ordinary their problems [are]. It is unlikely that they will be told that a diagnosis will be written . . . in their chart and that alarming consequences can result solely from having any psychiatric diagnosis.

On this sheet we've also identified one of the real problems with any kind of networking of personal health information: it isn't just the diagnoses, which are really best guesstimates in the first place, which is why we've tended to keep them confidential, but you can have incorrect information in your file for a number of reasons. It can be incomplete. It can be due to provider fraud, sloppy data edit entry, unreliable tests, or simply hurried health professionals.

The next piece in your package is an article from 1996 from our bulletin called Smart Cards: Dumb Move, looking at the whole issue of health information.

The next piece is the piece I'd like you to focus on when you're thinking about where we really want to go from here as a society around the whole issue of information sharing. It's the Smart Card Case Study from the federal House of Commons Finestone committee, which does a wonderful job of teasing out what some of the risks and benefits are that most of us may not think of when we're looking at sort of the so-called benefits or limitations of these kinds of initiatives. It's very helpful.

The next piece in your package is an example of the kinds of authorizations that Canadians sign every day without even giving it a second thought.

> I hereby authorize "any licensed physician, medical practitioner, hospital, clinic or other medical or medically related facility, the Medical Information Bureau, personal information agent, detective or security agent, or insurance company, that has any medical records or medical knowledge of me or any of my dependents to give to [the insurer] any and all . . . medical information for the risk assessment or the investigation necessary for the study of any claim, or to determine eligibility for group and life insurance."

I am told by family physicians that while at one time they used to get an authorization or a request for check-offs for certain diseases in order to determine someone's eligibility for insurance or jobs, it is not unusual now to be asked for photocopies of the entire patient file.

The next piece in your package tries to answer the question: won't more sharing of information without having to get permission improve patient and public safety and reduce administrative costs to the benefit of all? We're here to say that introducing more technology and putting more information in the hands of more people without people's permission will not improve the safety, efficiency, and effectiveness of health care. In fact, current and proposed legislative changes and practices around integrated health information systems are really creating new, serious public health threats.

If people don't go and seek care because they're concerned with the impact that that information will have on them, they will not seek care, and they will not disclose that information, and important communicable diseases will not be caught and will not be picked up. In fact, a Canadian Medical Association survey from 1993 found that over 7 per cent of Canadians had already not sought help from a health care provider for fear of it influencing their employment or their insurability.

To this end, I believe there are a number of solutions that your committee could grapple with. In a wonderful book that I read over the summer entitled *The Human Factor*, written by Kim Vicente, a lot of the recommendations and a lot of the issues he addresses in this book deal specifically with what he calls the hidden epidemic of medical care and what's behind it and what we can do to solve these problems. I meant to bring a copy of the book, but I would suggest that it should be mandatory reading for perhaps every elected official in Alberta.

Next in your package, another question. We were here when Value Drug Mart presented and the question about: should Value Drug Mart and other retail pharmacies be allowed to use personal health information without – without – someone's permission for monitoring therapy adherence, prescription reminders, and wellness initiatives such as diabetes and cholesterol testing and education events? The answer from every consumer group not only in Canada but around the world is no, no, no.

According to Terence Young, a former Conservative MPP and marketing executive and current president of Drug Safety Canada, major pharma have been chomping at the bit to get their hands on patients' info to push compliance for years. Wellness initiatives, monitoring, and therapy adherence are all just cover-ups for direct mail and telemarketing. We would encourage you to give thoughtful consideration to this.

We've also included an article in your package relating to I guess what we would see as one of the major challenges facing our society these days, and that's how well-intended initiatives around prevention and wellness have really just become a marketing tool for big pharma and a hungry health care industry that not only threatens to break the bank but actually poses risks of harm to all of us. This is an article by Dr. David Sackett in the *Canadian Medical Association Journal* entitled the Arrogance of Preventive Medicine.

Finally, we have included some quotes that we pulled out a number of years ago to circulate around Alberta about some thoughts about medical records confidentiality and privacy.

So, in summary, I would identify what our minimal recommendations or suggestions for your committee would be. First, stop, look around, find out what's happening in other jurisdictions, and listen to the people of Alberta. Two, we would recommend that you do not expand the scope of this act to other bodies until major issues have been resolved. We would recommend at a minimum removing the provider information from the act or any provisions that prevent access to provider information for system planners, the public, and the patients. Three, we would recommend that you do away with all patient charges and remove barriers to patient and trusted friends' and families' access to information as described by the rabbi. I understand the Ontario legislation has some possible options that you can follow up on that.

More importantly, what we would recommend and what our greatest hope was back in 1990 when the first talk of bringing computerization into health care came up was that it did provide the perfect opportunity to redesign the system so that so much more information is automatically generated and provided at point of service, whether it's an emergency department, a pharmacy, a whole number of situations where that information could be provided to people. There are numerous examples around that. It shouldn't be a separate function. It should be part of the day-to-day work of the system.

Next we want you to . . .

The Chair: Ms Armstrong, we would like some time for questions.

2:05

Ms Armstrong: Sorry. Okay. I'll just quickly go through.

Introduce new restrictions on access to information without consent; look to Manitoba for ideas. Define and restrict definitions of personal information. We also would ask that you look at insisting on cost/risk/benefit evaluations.

We don't believe that the requests we're making are anything more than the cost of doing business, and it needs to be factored in. No one is suggesting that retailers do away with giving receipts, and we don't think that copies of contracts or our health information should be an extra charge as well.

Finally, we think it's really terribly important that the committee insist that the province act on its duty to disclose what is happening in health care today. One of the major problems that we have, if I can just finish off with this, is that, as was clearly shown on the survey by Albertans regarding their health information, they have a lot of anxiety about what's happening with their health information. One of the things that we've discovered in recent years in health care is that anxiety can have a tremendous impact on people's stress levels, and stress in turn can have a very negative impact on people's health.

As a matter of fact, this is an example of what constant stress can do to the system: one's hair stands up, pupils open wide, blood clots faster, lungs work harder, the heart beats faster, and more blood containing sugar and oxygen goes to muscles, heart, and lungs. Therefore, we would suggest that maintaining the confidentiality and privacy of people's personal health information and ensuring access to information so that they can make informed decisions are absolutely essential to the health of individuals in Alberta.

Thank you.

The Chair: Thank you, Mr. Phillips and Ms Armstrong. We have a little less than 15 minutes left for questions, and we're going to start off with Mr. Lukaszuk.

Mr. Lukaszuk: Mr. Chairman, I withdraw my questions.

The Chair: Okay.

Ms Blakeman: I have a couple of questions. In your response the CAC made comment on the implications of extending the scope – this is question 3 that was in the workbook – but didn't indicate what you wanted. Can you tell us what you wanted?

Ms Armstrong: We at this time do not propose expanding the scope of the act. The problem is that it's sort of like, you know, if I tell a secret in this room with 22 people in a confidential nature, the chances of it remaining confidential are far more significant than if I go to the Legislative Assembly and provide that same information and ask it to be kept in confidence. We don't believe that if you expand the circle of care – and we're particularly adamantly opposed to extending allowing information to be provided to insurers for payment purposes without permission as well.

Mr. Phillips: If I can add. One of the problems is that people aren't really sure who is going to be in that circle of care, and that's why we'd like to see this exercise sort of expanded and moved into the community. One of the things that needs to be done is to say: okay; if we add insurance payers to the circle of care, who actually ends up getting access to the information? So case studies need to be developed to follow through: okay; if this happens, who gets the information, and is this where we want the information to go?

Ms Blakeman: Okay. Thank you. Got it.

There was some short discussion about the inaccuracy or accuracy of collected health information. Do you have any statistical information that you can give me or in your personal experience any numbers at all to give me some kind of idea of an estimate of the rate of inaccuracy of collected information? You've referred to the billing codes that are used and that sometimes doctors may need to account for time and use a billing code, et cetera, et cetera, but where are we at here? Five per cent? Ten per cent? Fifty per cent? How much of that information? Give me something to work with here.

Ms Armstrong: Well, I guess the challenge would be that in order to do that, we would have to have access to our own records, and we would have to have access to providers' records, which makes it a challenge.

Ms Blakeman: Give me something here, or I'm going to assume that it's nothing.

Ms Armstrong: Well, I guess what I'm saying is that there have been numerous reports. Perhaps we can direct this to Alberta Health as well. In Ontario I testified in a court case related to someone whose physician had been sent to jail for fraudulent billing, and he discovered that in the billing records of OHIP not only had he been billed for visits that hadn't occurred, but the diagnosis for these visits included things like alcoholism, mental health problems, a brain tumour, a number of things. Now, when he applied to have these removed from OHIP, OHIP initially refused and gave him the option of putting a note of dispute on the chart. I guess my question would be: could Alberta Health provide us with an idea in their audits of physicians' billings of how many cases of, let's say, even outright fraud as opposed to confusion have been identified around the billing data of physicians compared to records?

Mr. Phillips: Also, when you go into a hospital, they take your information more than once. It's just standard practice. Everybody you see takes your health history.

Ms Armstrong: I guess the only other point that I would add: our experience in other industries, like in the credit reporting industry, banking industries, suggests that there are inaccuracies in at least 40 per cent of files.

Ms Blakeman: Thank you. That gives me somewhere to start.

The Chair: Ms Blakeman, do you want to direct that question to Alberta Health, or do you have any interest in that question?

Ms Blakeman: Yes, I do actually. Yes, I would like to direct it.

The Chair: When you get finished, then, we will allow them.

Ms Miller: We'd like some clarity on the question.

Ms Blakeman: I'm just wondering: since this act was brought in, how many charges of fraud or misbilling?

Ms Armstrong: Or not how many charges, but how many incidents – perhaps the AMA could even help us here – of identified wrong billing or fraudulent billing have been identified?

Ms Blakeman: Or however you account for this. There must be a system which you check, and if you're able to use that, don't invent a new system, but give us what you have.

Ms Miller: We'd have to investigate in terms of where there are perceived fraudulent claims. I don't know. We'd have to investigate.

The Chair: All right.

Did you have another question?

Ms Blakeman: I do, but if there are others, I'll go to the back of the list.

The Chair: Okay.

Mr. MacDonald.

Mr. MacDonald: Thank you, Mr. Chairman. I have an interpretation of this act, Bill 40, the Health Information Act, and we've discussed this in detail in the last two days. The health services provider information does not have the same or share the same characteristics as my personal health information. If we were to go ahead with medical savings accounts in this province – I hope we don't, but if we did – in light of this legislation what are the implications of that?

Mr. Lukaszuk: I object, Mr. Chairman. First of all, if the member could establish relevance. I'm not sure what expertise the witness would have to answer such a question, unless he's asking Alberta Health, and still, with relevance to the topic at hand, reviewing the Health Information Act, enlighten me what the relevance is.

The Chair: Mr. MacDonald.

Mr. MacDonald: Yes. Through the chair to the hon. member, in the last two days we have discussed in detail the health services provider information, which is certainly included in the Health Information Act under section 37, and we could use my own personal health information, which is discussed at length in this act.

Relevance. Of course this is relevant, and if this is not a time nor a place – we are to look into the future. The chairman this morning said that we have issues to deal with and we have issues to deal with into the future. One of them, unfortunately, possibly could be the medical savings accounts, and we need to know the answer to this question. This group has made reference to that, if you'd care to take the time to read it, in a letter dated September 29, 2003, to the hon. minister of health.

So, certainly, Mr. Chairman, I consider it to be relevant.

The Chair: I don't want to spend a lot of time here on relevance.

Mr. Phillips, do you or Ms Armstrong have any comment on this question?

2:15

Ms Armstrong: The only comment we would have – and I think it's a very important question, Mr. MacDonald – is that it was before the IMS issue around prescribing ever came to the attention of the public. Mr. Phillips and I had attended the debriefing for the Mazankowski committee report. In presenting a vision of the future where people would not have the services paid but be provided with dollars to go out and purchase the services themselves in an informed marketplace, being one of those options that was presented, we raised the question at the committee: how could we possibly make a decision about what would be our best value for the money without access to that information? Indeed, we had requested of the Privacy Commissioner an interpretation of section 37(2) before the IMS issue came up.

Mr. Lukaszuk: Well, Mr. Chairman, if we are to continue in that vein, the hon. member is asking the witnesses to speculate what the impact of any amendments to this act, which haven't yet been established, would be on a concept which isn't even government policy, nor is it the law, nor is it a practice in Alberta but is simply speculation. So speculate how a speculation would affect a speculative system. This is not productive time of the committee. Again, I must advise that I find this to be totally irrelevant to the topic at hand.

Mr. Phillips: I would suggest that the mandate be expanded to look at what the implications of the act exactly are. One of our problems with Mazankowski is that he didn't do an environmental scan. He came up with, you know, what should happen to the health system in Alberta. He didn't look to see what was happening here.

I think that what this committee needs to do is look at the implications and what's happening under the existing Health Information Act and then invite people to speculate, if you will, what they see the outcomes of changes to this act are going to be.

The Chair: We're down to the last two minutes of this presentation. Is there another question that someone would like to ask? I know Ms Blakeman would. Mr. Lougheed, do you have a question?

Mr. MacDonald: A point of order, please, Mr. Chairman. A point of information I think would be more appropriate. On the revised agenda that has been circulated, this presentation is to end at 2:25.

The Chair: We started early, Mr. MacDonald. The other one ended sooner.

Mr. MacDonald: Oh, okay.

Mr. Lougheed: Your presentation, to my mind, has certainly touched on a lot of things. One of your initial comments was that the people that should know don't get a chance to know, and you alluded to the rabbi's presentation. Then you said that other people get to know and they shouldn't know.

I'm having trouble understanding what things in your minds would fall into those categories. Just as an example, people may choose not to have family know that they are in the hospital, and somehow you've sort of implied in some of your examples in your handout here that that information should be freely available. What you're saying seems to me to be contradictory.

Ms Armstrong: If I could suggest, the patients' stories that we have included in your handout I think will elucidate what our concerns and our issues are. Again, it's sort of the issue of: where is the exception to the rule? The statement that I'd made was with regard to the fact that it seems like everybody can have access to this information for a whole number of purposes, including legal counsel or the Canadian Medical Protective Association, but someone's family member who's there at their side advocating on their behalf and being asked to make decisions about their treatment on their behalf often can't have that information. Those quotes do not come from me. They come from other people who've expressed that to me because of a particular incident that they've encountered in care. Many of those stories are detailed in here, and I think they're very helpful. They helped me understand what some of the issues were.

The Chair: Thank you.

As a committee we have allocated an amount of time to this portion. We have the next group ready to go, but I'm going to allow one more question before we adjourn this part. Dr. Pannu, you've had your hand up for quite a while, so we will allow you your question, but we ask for brevity.

Dr. Pannu: Thank you, Mr. Chairman. I'll try. I want to thank Mr. Phillips and Ms Armstrong for their very good presentation. I think you raised some important issues for our serious consideration.

This morning we spent some time thinking about expanding the scope to include perhaps insurance companies. At the moment, of course, the bill applies only to public institutions. Private institutions are covered under different legislation. But insurance companies have in their possession, as you suggested yourself, lots of information concerning our health records, rather comprehensive information. Do you have any position on how to protect individual health information privacy once it gets into the hands of insurance companies?

Ms Armstrong: That's very difficult. A number of us here in Canada struggled very hard to bring in PIPEDA, the federal act around this, precisely over these kinds of issues. That would be a long answer, so I'd be pleased to discuss that with you after the committee.

I think the other important thing that we would ask the committee to consider: when you're looking at any expanding of the scope of the act, what is probably most disconcerting to our association and probably to the people in Alberta is the number of exceptions to disclosure or use of information without your permission. In fact, what we would encourage you to do is to not expand any more uses without permission and try and claw back the permission requirements where you can.

The Chair: Yes, Ms Blakeman. Could we ask you for real brevity?

Ms Blakeman: Yes, you can. You appear to be contradicting yourself, and I need you to clarify this. You've given us the registration information, how much it is, but you're on record now as saying that you agree with what the rabbi was asking for. Now, that's a situation where there is a by-consent list, self-identifying as being with a particular religious faith community. He was asking for access to additional without-consent information in order to be able to identify other members of his community using last names. You said in other examples that you don't want more without-consent information out there, but you appear to agree with what the rabbi was saying. Please get this one on the record clearly.

Ms Armstrong: I think you have to look at the purpose that information is being shared for and the ability of the people or the intent of the people using that kind of information. So it's the purpose of that information and how far it will go beyond that that determines which choice you will make. In fact, what we suggest is that on these issues that you're struggling with, one of the big problems that everyone is having is that no one really knows or understands what's going on or what's happening, whether it's with their banking or with their health care. We would strongly advise you to urge this government to consult Albertans in a much more extensive process and ask Albertans that question.

The Chair: Mr. Phillips and Ms Armstrong, thank you very much for your presentation. On behalf of the committee I extend our sincere thanks to you for appearing today. The comments that have been made today will be available in *Hansard* in a few days, so you're certainly welcome to those. Again, thank you very much for coming and making an interesting presentation.

Mr. Phillips: Thanks for the opportunity.

The Chair: Committee, we will adjourn until 25 minutes to 3 while the next group sets up.

[The committee adjourned from 2:24 p.m. to 2:32 p.m.]

The Chair: I will call the committee back to order just a little bit early. It seems like everybody is here and ready to go, so let's get started.

I'm very pleased to welcome the Alberta Medical Association here today. We are pleased to have Dr. Jane Ballantine, Dr. Brendan Bunting, Mr. Jon Rossall, Mr. Ronald Kustra, and Ms Shannon Rupnarain.

Before we proceed with your presentation, I will ask the members of the committee to please identify themselves for the record and for your benefit.

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

Mrs. Dacyshyn: Corinne Dacyshyn, committee clerk.

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

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

The Chair: Thank you. We will allow you to proceed. We would only ask that you save us some time for questions, because I think there will be many questions.

Thank you very much, and please proceed.

Dr. Ballantine: Thank you very much. First of all, I'd like to ask for your indulgence as I became president of the Alberta Medical Association on Saturday. So thank you for allowing me to bring my learned colleagues with me to present to you.

It's a privilege to be here, and good afternoon. I really thank you for this opportunity to meet with you today. I'm very pleased to discuss the Health Information Act, because it's a huge issue for us as physicians and for our patients.

The mission of the Alberta Medical Association is to stand as an advocate for our physician members, providing leadership and support for their role in the provision of quality health care. We represent over 7,700 physicians, students, and medical residents. They look to us for leadership on issues of health privacy and health information. So when the Health Information Act became law in 2001, our board of directors agreed that we had a responsibility to our members to help them deal with the Health Information Act by providing education and tools. We invested substantially in creating manuals, tools, and templates. We also printed numerous articles in our publications and provided individual support.

This year we welcome the opening of this legislative review. As we prepared our submission, we revisited what we had said in the past and the concerns we raised at that time. We looked at everything our members have told us since 2001. We talked to the board, we talked to our 105 physicians who make up the representative forum, which is the governing body of the Alberta Medical Association, and who represent every practice type and geographic area. This process confirmed that what we have said in the past about the Health Information Act is still relevant, and it also pointed out some positive developments that have arisen from the Health Information Act.

Physicians are much more aware of their legislated requirements for privacy of health information than they were three years ago. They have more structure around their policies and procedures and have filled in gaps in those policies and procedures. These are all good things.

There are, though, some provisions of the Health Information Act that continue to trouble us. In our submission we made 32 specific recommendations. I'm sure you're all happy to know that I'm not going to go through all of them, but I'd like to talk to you about the fundamental issues that lie behind them. Then with the help of my learned team here I will take any questions that you may have.

I'll start with the big one in terms of our issues. The AMA is very, very concerned that in nondirect care situations the Health Information Act fails to sufficiently protect the confidentiality of patient personal health information. When it comes to direct care, where health care providers use health information to provide care and treatment the patients need, the Health Information Act has created a reasonable balance of privacy and information flow. What the Health Information Act lacks is a fundamental commitment that in nondirect care situations protecting patient privacy should be more important than sharing information.

You know, patients expect that their physicians and other providers will share their health information in order to provide the best possible care. Patients don't expect, though, that their information can be shared without consent for all of the nondirect care purposes authorized by the act. That's where the problem lies. Patients talk to us, to their physicians, with the expectation that what we've discussed with them will remain entirely between us. Because they trust us, they tell us everything that we need to know in order to properly diagnose and treat them, and because of that, we want to maintain that level of trust and ability for patients to tell us the things we need to know as well.

Now, if a patient doesn't believe that I'm able to protect the information that my patient shares with me, if my patient is afraid that it will end up somewhere else and be used for things not related to my patient's care and treatment, my patient is not likely to be completely open with me. My patient is going to withhold or alter information, and when I make a medical decision based on that incomplete or inaccurate information, my patient is not going to receive the best care.

The Alberta Medical Association believes that before it does anything, the Health Information Act should establish patient privacy as the most important consideration. Patient privacy should be regarded as more important than sharing information for nondirect care purposes. We've suggested that this might occur by moving sections 57 and 58, what has been termed the prime directive of the HIA, to a preamble of the HIA. This way, at the outset it will be clear that in all situations health information must be handled with the least amount of information and the highest degree of anonymity. The Alberta Medical Association believes in putting patients first. By making this change, the Health Information Act would begin with the idea that patient privacy comes first, because if it doesn't, quality care will suffer.

In the same area of protecting privacy and confidentiality for the purposes of collecting, using, and disclosing health information, section 27 allows government or regional health authorities and others to use individually identifying health information to manage the health care system or develop public policy. In our opinion, it's both unnecessary and inappropriate to use identifying information for those purposes. We have never heard a convincing reason for doing so. But if that is going to occur, if identifying information is going be used for any nondirect care purposes, then we strongly believe that express written consent must be gathered first.

I can't emphasize enough that if patients can't trust our ability to safeguard their health information and maintain their right to say when, how, and by whom it is used, they will not share information completely, and the care they receive will suffer.

2:40

However, there are some groups who need to use individually identifying information without consent because they perform important functions in the health care system. Health regulatory bodies like the College of Physicians and Surgeons of Alberta need to use identifying information to protect the public and regulate the profession; the Canadian Medical Protective Association, that supports physicians in medical legal matters; third-party carriers like insurance carriers for drug plans, for purposes of paying for health services provided to the patient.

I'll note that this last exemption is intended to allow payment to flow for drugs and services provided to patients. It should not apply to other commercial purposes, and I'd like to thank and commend the office of the Information and Privacy Commissioner for his perspectives on this issue.

I'll move on now to the issue of the Health Information Act scope. I know that this is a major part of your discussions. The Alberta Medical Association supports expanding the scope of the Health Information Act to cover all public organizations and all private companies, large or small, that collect, use, or disclose health information. That would include health information in employee files, ambulance operators, WCB, Blue Cross, and health service provider information.

By ensuring that all health information collected, used, or disclosed in this province is subject to the Health Information Act, you've created a level playing field instead of a legislative minefield. Currently doctors are subject to four different pieces of privacy legislation depending on who the patient is, where the care is delivered, or who the payer is. I personally don't treat my patients in a piecemeal fashion. Why should their health information be any different?

A third issue we'd like to bring to your attention is the area of access rules. Specifically, clarity is needed around section 104, which allows individuals who can't act on their own behalf to receive appropriate representation under the Health Information Act from guardians, advocates, and others. This section of the Health Information Act is being abused by some members of the legal community. Before the Health Information Act, fees for providing medical records to lawyers were uninsured services, and general guidelines for billing them were negotiated between the Alberta Medical Association and the Law Society of Alberta. These fees recognized the time and expertise of physicians required to assist with judicial inquiries. However, since the Health Information Act, lawyers have said that acting as authorized representatives entitles them to pay only the $25 basic fee under the Health Information Act regulations when receiving a copy of a medical record.

Lawyers do not need section 104 authorization in order to get the health information they need for judicial purposes. We physicians are compelled to provide it. So if section 104 is not needed to access the patient's information, then using it is nothing more than an attempt to gain at a very low price a valuable service that lawyers had previously been willing to pay for appropriately.

Along that topic I'd like to talk about regulated fees. Fees that patients pay for access and providing records should not be prohibitively high, and we fully support that patients have the right to their own information. But fees should sufficiently compensate physicians and our staff for our time and effort to assist the patient with the access request.

You can read in the regulations a list of items for which I can charge a maximum of $25 as a basic fee: everything from clarifying the request to obtaining necessary consent to shipping the information. Yet in Alberta many professional fees set by the government are much higher. As I'm sure you all know, it costs $61 to register your car. A $25 fee to handle and process delicate health information and produce a copy of a record is too low in today's environment.

We also have a concern regarding the powers of the Privacy Commissioner. Today an individual or organization that inappropriately uses health information may continue indefinitely with that activity while the matter winds through the courts. For example, when the commissioner ruled that Alberta pharmacists and pharmacies have been inappropriately disclosing physician prescribing data to IMS Health, Canada, the commissioner was unable to halt the activity once IMS launched an appeal. As you all know, appeals like that can take years. Meanwhile, the prescribing data continues to flow, and this is happening against express wishes of Alberta physicians who've even committed it in writing to IMS and requested that they stop. The Health Information Act should be strengthened for situations like this, so the commissioner has the authority to stop such behaviour unless the offender can prove that there is reason otherwise.

The last area I'd like to discuss today is the concept of the Health Information Act and the electronic health record. Developing an electronic health record is a major reason to revisit the Health Information Act. Physicians are excited about the potential of the electronic health record. It will improve care, it will enhance efficiency, and it will improve the health care system.

We also have some serious concerns about the electronic health record, because for all of its benefits it threatens to remove our ability to know or control when others use or disclose our patients' health information. In Alberta's electronic health record that is used across the province, that capability has been lost. So the Health Information Act is critically important as the electronic health record is developed. If the Health Information Act does not sufficiently protect patient information, then the electronic health record will not be built with the same precautions.

For the most part I've already discussed the Health Information Act provisions we emphasize with respect to the EHR. They relate primarily to the patient's right to know who uses his information, when, and for what purposes, particularly for nondirect care purposes. With this right the patient then has knowledge to make an informed decision to consent to or revoke consent for the use of his health information when it isn't about providing the care and treatment he needs. That ability and that confidence is what always allowed the doctor/patient relationship to exist and for information to be exchanged in trust so that quality care can be delivered. That is the only reason that health information may always be used with perfect justification. For any other uses you must allow the patient to exercise his right of consent to control any other use of his information.

With that, I'll conclude for today. I thank you for your time and your consideration, and I wish you all good luck with a big job ahead of you, and the Alberta Medical Association looks forward to working further with you.

Thank you.

The Chair: Thank you very much, Dr. Ballantine. May I just, on behalf of the committee, also congratulate you on your newly elected position and wish you the very best in that important assignment.

We will now open for questions, and I'll call on Mr. Lukaszuk for the first question. Then I'll move back to my chair so that I can see the committee's hands better.

Mr. Lukaszuk: Thank you, Mr. Chairman. What a way to start a new job; right?

I have a few questions for you, and I'll quickly ask them, and maybe you can answer them.

In slide 8 of your presentation you put a bit of a logistic equation saying: patients' trust in physicians' stewardship equals good quality of care; patients' mistrust equals poor care. Now, if I put myself in the position of a patient, in order for me to trust you as a physician, I have to have some information on which I will base my trust. Otherwise, it's not trust. It's faith if it's not qualified and if it's not predicated on factual information.

Now, you also argue that section 37 properly protects care provider information and that that information should not be issued to me as a patient or any other body because physicians ought to be protected from companies like IMS or others. I see a bit of a conflict here because if I am to trust you, I need to know about you. As a patient I want to know what your prescribing patterns are. I want to know what your record relevant to infectious and other incidents may be in order for me to trust you as a physician and particularly if you're referring me further on to other physicians. That's something that as an informed consumer I would want to know. So how do we balance this protection of a physician and my trust being informed and not simply relying on faith?

2:50

A second question would be that you made a reference relevant to lawyers circumventing the contractual fee agreement, and I think you're the second person to bring that up. I heard that somewhere in this committee before. But I'm wondering: if that standard is to be then applied, is there any room, in your opinion, for a counterbalance? I know that physicians routinely charge what I would imagine to be high fees, ranging from $50 to several thousand dollars, for medical/legal reports, IME reports. Many of them can be boilerplate reports: the body of the report doesn't change; specific information does. So if we are to scrutinize the fees that lawyers do or don't pay for personal information of their clients, how do we then justify the fees that physicians and particularly specialists charge for medical/legal IMEs, which also is sharing diagnostic and treatment information at a level significantly higher?

Dr. Ballantine: All right. I hope to have gotten most of them, but first of all I heard an issue between trust and faith. The issue was building a relationship.

I would encourage my patients to be informed consumers. However, when they bring me the article off the Internet, I'll remind them that it's not peer reviewed, I'll remind them what that means, and I wouldn't expect them to be able to take information and compare it to standards or the current literature on infectious diseases to know what my infectious disease practice was like compared to that of another physician. Nor would I expect my patients to know that my practice focuses primarily on diabetic individuals and, therefore, be able to factor that in.

So I think that in some ways the information that you're saying might be helpful can't be fairly viewed. It's not for me to say that I could give you advice on consumer advocacy; I can only advocate on the behalf of patients. So in terms of the trust I would say that it's something that you build over time, that you build in terms of how well you have provided for your patients. If so, maybe what you want is a testimonial collection of information about physicians. Because I'm not sure that prescribing habit gets at the information you truly want.

Mr. Lukaszuk: By saying that . . .

The Chair: Briefly, Thomas. We do have others.

Mr. Lukaszuk: On that first question – I hope you get to the second one – by saying that, you're undermining my ability to take empirical data and make an informed decision based on it. Perhaps not everyone can, but if you have a practice that specializes or focuses on treating diabetes and I happen to develop that medical condition and some physician refers me to you, I as an informed patient want to know what medications you routinely prescribe and other aspects of your practice before I put my health in your hands. That's what I call trust versus faith.

Dr. Ballantine: Okay.

Dr. Bunting: Could I answer that, please? There is no present repository of information like that, and I would suggest that if you had questions like that for a doctor that you wish to consult, you would ask that doctor before you entered into a relationship like that.

Information presented in a very abstract way can be confusing, and I'll just give you one quick example. Let us say that you consulted my prescribing information and you saw that I prescribed massive amounts of antidepressant medication. You might think that that was a bad thing, but if I were then to come back and tell you that in fact 80 per cent of my patients were depressed, it would make a difference to how that information was viewed.

So abstract information can be confusing, and I think that the best way to establish, you know, a relationship with a doctor that eventually will end up in a trust-based relationship would be to talk to the individual doctor about what practices you might expect in your ensuing relationship.

The Chair: Is there a second answer to that, Dr. Ballantine?

Dr. Ballantine: The second question, I understood, was about lawyers and the fees, but you expanded it to medical, legal, and otherwise, so I need to preface this by the fact that I'm a primary care physician, so I can't speak at all to specialists' fees and don't know. But usually fees are based on a fee guide that is created by the Alberta Medical Association as a guide in relation to what the physician would make during the time that they spend doing that, an expected amount of time that's been committed to it.

I can't give you an example, because it's often based on an hourly rate based on how long it takes me to read the chart, go through the requests from the lawyer, read through the questions or additional information, all of the previous insurance forms filled out, and then write an appropriate medical/legal report that involves an opinion as well as chronicling all of the times I've seen the patient. That becomes an hourly thing that's justifiable based on how much time you spent.

Mr. Kustra: The other thing I would add to that is if a legal counsel feels that the fee from a physician is out of line, that's certainly appealable. There's a joint mediation process or arbitration process set up to deal with that. Remember as well here that the legal counsel is paying not just for the information but for the professional opinion, and I'm not sure what a professional opinion is worth. Your comment about boilerplates probably has some resonance with a lot of people.

The Chair: Okay.

Let's move to the next question. Ms Blakeman.

Ms Blakeman: Thank you. In reviewing the AMA's original comments on this bill when it was being debated in the Legislature and comparing it to the comments that you're bringing forward now, in both cases you express concerns about section 35(1), which is identifying the other bodies where information can be disclosed without consent of the individual. That again appears, but in addition I'm wondering if you still hold concerns over section 39(1), which is allowing the minister or the department to disclose such information "without the consent of the individual . . . to another Minister of the Government of Alberta for the purpose of developing public policy."

In other words, individually the minister of health is able to have identifiable health information and pass it to others: cabinet colleagues or other departments. You expressed reservations about that before. Do you still have those reservations?

Dr. Ballantine: I would say that we do in the sense of the necessity of the identifiable part of the information being necessary to make policy or other decisions. I have yet to see justification for why that's necessary.

As to the exactness of it compared to what we said before, I would need to ask some of my colleagues who have been involved in the process.

Mr. Kustra: The general principle continues to apply, and we were very concerned, as you've rightly identified, Ms Blakeman, in the year 2000, I guess.

Ms Blakeman: Okay. Thank you.

Dr. Pannu: Dr. Ballantine, both in the brief and in your oral presentation you have suggested that there be included in the preamble to the existing piece of legislation two principles: least amount of information and highest anonymity. Is this suggestion predicated on your concern that the current legislation doesn't do so, that it in fact doesn't follow those principles? If that is the case, then starting from those premises, those two basic principles, what changes throughout the act would you think would need to be made to embody those principles in the act?

Dr. Ballantine: All right. Well, first of all, I'd just like to point out in the submission you spoke to earlier of November of 2000, Ms Blakeman, that we talked about consent as being something that we were concerned about. If I may read verbatim from there.

> Consent is the corner stone of access to health information. It is the protection afforded to individuals who disclose confidential information to their caregivers and represents the sole control the patients maintain over information, which they own. It is critical that express consent [should] be required whenever confidential health information is going to be disclosed to a Third Party.

An additional paragraph under consent on page 4 in the 2001 submission:

> In the view of the [Alberta Medical Association] the requirements for consent in the Act are insufficient, and the opportunities to disclose confidential health information without consent too numerous, especially where the recipient is government, or the Minister himself. It is not enough to point to the sections requiring the least disclosure necessary under the circumstances; the very fact that there is discretion in the hands of the Custodian underlines the lack of protection to the patient.

I mean in that that the custodian who has no relationship with the patient now gets to make the decision. The irony in this is that those are words from our submission in 2000, and we're even more adamant now.

3:00

Ms Blakeman: Thank you.

The Chair: Well, I will have a question, then, if there are no others. I noticed in your recommendation, Dr. Ballantine, that you have recommended expanding the scope to include several other players. Could you comment specifically on why you've recommended improving the scope to WCB and Blue Cross?

Dr. Ballantine: Certainly. Currently in my office I have to take time out of seeing patients to sit down and go through a chart to determine what rightfully gets released to whom based on where the original information was collected. Even though the patient says you can release it, if it's WCB, it can't be released in a legal request.

Going back to an earlier question, it does take time and it's a responsibility that I can only delegate if the rules are clear and obvious. Right now there are four different sets of legislation that I have trouble getting straight, so it's unfair of me to request that my staff know the difference and on my behalf execute it. So the whole idea would be to create an arena in which the simplest or clearest possible dictum prevails, and it prevails to all health information under any circumstances. I think that would be the cleanest, and that's the reason for suggesting it be expanded.

Mr. MacDonald: Could you tell me, please, how many members of the Alberta Medical Association have signed up to the electronic version of the management data system for health information?

The Chair: Mr. MacDonald, we just need you a little closer to the microphone. I'm sorry.

Mr. MacDonald: Okay. To date how many doctors in this province have access to the electronic database that Alberta Health is currently implementing?

Dr. Bunting: We don't have that information. It's important for members of the committee to understand that there are two types of electronic information. There is one that is called the electronic medical record, and that is doctors' records that are computerized within their offices, and almost 2,000 doctors in the province have signed up to that type of arrangement.

Now, your question, I believe, was about how many have signed up to the electronic health record, and that is where information is shared with hospitals, with pharmacists, et cetera. That is not available all over the province as yet. For example, in my region in central Alberta I cannot do that even if I want to do that because it's just not quite been rolled out yet. It's in the pipeline, but it hasn't happened yet. It also requires investment of money and an update of my equipment and software and so forth to do so. So doctors are looking at this critically, but I'm not sure just how many have signed on yet.

Mr. Kustra: Just to add to what Dr. Bunting said, I think it's important to remember that when you look at what's happening with the electronic health care system, Alberta is so far ahead of the other provinces. It's wonderful. When we get together with our colleagues from other provinces and that, they're just amazed at the steps that have been taken in both computerizing doctors' offices and moving ahead with the health regions. It's just tremendous.

Dr. Pannu: Dr. Ballantine, you talked about the EHR leading to undermining if not removing physician control over patient information. It's clearly a concern. On the other hand, the medical profession in general is quite excited about the EHR. So your concerns are rather specific, not just about the overall transformation. What are they?

Dr. Ballantine: My office was personally exceedingly very excited about the electronic medical record. We are now six months into it, and we're wondering if we can keep going. But we know that there's light at the end of the tunnel. The initial changeover is quite an investment of time and energy on all of the staff and the physicians.

Overall, I have no doubt that when I get a phone call at night when I'm on call, I can sit at the computer and call up my patient's record and know what other drugs they're on without asking them, know what I can prescribe if I need to. Light-years ahead. So I can definitely speak to why the profession as a whole understands the benefit of having that information accessible when you need it to provide the quality of care that the patient deserves at the time, right then and there, is imperative, and it's going to improve the quality of care.

The concern physicians have is that as the person who may have been the initial custodian who in fact collected the information, I have no ability currently, if we were to hook up, to know where that information went, who accessed it, or whether it was accessed appropriately. That's the fear physicians have.

Dr. Pannu: On the very last point that you made, is that likely to erode the trust relationship between you as a physician and your patients? That's one of the major concerns that you expressed at the very beginning of your presentation. The point is: what's the negative impact of physicians losing control over health information regarding their patients, what it does to the relationship?

Dr. Ballantine: The greatest impact I think it will have will be in terms of a discussion with the patient. If an educated, informed patient knows or asks me, "Can I protect this information?" I have to say no. If they understand that from their own viewpoint of what's happening in the system, they will not tell me everything. They may not answer a question entirely honestly. I may not know their whole past history in terms of either sexually transmitted diseases, psychiatric diagnoses, some other things that might be very, very relevant.

I put it out maybe in an individual sense, that I often wonder: if I have an individual who might happen to be in the public eye whose information is safe with me but their Viagra prescription is now public, a record that anybody else can access, I would consider that they might be quite concerned about that, and it might lead to substandard care and me as a physician not knowing because they might go somewhere else thinking that it wouldn't be in the same place.

The Chair: Mr. Lukaszuk, you have an additional question?

Mr. Lukaszuk: I do. As the technology improves to the point where we now are at a frontier where health care providers can or will soon be able to share this information, would you imagine – and I'm asking you I guess to speculate in an area where your expertise may not lie. I imagine also that the technological advances in preventative measures for the leaking of information and hacking into computer systems will probably improve at an equal rate if not greater rate. Do you find that we are simply speculating at this point that there may be a deterioration of the relationship between a doctor and a patient assuming that the improvement in security doesn't occur?

Second of all, is it also reasonable to conclude that perhaps those patients soon will not need to disclose that information to you about their Viagra prescription? You will have that on your electronic health record, so you need not ask him any more. It'll be there.

Dr. Bunting: I think one of the things that patients have really enjoyed in their relationship with their doctors over the years is the ability to know that the information they share with their doctor is not going to be shared with anybody else without their consent. If we talk about electronic methods of collecting information or keeping records, it should really be no different than how it's always behaved. We certainly see that there is potential for change when you introduce the electronic environment.

It's quite interesting. I've had computers sitting on my desk for several years now, and I would say that 95 per cent of the patients think that it's already shared with everybody all over the place anyway. It's my job as a doctor to try and, you know, troubleshoot and see what's coming in the future and to try and protect the relationship and the privacy of information that we have always enjoyed with our patients. So we're in a privileged position.

We also have an opportunity to work with others. You know, Mr. MacDonald talked about how many doctors have signed on to this new system. Well, I think some are just sitting in the bushes waiting to see exactly how it's going to work. I think we're very enthusiastic about the whole project, but we do not want to undermine the type of relationship and the trust that we have with our patients.

3:10

The Chair: Thank you.

Dr. Ballantine, having no other speakers and a couple of minutes left, I will ask a question that I'm surprised hasn't been asked, and that's to do with police access to medical records. We've had considerable debate here around that one, and I think I know what has been officially said by the AMA. It's going to be a controversial discussion, so perhaps you or one of your colleagues would like to just comment on your position on that and why you take that position.

Dr. Ballantine: I would reiterate that for care purposes I think information should be shared. For the purposes of noncare it should be discretionary, honouring the patients' rights first. That's all I can say.

The Chair: Mr. Lukaszuk, I knew that would do it.

Mr. Lukaszuk: But why? We had various police departments here, Calgary, Edmonton, telling us that for the benefit of society, giving us an example of an individual showing up in a local emergency room with a bullet wound and just 15 minutes ago there was a shootout, gang related – why would simply registration information, not diagnostic and not treatment but registration information, not be released?

Dr. Ballantine: I believe my answer was discretionary: trying to honour the patients' rights. There may be points in time when the doctor uses their own discretion to release information, but the doctor still maintains the patient's health, in particular health's best interest, as their primary concern.

The Chair: On this point, Ms Blakeman.

Ms Blakeman: Thank you. This is a two-parter, and it's following up on this whole question. What we have is a situation where police can already get that information. If it's life-threatening circumstances, they definitely get the information supported by law in all of these examples. If they're in hot pursuit, they definitely get the information. If it's information under child welfare and a child is at risk or if it's the Protection for Persons in Care Act, they definitely get the information.

So it's not life threatening. We're not in a big hurry here. The registration information covers some 19 different categories of information. What I'm wondering is: is the AMA supportive of seeing legislation that more directly deals with the issue? The issue at hand seems to be: if we have someone presenting with gunshots, knife wounds, or severe beatings – and that seems pretty apparent; there's has been a crime committed – at this point health professionals are precluded from identifying their very suspicious circumstances to the police. Would you find it helpful if there was specific legislation that dealt with and required that health professionals report to police in evidence of those three circumstances rather than changing this legislation to release information in non life-threatening situations as I've described?

Dr. Bunting: You know, I've worked in an emergency department in Alberta for almost 30 years, and I consider myself to be on the same team as the police officer, in fact very much so. In former days there was a legislative requirement that you had to report certain specified items, and gunshot and knife wounds were part of it. The laws have changed, and it is confusing. At the same time, what happens is that the authorities and other parties actually approach the hospital or the regional health authority for access to the records. Generally speaking, the individual doctor is kept out of the loop.

Now, in terms of, if I see a gunshot wound, should I phone up the police officer and say, "There's a suspicious circumstance," I'm really not sure what the proper answer in a legal way is. I know what I do do. Generally speaking, you know, I ask the patient: do you wish to speak to the police about this? That's something where some of them say yes and some of them say no. But it is very difficult in the present milieu to know what to do, and any clarity that you people can come up with will help us immensely.

Dr. Ballantine: Just a further answer, if I may. At a recent board meeting where we discussed exactly this issue with 13 board members around the table, we had both ends of the argument argued quite nicely. I wish we could say that we could help.

The Chair: Dr. Ballantine, thank you very much to you and your colleagues for a very interesting presentation. Thank you for taking the time to come and present to us today and for giving us the information and answering the questions. Certainly we recognize that the committee has an interesting challenge in front of it, but thank you for your help and your support.

Dr. Ballantine: All right. If we can be of any help, please let us know.

The Chair: We are going to proceed here. You're certainly welcome to stay and watch the rest of the proceedings or leave, whichever you prefer.

Dr. Ballantine: Okay. Thank you.

The Chair: I'm going to ask the committee to stay in place, because it seems like if I let them go, it's hard to get them back. We are going to go on with the agenda.

Wendy, would you like to finish up the analysis that we started this morning?

Ms Robillard: Certainly. I believe we left off at question 26, which is, "Should the HIA be amended to include stronger provisions to protect the confidentiality of genetic information?"

We had 13 organizations and one individual respond. Five organizations were against including stronger provisions to protect genetic information as they felt that this information is no more or less confidential than health information generally.

One organization has no position at this time, and one individual and seven other organizations recommended amending the act to address genetic information as follows.

- prohibit disclosure of genetic information without individual consent . . .
- amend definition of diagnostic treatment and care information to include genetic information . . .
- amend definition of personal health information to include genetic information . . .
- define genetic information.

The Chair: Comments? Questions?

Okay. Question 27.

Ms Robillard: Question 27 is on an informed/knowledgeable implied consent model, and that's being deferred to the next meeting.

Ms Swanson: Question 28 is: "Are the research provisions in the Act reasonable, effective and operationally effective? If not, why not? Please provide your suggestions for improvement."

Seventeen of the submissions commented on the research provisions, including one individual and 16 organizations. The RHAs were generally satisfied with the research provisions, though one acknowledged potential burdens for researchers and custodians.

There was relatively little overlap of suggestions for change, but a significant portion dealt with the research ethics committees. The suggestions: include mental health, aboriginal, and other special populations in their composition and professional development; reinforce standard approach to disclosure in ethics board review and establish means to resolve disputes between ethics boards when they're reviewing the same proposal; change terminology from "research ethics committee" to the more standard "research ethics board;" explicitly authorize the OIPC to publish ethics committee research approvals on a web site; delete ethics committee responsibility to assess safeguards for health information; increase size and number of committees but not their scope.

Four of the submissions dealt with the matter of consent for disclosure of individually identifying information. Two were from university submissions and dealt with the need for surrogates to be able to consent to release of information for research.

Another suggestion was to enable custodians to authorize researchers to contact individuals directly for research in exceptional circumstances.

3:20

Another suggestion was to allow custodians to obtain consent in advance for disclosure for all research purposes and, finally, to explicitly exclude investigations for purposes of program evaluation, quality improvement, or quality assurance from the requirements for ethics review and other research provisions.

The Alberta Cancer Board made a number of other additional suggestions including identifying the researcher as having custodian-type obligations in regard to safeguarding health information and including the responsibility to manage students who are research assistants as "affiliates" to the researcher. They also suggested clarifying the difference between consent for disclosure and consent to participate in research.

They suggested allowing de-identified data to be retained for additional research, clarifying whether research disclosures to another custodian require an agreement, and clarifying whether research projects requiring data matching require a PIA.

The Health Quality Council recommended its mandate be reflected in the scope and purposes of the act. CIHI suggested legislation be transparent about the role of agencies like CIHI as bodies designated to collect and analyze health information for purposes of health system management and research and also to be clear about the authority enabling disclosure of defined data sets for these purposes.

The government of Alberta in its submission asked the committee to address concerns of researchers by considering whether or not custodians or Alberta Health and Wellness should continue to be required to disclose the least amount of information at the highest level of anonymity when an ethics committee has approved the project and recommended that consent is not required.

The Chair: Comments or questions?

Okay. I guess we can move to the last one, part 6.

Ms Robillard: Part 6 deals with duties of the custodian, the commissioner, general provisions, regulations, and other.

Question 29: "Are the duties and obligations on the custodian appropriate and reasonable?"

We've heard now from 12 organizations and one individual in relation to this. Two organizations agreed that the duties and obligations are appropriate. CBS raised a concern about the impact of the privacy impact assessment process on a national initiative and the requirement for provincial approval.

Eight organizations recommended changes to the current duties and obligations including amending or removing the information manager agreement, that the least amount of information necessary provision should not apply to information collected in the provision of a health service, removing the requirement to protect health information stored or used outside of Alberta, modifying custodian obligations in respect of affiliates, amending the information manager agreement requirement so it does not apply to information managers who are custodians, defining affiliates differently, streamlining the PIA process, implementing stricter controls on data matching, clearly defining affiliates and custodians, clarifying the scope of affiliates and custodians, circumscribing requirements for PIAs, decreasing custodian obligations and amending the disclosure notification, and considering the need for information manager provisions.

The individual recommended ensuring a stringent system of periodic audits of internal controls.

The Chair: Okay. We are on 30.

Ms Swanson: Question 30 is about the role of the commissioner. "Do you have any suggested changes to this part of the Act? If so, kindly identify and explain the rationale for the change(s)."

The committee received 10 comments from eight organizations and two individuals. Six recommendations for changes to the general powers of the commissioner were made. These included two suggestions from the office of the Information and Privacy Commissioner, the first being

- explicit power expressly authorizing Commissioner to conduct audits. Commissioner [now] has explicit power of investigation to ensure compliance with HIA, but [does not have] explicit authority to conduct audits or compel information for an audit.

The commissioner also suggested explicit authority to consult extra-provincially and to enter into agreements with other commissioners and delegate extra-provincially where privacy legislation from more than one jurisdiction applies to an incident. Intent is to minimize burden for custodians.

Another suggestion came from the College of Physicians and Surgeons, who suggested authority and responsibility to take custody or seize and to administer health records for which the custodian is unable or unprepared to do so. These relate to the orphan records.

Another suggestion, from the Alberta Long Term Care Association, to create a power to impose penalties on those who make complaints the commissioner considers frivolous or vexatious, to serve as a disincentive.

An individual suggested that the commissioner have powers over all holders of health information including for-profit organizations.

A second individual suggested power to rule on cases where there appears to be a miscarriage of justice with regards to any government Act.

The health boards of Alberta suggested that if the OIPC maintains a role in accepting PIAs, the process should be streamlined for efficiency.

There were two recommendations for changes to disclosure to the commissioner, section 83(3). The Calgary region suggested that the custodian be provided with the name of the affiliate who makes disclosure to the commissioner in accordance with that section in order to allow the custodian to investigate and defend the accusations.

The AMA suggested that section 82 be amended. This is the duty to comply with an order, that it be amended so an offender found in breach of HIA does not have the opportunity to continue indefinitely with practices until the question can be settled in the courts.

A health authority recommends amendment to notifying others of review and mediation to allow some discretion on the part of the commissioner.

The Chair: Question 31.

Ms Robillard: The question: "Is the list of substitute decision makers appropriate?"

Eight organizations and one individual responded. The individual and three organizations feel that the list of substitute decision-makers is appropriate. Five organizations suggested amendments including

- allow for broader disclosure to family members . . .
- include provision for injured, incapacitated adults with no personal directive or power of attorney, who are not covered by the Mental Health Act and cannot consent . . .
- enable the substitute decision maker for an incompetent individual to provide consent to allow researchers to access records . . .
- capture a family member or person with a close personal relationship to a resident who is prepared to act as spokesperson and who is appointed by a party of family members or where there is no family member, appointed by a party of persons with a close personal relationship to the resident, if the choice is not contrary to the expressed wishes of the resident . . .
- consider amendment to enable a "next friend" or "guardian ad litem"

to act on behalf of the individual.

The Chair: Questions?

Question 32.

Ms Robillard: Question 32 is a question around the offences and penalties.

We received nine responses from eight organizations and one individual. The AMA noted that no penalties have been imposed under the act and that therefore they could not comment on whether this was appropriate. Five organizations view the current offences and penalties as appropriate, but two suggested changes including

- add protection to non-recorded information by making it an offence to use or disclose such information in contravention of the Act . . .
- eliminate use of limited registration information by the custodian for fundraising as an offence . . .
- clarify when fines will be imposed for violation . . .
- set a cap on the aggregate amount of civil fines to impose on a custodian annually . . .
- clarify whether fines can be imposed only on custodians or whether fines can be imposed on an employee of a custodian.

Two organizations and an individual did not see current penalties and offences as appropriate. Suggested changes include

- increase fines and impose higher fines for private entities to ensure deterrence . . .
- modify the prohibition on using individually identifying health information to market any service for a commercial purpose to allow custodians to use discretion when there is obvious benefit to patients to receive a health service the custodian provides, by clearly defining the line between continuity of care and commercial activity . . .
- provide legal protection from penalties imposed by the Commissioner where the custodian has acted in good faith in relation to an action by an affiliate.

3:30

Dr. Pannu: The second-last bullet: "modify the prohibition on using individually identifying health information to market . . ." What kind of modification to the prohibition is suggested?

Ms Robillard: I don't recall that there is a specific issue. The recommendation is to remove 'commercial' limitations to the provision of health services.

Dr. Pannu: So is it removing prohibitions or enhancing them and strengthening them? There's the question.

Ms Robillard: They want to be able to market.

Ms Swanson: Yes. They want to allow custodians discretion to use that information when they, in their judgment, feel that there is an obvious benefit to the patient.

Dr. Pannu: Oh, I see. So the Value Drug Mart people are saying this.

Ms Swanson: Yes.

The Chair: Question 33.

Ms Swanson: Question 33 is about any suggestions for improvements on the rules contained within the health information regulation.

Seven organizations commented. Suggested updates to the regulation, basically housekeeping: to change some references to the repealed section 59; to replace in section 2(b) the name of a particular committee, Billing Practice Advisory Committee, with a more general statement that would allow for a committee serving the same purpose but not actually naming it.

One deletion was suggested. Requirement for a written agreement respecting information to be stored, used, or disclosed outside Alberta was suggested for deletion by the Calgary health region.

There were a number of additions suggested. The ALTCA suggested principles for technical, physical, or administrative security and reference to the electronic transmissions act or guidelines for electronic records and signatures. Capital suggested rules regarding retention, disposal, and archival storage of records. There was a suggestion to harmonize retention period for records and to specify the scope and content of information manager agreements or remove the provision.

The Chair: Question 34.

Ms Swanson: Question 34. There was no specific question on this topic, but it was a theme that came through in a number of submissions about legislative harmonization. We had about 10 organizations who commented. Organizations favouring consistent rules or consistent rules respecting some matters across Canada. The Pharmacists Association of Alberta supports a national framework of health information rules substantially similar to PIPEDA to enable information movement across borders for good patient care. The Alberta College of Pharmacists supports harmonizing consent rules in the HIA, PIPA, and PIPEDA. They support the principle of reasonableness, verbal, and implied consents, and suggest using the PIPA as a model. Value Drug Mart supports unifying all health information privacy legislation and requests assistance dealing with affiliates outside Alberta. Health boards of Alberta support a national framework without PIPEDA's implied consent requirements. The Canadian Mental Health Association supports the pan-Canadian framework requiring jurisdictions to confirm patient consent for disclosures outside their boundaries. CIHI supports the principles of legislation being as consistent as possible across Canada and the pan-Canadian framework.

The AMA and CPSA support harmonizing all of the privacy legislation they are subject to: HIA, PIPA, FOIP, and PIPEDA. The AMA specifically supports all health information being subject to HIA to simplify health information management and to facilitate Albertans' understanding of the rules.

The OIPC notes the second FOIP review recommendation to consider FOIP and HIA harmonization based on input from stakeholders subject to both Acts.

The health boards of Alberta support harmonization more broadly to include HIA and legislation respecting WCB, ABC, AADAC, schools, and so on; the Health Professions Act; the RHA; other provinces; and PIPEDA, but not its implied consent provisions.

So there were many comments about harmonization but no consensus.

The Chair: Thank you.

Question 35, last but not least.

Ms Robillard: This issue is another issue where there was no specific question but where there were many issues raised. It's around two issues. The first is the requirement that custodians maintain disclosure information, and the second, the requirement that custodians notify people when they're making disclosures.

We had seven comments from seven organizations. They suggest the removal of section 41 requiring a record of every disclosure, including disclosures between custodians, and retention of those records for 10 years. If the section is retained, changes were requested: removing section 41(1), notification requirements; removing its application to section 35(1)(a), disclosures, which are custodian to custodian; removing the requirement for notation of purpose of disclosure without consent when disclosure is part of an electronic batch process with automated audit capability since this is impractical to maintain for batch processing; changing section 41(2), retention period, from 10 years to two years, which would be consistent with the requirement to maintain prescriptions.

The AMA and the Canadian Mental Health Association took a different view, suggesting a detailed audit log is required to show who accessed the information and for what purpose in order to ensure consistency with authorized purposes.

With regard to section 42, there was a recommendation regarding removal of the written notification of purpose and authority. The provision is seen as impractical or impossible in direct care and is redundant given that custodians must judge the disclosure to be appropriate and express, written consent has been collected. If the section is retained, they advise limiting the notification of purpose and authority for disclosure to diagnostic, treatment, and care records, applying it only to nondirect care situations removing the requirement where disclosure is to the individual the information is about.

The Chair: Thank you very much, Wendy and also Evelyn and Linda, for your preparation for today's analysis, and we certainly offer our condolences for what lies ahead.

Ms Robillard: I do have a question, if I can. We stated earlier today that there are some priorities in terms of the committee's work in relation to the act based on the terms of reference; that is, to address the scope, to address the impact of the electronic health record, and to consider harmonization with the pan-Canadian framework. At this point in time we would certainly entertain any other priorities that the committee could identify for us in terms of focusing some of the work that we have ahead of us in the next less than two weeks.

The Chair: Would it also be okay, if they don't have something right now, that they could contact you and let you know?

Dr. Pannu: Mr. Chairman, I've been thinking about some of the discussion that we had a couple of weeks ago about the contracted private delivery of services and, therefore, the sharing of information that would be necessary between authorities that contract out the service to be provided and the providers of the service, how those private providers might be subject to laws outside of our country such as the PATRIOT Act, and what kind of issues are there. To me that's an important issue. We all recognized it. I wonder if there is any attention, then, that can be paid to it. The minimum, I would suggest, is that at least if we could hear from a sister province if they've done some work on it as to what kind of questions they think that issue raises. That'll help us determine whether we have either time or energy or at least some space in our report touching on those questions if not addressing them comprehensively.

3:40

The Chair: Do any of the staff have comments on that?

Ms Swanson: I was just going to comment. My recollection is that when the Information and Privacy Commissioner was here, he undertook to obtain a copy of the report from the Privacy Commissioner in British Columbia when the report is available and to review it on behalf of Alberta and to issue a report of any implications. Is that correct?

Ms Inions: To go back to the record, I think he was going to comment on the implications of any recommendations made by the B.C. commissioner to HIA, its application to HIA, because of course they'd be looking at it in the context of a British Columbia FOIP type of legislation.

One thing I perhaps could do – I'm just back in the office from the summer – is to inquire as to the status of the B.C. commissioner's work in this area and apprise the committee of what stage that's at, and then we can maybe go from there.

The Chair: We have two other questions. Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. I appreciate what Dr. Pannu is getting at. Mr. MacDonald was speaking to that issue prior. The review that the commissioner in British Columbia is doing – and I stand to be corrected – is only relevant to the USA PATRIOT Act and how that affects any potential flows of information. We currently and we have in the past exchanged medical information for purposes of delivery of care to our patients not only with the United States but other countries.

So I'm wondering: if we are to take this path as a committee and even discuss any potential exchanges of information with the United States, are we now going to go country by country and identify what other countries we have reciprocal agreements with for care provision and get commissioner's opinions and reports on all the countries? Why just exclude the United States or pick on the United States?

The Chair: Thank you, Thomas.

It seems to me we have a lot of work ahead of us, and expanding into that scope of area is probably going to be difficult to do. Perhaps what's happening could be referred to in the report, and it should be monitored. But I really don't think we're going to have time to give a lot of time for discussion to this item.

Anyway, having said that, Ms Blakeman, I have you on my list.

Ms Blakeman: Thank you. Did you by any chance keep track of the requests you've had? I'm wondering if you could run them back by us, because in some cases I may take back some of the stuff I asked you to do and do it myself. I'm having difficulty priorizing for you because I've forgotten what all we've asked you to do.

The Chair: Will they not all be in *Hansard*, Ms Blakeman? I mean, everything that's said here is recorded.

Ms Blakeman: Yeah. Yeah, sure. You want me to go through *Hansard* and pick it out?

The Chair: Well, no. Not right now.

Ms Blakeman: I'll get right on that.

Mr. Lukaszuk: It's on the Internet.

Ms Blakeman: Well, I was just trying to save them some work.

The Chair: Well, okay. I think the point is fair. Could we make a list and get it to the committee so that they know? Not right now. Could that be sent by e-mail or whatever to any member that wants it so that in case there's an item that's not covered, we can cover it?

Ms Blakeman: No, no. This wasn't to make more work, so having to go through and pull that stuff out and do a list and send it back to us is just more work.

The Chair: However you look at it, it's more work.

Wendy, do you have a comment?

Ms Robillard: I can highlight a few things that I have at hand. I'm not sure, Karen, if your memory is better than mine. We did have a request to obtain information on tax returns, what was required for income tax purposes, to get information about hospital admitting forms and what information they seek from individuals, the rationale for including health service provider information in the act, to follow up with the EHR Data Stewardship Committee and to look at having them bring some information back to this group, to look at how many incidents of identified wrong billing or fraudulent claims there are in Alberta. I believe that's it in terms of issues assigned throughout the last two days.

In terms of priorizing, I was really hoping to get some assistance in terms of priorizing the questions that the committee will have to consider and make recommendation on, of which we have some 36.

The Chair: Okay. I don't think the time frame today is going to allow that, so I'm going to suggest to committee members that if they have additional comments, please notify Wendy as to their priority. I will also give some attention to that.

So that brings us to Other on the agenda. Are there other items committee members would like to raise?

I certainly want to thank the committee for their diligence today in covering a lot of ground and hearing some good submissions and asking some good questions. I would remind the committee that we are meeting again on September 27 and 28, so we're down to four more meetings.

So on the 27th and 28th, briefly, Wendy, we will be looking at options. Will we be doing more analysis? You know, in view of other submissions which may come in, how will we approach that?

Ms Robillard: As other submissions may come in and the submissions that have not already been incorporated, yes, we'll try and update that and bring that back as it relates to issues and recommendations that need to be made.

The Chair: Especially if there are diverging opinions or points of view.

Ms Robillard: Absolutely.

Ms Miller: In the interests of the time and if we don't hear from committee members in terms of priority areas around the questions, would it be reasonable for us to make some assumptions based on the discussions we've heard? It will be almost impossible for us to develop full options for all of those questions between now and the 27th.

The Chair: I certainly think that's fair that you would priorize. So what you're saying is that you will priorize . . .

Ms Miller: We will have to choose which ones we think we can develop reasonable options for in that given period of time.

The Chair: And considering the debate and the questions we've had, I think you have some basis for that.

Ms Miller: Yes.

The Chair: Okay.

Mr. MacDonald.

Mr. MacDonald: Yes, Mr. Chairman. I was just going to confirm. The meeting on September 27 and the meeting again on the 28th are to start at 9 a.m.?

The Chair: That is correct. We've been fairly consistent on that one. I'm curious why you would ask that question. Never mind; it's a fair question.

Okay. Any other questions?

I would accept a motion to adjourn. Thomas. All in favour, please say yes.

Hon. Members: Aye.

The Chair: Opposed, please say no. We're adjourned until September 27.

[The committee adjourned at 3:49 p.m.]