Title: Thursday, October 7, 2004 HIA Review Committee
Date: 04/10/07
Time: 9:03 a.m.
[Mr. Jacobs in the chair]

The Chair: Good morning, everyone. Again we welcome you to this meeting of the committee on the health review. I'm pleased that you could be with us today. Hopefully, this will be the second-to-last day of this committee meeting.

You should have all received via e-mail a draft copy of the report earlier this week. Does anyone not have a draft copy? Okay. Very good. Basically, that is the item for discussion by the committee today, to review the draft document and, hopefully, finalize that document so that it can be presented to you next week as a final copy.

I guess that at this point, before we get into the agenda and other items, I will ask the committee members to please introduce themselves for the record, and then we'll go to staff.

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

Mrs. Sawchuk: Karen Sawchuk, committee clerk.

Mrs. Dacyshyn: Corinne Dacyshyn, committee clerk.

Ms Sorensen: Rhonda Sorensen, communications co-ordinator.

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

The Chair: Thank you very much. Again, welcome to everyone. Just to make sure that everyone has copies of some of the information which has been received from various stakeholders since the last meeting, you should all have a copy of A Principled View on the Value of Access to Health Services Provider Information from IMS for information.

Also, I believe that another member of the committee, the vice-chair of the committee, has received another document for information that she would like to circulate. The envelopes were sealed with your names on them, and we have to make a copy, so they're going to use mine to make a copy for staff members.

Before we go to the approval of the agenda, are there any other such items that any committee members want to share or comment on or questions on the documents for information that have been tabled? Okay. You have the agenda before you, a pretty simple agenda. If it meets with your approval, could I have a motion to adopt?

Ms Kryczka: I so move.

The Chair: All in favour? Opposed? Seeing nobody in the negative, I will say that the agenda has been adopted.

Wendy and Evelyn will be leading the review of the draft document today. So as we go through that, it's important that we have your discussion, your comments, and your questions. It's important that we make, you know, decisions knowing the implications and understand what is being presented, so I would certainly encourage committee members to ask questions when you have them and to participate in the discussion.

Ms Miller: Mr. Chair, we were proposing for your consideration that before we go through the draft document from beginning to end, in order to streamline the discussion, hopefully it would be helpful to first tackle the two health service provider issues – the first part of that, obviously, the scope issue, as well as the research issue associated with providers – have that discussion with the committee, if that makes good sense, and then go through it. Or did you want to go through it from beginning to end as the document is laid out?

The Chair: Okay. We'll put the question to the committee. Ms Kryczka, did you have a comment?

Ms Kryczka: Well, I guess what I feel is that it's a big area around the research issue, and we have new information. I would like to propose that we, if we can, deal with that later rather than immediately. I have concerns that there hasn't been time for members to read the material that we've just received.

The Chair: Any other comments?

9:10

Mr. Lukaszuk: I would concur with that. I wouldn't mind reading some of the information. There's a voluminous one from IMS and the memo. I'd like to take a few minutes to read it maybe prior to lunch or over lunch, whenever time allows.

The Chair: It would appear that we have some concern about dealing with that one right now. Maybe we should just start at the beginning, and we could even leave that one until later in the morning or early afternoon so that the members could have a chance during the coffee break or lunch break to read the additional information.

Ms Miller: Sure. My apologies. I wasn't aware that you had received some new information.

Should we leave, then, both aspects of the provider issue in terms of scope as well as research till later on?

The Chair: I think that would be appropriate, Linda, yeah, because they do relate and we should talk about them together.

Ms Miller: Okay. Certainly.

The Chair: Is it agreeable to the committee if we leave both aspects, research and the commercial aspect, to be discussed in the same time frame in the meeting? Okay.

Well, what do we do then? Go back to page 1 and start? Okay.

Ms Miller: I'll turn it over to Evelyn now.

Ms Swanson: Thank you. We're going to go through the report page by page, but I thought that I would start by just giving you a little bit of background about the process of drafting it. We did go back to all of the materials that came in and the summaries of the submissions to prepare a short statement about all the input that was received on each of the questions.

Also, we went back to the consultation guide and took a look at the specific question and the information that was provided to stakeholders for their response and tried to capture at least the essence of the discussion and the considerations and the conclusion; that is, the resolutions that were made by the committee last time around. Because the resolutions were not really specific, I did try to draft recommendations that were specific and that captured the

intent. I know you'll want to look in considerable detail at the wording of the recommendations to make sure that they do reflect your intent.

The Chair: Evelyn, we do have a question.

Ms Kryczka: I would just like to ask: if the committee members want to make any comment at all on the formatting of the report – this is separate from content – do you want to allow time right now for comments, or should we just wait till the end of the day? I think that presentation of a report, visually, not only the content, is also important. I realize that this is the first draft.

Ms Swanson: It definitely is important. What you see here is just straight typing; it's not been formatted. Rhonda from communications has been working on a format and will be able to tell you about it. Since it's a question that has come up, maybe we should do it now.

The Chair: Karen, do you have a comment here?

Mrs. Sawchuk: Mr. Chairman, we did start a format that would follow the consultation guide, where it shows the question and it's like a two-column type of affair. What the committee has to focus on today – and Evelyn and I were talking about that this morning – is the actual content of the recommendations.

Ms Kryczka: I know. I understand. I'm just saying: if we have any comments that we would like to make on it, can we do it now, take two minutes, or do it at the end of the day?

Mrs. Sawchuk: Well, we haven't made copies for all the members, Mr. Chairman. I mean, we could do that, but the format that we see isn't complete.

Ms Kryczka: I see. Okay.

Ms Swanson: Perhaps we could come back to that question late in the day.

The Chair: Ms Kryczka, were you going to make some suggestions for formatting or just comment on process?

Ms Kryczka: Yes, and later is just fine.

The Chair: All right.

Okay. Go ahead, Evelyn. Oh, before you do, I just want to acknowledge Mr. Goudreau, who has just come in. Welcome, Hector.

Mr. Goudreau: Good morning. Thank you. Sorry I'm late.

Ms Swanson: I thought I would start by asking the committee for general comments about the paper. I hope you've had a chance to read it. I know that the time was very short, but if you have some general comments – I've got a comment about format already, but we'll deal with that a little bit later – anything around the general shape of the document, the content, tone, style. Any comments that you'd like to pass on at this point?

Dr. Pannu: Mr. Chairman, just one comment that I would like to make with respect to that at this moment is that the draft quickly moves on to the recommendations. Perhaps you'd have a bit of a preamble or introduction of the general issues that came up in the debate. They're not reflected in the recommendations or touched on or at least noted as concerns.

One that I find missing here and that affects, in my view, our ability to protect the privacy of the information of Albertans with respect to their health records has to do with the potential impact of the USA PATRIOT Act. We discussed it, and there's no reference to it in the document at all. It's in the preamble perhaps. That's an issue that must be noted, in my view.

The Chair: That will be of course covered in the minutes and in the official transcript. You're suggesting that it should also have been in the draft document.

Dr. Pannu: Yes, in the preamble. Obviously, it's not a recommendation here but certainly in the preamble. We have asked the Information and Privacy Commissioner to report to us. Formerly he was here before us, and we made the request. We need to have it noted here as a matter that has not yet been resolved or addressed.

The Chair: All right. Any other comment?

Ms Blakeman: I think it's natural to seek a structure that we can keep returning to, and the structure that was chosen here is the questions that went out in the workbook. We keep returning to that – and this relates somewhat to Dr. Pannu's points – but we're not capturing any other topics or issues that were brought up and debated by the committee in the context of going through this process.

I'm looking forward to the detailed examination. I am hoping I'm going to be proved wrong, but in my initial examination and review of the document, in going back to those original workbook questions, starting with scope and inclusion or exclusion, et cetera, some of the issues that have come up like the PATRIOT Act, some of the other concerns that I have raised and others are not included in here because they don't hang their hat on one of those hooks of the original questions in the workbook. So it doesn't reflect the work of the committee. It simply goes back to the questions in the workbook, and that's part of my concern: there are discussions that are missing from this. I'd like to go through the document, and then we'll have a clearer idea if any of that did make it in or not.

The Chair: It's noted.

Mr. Lougheed: Well, Mr. Chair, perhaps a concession in the preamble to state that the *Hansard* is available and has the entire record of the discussion. Anybody who's interested in the other points that were brought forward can find them all there.

The Chair: Okay. Thank you, Rob.

Thomas, or Mr. Lukaszuk.

Mr. Lukaszuk: Thomas is good. Okay. Let me qualify that. Thomas is very good.

I find it to be an unusual request. It's a report. This committee has the privilege of having its debate recorded in the official *Hansard*, so if anybody wants to see by which means the recommendations have been derived from, they can easily refer to the *Hansard* and read all the debates and discussions and the arguments prior to each vote on each recommendation. I have yet to see a report that would in its recommendations have a preface of all the arguments that were stated in that debate, just like bills don't have dissenting opinions in them either. That's what the *Hansard* is for. So do we

really want to now take dissenting opinions and then put them in a report? I see that as counterproductive.

9:20

The Chair: Thank you, Thomas. Anyone else?

It seems to me that the function of the technical team was to evaluate the questions as discussed by the committee, as were sent out to Albertans for their comments, and it seems to me that we are discussing this within the context of the questions. So for additional items I tend to agree with Mr. Lougheed and Mr. Lukaszuk that you can reference those in *Hansard* and in the minutes, and I fail to see why we would need to reference all the discussion in the committee, except the discussion that referred to the questions that were before us. I don't know.

Linda, Wendy, Evelyn, any additional comments here?

Ms Miller: We take your direction.

The Chair: Okay.

Dr. Pannu: Mr. Chairman, it's clear that I've not succeeded in persuading the chair and many of my other colleagues around the table with respect to my request that reference be made to our discussion of the USA PATRIOT Act and its potential impact on the ability of this act in its present form or its amended form to be able to serve the purposes that are stated in the preamble, the most important ones of which have to do with the protection of the individual's health information.

It is true – you're absolutely right – that the questions in the document that we sent out to Albertans for consultation purposes did not raise that as a question, but that doesn't mean that this committee should not in fact seriously address the overarching question of how this act and amendments that we are proposing might all be undermined by something else that has been brought before the committee, i.e. the USA PATRIOT Act.

We know that the B.C. Information and Privacy Commissioner is looking at the matter. We as a committee have made a note of it. Certainly, in the *Hansard* that information is available, but most Albertans don't have the time that you and I have – and we get paid for it – to look at the *Hansard* and everything else. Most Albertans would probably be looking at our report and not the *Hansard* to make a judgment on whether or not we have addressed all the issues that are pertinent to the review.

One of the most pertinent questions, as I said, is another piece of legislation outside the control of this Legislature or this country which may impact and might undermine our desire and our commitment to protect and respect the privacy of the information related to health records of Albertans.

The Chair: Okay. Anyone else?

Mr. Snelgrove: Mr. Chairman, we were charged with reviewing the Health Information Act, not with trying to interpret or presume what effect some American bill would or would not have on this, nor would any other province necessarily unless it refers through the framework. That's what we did.

The process is open. It's recorded. That's part of coming to conclusions, which is what a report is all about. So while it's fine to try and use the process for whatever benefit you might like, the report is the conclusion, and that's all that really matters in it. People can go back as thoroughly or as unthoroughly as they want to review *Hansard*. Members are more than welcome to take from this room whatever they choose, but the report simply needs to state what we found out.

The Chair: Thank you very much.

I'm going to ask Dr. Pannu and Ms Blakeman if we could continue with the discussion of the draft document, and at the end of the day, Ms Blakeman, you already alluded to, I believe, that you'd like to hear the discussion to see if some of the items you had concern about were referenced or not. So could we proceed with the discussion of the draft document as it is before you?

Then, you know, if members want to add, by resolution, to the document to be in its final form, certainly I would accept those kinds of resolutions. But could we go through the document, discuss the document as per recommendations, and then spend a couple of minutes at the end of the meeting to see what advice the committee wants to give to the technical team as to the preamble or whatever to the final document? I would like to get into the draft document and get that discussed while we're still early in the day so we have sufficient time to cover the document.

Dr. Pannu: With me, Mr. Chairman, that's fine, I think, so long as we have the opportunity to return to that issue later on. I think we need to proceed with the substance of the report.

The Chair: But if it's going to be included in the final report, it would have to be by agreement of the committee, by consensus.

Dr. Pannu: Well, indeed, of course. Nothing will be included in this, I guess, without the agreement of the committee. That's my understanding.

The Chair: Yeah. Okay.

All right. Are we ready to start then, Evelyn? Let's go. Were there any other comments on the content of the report, the style of the report? Those issues have been raised already. Were there any others?

All right. I guess we're ready to get into the report.

Ms Swanson: Okay. Thank you. The report that you see before you does not include the introduction, as was mentioned a few minutes ago. Rhonda and Karen are going to prepare an introduction, acknowledgments, and a list of the committee members and the committee terms of reference, and that will all be at the very front of the document along with an executive summary. I believe the executive summary usually includes a listing of all the recommendations. So all of that would precede what you see here. I was focusing more on capturing the recommendations and the stakeholder input, the content. So that's what you see here.

I started my set of responsibilities with a short description of the consultation process and the number of responses from stakeholders, the number by category of stakeholder, and I identified the number of submissions that came in orally, the oral presentations. So that's basically what's on page 1. Are there any comments about the first page up to that point, the consultation process? Okay.

Moving ahead, then, to the purposes of the act. This was the first area that stakeholders were asked to provide input on. On page 2 we come to the first recommendation of the committee: "The seven key purposes in the Act should be retained in their current form." That wording reflects your intent?

The Chair: Silence gives consent.

Ms Swanson: Okay. Moving on to the definitions then. I think we

captured in the first three or four paragraphs the nature of the input from the stakeholders and talked about where some of the definitions dealt with substantive matters. They are dealt with elsewhere in the report and not detailed here.

I've made a note to the committee about an item that in pulling together all the loose ends I omitted last week when we met. There was another housekeeping update about the definition of custodian in the issue paper. This was a very straightforward thing. I believe that the Regional Health Authorities Act as referenced in the definition of a custodian and the HIA contains an incorrect reference number. It references section 18 and it should be section 17, so it's just an error that should be corrected. If the committee would agree, we would have a recommendation to correct that error just as a housekeeping amendment.

9:30

Mr. Goudreau: Mr. Chairman, I'll make a motion that
> we change to reference section 17.

The Chair: Thank you, Mr. Goudreau.

Questions on the motion? All in favour, raise your hand. Opposed? Carried.

Ms Swanson: Thank you. So that would be recommendation 2.

Recommendation 3 is that "Alberta Health and Wellness should clarify terms and definitions in its guidelines for use by stakeholders."

If there are no questions, then, on that section, I will move on to the scope of the act.

The Chair: Okay.

Ms Swanson: In this section we identify some background about the bodies that are currently included within the scope of the act as custodians. We talk a bit about affiliates and also identify some of the agencies that are outside the scope. We reference the controlled arena that's created within HIA which allows for custodians who are identified in the act to collect, use, and disclose health information without consent for the purposes listed in the act. It also creates rights of access to individual information and provides protections for individuals.

We talk a bit about the other legislation that has been introduced since HIA came in and about the entities that could be included in the act or were considered for inclusion in the act. The first group that we're looking at would be Alberta government departments and local public bodies. So the first recommendation in this section, which is 4 in the report, says that "other government departments and local public bodies should not be brought within the scope of HIA."

Now, I have another note to the committee here, another item that I wanted to make sure that the committee has a chance to consider because I didn't raise it at the meeting last time.

The University of Alberta and the University of Calgary did in their submission suggest that their universities and perhaps others that have health clinics should be included as custodians under the act. They make that argument because the universities do have medical clinics that their students use, and these clinics are staffed by doctors and physicians who are custodians, but the university provides all of the infrastructure for those medical clinics. So they in a way have corporate responsibility for those clinics, and they provide the networks for participation in the electronic health record. They hire the staff who keep the records of the medical clinics, but because they're not named as custodians, they have no explicit responsibilities under the act to enforce the act to ensure that the medical clinics are operating in compliance with the act. Only the physicians in the clinic have those responsibilities. So they're pointing out an issue that they feel should be addressed by making the universities custodians.

I think there are potentially three ways to deal with this at this stage. One of them would be to amend recommendation 4. You could theoretically decide that they should be custodians at this point and just amend this and say: with the exception of the university medical clinics. Another option would be to defer this question to the committee of the Legislature in 2005 which will be looking at the question of what additional health service providers to bring within the scope of HIA. So that's a second option. A third option might be to decide at this point to exclude them completely.

Our suggested response would be to defer it to a committee in 2005 and look at it in the context of all of the health service providers that will be considered at that point.

The Chair: Do we have comments or questions from members of the committee?

Dr. Pannu: Mr. Chairman, I'd be willing to move that
> this matter be addressed by the committee to be struck to deal with other matters as well as this in the spring of 2005.

The Chair: All right.

Dr. Pannu: May I add something to it? We are of course assuming that such a committee will be struck. I think it might be wise for this committee to make that clear to the Legislature in its recommendations, that it thinks that such a committee must be established.

The Chair: Agreed.

Okay. We do have a motion from Dr. Pannu regarding option 2, I think that would be.

Mr. Goudreau: Mr. Chairman, just to make the committee aware, I truly believe that Grande Prairie Regional College also has their own medical clinic and they're offering services there. So when we talk about universities, I think we need to talk about, you know, general educational institutions that might have clinics.

The Chair: Thank you. It seems to me that would even be further argument to defer to the recommended committee in 2005.

Any other questions on the motion by Dr. Pannu recommending deferral to the recommended committee in 2005?

Ms Kryczka: On universities and other educational institutions?

The Chair: Yes. Is that correct, Dr. Pannu?

Dr. Pannu: Yes.

The Chair: All in favour of the motion, please raise your hand. Opposed? Carried. Okay.

Ms Swanson: On the next page we have the committee's recommendation that "ambulance operators and ambulance services should be brought within the scope of HIA." I think that was pretty clearly supported.

Next, recommendation 6 is about the committee of the Legislature in 2005, stating specifically:
> A committee of the Legislature should be established early in 2005

> to consider the inclusion of some additional privately funded health professionals regulated by the Health Professions Act, and organizations with the primary purpose of providing health services.

Is that wording appropriate?

The Chair: Everyone okay with that recommendation?

Dr. Pannu: The recommendation starts by recommending the establishment of a committee, and it seems to me that it wouldn't be entirely appropriate to limit the reference to the establishment of a committee to consider this one issue when in fact we have identified many other issues. So the suggested framing of the recommendation perhaps needs to be changed a bit because it seems to me that there's a consensus around the committee – I would test it if necessary – that such a committee be established which will consider other matters as well as this one.

Ms Swanson: Yes.

The Chair: Can that be covered in the final document, to reflect the wording with the point that's been made by the member?

Ms Swanson: Yes. Just off the top of my head, it could be amended to say something like: a committee of the Legislature should be established early in 2005 to consider among other things the inclusion of additional privately funded health providers. So we could frame it that way, or you could make a recommendation right at the beginning that deals with the establishment of the committee to deal with a number of matters. That would be a different way to do it, and you might want to do that.

Dr. Pannu: That would be preferable.

The Chair: I'm hearing positive comments for making this recommendation a basic recommendation at the beginning of the report, which I think is a good idea because so many of the committee for various reasons – time, length of time, et cetera – have not had the time to deal with many of these issues. It is a very important recommendation of this committee, and without that recommendation and the implementation of the recommendation in my view the committee's work is not complete.

I see agreement for that one.

9:40

Ms Swanson: So I will add a recommendation specifically about establishment of the committee to look at a number of matters that could not be developed fully at this time.

The Chair: I believe that reflects the view of the committee. Okay.

Ms Swanson: The next recommendation deals with the Workers' Compensation Board, that it should not be included under the Health Information Act.

Recommendation 8 on page 6 is that "Alberta Blue Cross should not be brought within the scope of HIA."

Recommendation 9 is that "personal health information held by employers should not be brought within the scope of HIA."

The Chair: Okay. We have a question.

Ms Kryczka: Actually, my question is not on 9. So after that's dealt with.

The Chair: That's fine. Do you want to go back to it?

Ms Kryczka: When number 9 is dealt with, I'd like to comment on scope.

The Chair: Well, we are dealing with 9 now; are we not?

Ms Swanson: Yeah. I just mentioned that 9 is about personal health information held by employers, and the committee has recommended that it should not be brought within the scope of HIA.

The Chair: Are there any comments? Okay. It seems that the committee has agreed with that recommendation.

We are going to skip over health service provider information until later in the day; is that correct?

Ms Swanson: That's right.

Ms Kryczka: Could I make my comment, Mr. Chair?

The Chair: Oh, sure. Sorry.

Ms Kryczka: There's quite a bit of preamble under Scope, and I guess what I want to point out here is that especially when we looked at a potential recommendation including universities and educational institutions as custodians and looking at the summary on stakeholder recommendations, we have the Health Quality Council of Alberta asking to be included as custodians. The reason, I think, is very significant: to allow them "access to information to evaluate, monitor, and report on performance, quality and safety."

The Health Quality Council is an arm of Alberta Health and has a very important function. There was reference in our summary sheets about two health information and research organizations making comments about their specific inclusion in the act, the Health Quality Council and CIHI. Well, that's a national body, and they weren't asking to be a custodian. We were saying that we need to be able to disclose limited personal health information for specified purposes, and I don't see this included at all in the preamble; in particular, the Health Quality Council.

I'm sorry, but I don't have my initial copy of these summaries, where I made many notes, and I don't know what the committee decided. I guess I'm just saying that this was a specific request for their reason to be included as custodians, so if we are considering the universities, we should definitely consider the Health Quality Council.

The Chair: Does any of the technical team recall previous discussions that you'd like to comment on?

Ms Swanson: We do recall that it was raised, and the member is correct: we didn't get back to it. So I think that it's appropriate to get back to it now.

We did do a little bit of follow-up work on what the implications might be of naming the Health Quality Council as a custodian. I think our conclusion is that their access to information might actually be better as an affiliate to Alberta Health and Wellness than it would be if they were an independent custodian. The legal group did do some analysis on this, and I would just ask Holly if she would like to comment further.

Ms Gray: Yes. When we looked at it, the council is an affiliate of the department, which means that it technically has access to what the department has. It would still be bound by the same principles

of highest level of anonymity, need to know. But as a stand-alone custodian it may not have access to some of the information that the department has access to, because the minister has access to information that some other custodians don't have related to billing and those types of systems. They actually probably are better off being an affiliate for access reasons.

There's also a concern whether as a stand-alone the council would be able to put the appropriate infrastructure in place to meet the physical security and administration safeguards that are required by the act. They're quite substantial; they're quite important. With the structure of the council itself in that it's supported administratively by the department, it does not have its own infrastructure to handle those things, and as an independent custodian it would need to put all of those technical and physical and administrative safeguards in place.

So in looking at all of those issues together, it was felt that they probably are in a better position as an affiliate than as a stand-alone custodian.

Ms Kryczka: Okay. I would basically draw the attention of this committee to their rationale for wanting to be a custodian. I think that's critical. It is to allow them access to information to evaluate, monitor, and report on performance, quality, and safety, which is their mandate. So by deeming them to be an affiliate, are they able to perform their mandate? I think this is very important.

Ms Miller: We believe they are well able to perform their mandate as an affiliate of Alberta Health. However, where the difference lies – and I believe one of the reasons that they may be arguing for custodian status is that because they're an affiliate with Alberta Health and Wellness, when they strike an arrangement with a researcher to do research on their behalf, the researcher still needs to sign a contract with Alberta Health and Wellness directly because we are the custodian that is disclosing the information.

At times I believe the quality council has found that they have not understood why they can't independently sign the research contract. I think those may be some of the administrative issues that they're referring to. However, for them to function as an independent custodian, that would mean they'd be able to use the data that they hold in custody, and at this point in time I'm not aware of them actually holding any data in their custody. They rely on the data that is held in custody by Alberta Health primarily and/or other custodians.

Ms Kryczka: I guess my last comment pretty much would be that there's a reason why they are being asked to be custodians. There's a reason, and the reason is maybe that they do not have access to information, et cetera, et cetera. I read that, as I've already said. So I'd just make my point. If "affiliate" will provide that rather than "custodian," then I'm okay with that.

The Chair: Thank you, Ms Kryczka.

So they are an affiliate now?

Ms Miller: Yes, they are, and I believe they have access, in fact better access as an affiliate than as a custodian.

The Chair: My question is from the member's comments. Have they been frustrated in trying to get information which probably is quite relevant to their function as a committee?

Ms Miller: Yes. I believe they would tell you that they've been frustrated. Some of that frustration, I think, is indicative of new legislation, understanding the legislation, the need to clarify between the department and this quality council what constitutes research versus quality assurance activity. So, yes, you know, the frustration exists – I would not deny that at all – but I believe that we can work through that. Certainly, as an affiliate status I would support Holly's statements that they would actually likely have greater access than they would as an independently named custodian.

9:50

The Chair: All right. Thank you.

Dr. Pannu: Mr. Chairman, I was listening to the very appropriate comments that were made by – I'm sorry; I'm not getting the name.

Ms Gray: It's Gray.

Dr. Pannu: Thank you.

It raised a question in my mind whether the council should not in fact be renamed or designated as a custodian, because as is, as an affiliate of the department, it has access to a lot more information than it would have if it were a custodian, to the information that it needs given its mandate. Am I right?

Ms Gray: Theoretically that might be possible, but when you apply the principles of highest level of anonymity with need to know and the other guiding principles, the council would only be able to access that information that it legitimately needed. That would be no different than any other affiliate that the department is working for. If the council is undertaking, you know, and researching matters on behalf of the ministry, they will have access to the information that they need to know to complete the task that they've been asked to complete. So they don't have carte blanche access to all the information held by the department.

Dr. Pannu: Well, that was my concern. I misunderstood you then. I thought that in their present status as affiliate they have carte blanche access to any information that they request.

Ms Gray: No, they don't have carte blanche. It would be the same principles that the ministry itself exercises, that they only disclose information under the principles of, you know, limiting access: only the amount that's required to complete the task at hand, the highest level of anonymity, and need to know.

So even though the department has a greater database, my comment was more in the context of the notion of them being a custodian on their own, supporting Linda's comment that they do not have their own database. If they have no database, clearly being an affiliate gives them access to greater information than if they were stand-alone.

Mr. Snelgrove: Mr. Chairman, I think this would all be covered or be reviewed with that committee in the spring when we talk about other health professionals and other service providers and how it relates to them on the scope. So they may be all valid points, but they'll be dealt with in the spring of 2005.

The Chair: Okay.

I would just make this observation. Holly, you used a couple of words which frustrate me a little bit: "theoretically" and "technically." I'm not sure what those mean.

Ms Gray: It means that when legislation is drafted, it's drafted in a scope that allows a certain flexibility for the situation. Legislation

is never drafted with a specific context in mind. When we draft HIA, it has to be flexible enough to suit all of the custodians in the province for all of the purposes, including the ministry, people who are providing health services.

So it has a broad context, but the limiting principles are put in place to ensure that disclosures are done in a way that are appropriate for every situation. Custodians as health professionals are required to exercise that discretion. We've permitted that discretion, and I believe that's the appropriate balance between access and privacy.

The Chair: Okay. Thank you. That's helpful.

Mr. Snelgrove, are you suggesting that we include this quality council for further discussion in the committee that's going to be?

Mr. Snelgrove: Mr. Chairman, I don't think that we need to name specific ones that would and wouldn't. I think that the scope of it should be broad enough to cover the ground it needs to cover. Those are very important people, very important jobs. I'm sure they'll be dealt with in the fullness of time. But I would not want to start saying, "Them, them, them" or "Not them" in the discussion. Let's leave it open.

The Chair: Okay.

Ms Swanson: Just for the information of the committee, we do have another recommendation in the report, on page 21. It's recommendation 35.

The Chair: Page 21? Is that correct?

Ms Swanson: Page 21, and it's recommendation 35.

Now, this recommendation would deal with CIHI's request, and it could easily accommodate the Health Quality Council if the committee feels it needs to have another look. It may be a new category of entity under the act with some specific rules around it.

The Chair: So when you follow the committee's recommendation to put the recommendation for another committee in 2005 earlier in the draft for the final document, are you going to include – I think the committee said earlier that we didn't want this new committee to have the scope to relook at all the issues that this committee has looked at. So I assume that you're going to have to sort of clarify and define some of the issues that need to be considered by this recommended committee.

Ms Swanson: Yes. We haven't brought all the recommendations together in this particular format, but we could, specifying all of the activities that you would like the 2005 committee to deal with. Right now there are several tasks identified in recommendations for that committee.

The Chair: I guess my question is: will all those be identified in the first recommendation that the committee be struck?

Ms Miller: We'll just go back in our notes. I believe that last time we met, we proposed that the committee of 2005 focus on three or four primary areas, of which many recommendations relate to those three or four categories. Just off the top of our head – we're looking for our notes on what the actual naming of those categories, areas were. So it is a limited review around those substantive areas.

The Chair: All right. Thank you, Linda.

Ms Kryczka: I just wanted to make that point. I would like to leave it and probably everybody else would like to leave it and carry on. If there's anything else related, I think it would come up under that disclosures for research purposes section on page 20.

The Chair: On page 21?

Ms Kryczka: It starts on 20, and it will come up later.

The Chair: All right.

Dr. Pannu: Mr. Chairman, with respect to your comments on the first recommendation of the committee, to establish a committee for 2005, I think that as part of this work, the three or four areas that Linda has reminded us we thought would be general areas to be addressed by this committee, there would be one thing to be added there, you know, a task of the committee. Plus, of course, we could reference the specific recommendation by number which would require the attention of that committee in that place. So that's how we could consolidate it.

The Chair: Yes. The technical team will bring that forward next week in the final document for your consideration.

Ms Miller: Sure. Certainly.

The Chair: All right. Where are we going next, Evelyn?

Ms Swanson: We are going to skip over health service provider information, which will take us to page 10. On page 10 the first item dealt with there is nonrecorded health information, and the committee recommended that "the definition of health information should not be changed to include non-recorded information."

The next section deals with the individual's right to access health records, and again it provides a little bit of background on what the current rules are and what the stakeholders had to say and what the committee considered. The recommendation, recommendation 12, states that "the Act should be amended to 'stop the clock' until the Information and Privacy Commissioner renders a decision on a custodian's request to disregard an access request under s. 87." Okay. No comments? I'll move on then.

Recommendation 13 was that "exceptions to the individual's right to access the individual's own information be retained in their current form."

Recommendation 14: "A review of the fees for access to health information records should be deferred to the Regulation Review in 2005."

Recommendation 15 on page 12: "Alberta Health and Wellness should consider the need for more clear and transparent rules for the electronic health record prior to the next full review of the Act by a committee of the Legislature."

10:00

Dr. Pannu: I'm concerned about this recommendation in that it postpones the whole matter of establishing clear rules with respect to "more clear and transparent." It perhaps is related to electronic health records too, but three years from now, roughly – you know, the arrangements for electronic health records are being put in place as we speak. I understand that the Capital health authority in fact has some electronic health records already in place. There is a need, I think a more urgent need, for the rules on transparency and clarity to be in place now rather than having to wait for three years. I think that Albertans would feel much more assured that we are doing the

work that we need to do in order to make the practices and rules more transparent and clear.

So I have a suggestion here, which I could certainly make in the form of a motion – I'll do it, with your permission, later – that we should put this matter before the next committee in spring 2005 to respond with some degree of dispatch to this matter as soon as the next opportunity arises, which would be in the spring of 2005. I'm willing to so move.

The Chair: Okay. I will accept the motion, and I'm sure there'll be some comments about the motion. Questions?

Well, my initial question, Dr. Pannu, would be: do you think that we will have made sufficient progress on the development of electronic health records by January or February of 2005 and that that committee will really be in any better position to make a recommendation than we are at this point as compared to a committee three years down the road?

Dr. Pannu: Mr. Chairman, I would certainly acknowledge, as we have done around this table before, that the progress on EHR has been slower than was anticipated and hoped for, but sufficient progress is being made, and these are rules about transparency and clarity. They need not have to wait until the EHR system is fully operational. In fact, these rules need to be there in order for the system to become fully operational and one that we can all place our trust in. So I think that the rules need to be in place now to provide guidance for the EHR system to develop as it should, rather than waiting for three years.

The Chair: Okay. Any other questions?

Mr. Snelgrove: I guess it would be extremely difficult to put the rules in. It's difficult to prescribe the rules when we're not exactly sure what the system is going to be. I think that if we understand that the principles of the Health Act have to be followed, whether it be on paper or electronically, and that the seven guiding principles are the same, then I'm not sure what we could put in place that would either expedite or slow down the electronic health record. I mean, if the privacy of information is paramount and the principles for both written and electronic are the same, I'm not sure that we need to address that issue until we understand the system.

The Chair: Thank you.

Mr. Lukaszuk and then Dr. Pannu.

Mr. Lukaszuk: Thank you, Mr. Chairman. Maybe this argument is a little premature because this committee has no ability to direct what the jurisdiction of the next committee will be. So if there is a committee struck in January or February of 2005 and they in their own minds feel that they are in a position to address this issue, they definitely may, and if they feel that they are not, they themselves can defer it to the three-year review. I don't think we have any jurisdiction over what the next committee will or will not look at.

The Chair: I guess what we would be doing, Mr. Lukaszuk, is simply making recommendations. Certainly they could go beyond that.

Dr. Pannu: I think you have made my point, Mr. Chairman. I think what the next committee will in fact address will perhaps have to be determined when that committee is established. We are making recommendations with respect to the business that we think would need their attention. So my motion simply is an attempt to put this matter before this committee to be struck and for them to then decide what information they need.

The Chair: I understand. Do any members of the technical team have any comments or questions about this motion before we put it to the vote?

Ms Miller: Just a comment. I can certainly understand the need for pursuing ongoing clarity and transparency. I certainly respect that completely, but the evolution of the electronic health record I believe today has established some reasonable rules and continues to work at defining it, rolling it out, and ensuring clarity and transparency. I think that where some of that clarity and transparency would be achieved is part of the work around the pan-Canadian framework and the consent issue when it comes to Albertans understanding how their information will be shared electronically. Over and above that, I don't know that there would be much more that we would be aware of early in 2005 that we're not currently aware of. But, you know, we'll obviously take your direction on that.

The Chair: Thank you.

Mr. Goudreau: Mr. Chairman, I guess the use of electronics in record-keeping and all types of transactions is moving extremely rapidly, and I agree with Dr. Pannu in the sense that there's a certain amount of urgency to look at that and be on top of it. If I can quote the recommendation, it says that "Alberta Health and Wellness should consider the need for more clear and transparent rules for the electronic health record prior" – and I emphasize the word "prior" – "to the next full review of the Act by a committee of the Legislature." So basically the recommendation indicates here that this be reviewed even before that committee is struck.

The Chair: Good point.

Dr. Pannu: I think the recommendation here certainly makes a reference to the work that the Department of Health and Wellness needs to do prior to that. That's clear. That's not my concern. My motion is about the legislative committee addressing that on its own when it is established in the spring, and as you said, there's an urgency to this matter. Matters are moving ahead quite fast. I think we as a Legislature committee need to return to this issue as well as encourage the department to do its own work.

The Chair: Thank you.

Dr. Pannu's motion, then, is basically to recommend that

> this subject be considered by the committee that's going to be recommended to be formed early in 2005.

So if this motion passes, then it would become one of the recommended priorities for that committee.

Are you ready for the question? Okay. By show of hands, in favour of the motion, please raise your hand. Opposed? Carried.

Recommendation 16.

10:10

Ms Swanson: Recommendation 16 is that "a provision should be added to HIA to allow for the collection, use and disclosure of a unique identifier for health service providers for authorization and authentication purposes in the electronic health record."

Dr. Pannu: I wonder, Mr. Chairman, if this recommendation is in fact redundant. This recommendation 16, in my view, is now redundant. I think it becomes part of the package that recommendation 15 entails.

Ms Miller: This is a specific issue that we have certainly come across in our developments to date around the development and rollout of an electronic health record, and it has become a substantive issue and almost at times a barrier to effective rollout of the electronic health record. Making this recommendation and having that accepted and drafted in legislation would certainly enable the electronic health record. This is one area where we have considerable experience and do encourage the committee to consider that.

The Chair: So your recommendation is that we need to do this now and not wait until some future date?

Ms Miller: Yes.

Dr. Pannu: I'm certainly willing to seriously consider your view on it, but you need to elaborate on it for me. You say that its absence is an impediment in the development of the EHR system?

Ms Miller: Yes. For people or custodians or affiliates of custodians to have access to an electronic health record, we need to ensure that we have provided the right access to the right person, meaning that they have the authority for the role they have and that they are indeed who they say they are. To do that, you need to uniquely identify everybody at an individual level who has access. The way to do that consistently across the multiple number of information systems that the electronic health record pulls together, if you will, is only through the establishment and use of an identifiable number, and that's what this number is referring to.

Dr. Pannu: With the jurisdictions that are currently quite advanced in establishing their electronic health records, such as the Capital health authority, how are they able to make progress if this information is so critical to the development?

Ms Miller: Yes. We have found a workaround, if you will. We're using and have received permission from the Privacy Commissioner's office to use the registration number. For licensed professionals that works because as a licensed professional you have a registration number. However, that has been after much discussion and review of the legislative authority to do that.

Where that doesn't work is when we get to unlicensed professionals. They don't have registration numbers. You know, those kinds of categories of service providers who, given a particular role and with a particular custodian, would need in many cases access to the electronic health record. So that's where we need this unique identifying number for each provider regardless if the person is a licensed practitioner or not.

The Chair: Wendy, yes, go ahead.

Ms Robillard: Yes. I'd also like to clarify a few other points. Linda is right. Within a custodian organization they have ways to identify the affiliates and to use that identifier within a custodian organization. However, affiliates work for multiple organizations. Nurses work for one region and they work for another region. Doctors work in Edmonton; they also fly up to Grande Prairie and provide service. Every time they enter the system, we want to know if it's the same individual with the same privileges or not. So the minute we link it provincially, we need to know, when a person accesses a provincial EHR, if it's that person in Edmonton or if it's another person in another jurisdiction. So we need to be able to create and share numbers across jurisdictions so that we know, when people are accessing information consistently, that it's the same person.

Right now every employee has a unique identifier in each health region and in each role that they perform, so that's a challenge. We don't know that they're the same people. This way we'll know who is accessing across systems, and it will be consistent between systems. So if an individual is only using an electronic health record within Capital health, they'll have a number that Capital health can relate to, but the minute they start linking to any other systems, we need to know who that is as well.

Ms Blakeman: For clarification, then, we could have health providers with a number of different unique identifier numbers? Thank you.

Dr. Pannu: My question is to Linda. She referred to some unlicensed professionals. I thought professionals who provide health services – professionals by definition have to be licensed. So who would be the ones that are not licensed and are providing professional services?

Ms Miller: By the truest definition of the word "professional" you're correct, Dr. Pannu. I probably should have used the comment, "unlicensed health care providers." A group that comes to mind would be aides, nursing care aides, frequently employed in home care facilities that do provide direct care to residents of those facilities. That's a typical example of an unlicensed health care provider.

When I say "licensed" in this context, I mean licensed by a professional association like the College of Physicians and Surgeons and the Alberta Association of Registered Nurses.

The Chair: Okay. I'm assuming that we can accept this one and move on. But before we move on, I propose we take 15 minutes for a break. Is that agreeable? Okay. We'll reconvene at 10:35.

[The committee adjourned from 10:17 a.m. to 10:36 a.m.]

The Chair: Are we ready to go with collection of health information, 17? All right.

Ms Swanson: Yes, we are.

While we were on the break, we did follow up on a question that was asked earlier: what are the overriding issues that the next committee of the Legislature would deal with in 2005? Would you like me to just run through that first? It will provide more context as we're going through.

The Chair: Sure. Very good.

Ms Swanson: First of all, there are four main areas. There are a number of specific recommendations, but they really boil down to four main areas. One is the scope of the act and its application to health service providers; that is, professionals and health service organizations. The other one is the recommendation around taking a look at a new type of entity that has as its principal mandate the manipulation of health information, like CIHI. So all of those relate to scope. We also said that because the committee would be looking at new entities, it would be important to look at the purposes for which they can collect, use, and disclose information. So that's one bundle around scope.

The second major area would be follow-up on the pan-Canadian framework once that is finalized. Consent is a really big issue, and genetics is another issue that might be dealt with in the framework. There would be some other points as well, but the big one is around consent.

The third major area is the powers of the Information and Privacy Commissioner. There were a couple of items deferred.

The fourth area is the electronic health record, that you've identified today as one that you want the committee to look at, and the question around clear and transparent rules.

The Chair: Thank you very much, Evelyn.

Seeing no questions, we can perhaps move to 17.

Ms Swanson: Recommendation 17 deals with the collection of health information. The committee recommended that "no changes are required to the duty to collect health information directly from the individual except as authorized."

Recommendation 18 deals with a request from Canadian Blood Services. The committee recommended that

> provisions respecting collection of health information for public health purposes should be considered by a committee of the Legislature early in 2005 when additional health service providers are considered for inclusion within the scope of [HIA].

Recommendation 19: "Provisions respecting the collection of information about the individual's family health history without the consent of family members should not be amended."

Recommendation 20: "The duty to inform individuals about information collection practices should be reviewed by a committee of the Legislature early in 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized."

Then if there are no questions or comments on those, we'd be moving on to the use of health information and again have provided a bit of background on what the current provisions are and some information about what the stakeholders have to say. Committee recommendation 21 at the bottom of page 14 was that "no changes are required to the current list of purposes for the use of individually identifying health information without consent."

Recommendation 22: "The new committee of the Legislature should consider the list of authorized purposes for the use of identifying health information when it reviews the addition of health service providers and health service organizations early in 2005."

The Chair: Okay. Let's go to elements of consent.

Ms Swanson: Recommendation 23: "A committee of the Legislature should consider the matter of consent in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized."

Okay. Under Discretionary Disclosures without Consent the recommendations start and conclude on page 16.

Recommendation 24:

> The Act should be amended to allow for disclosure of individually identifiable diagnostic, treatment and care information without consent to:
>
> - Health departments of provincial, territorial and federal governments for health services provided to persons under their jurisdiction
> - Alberta government departments or federal government departments for determining eligibility to receive a health service or a health-related service or benefit, or for payment purposes
> - Third parties for payment purposes
> - A successor where the custodian remains a custodian but transfers records
> - First Nations police services on the same basis as permitted to other police services.

Dr. Pannu: If you'll refresh my memory on it – I don't have a copy of the act before me. The provisions in the current piece of legislation: they clearly are inadequate or absent. Is that why we're making these amendments? If so, equally so in all of these areas? How have we functioned without them so far? You know, payments have been made; third parties have been paid.

Ms Miller: I believe my answer the last time this was raised was that we have continued to respect long-standing practice and need to have that reflected in legislation. You're right; all of the above has continued to carry on in order to manage the system appropriately.

Dr. Pannu: Wendy is shaking her head, saying no.

Ms Robillard: Some practices. The "third parties for payment purposes" clearly has. We've had discussions with the commissioner and the stakeholders and arrived at that. As Linda said, in the first situation we continue to disclose to other provinces. However, "determining eligibility to receive a health service": no, we have not disclosed on that basis very clearly.

"A successor where the custodian remains a custodian": again, in consultation with the commissioner's office, yes, that did happen. Files transferred because responsibilities transferred.

"First Nations police services": I can't speak to that one because that would be primarily from other regions. They don't typically come to the department to request information.

Ms Miller: Wendy is correct.

10:45

Dr. Pannu: The first bullet there I think addresses matters related to migration, people living on one side of the border accessing services on the other side of the provincial border. Is that it?

Ms Robillard: Yes. Or individuals travelling, et cetera. Yes.

Dr. Pannu: Okay.

The Chair: Okay. Recommendation 25.

Ms Swanson:

> The Act should be amended for consistency with the Health Professions Act to authorize professional bodies to retain health information used in an investigation or a hearing for ten years instead of destroying the information at the earliest opportunity.

Recommendation 26:

> The Act should not be amended to authorize disclosure of individually identifiable diagnostic, treatment and care information without consent to:
>
> - Collaborative or integrated programs
> - The Canadian Medical Protective Association for medical-legal purposes
> - The clergy or any person, the presence and location of an individual in a health facility
> - Any person to address a complaint or allegation made in a public forum.

The Chair: This bullet on clergy: is there not some way we can make it so that clergy can visit their people?

Ms Swanson: They can on the basis of consent.

The Chair: But what if I'm dying and they want to come in and visit me before?

Ms Swanson: Wendy would like to comment on that.

Ms Robillard: Yeah. I think there's also provision for family

members, obviously, to contact the clergy, assuming that the family is also engaged with that organization or would know of the individual's desire to have somebody come visit.

Dr. Pannu: On the same item, Mr. Chairman, the question that came to my mind was: how will the clergy be identified? The clergy's own claim that he or she is a clergy who wants to visit such said person, or would there have to be some proof of identity? It does open up the field to this question: could some pretenders go in on that basis?

The Chair: Identification of clergy. Any comments?

Ms Robillard: I would presume that in most organizations they would be familiar with the clergy because they visit on a regular basis. I presume that if there's a new clergy member that comes or somebody who hasn't previously visited, yes, they would probably make some inquiry. I'm not sure, again, because we're not on the front line, exactly what would be required at a regional health authority level.

The Chair: Anyone else?

I'm not sure we've alleviated the rabbi's concern here.

Ms Miller: No, we haven't.

The Chair: It strikes me that there's got to be a better balance here.

Ms Blakeman: We've clearly had this discussion twice now, and we voted against it. It appears on page 326 of the September 28 *Hansard* recording that they already have access to a list of people who have identified – in other words, have given their consent – that their individually identifying health information would be released to lists of clergy.

The question was: did the rabbi and others get access to the entire list of everyone in the hospital to go through it, comb through it, to see if they could choose other people off that list? We've done this twice.

The Chair: Okay.

Let's move on. Recommendation 27.

Ms Swanson:

> The Act should not be amended to:
> - Remove ability to disclose to the Chief Electoral Officer
> - Restrict disclosure without consent to purposes related to direct care and treatment
> - Require the individual to be notified before disclosure without consent [or]
> - Prohibit disclosure of psychological raw test and data scores except to those qualified to interpret them.

Mr. Snelgrove: Mr. Chairman, if I might. Just the way the last two are written does not leave it very clear what they're doing. It's kind of like a double negative there. You'd think it would be more appropriate to say it in the positive.

The Chair: The last two bullets?

Mr. Snelgrove: Yeah. "Should not be amended to remove": it doesn't make sense.

Ms Swanson: The wording is a bit convoluted. I'll see what I can do.

The Chair: Okay. Thank you.

Disclosure to police services.

Ms Swanson: Okay. In this one we have identified background information again about how the act currently works and applies, what the stakeholders said about the matter, and particularly what kinds of things the police services were asking for.

Then the committee recommendations on page 18, a series of recommendations starting with 28:

> The Act should be amended to allow discretionary disclosure to police services of limited registration information, limited diagnostic, treatment and care information and limited health service provider information when the custodian has reason to suspect that a person seeking health services has been involved in some form of criminal activity. For example, disclosure could be limited to patient name, address, location in a facility, date of admission and name of physician.

On this one I did clarify in the actual wording of the recommendation that this is a discretionary disclosure. It's not a mandatory disclosure. That one is dealt with, I believe, in recommendation 30. So this is a discretionary disclosure, and it would be a responsibility of the custodian to make the determination of whether or not they suspect a person has been involved in a criminal activity.

The Chair: Okay. Mr. Lukaszuk, followed by Dr. Pannu.

Mr. Lukaszuk: Thank you, Mr. Chairman. I'm not sure if the wording of this recommendation fully reflects what the intention of the committee is, as it says "discretionary disclosure" when the health care provider feels that the person was involved in a criminal activity. But what we dealt with were instances where a police officer arrives at an emergency, describing an event, and looking for a person with certain types of afflictions, you know, wounds.

Now, do we still leave the discretion to the health care provider to decide whether he feels that that person would have been the suspect of this criminal activity? It becomes very convoluted. You know, just to bring it down one more notch: a police officer arrives at an emergency and says, "I'm looking for somebody who was shot or stabbed." The service providers will have to make the decision whether their shooting victim was indeed the person whom they want to disclose to the police officer. Is that the right shooting? Is that the same victim? Are they linking him to the same crime?

The Chair: Thank you, Thomas.

Any response to that, Evelyn or Wendy or Linda?

Dr. Pannu: Recommendation 28: I just want clarification, Mr. Chairman. Is my understanding correct that the amendment changes the existing provisions for disclosure, in this case with respect to the second bullet under existing ones, and the only change is "unless disclosure is contrary to the express request of the individual," that it's not the express request of the individual, that is the patient, but the discretionary judgment of the care provider – right? – that now prevails?

Ms Swanson: Right.

Dr. Pannu: Okay. Thanks.

The Chair: Did you have a comment on Mr. Lukaszuk's question, Linda?

Ms Miller: Just interpretation. If we were to remove the phrase "discretionary disclosure" on behalf of the custodian, that would

mean that the custodian would have no discretion at all. It would be completely at the interpretation of the police. I just bring it for clarity, for the committee's understanding.

Mr. Lukaszuk: Well, we know how the custodians feel about this particular issue. They're very resistant to disclosing any information. Now, if you have "discretionary," you know how the discretion will be applied. Will that put our police officers in any better position following the amendment than they are right now? Why need we leave the discretionary authority to the service provider when a police officer arrives requesting a list of patients with a particular type of wound that could be related to an incident?

10:55

The Chair: When the committee dealt with this issue, we had two or three options to choose from. As I recall, we selected one option, and then we had an additional motion, which is covered in item 30. Does someone have a copy of what we looked at last time?

Ms Blakeman: Well, it appears on page 3 of the discussion paper Disclosures to Police Services. The motion itself by Mr. Lukaszuk is appearing on *Hansard* page 295. He moved that "the committee adopt recommendation 3 as it appears in the document entitled Discussion Paper: Disclosures to Police Services."

The Chair: Would you read number 3?

Ms Blakeman: Number 3 reads:

> Disclosure of registration information and limited disclosure of diagnostic, treatment and care information and possibly health service provider information when it is reasonably suspected that a person seeking health services has been involved in some form of criminal activity. For example, disclosure could be limited to patient name, address, location in a facility and date of admittance.

The Chair: Thank you, Ms Blakeman.

Mr. Lukaszuk: Hence my point. That recommendation nowhere gives the service provider the discretionary authority. The word "discretion" doesn't appear in recommendation 3.

Ms Swanson: Just to make the comment that the option was not explicit about whether it's mandatory or discretionary, so I think it's appropriate to draw a conclusion about which was intended. The second is that it doesn't specify who would have reason to suspect. For clarity purposes it probably should specify who would be the party suspecting.

The Chair: I believe the word "reasonable" was used in the one Ms Blakeman read. Is that correct: if there was reasonable evidence?

Ms Blakeman: Yes. "Reasonably suspected" is the quote.

Dr. Pannu: I think, Mr. Chairman, that the amendment made in recommendation 28 considerably strengthens the chances that the care provider will take into account the concerns of the investigating police officer.

The reason I say this is because the matter of making a decision based on first-hand medical knowledge of the patient, you know, what state that person is in, what kind of wound it is, whether the person is intoxicated or not or whatever or smells of gunpowder or whatever – now the ability of the caregiver to get this information and then make a discretionary decision on it is enhanced considerably because the ability of the individual patient to prevent that from happening has been removed by way of amendment 28. That to me is as far as we should go. We shouldn't now go beyond this to make it mandatory to provide the information on request.

If I recall, the silver-haired doctor who was here before us representing the AMA said it very clearly, that his experience says that we do provide information and we do worry about, you know, criminals using hospital facilities as refuges. All he said we need is this removal of the ability of the person who allegedly may have committed a crime to be able to say: well, you can't disclose this information because I ask you not to. That ability has been removed, so I think that fixes the situation and strikes a good balance between the ability of a health care provider and an institution to on the one hand protect the privacy of people who go there for services and on the other are concerned about public security and the ability of the police to enforce law at this stage through investigation and getting co-operation of the institution or person involved from the side of the health care provision.

The Chair: Okay. Thank you.

Mr. Lukaszuk: Mr. Chairman, with all due respect, we're not here to renegotiate or reargue the motion. I have put a motion on the floor with very specific wording in it reflecting that over recommendation 3. The word "discretionary" was not included in my motion. We have duly voted on this. It passed by a resounding majority. I suggest right now that in order to honour that vote, the word "discretionary" be removed from recommendation 28.

The Chair: Okay. I would like to have the other comments before we deal with that.

Mr. Lougheed: I would concur with the last comments. As I recall – and I'm looking at the option 3 that we voted on – option 3 says: disclosure when it is reasonably suspected that a person seeking health services has been in some criminal activity. Here it says in 28: allow discretionary disclosure when the custodian has reason to believe that a person has been involved in some criminal activity. So it seems that when I voted on 3, it was with the expectation that there would be disclosure, not that there may be some other considerations taking place.

Mr. Snelgrove: Mr. Chairman, it depends a great deal on where you put the term "discretionary" in context. The discretionary disclosure limits what you release. If you take it as the sentence says, that they will release discretionary information, "discretionary" probably confuses it more where it is. Because we've limited what is nondiscretionary, what is discretionary information? So if you read the sentence that they will release discretionary information, or disclosure – their name, the incident, the time, the medical treatment but not whether he's HIV, whether he's this, or whether he's that – they would give the discretionary information to the police officer.

If you want to jump aside and say that they then have the discretion to release that, that's not what the sentence says. It says "discretionary disclosure." In our terminology of this document, we have different kinds of disclosures. So you might want to clear up the wording, but this doesn't say that he has the discretion to release it; it says that he will release the appropriate information.

Ms Blakeman: Well, the question of whether it's mandatory or discretionary disclosure is not in the original motion as proposed by Mr. Lukaszuk. He refers to the words as written on the page, and they do not qualify in any way. So neither "mandatory" nor "discretionary" appears in the original motion, and that's the motion

that Mr. Lukaszuk put forward. In the motion that follows, it does clearly say "mandatory reporting." So I don't know why Mr. Lukaszuk didn't put it in in the first place, but it's not in there; he just refers. The sentence starts with "disclosure." It doesn't say mandatory disclosure. It doesn't say discretionary disclosure. It just says disclosure.

The second thing that's missing from there is by whom? It doesn't say on whose basis someone is reasonably suspecting. Is this the police officer's suspicion or is it the health provider's suspicion that is reasonably suspecting? So there are two flaws in the original motion.

Mr. Lukaszuk: Well, you know, I'll give a lot of credit to those who try to block this motion right now in trying to get a second kick at the barrel, but the motion is very clear. If you read the *Hansard* prior and read the arguments, the answer would be very clear to you. The motion is not in a vacuum over there.

If you were to take recommendation 28 and simply remove the word "discretionary," it will exactly reflect what the intention of my motion was. If there's anybody that can't clarify what the intention of my motion was, I can do it for you now on the record. The motion was that the discretionary aspect was not to be included. Whenever police have reasonable and probable grounds to believe that there is a patient in the hospital that could be involved in any criminal activity, that information should be provided to them under that mandate.

11:05

So I suggest, Mr. Chairman, that the recommendation, in order to reflect my motion as it was passed, read that the act should be amended to allow disclosure to police services of limited registration information, limited diagnostic treatment and care information, and limited health service provider information when the custodian has reason to suspect that a person seeking health services has been involved in some form of criminal activity. For example, disclosure could be limited to patient name, address, location of facility, date of admission, and name of physician.

The Chair: Mr. Lukaszuk, the discussion here revolves around whether or not recommendation 28 reflects the intent of your motion.

Mr. Lukaszuk: Right.

The Chair: You're submitting that it does not. Are you prepared to make another motion to amend this recommendation?

Mr. Lukaszuk: Yes, I am.

The Chair: Okay.

Ms Gray: May I clarify one thing before you move?

The Chair: Certainly.

Ms Gray: In my view what the committee wants to accomplish in this recommendation is mandatory reporting. Probably they should take out the words "allow" and "discretionary." Allow is permissive. If what you want to be is directive, then probably you should substitute the word "require" or "mandate," something that specifies, if that is the committee's intent.

The Chair: Mr. Lukaszuk, are you in agreement with that? It's your motion.

Mr. Lukaszuk: That's correct.

Mr. Chairman, to reflect the requests of the police service departments from Calgary, Lethbridge, and Edmonton and to reflect the nature of the discussion that led to the final voting on this motion, we have to amend recommendation 28 in such a manner that it is clearly understood that there is no discretionary authority to withhold information from law enforcement services by custodians when law enforcement agencies have reasonable and probable grounds to believe that individuals involved in either criminal activity, motor vehicle accidents, or other matters under investigation are in receipt of medical care at a given facility.

The Chair: Okay. Questions?

Ms Blakeman: A request for a recorded vote on the motion.

The Chair: Yes, certainly.

Dr. Pannu: Mr. Chairman, I think Mr. Lukaszuk's point of view is that it's essentially clarifying, but there's a major change, it seems, in the intent behind the motion. As Holly suggested, we're really moving towards a watertight mandatory sort of, you know, disclosure obligation. It does raise some important questions about the ability of hospitals and other such institutions to strike the kind of balance that they are also obliged to by their professional legislation and by the ethics that govern their conduct and the needs for the police to be able to make sure that undue use of institutions such as hospitals is not permitted, particularly by people who are likely to have committed crimes.

In my view, if we remove the word "discretionary," I hope that will satisfy the hon. member, but what's being proposed is going too far. I think we need further consideration of this matter. Just quickly making such a radical change on the spur of the moment wouldn't seem to be appropriate to me.

The Chair: All right. Thank you.

Mr. Goudreau: Mr. Chairman, in the recommendation, the third sentence. It sort of says, "Limited health service provider information when the custodian has reason to suspect." Just the fact that is says "has reason" still leaves it quite open for the custodian to make that decision. So we're really not forcing the custodian to do it. He still has to have reason to be able to go forward with that.

The Chair: Thank you.

Mr. Lukaszuk: Well, I can make a motion with the new wording of the recommendation if it's appropriate at this time.

The Chair: Okay. Could I take Mr. Snelgrove, and then we'll come back and clarify the motion.

Mr. Snelgrove: I don't have any problem taking out the "allow discretionary" at the start, because I think we want this to be reported. But we also have to protect the disclosure, which is where I connected the "discretionary." So when you go to the next sentence, where it says "for example, disclosure," that is an explanation of what the discretionary disclosure would be: not that they wouldn't have to report, but they would only report what was relevant information.

If you're going to remove the "discretionary" at the start or at the basis of the motion, you have to put it back in at the end, saying that we have no intention of them releasing all information, just relevant,

or discretionary, disclosure. I agree with the mandatory reporting, but you have to put fences around what they can report.

The Chair: Thank you. Good point.

Ms Gray: I believe the intent behind the recommendation is that the disclosure would be limited to those items that are set out here. If the committee wants to consider, you know, whether that reflects what the committee wanted, I think it's worth looking at and considering. But I believe our view is that if we put this amendment into effect, the disclosure would be limited to those items that are listed in the recommendation, and if the conditions are met, the police would be entitled to all of that information if it's mandatory. If it's discretionary, yes, they could give some or all, but if it is mandatory, the police would probably take the position that they are entitled to all of that information that's itemized.

The Chair: Thank you.

Mr. Lukaszuk, are you intending to move an amendment here?

Mr. Lukaszuk: Yes, Mr. Chairman. I'd like to move an amendment to recommendation 28 to read as follows:

> The Act should be amended to mandate disclosure to police services of limited registration information, limited diagnostic, treatment, and care information, and limited health service provider information when the police have reasonable grounds to suspect that a person seeking health services has been involved in some form of criminal activity. For example, disclosure could be limited to patient name, address, location in a facility, date of admission, and name of physician.

The Chair: Mr. Snelgrove, does that satisfy your concerns?

Mr. Snelgrove: No, and I'll tell you why. It's not just the police. If an ambulance picks someone up at a gang shooting, they should be the first call to go to the hospital, obviously, and then they should be reporting it. But when someone shows up at the hospital, the police may not have any idea there's been a crime or there's been a shooting. If you wait for them to ask, I think you're missing – the providers should be the ones that report. They're the first one that'll know. Or the police. I mean, you can connect it in there. But most certainly the ambulance and the hospital should.

The Chair: Thank you.

Ms Gray: I'd just like to point out one issue that may arise in the practical application of this. If you have a provision that says that a custodian must disclose when the police have reasonable grounds, I think the custodian may be put in a position of asking the police to provide evidence or something that establishes the reasonable grounds. I'm not sure what that will be. It will probably be different for each custodian based on the legal advice they get and based on the various situations that they involve.

When you switch the person on whose reason or belief we're basing this provision, it may raise an issue where police will come and say: I have reasonable grounds to suspect that a person seeking health services has been involved in some form of criminal activity, and therefore I want this information. The custodian may say: all right; I need something to show that you have reasonable grounds. I can't speak for the custodians to say what that might be. It might depend on the circumstances. The department probably is not going to be in that position. A health service custodian may simply say: well, you need to sign a piece of paper and verify that you have reasonable grounds. They may require more. They may take the position that if you have reasonable grounds, you should have a warrant or a subpoena. It's just an issue that you should be aware of that might have practical implications.

11:15

The Chair: Thank you.

Mr. Lukaszuk: Would the reasonableness of the grounds be tested at the moment of request, or would a police officer be simply signing a form indicating that it is his belief that he has reasonable grounds? If in the future the person whose information was accessed wants to challenge the police, then the decision whether the police had or had not reasonable grounds could be determined by the Privacy Commissioner or the courts.

Ms Gray: Yes. It's likely to be the courts in a criminal context. I don't know the answer to that. It may depend on the situation. I expect that a court would look at it at the time that the power was exercised.

Mr. Lougheed: The first part of the motion talks about "limited registration information, limited diagnostic, treatment, and care information and limited health service provider information." It seems inappropriate to have the "for example" in the second sentence, which doesn't state anything about the "limited diagnostic, treatment, and care information." If the discretionary disclosure, as was pointed out by Lloyd, is limited to these things or if we want to identify that these are the four different things that can be allowed, then it doesn't agree with the first part, which I think almost should stand alone without this "for example" there.

The second point with respect to the discussion here. It seems that it's the custodian that has to have the reason to suspect that there's been some criminal activity, and it doesn't say where he gets that information from. If he sees that he has a bullet hole, it's hard to say how the physician would interpret that. If he gets it from some other source, what other information comes to him if he has "reason to suspect," that seems good enough for me.

The Chair: Thank you. Bullet holes are pretty good evidence.

Ms Miller: Just a point of clarification to the comment. Location of facility and date of admission are considered diagnostic, care, and treatment information and even, potentially, physician names.

The Chair: Thank you.

Mr. Lougheed: Would you repeat that, please?

Ms Miller: Sure. Location in a facility and date of admission are considered diagnostic, care, and treatment information and potentially even physician names.

Mr. Lougheed: I don't dispute that, but you're reversing what my statement was.

Ms Miller: Sorry. I'm not meaning to.

Mr. Lougheed: The statement is that there could be discretionary diagnostic treatment. I agree that patient name is part of diagnostic treatment, but there may be more than patient name and the location of the facility and so on. There may be more than that, to my mind.

Ms Miller: The intent of including examples was to add clarity in terms of the kinds of limitations that typically would be involved.

Mr. Lougheed: But my point is that it obscures it. It doesn't add clarity. It limits it.

Dr. Pannu: I think the example that's given here elaborates on what's meant by limited information, that this is what's meant by releasing limited diagnostic information, and that would be the limits to it. That's what it seems to suggest to me. When you say limited diagnostic information, then I say: give me some examples. What kind of diagnostic? You are saying: here it is.

Ms Miller: Yes, and perhaps the confusion is that we've just stated it as an example and not, "This includes and is limited to the following," which would add more clarity, but they do reflect the categories as identified earlier in this section.

Mr. Lougheed: What is being stated, though, seems to contradict. I think you stated earlier that from the legal profession's point of view if this example was in there, that would limit what was being disclosed to these things, if I heard you correctly, which seems to be more limiting than the stem of the recommendation.

Ms Gray: Yeah, I believe the intent of the recommendation, although it's worded this way, was to use the information that is itemized at the end as the category of information that you can get that is limited: registration; limited diagnostic, treatment, and care; and limited health service provider. So perhaps that's just an issue that can be revisited and clarified for the purposes of accomplishing what the committee intended.

If the limited registration information, the diagnostic, treatment, and care and health service provider information that you intended to be able to disclose to the police were those items at the end, then we'll simply clarify that and itemize them. Because in legislation we'll either have to – my recommendation would be to itemize what it is you're interested in disclosing. When you use the terms that are used a littler higher up, although they might be fine for a recommendation, for legislation that would be ambiguous.

So I would recommend from a purely legal point of view that the committee determine exactly what types of information they would like to disclose to the police and put that in the recommendation.

The Chair: Wendy.

Ms Robillard: Yes. As I go back to the discussion and consideration in oral presentations, it's my understanding that we are trying to give the police some information but a limited amount of information to enable them to obtain a warrant, which enables them to come back and get all kinds of information should the warrant require it. I think we were trying to respond to their issue around their inability to even be able to obtain warrants to then get the further information. I think the discussion, as I recall, from the police in the oral presentation was that that was their primary focus and their primary concern. It may not be the only concern, but they were clear that it was the primary concern. I just wanted to bring the committee back to that point as well.

The Chair: Okay. Mr. Lukaszuk, we've been trying to get to you for quite a while, so go ahead.

Mr. Lukaszuk: Thank you, Mr. Chairman. Indeed, that is the intention of this entire motion, to give police enough information so that they can secure a warrant and then access any other information that they may require to execute arrest.

I may bring an amendment to my motion. I'm not sure if the four examples that are given in the last sentence following the "for example" will be sufficient. They don't include the nature of an injury that a patient is suffering, which may be important to link a person to an incident in order to be able to secure a warrant in front of a justice. Simply appearing before a justice and asking for a warrant for an individual is not good enough unless you can link that person to an incident and show the judge that you need access to that person's health records because it is that person. Those four items that you use as an example would probably not reasonably achieve that in the mind of a justice of the peace or a judge. So we would have to include some nature of injury or some limited diagnostic information, which is in the first sentence but not in the second one.

11:25

Going back to this discretionary authority, why not grant the medical professionals the authority to make a decision whether a police officer has or hasn't reasonable grounds to believe? Simply from the fact that it would be unreasonable to the custodians or the medical professionals to ask them to make that decision. What can they base their decision on? They're providing medical care to an individual who is suffering from some abrasions or wounds or whatever it may be. How can they possibly, based only on injuries, conclude that this is as a result of a criminal activity? Even though, as the chairman indicated, a gunshot wound is pretty good evidence, it would be very unreasonable for a medical doctor, when the only piece of information he has is a patient with a bullet, to conclude that this is from a criminal activity. Maybe somebody tried to commit suicide. Maybe somebody accidentally shot himself. Not necessarily does it have to be criminal.

So I don't think that at any given time custodians have sufficient information to be able to conclude that something is as a result of a criminal activity, particularly when the patient probably will tell him that it's not, and then disclose that information to a police officer. They simply don't have sufficient evidence; hence, the grounds will have to be established by the police.

The police will have to have reasonable grounds to believe that someone may have been involved in a criminal activity, based on their preliminary investigation coupled with the injuries that a subject has in the hospital. Then, as per protocol, as per the due course of law, if police have acted prematurely or have obtained evidence under false grounds or under insufficient grounds, their investigation will collapse upon that in a trial or in a judicial review.

The Chair: Mr. Lukaszuk, correct me if I'm wrong – and I probably am – but what I thought we were trying to do here was to mandate custodians to report patients where there's evidence of criminal activity, whether it's a gunshot wound or a knife wound or whatever the case may be. If someone looks like they've been beat up or shot or knifed or whatever, the custodian should assume that perhaps something is untoward here and would report it to the police. We require it to be reported to the police. It's not that they have the discretion to report it, but they need to report it to the police. Am I correct with your thinking here?

Mr. Lukaszuk: You're correct, but in addition to that, when they are not the primary reporters, when the police arrive with questions, they should also be forthcoming and provide the police with enough information so they can secure a warrant.

The Chair: Okay. Forgive me, but they may not know more than what they see or what they examine or what they find. So you're suggesting that all the evidence they have be submitted, disclosed to the police?

Mr. Lukaszuk: No, Mr. Chairman. Our debate and our vote was that if a police officer arrives at an emergency and says, "Have you anyone with gunshot wounds in your ward?" they provide the police officer with enough information so he can go to a judge, obtain a warrant, and then pull that entire record and be able to arrest a person.

The Chair: All right. Does the technical team want to take another shot at this one? Mr. Lukaszuk, your motion is on the table, so if you want to proceed with the motion, we will.

Mr. Lukaszuk: Well, if the technical team can provide us with a better wording more reflective of what the initial intent was of the initial motion which was passed by the committee, then I would rather have them take a shot at it. They're much more competent at doing so than I am. So if they draft something more reflective of the intent, I would be happy to pull my motion off the floor right now and then vote on the new wording.

The Chair: Okay. I guess we'll go to Linda or Wendy or Evelyn or Holly for some response to that.

Ms Miller: Sure. We can certainly work on wording over the lunch hour rather than doing it on the spot, but we just need a little bit of clarification so that we do come back with the appropriate intent of the committee.

Are we seeking with recommendation 28 to have mandatory disclosure of the limited information to police once the police present with an inquiry as well as mandatory reporting? So that means that the custodians would be required to actually take the first step of reporting to the police.

We understood by your recommendation under 30 that that's where the mandatory element came into being, where there would be mandatory reporting under those three instances where they needed to call the police directly and advise the police that somebody has come to their particular health service and that this has occurred. I need to understand what you want to capture in recommendation 28 as it differs from recommendation 30 so that we can draft the right thing.

The Chair: Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. Well, there are two issues. When the police initiate the investigation and ask questions, how much do we answer? The second one is: if police don't initiate, should the custodians, the health care providers, initiate by calling the police?

We have passed both. Under 28 we have passed that when police arrive and request information, we provide it to them. Under 30 there was a motion put by the Member for Edmonton-Centre, Ms Blakeman, that the government should consider passing a separate, stand-alone bill mandating the health care providers to initiate reporting suspicions to police. I support both and the committee supported both, so I would suggest to you that it would stand to reason to encapsulate both of them into 28, alleviating the need to deal with number 30. Why draft a stand-alone when you can address the issue in 28?

Ms Miller: Just a point of clarification. Under 30 our understanding, up until this point in time anyway, was that mandatory reporting would only be in the instances of gunshots, stabbings, and severe beatings. If we were to include mandatory reporting under 28, it would mean for that and whatever else might occur, you know, in terms of some suspected criminal activity. So that's the difference.

The Chair: I have two additional comments from Ms Blakeman and Mr. Lougheed.

Ms Blakeman: If I go back and look at the original request from the Edmonton Police Service, they were asking for disclosure of registration information without consent for law enforcement investigations and providing for disclosure of health service provider information without consent for law enforcement proceedings. Neither of those statements anticipates having the health service provider initiate.

The Lethbridge regional police were also looking for discretionary disclosure to police to be expanded to disclose registration information seeking a warrant, subpoena, or court order. Lethbridge did anticipate mandating health care workers to notify police with the same basic information when they treat a person whose injuries were caused in the commission of a crime.

The third one was the Calgary police, and they were asking for the information for the purposes of a warrant.

The Chair: Thank you.

Mr. Lougheed: Well, having neither extensive experience as a physician nor being involved in criminal activity, I would think that there are things I could agree with, the comment that I think Linda just made about, certainly, recommendation 30 as stand-alone for gunshot wounds, stabbings, and severe beatings. I had made the comment earlier, something about a gunshot wound, and of course it could certainly have been an innocent bystander who got in a crossfire. Was that criminal activity? Well, maybe that's something that should be reported or at least notify the police on because they don't know. Somebody just has a gunshot.

For example, a person smuggling drugs who had the container burst within a body cavity of one sort or another ends up in hospital. To my mind that's a criminal activity, and the police don't have a clue that that person is in the hospital. In the interests of the public and understanding the negative aspects of the drug part on the people we represent, I think that's something that should be reported without any question. It seems to me that 28 doesn't allow for discretionary disclosure. It's expected. I think the people I represent would expect that to happen.

11:35

The Chair: Thank you.

Ms Kryczka: I don't want to take us off track . . .

The Chair: Take us off. I'd like us to.

Ms Kryczka: Yeah. Not too far; right?

On the Protection for Persons in Care Act – and you were the chair, Mr. Chair. You know, this is more like in institutional care, such as long term care et cetera, that is government funded. Presently the act says that if you know that an abuse has taken place – anyway, it's mandatory reporting. So I think that there is in some way a similarity there. It should be the expectation. If you know about it, it should be mandatory to report it.

The Chair: Okay.

Mr. Lukaszuk, did I miss you?

Mr. Lukaszuk: Well, just to take us back to our previous debates, when I put the motion on compelling the health service providers to disclose information to police when requested, at that time I was

quite satisfied to rest at that point. But then the Member for Edmonton-Centre, Ms Blakeman, brought in a motion expanding that and saying: "No, no. We should go even further. We should now recommend to government to bring forward a stand-alone bill that would compel them to initiate investigations." When I heard that, I liked that. Definitely, the committee voted in favour of that.

I agree with Mr. Lougheed. Our constituents probably would expect us to support mandatory reporting of individuals who are reasonably suspected of criminal activity who arrive at our public health care facilities seeking help. If our technical assistance can help us to draft a recommendation that reflects my motion and the Member for Edmonton-Centre's motion into one, I think that would be the preferred option, not limiting it to just the wounds that she exemplified.

The Chair: I think the technical team have agreed to make that attempt.

Dr. Pannu, Ms Blakeman, do you have additional comments also?

Ms Blakeman: Yeah. From the beginning my concern with the proposal coming from the Member for Edmonton-Castle Downs has been that this motion is to deal with circumstances that are not urgent, because we already have laws in place by which the police can get this information if the situation is (a) life threatening, (b) urgent – in other words, they're in hot pursuit – and also covering vulnerable people, as has already been raised; in other words, if there is abuse of children or vulnerable people suspected under the Protection of Persons in Care Act.

The circumstances that are being described when we look at I guess it's now recommendation 28 are not circumstances that anticipate any urgency. So this is an officer who's got some extra time, is looking for a few people. They can go into the hospital and say: "I'm looking for Sam Jones. Is Sam Jones here?" I guess that if you're going to redraft this, we need the member to be very clear about under what circumstances he is expecting this to be used. It's not used in life-threatening situations. They already have the Criminal Code to do that. They already have all the provisions they need to do it under the Criminal Code. They don't need more. They don't need it if it's children et cetera.

So is he anticipating, then, that under nonurgent circumstances this is the kind of information that he is going to be expecting health care providers to be releasing? If he's going to ask the technical team to redraft, then he has to clarify that these are the circumstances that he's asking for, because I think he's about to propose something that is not Charter challenge proof, but he's welcome to do that.

The Chair: Okay. Before I give Mr. Lukaszuk the last word here, Dr. Pannu.

Dr. Pannu: Mr. Chairman, I think that it's important for us to look at these three or four recommendations as a package. Problems are arising because the four recommendations, recommendation 30 for example, cover some ground that I thought was ground some committee members wanted covered, you know, as reflected in the previous debate. If that ground is to be covered, then I think a separate, stand-alone piece of legislation might be, as Ms Blakeman suggested – although I had some concerns at that time whether it would be the right way to go.

Under 30, for example, there are cases – you know, the gang shootings – where there are criminals on both sides, and the wounded person may be a criminal as well and may not want the information to be disclosed. There may be other innocent victims whose privacy needs to be respected somehow if they so wish. So we need to be very careful where we are going and how far we want to go. Ms Blakeman drew our attention to the fact that there are already provisions built into existing legislation to allow the police under urgent circumstances to get the information, to have access to the information that they need.

The Chair: Okay. The committee has already voted on this issue previous to this.

Dr. Pannu: We are now revoting; aren't we?

The Chair: No, we're not revoting on that discussion.

Mr. Lukaszuk, are you leaving your motion on the table, or are you going to go to the committee for clarification and come back?

Mr. Lukaszuk: Mr. Chairman, no. I pulled the motion off the table, and I'm asking the staff to redraft it to reflect what has just been said.

The Chair: I think that's clear. I don't think we need to go into any more debate on what your intent is.

Mr. Lukaszuk: That's correct.

The Chair: Okay. So let's move on and try to cover a little more ground before lunch. We've got to do recommendations 29 and 30.

Mr. Snelgrove: Well, Mr. Chairman, let's skip that entire area and go to triplicate prescriptions.

The Chair: Yeah. I agree. Let's go to triplicate prescriptions.

Ms Swanson: Recommendation 32 deals with the triplicate prescription program. The committee recommended that "the Act should be amended to provide explicit authority for the Triplicate Prescription Program." Okay?

The Chair: Yes.

Ms Swanson: Moving on, then, to genetic information. The committee recommended that "provisions respecting genetic information should be considered by a committee of the Legislature in early 2005 when the pan-Canadian health information privacy and confidentiality framework is finalized."

The Chair: Okay.

Ms Swanson: Recommendation 34 deals with informed, knowledgeable, implied consent, and this also is being deferred to the committee of the Legislature to be established early in 2005. Okay?

The Chair: Very good.

Ms Swanson: Disclosures for research purposes.

The Chair: Did you want to do this one in conjunction with the other discussion?

Ms Swanson: Yes.

The Chair: So we'll discuss this one and the other disclosure aspect together?

Ms Swanson: Yes. We'll do that this afternoon.

The Chair: Okay. Thank you. Good.

Ms Swanson: Moving on, then, to duties and obligations on custodians. The recommendation is number 39 on page 22. The committee recommended that

> Alberta Health and Wellness consider the need for information manager provisions, information manager agreements, application of these provisions to custodians who are also information managers and the relationship between information manager provisions and affiliate provisions prior to the next full review of the Act by a committee of the Legislature.

So this was deferred to the department.

The Chair: Right.

Moving on.

Ms Swanson: Okay. Recommendation 40. The committee recommended that

> the requirement to note every disclosure of individually identifiable health information without consent should be retained and amended to not require notation of the purpose of the disclosure when the disclosure is made electronically through a system with automated audit capability.

The Chair: Recommendation 41.

Ms Swanson: Recommendation 41: "Alberta Health and Wellness should consult with stakeholders about the required period of retention for disclosure notations prior to the next full review of the Act by a committee of the Legislature."

Recommendation 42. The committee recommended that

> the requirement for written notification to the recipient of the purpose and authority for disclosure of diagnostic, treatment and care records should be retained, but amended to make explicit that the requirement does not apply where the disclosure is to the individual the information is about, and the disclosure is not in response to a formal application for access by the individual.

11:45

The Chair: Recommendation 43.

Ms Swanson: The committee recommended that

> no changes should be made to provisions respecting custodian duties in relation to affiliates, duties to protect health information outside Alberta, data matching, collection of the least amount of information necessary for the purpose, and privacy impact assessments.

Dr. Pannu: "Outside Alberta." Could you sort of elaborate what jurisdictions? Anywhere?

Ms Swanson: There is a provision in HIA that requires a custodian who is providing information outside the province, say, to an information manager or another service provider to have a written agreement specifying the security safeguards on that information. When the committee considered a request from a stakeholder to eliminate that provision, the committee decided no, it should be retained.

Dr. Pannu: I was curious about the "no changes . . . be made." But "duties to protect health information outside Alberta": this would be another provincial jurisdiction that we're referring to here, I think. That's all I'm trying to specify, this understanding.

Ms Robillard: Yes, it could be anybody outside of province. For instance, we have an agreement with CIHI in Toronto and Ottawa.

Dr. Pannu: Right. So it's a national scope but not beyond that. That's what I'm saying.

Ms Robillard: It just says, "outside Alberta."

Dr. Pannu: I know.

Ms Robillard: So if we entered into an agreement with somebody outside of Canada, these provisions would apply.

Dr. Pannu: Okay. That's what I meant.

The Chair: Okay. The commissioner, number 44.

Ms Swanson: Okay. The recommendation on the commissioner on page 24. Recommendation 44 is that "a committee of the Legislature established early in 2005 should consider the Information and Privacy Commissioner's request for explicit powers to audit and compel information for an audit."

Recommendation 45: the committee recommended that "a committee of the Legislature should consider the Information and Privacy Commissioner's request for explicit powers to enter into extra-provincial agreements and to consult and delegate extra-provincially in 2005."

Recommendation 46: "A committee of the Legislature should consider the matter of 'orphan records' in 2005."

Recommendation 47:

> The Act should not be amended to include a penalty for making repeated requests judged by the Commissioner to be vexatious, to extend the Commissioner's powers to include all entities with health information, to add a power to rule on miscarriage of justice, to deal with the process for privacy impact assessments, or to allow for release of the name of an affiliate who discloses a breach by a custodian to the Commissioner.

Now, there is an outstanding item here, and I've highlighted a note to the committee. There was a suggestion from a stakeholder to change the duty to comply with an order of the Information and Privacy Commissioner when the order is appealed to the courts. The committee requested some input from the technical support team about the options here, and I believe that Noela is going comment on this. Is that correct?

The Chair: Yes, Ms Inions.

Ms Inions: Yes. The members I hope have the letter. It's a letter dated October 5, addressed to the chair, responding to this question. Essentially, it looks at the issue of creating a duty to comply with a commissioner's order in the face of either before the time or after a judicial review has been commenced.

To change that provision to essentially remove the stay that is imposed in the legislation – section 82(4) provides for a stay of the order when there is still the right to appeal or the right to ask for a review of the order – would create some major implications for rights of individuals, a right to ask for a review of the order. So it gives you more background on the implications of what's being requested, and I would agree with the recommendation that this is not something that should be changed in the act. This is a provision that's parallel to the other privacy legislation and would have implications far beyond this piece of legislation.

The Chair: So you concur with status quo on this recommendation?

Ms Inions: Yes, I do.

Ms Blakeman: Are you able to give us any clear examples of how changing this would be detrimental to individuals? You used a particular phrase there. I mean, we have a case in front of us now where there is something being appealed, and there is no ability to put a stay in place so the behaviour, the activity, continues. I think this is involving IMS or the pharmaceutical companies or somebody again continuing to take information from the doctors, and they can continue to do that until we get a ruling. Well that, as we know, can be years. So can you give me the counterarguments then? What am I trying to balance this against? Can you give me examples of how this would negatively affect individuals if we change this?

Ms Inions: There is an example provided in the letter.

Ms Blakeman: I'm sorry.

Ms Inions: You probably haven't had time to take a look.

For example, if the commissioner ordered in the process of handling an access request to disclose records to the individual, there is a right of appeal to review that order. Should that right of review be taken and a court determine that the commissioner's order was in error, it makes the right of appeal moot because the individual already has the information that the court has determined they should never have gotten in the first place. So, essentially, it would have the impact, depending on the circumstances, of taking away the administrative right to review a commissioner's order.

It is frustrating to wait for these things to play themselves out. There's just no question. On the other hand, there are some very substantive rights at stake here.

Ms Blakeman: Thank you.

The Chair: Okay. Is the committee agreed with the status quo recommendation?

All right. I would suggest that we stop at substitute decision-makers, break for lunch, and reconvene at 1 o'clock to conclude the debate. We're adjourned.

[The committee adjourned from 11:53 a.m. to 1:02 p.m.]

The Chair: We will convene the committee. We welcome Dave Broda from Redwater to our midst.

Evelyn, could we start with substitute decision-makers, finish the rest of the document, and then go back and pick up the items we left on the table this morning.

Ms Swanson: Yes. We'll start with recommendation 48 on page 25. The committee recommended:

> The Act should be amended to provide a limited authority for a "next friend" or guardian ad litem to exercise the rights or powers of the individual where the exercise relates to the powers and duties of the next friend or guardian ad litem.

The Chair: Recommendation 49.

Ms Swanson: Forty-nine: the committee recommended that "Alberta Health and Wellness should review the matter of substitute decision-makers for consideration by a committee of the Legislature during the next full review of the Act."

The Chair: Recommendation 50, offences and penalties.

Ms Swanson: The committee recommended that "the offences and penalties under the Act should not be amended."

The Chair: Moving on.

Ms Swanson: Health information regulation. I have a note to the committee at the top of page 27. There was one suggestion that was missed when we presented to the committee last week. A stakeholder noted that the Child Welfare Act is being retitled the Child, Youth and Family Enhancement Act and that would necessitate another housekeeping amendment to the regulation. If the committee is agreed to that housekeeping amendment, then there would be three amendments to the regulation in recommendation 51.

> The Health Information Regulation should be updated to:
> - Delete s. 1(2) and the reference in 6(2) to the repealed HIA s. 59
> - Replace in s. 2(b) the "Billing Practice Advisory Committee" with "a committee of an organization referred to in s. 18(4) of the Alberta Health Care Insurance Act."

If the committee agrees:

> - Replace the reference to the Child Welfare Act in s. 4 to the Child, Youth and Family Enhancement Act when it comes into force.

The Chair: Okay.

Ms Swanson: Recommendation 52: "The requirements in the regulation specifying matters to be addressed in a written agreement respecting information to be stored, used or disclosed outside Alberta should be retained."

Recommendation 53: "Alberta Health and Wellness should consult with stakeholders and develop a regulation respecting retention, disposal and archival storage of records as part of the review of the regulation in 2005."

Recommendation 54: "Alberta Health and Wellness should consult with stakeholders to determine whether principles for technical, physical or administrative security should be added to the regulation in 2005."

Recommendation 55: "The Health Information Regulation should not be amended to include reference to the Electronic Transactions Act or to include the scope and content of information manager agreements."

The Chair: Looks okay.

Ms Swanson: So at this point would you like to return to the matter of the disclosures to police and finish that item?

The Chair: Sure. Have all the committee members got the proposed correction?

Evelyn, do you just want to make some brief comments? Then I'll ask Mr. Lukaszuk.

Ms Swanson: I think I would invite Holly to speak to the material that was handed out.

Ms Gray: Perhaps we'll just walk through the wording of the motion:

> The Act should be amended to mandate disclosure, without consent, to police services of:
> 1. patient name;
> 2. address;
> 3. location in facility;
> 4. date of admission;
> 5. name of physician; and
> 6. nature of the injury;
>
> when:
>
> (a) for purposes of obtaining a warrant or subpoena, and when the police have reasonable grounds to suspect that the person

seeking health services has been involved in some form of criminal activity; and makes a request for that information; or

(b) a custodian has reasonable grounds to suspect that the person seeking health services has been involved in some form of criminal activity.

The Chair: Mr. Lukaszuk, are you in agreement with this proposed amendment?

Mr. Lukaszuk: Definitely. I find that it truly reflects the discussion of the committee.

The Chair: Okay. Anyone else want to speak to the proposal?
Okay, then. We are agreed?

Some Hon. Members: Agreed.

Ms Blakeman: Are you calling the vote on the motion?

The Chair: Yes.

Ms Blakeman: I had requested a recorded vote on that motion some time ago, Mr. Chairperson.

The Chair: All right. We are going to do a recorded vote here. So I will call the roll, and for or against the amended motion.

Mr. Broda: For.

Mr. Snelgrove: Agreed.

Mr. Lukaszuk: For.

Mr. Goudreau: Agreed.

Ms Kryczka: Agreed.

Mr. Lougheed: Agreed.

Ms Blakeman: Opposed.

The Chair: Very good. Carried.
Okay. Did we need to clean up 29, 30, whatever it was?

Ms Swanson: That's right.

The Chair: What pages are those on?

Ms Swanson: Page 18.

The Chair: We're going to page 18, and 28 is now amended, so 29. Who's going to cover that one?

Ms Swanson: Recommendation 29 deals with a request made by, I believe, the pharmaceutical association or the college and supported by both in any event.
It reads:

The Act should be amended to authorize discretionary disclosure of limited health information to police services where a custodian has reasonable grounds for believing a prescription reveals or tends to reveal that an offence has been committed or is being attempted, including the individual's name, address, date of birth, personal health number and address, the drug, dosage, prescriber's name and address, a copy of the prescription, and any other health information contained on the prescription.

We did go back after the committee discussion to identify more specifically what information might be required, and our understanding is that this is the type of thing the police would ask for.

1:10

The Chair: Okay. Comments or questions?

Ms Swanson: Just one more point. We should add "without the consent of the individual" to this statement because I know that that was the intent.

The Chair: Okay.

Ms Swanson: At least, I thought it was the intent.

Mr. Lougheed: I didn't hear whether somebody else had commented. We have a little bit of a parallel to what we had before with the discretionary comment in there. I thought Thomas was going to jump on this.

Ms Swanson: We'll go back to the record, but I believe the pharmacists asked for discretionary authority. That is, when they believe this to be the case, they would contact the police. They weren't asking for being required to report. So that's just a point of clarification.

The Chair: Yes. Very good.
Are we okay with it then?

Hon. Members: Agreed.

Mr. Goudreau: With the addition of "without the consent of the individual."

The Chair: Yeah, right. Thank you, Mr. Goudreau.

Mr. Lougheed: Just on the same kind of point, when those folks were in here, they talked about somebody changing it from 10 pills to 100 pills or whatever else, and for the same reasons that we went around for 28, instead of the pharmacist having the option to make a call to the police services, I would prefer to see that he definitely make that call. If there's an attempt to up the number of pills on a prescription for whatever reason, probably not for their own health interests but rather some other criminal reason, then I don't think it should be discretionary. That's my sense of it.

The Chair: Okay.
Anyone else?

Mr. Snelgrove: I think the difference is that these people wanted to be able to do that. In the other case the providers didn't want to have to do that. So we're enabling these people to do what they wanted, what they felt was necessary. I think we have a little bit different situation in it.

Mr. Lougheed: I'll speak to it. You had a group of people, maybe the representatives. I don't know how far and wide the desire was on the part to disclose. Again, representing, I think, the expectations of my constituents, they would think that this should happen, not that it's something the pharmacist decides to do on his own.

Mr. Snelgrove: I can certainly agree. To put it in context, if you were to find out as a criminal element that you had a pharmacist who

was playing the game with you and they had the discretion to not report, then I can see your point. You're going to make it mandatory. I would have no problem, then, to remove "discretionary."

The Chair: It seems like this is what they wanted, but, Mr. Lougheed, your point is that it's not quite strong enough. You want it mandatory.

Mr. Lougheed: We're just giving them what they wanted in spades.

Ms Kryczka: Well, I guess we can't make assumptions here because they're not here, but maybe they were going with a halfway measure thinking that we would not go for the full measure. I have no idea, you know, what they would want.

Mr. Lougheed: Speculation. Hypothetical and theoretical.

Ms Kryczka: Totally. Totally. All those.

Mr. Lougheed: I'll make that motion: delete the word "discretionary" from 29. Sorry. I guess we're back to the same debate. We have to take out "authorize discretionary" and say "mandate disclosure."

The Chair: Okay. I have a motion from Mr. Lougheed to amend 29 to

> the act should be amended to mandate disclosure.

Mr. Lougheed: Remove the words "authorize discretionary" and replace with "mandate."

The Chair: Okay. Before I call on Ms Blakeman, is everyone clear on the amendment?

Ms Blakeman: A recorded vote on the motion, please.

The Chair: Yes, of course.
Any other questions on the proposed amendment?

Mr. Goudreau: Just a comment. Basically, I'm satisfying myself to use the word "mandate" on the basis that in the second sentence we still use the words "has reasonable grounds," and in the previous motion we use those words as well. So there's still some flexibility on the individual's part there.

The Chair: Thank you.
Okay. I'll call the question. A recorded vote. Roll call.

Mr. Broda: I agree to change it.

Mr. Snelgrove: Agreed.

Mr. Lukaszuk: Agreed.

Mr. Goudreau: Agreed.

Ms Kryczka: Agreed.

Mr. Lougheed: Agreed.

Ms Blakeman: Opposed.

The Chair: Thank you.
Recommendation 30.

Ms Swanson: Recommendation 30 is: "The Government of Alberta should consider introducing separate stand-alone legislation requiring mandatory reporting by custodians to police services of gunshot wounds, stabbings and severe beatings."
Our conclusion is that that's been replaced by the new number 28.

The Chair: Okay.

Ms Blakeman: No. I disagree, respectfully, with the technical team. I was clearly looking for stand-alone legislation which I felt addressed a problem with the legislation, and I'm still interested in stand-alone legislation. This is exactly as I wrote it and proposed it, so I don't think there's any question of the wording. I believe that it was voted upon and passed, and I would like to see it go forward. I recognize that it can appear to be a duplication, but I believe there's still strong argument that it is not and that it is requiring stand-alone legislation.
Thank you.

The Chair: All right. Anyone else?

Ms Kryczka: Well, I guess I should've said this earlier – but I didn't – when we were voting on this. My concern – and maybe someone could answer this for me – is with the Protection for Persons in Care Act. I mentioned this morning that it requires mandatory reporting – it's not custodians, but it is by employees in an institution or a health care centre – to report to administration and then to report to the police services as a last resort. What my main concern was when this was set in, having not expressed it then, but I'm going to now: would this be at all in conflict with the PPIC Act? If we had legislation like this, could it override that particular act?

The Chair: Okay. Can someone answer that question as it relates to the Protection for Persons in Care Act?

Ms Miller: We'd have to go in and have a look at that more closely before we gave an answer.

Ms Inions: I can make some general comments. The HIA does allow disclosure pursuant to another enactment, so in that respect it does dovetail with other legislation. In other ways it would conflict. For example, under the Protection for Persons in Care Act you cannot disclose health information under that act, even though you're reporting abuse in a care setting, without consent of the individual. So it's still a consent-based disclosure of health information. Under the Child Welfare Act it's different. There is a mandatory reporting duty, and then that goes to the director of child welfare and often to the police.

The Chair: Thank you.
Mr. Lukaszuk.

Mr. Lukaszuk: No. Thank you.

Mr. Snelgrove: I think Ms Blakeman is absolutely right. We've dealt with this. We talked about it, voted in favour of it. By itself this other recommendation may not be accepted. It also shows our fallback position here. I think we should just go on with it: leave it like it is.

The Chair: You're right. We did vote on it. We did accept it. If it is the committee's wish to leave it there, then so be it.

Hon. Members: Agreed.

The Chair: So 30 is agreed to as stated under number 30.
Recommendation 31.

1:20

Ms Swanson: Recommendation 31 deals with the matter of investigation of fraud, and at the last meeting the committee agreed to defer this item to Alberta Health and Wellness. It reads:

> Alberta Health and Wellness should investigate the need for provisions to allow the disclosure of health information by Alberta Health and Wellness or other custodians to police services where there is reason to believe that an individual has committed fraud in obtaining Alberta health care insurance coverage, health services or health benefits from the publicly funded health system.

In light of the Auditor General's report now, because the Auditor General has concluded his investigation, we are wondering if the committee would want to make a more substantive recommendation rather than deferring this to the department for further investigation.

Mr. Snelgrove: If your point is that we don't need to investigate the need because that's been pointed out as obvious, then that's fine. We can remove the part that says "investigate the need" because it's not there. Do we need to add after that "without consent" as we did in 29? I think all we need to do is remove the part that says: if we need this. Obviously, we do. Everything else, I think, is fine.

Ms Swanson: Yes. We would need to add "without consent."

The Chair: Okay. Are we agreed to that?

Ms Blakeman: Sorry. Can the technical team just go through the "without consent"? Whose consent is it on each side of this?

Ms Swanson: It would be without the consent of the individual the information is about.

Ms Blakeman: And we believe that that is the same person that would be committing the fraud, or is it possible that this could be other people?

Ms Miller: That would depend on the investigation. I think that what we're proposing here is that the act would enable Alberta Health and Wellness without the consent of the individual to be able to investigate potential fraud in obtaining health care insurance coverage, health services, or benefits from the publicly funded service. So it's the same kind of structure as the previous ones.

Ms Blakeman: Yeah. My concern is always that when we start putting anyone in a position of disclosing personally identifying health information without their knowledge or consent, I'm always a little uneasy. Obviously, if we're talking specifically about someone that we have concerns, you know, has received 230 health care cards, then we're pretty sure that we're investigating that individual that's directly connected to the fraud. I'd be really concerned if we started looking at anyone else's health information. Are you confident that the wording that is in here would address the situation on which I'm expressing concern?

Ms Miller: I would suggest that we take this back for drafting, and we'll bring it back to the next meeting.

The Chair: All right. Is that agreeable to the committee? All right. Good idea.
Are we back to page 7 then?

Ms Swanson: It starts on page 6.

The Chair: Okay. We're on health service provider information, page 6 of 28. Does the technical committee want to make any comments about the two segments that we're dealing with here, research and health service provider? How are we going to do these two together? What is the plan?

Ms Miller: We believe that there are some linkages, although they do refer to different sections of the act. I would like to propose to the committee that we do the explanation part for both the scope issue around health service provider information in terms of privacy protection under the act as well as the research provision before we get into the debate about what the recommendation would be. I'm sure there'll be many questions following just the opening and clarification of some of the background information. Would that be acceptable?

The Chair: Is that agreeable to the committee? Okay.
Go ahead.

Ms Miller: Evelyn.

Ms Swanson: Thank you. Just a bit of background. Some of this has been covered in previous discussions, but health service provider information was included under HIA to ensure transparency to health service providers about the ways their information could be used and when it could be disclosed.

Alberta Health and Wellness holds significant databases with information about physician practices as a by-product of billing. Pharmacies are another custodian that have significant databases with physician information. That's a by-product of filling prescriptions.

Physicians maintain that their identifiable information should be used appropriately by custodians and protected from unauthorized use and disclosure without consent. The act permits disclosure of basic business card information as well as disclosure to professional bodies for carrying out their duties, and the act permits disclosure to noncustodians only if it's authorized or required by an enactment of Alberta or Canada or if the provider consents to its disclosure. The policy intent here was to require that custodians obtain the provider's consent for disclosing identifiable health service provider information to noncustodians for use by noncustodians for a commercial purpose.

When we asked stakeholders whether they agreed with the inclusion of health service provider information under the act, we received responses from about 19 bodies. They fell into two groups. One group primarily supported the approach and the inclusion of the information and the protections under the HIA. Although I didn't list them in the document, I'll just name them. These include the AMA, the College of Physicians and Surgeons of Alberta, Alberta Blue Cross, an individual who responded, the Calgary health region, the College of Physical Therapists, the Alberta Long Term Care Association, and STARS.

There were two organizations that said: we agree with protection. Aspen health authority said that it might be better placed in other legislation such as professional legislation, and the universities thought that it's better placed in FOIP. The city of Edmonton commented that bodies subject to FOIP should not be subject to HIA. Capital health did not state a position.

The Pharmacists Association of Alberta and pharmacy-related stakeholders took the opposing view, that health service provider information should not be included in HIA, or HIA should be amended to eliminate the protections. These stakeholders included IMS Canada, the Pharmacists Association of Alberta, the College of Pharmacists, the Canadian Association of Chain Drug Stores, and Value Drug Mart.

The pharmacy-related stakeholders view the current protections for health service provider information as too broad or inappropriate under HIA. Some suggested multiple alternatives that they believe would be appropriate, and there are five different variations listed here. We've taken a look at them, and we conclude that all of these sections would likely have the effect of allowing the continued disclosure or sale of identifiable physician prescribing information.

In addition, Alberta Health and Wellness made a suggestion to allow the disclosure of health service provider information for research purposes. Although we did recommend as a technical team that the inclusion in the act of health service provider information be retained and, if necessary, the provisions clarified, we believe that there is justification for amending the act to allow for disclosure of health service provider information for research purposes on the same basis as patient information, including ethics review and custodian consideration of the overriding principles, the least amount of information, and the highest level of anonymity necessary for the research.

1:30

The central issue that was identified through the consultation is disclosure of identifiable information without consent about the professional practice of one health professional by another health professional to a noncustodian for analysis and subsequent disclosure in identifiable form. The submissions included reference to what other jurisdictions do. The committee asked us to bring back some information. We brought some material back to the last meeting and have summarized it here and supplemented it with a little bit more investigation since that time. If you'd like me to go through it, I can.

The Chair: Does the committee want that information? Oh, okay. They want you to go through it. Okay?

Ms Swanson: Okay. In British Columbia the bylaws of the College of Pharmacists specifically prohibit the release of information for commercial purposes if it would permit the identity of the practitioner or the patient to be determined. Information may be released for noncommercial purposes in accordance with the Pharmacists, Pharmacy Operations and Drug Scheduling Act, the bylaws, or with the express consent of the practitioner, patient, and pharmacy manager. Pharmacists and the PharmaNet Committee – and the PharmaNet Committee is responsible for the administration of the provincial drug database called PharmaNet – are not allowed to disclose patient records, including the physician's name for purposes of market research. Provider-identifying PharmaNet information cannot be disclosed for research purposes in general under B.C.'s current pharmacy legislation. B.C.'s FOIP Act indicates that information cannot be disclosed if it's an unreasonable invasion of a third person's personal privacy and disclosure of a name to be used for solicitations is presumed to be an unreasonable invasion.

In Saskatchewan a regulation is being proposed under the Health Information Protection Act, and in their consultation paper the department says that the proposed regulation

> will protect the privacy of prescribing information by preventing Saskatchewan pharmacies from disclosing information about another trustee (e.g. physician) that is collected by pharmacies along with personal health information about an individual.

If the regulation is passed, "Pharmacies will only be able to disclose information about another trustee (e.g. physician) for a purpose that is consistent with the reason the information was initially collected." These regulations will not apply to statistical or deidentified information where the provider cannot be reasonably identified.

In Manitoba the Personal Health Information Act does not apply to health service provider information, and the Pharmaceutical Act does not address the matter. The Manitoba Ministry of Health is subject to the Manitoba FOIP Act. The ministry holds drug-prescribing information in its databases and does not disclose the physician's name without consent.

The Manitoba Pharmaceutical Association is the regulatory body for pharmacists in Manitoba. Our information is that the council of the MPA passed a motion on February 18, 2002, which proposes that the council remain with the status quo and that "pharmacies are instructed not to release prescriber information to prescription data collectors which is consistent with the wishes of the College of Physicians and Surgeons."

Ontario will implement its new health information privacy legislation this fall, and it did not include protections for health service provider information.

In Quebec an act respecting the protection of personal information in the private sector applies to personal information, which is defined as any information that relates to a natural person and that allows that person to be identified. The act was amended in 2001 to add section 21.1, dealing with information on professionals. Under this section the commission on written request and after consulting the profession concerned may grant a person authorization to receive personal information on professionals regarding their professional practices without consent if the commission has reasonable cause to believe the communication protects professional secrecy, it does not allow identification of the person to whom the professional service is rendered, and it does not otherwise invade the privacy of the professionals concerned. The professionals concerned will be notified periodically of the intended uses and given opportunity to refuse the use or preservation of the information, and security measures are in place to ensure confidentiality of personal information.

The Quebec legislation also allows the commission to grant authorization for a person to receive personal information for study, research, or statistical purposes without consent if it is of the opinion that the intended use is not frivolous, the ends cannot be achieved without identifiable information, and the information will be used in a manner that will ensure its confidentiality. Any authorization is granted for a set period and on any conditions imposed by the commission. The commission can revoke the authorization if it believes that the person authorized does not respect confidentiality or other conditions imposed.

Nationally, the Canadian government and the PIPEDA legislation, the former federal Privacy Commissioner issued a decision under PIPEDA after complaints were filed that physician-prescribing information is work product and not personal information. As a result, the information is not protected under PIPEDA.

So those are the circumstances in other jurisdictions. Ontario does not provide any protection. Manitoba's ministry does not disclose, but it's not specifically protected in their legislation. Their College of Pharmacists appears to have issued a motion on the topic. Saskatchewan does not currently protect the information, but it is proposing a regulation to do so.

The Chair: Evelyn, could we take a question at this point?

Ms Swanson: Sure.

The Chair: Mr. Broda.

Mr. Broda: Yes. Thank you, Chair. I've been doing a little bit of research. I'm not here to protect any particular agency or whatever, but personally I don't think that the Health Information Act that we're reviewing has anything to do with workplace information. I think that the act is here to protect the citizens, the patients, not what's happening in the workplace, as I said earlier. It's not under PIPEDA. I'd like to know from the technical staff whether when we go into the pan-Canadian, when it all ties in together, that will be included in there. I believe that this particular clause, 37, has no place in the Health Information Act. It may have in others, but at this point I think that we're dealing more specifically with individuals, patients, not workplace.

The idea that a person may solicit a physician or whomever – the physician has the ability to say: no, I don't want any solicitation. He can put a sign on the door. He can protect that in his own way. That's his choice. By putting legislation in saying, "Well, we're going to protect you" – there are salespeople that go to physicians' offices on a daily basis, and they welcome the product, but if they are so fearful of this, then they have the ability, as I said, to say no.

1:40

Ms Miller: In terms of the pan-Canadian framework it is referenced. However, the purpose of the pan-Canadian framework is for those legislative provisions that, it is viewed, need to be harmonized across the jurisdictions. So that is the fundamental prerequisite, if you will, in terms of what is being addressed specifically in the pan-Canadian framework.

If I could, Mr. Chair, I'd like to take a moment to explain the linkage between provider information and patient information – often it is the same – and maybe help to explain the perspective of why there is some logic for why provider information is protected in HIA as well as patient information. Visually I think I can explain it better than through words, if that's acceptable to the committee.

The Chair: It is. Can everyone see the visual information?

Ms Miller: I'm being general here for the committee's discussion purposes. There are other components and databases.

When you're developing a database for information purposes, the three categories of information that are relevant in this discussion are the provider-specific information. Typically, you'd think of that as the registration information, the demographic information about the providers: where they practise, potentially their age, et cetera. So when I read in this category, that's what I'm referring to. So it's kind of what we generally think of as registration information, including demographic or tombstone, as you've heard in this context. The same idea also extends to when we're talking about a patient that accesses health services information. You need to know certain demographic information about this patient to ensure that you've got the same patient when you want to link records, et cetera.

The information that we're debating here, I need to explain, is what we call service event information. What that is in this instance is drug information, the types of surgery I had, the other types of medical procedures I had. I mean, it just goes on and on and on. Depending on the type of database you're putting into place, maybe one database captures surgery and another captures home care service events. Do you see where I'm going?

Where there's a linkage between provider information and patient information is when you link this specific service event information to the patient's name – in this case I'll use my own name, Linda Miller – it becomes patient information, therefore protected under HIA, logically. It's the same information that you connect to the provider, that we are now referring to in this setting as provider information. This is the information of most interest for research purposes and for other purposes that we've heard about through the committee's deliberations.

So you can see that there is a strong relationship between the categories of information. There are not separate databases per se that just have provider that aren't about patients. It's what you're linking them to that makes it either patient information or provider information. So I wanted to take the committee through that explanation, hoping to explain some of the rationale.

Mr. Broda: A question on that part. I agree with what you're saying; however, the provider information that you're having would not include the patient disclosure. It may disclose the drug utilized but doesn't have to include the patient's name.

Ms Miller: That's true.

Mr. Broda: To say that one links to the other, yes, in essence on the procedures, but the individual – and that's why I'm saying that we're protecting the individual's rights, the patient's rights. The provider is not providing any patient's name, address, or anything like that. That's not what is being asked for. We're looking at research purposes, what kinds of drugs are being used, how we are utilizing the drugs. It doesn't specifically identify you or me. All we're saying is: okay; if this physician has been doing X number of whatever treatments, he knows already what treatments were made, what drugs were prescribed – that's the information that may be used for research – what kind of drug utilization we have, and are there savings that we can do for research purposes? That's where I disagree that this provider information is essential in this act.

Ms Miller: If I could, to respond. That's why we want to propose that there be a recommendation from the committee that allowances be accommodated in the act so that information gathered and linked this way provides access to provider information. The department totally agrees that we need to do research and enable that in terms of understanding what's happening in the system from a provider perspective, but we want to do that under the auspices of bona fide research.

In many cases that can be done in nonidentifiable form, even from a provider perspective, in terms of understanding the trends in the health care system. You can aggregate, and when you aggregate, that means it's not identifiable. There are so many people, providers or patients – it doesn't matter – in what we call a cell size that you couldn't identify that it was this provider or this particular patient.

Mr. Broda: Okay. If I may further, Chair. If I were the provider – and I'm going to say physician in this case – when research is being done, it's usually done in aggregates of 20 or 30 physicians at one time. My understanding from the research that I have done is that it's never specific to a provider himself. Yes, he's done so much, but you wouldn't even probably on their marketing side, if you want to call it that, really identify this one specifically. At least that's my understanding.

Ms Miller: No. There is considerable research that requires identifiable information, be it on the patient side or even the provider side. I believe you can market the aggregate form. I'm not in the marketing business, so I obviously can't comment any further than that. However, there is marketing underway where it is at the identifiable form.

The Chair: Okay. One more, and then Mr. Lukaszuk.

Mr. Broda: If I may, one more last one, sure. Thank you. Again, when we look at the provinces as you identified, a lot of them are not including it. But even one of our own regional health authorities indirectly agrees, however, and says that the region believes the current provisions are very strict and can hinder quality assurance and approved activities and could potentially affect patient safety. That's where I'm saying that I think this clause should be thrown right out.

The Chair: On this point, Evelyn?

Ms Swanson: Yes. We put that in there because we thought it was very important, and we did follow up with Calgary to try and get some more specifics.

Wendy, would you like to speak to that?

Ms Robillard: The region was unable to provide us with an example of where quality assurance activities have been hindered. They did, however, have a discussion relative to the potential if a health service provider was not behaving professionally or if there was question about their professional practice and they'd moved from employer to employer before the issue could be addressed, but it had not actually happened. It was something they were considering.

The Chair: Okay. Thank you, Linda, for the visual presentation.

Mr. Lukaszuk.

1:50

Mr. Lukaszuk: Thank you. Looking at your chart, you advised that there are the linkages between the patient, the database, and the service provider, and even though one discloses only the first two rows, being the provider and the service provided, there is some affiliation to the patient because obviously if a service is provided, there has to be a patient, but the provider information may not be aggregate. As you said, often or at times, if need be, it may be identifying a provider. But the patient information by way of releasing only column 1 and column 2 is aggregate; isn't it?

Ms Miller: When you're grouping it by provider, yes. When you're disclosing provider information, you would not be disclosing patient identifying information.

Mr. Lukaszuk: Okay. Then I'm satisfied that patient information is sufficiently protected.

Now, with respect to the providers I believe it was Mr. Broda who advised that physicians have means of protecting themselves from unscrupulous reps of perhaps pharmaceutical companies, who may be targeting them to start prescribing certain products, by simply choosing not to see them, and they already do that. Some choose to see them; some choose not to see them, as I understand. Then if the patient information is given out only in aggregate, which we established – we established that the doctors have means of protecting themselves from unscrupulous salesmanship – give me some other reasons why we should continue protecting the provider information when those two things are satisfied.

Ms Miller: Certainly. This gets back to my initial comments around trust and building trust in the system because many of those service events in the health care system are generated by providers. Almost all of them are, actually, and many of those are by the physician community.

The need to have that service event category, if you will, as per my diagram is so critical to understanding the health care system. That is fundamentally what the electronic health record captures. Should the providers perceive that there is not protection for information that's been grouped on the basis of providers, the concern is that providers themselves will be reluctant to share that service event level information that is so critical to the health system.

The Chair: On this point, Mr. Lukaszuk.

Mr. Lukaszuk: Yes. Thank you, Mr. Chairman. Then, in that vein, once we fully implement the electronic health record database, this section will be a moot point because that protection will disappear for physicians anyhow. They will be voluntarily sharing it; won't they?

Ms Miller: At this point in time there still is considerable discussion underway with providers, including physicians, about getting their agreement that they need to share from their physician office electronic medical records, if you will, around the service event data to the electronic health record.

The Chair: Yes, Mr. Lukaszuk, one final.

Mr. Lukaszuk: Thank you. You're gracious, Mr. Chairman. To me that is not an argument. If we make them share information with us, they will become reluctant in sharing it, but that's not a reason for not sharing it. You know, they may become reluctant in co-operating with us on the electronic health record, and that's fine, but I'm looking for a root cause. Why would they become reluctant? Why would they not like to? Give me a good reason why this is wrong for Albertans.

Ms Miller: I'm worried about the trust issue, Mr. Lukaszuk. I concern myself that if they feel the information will be used inappropriately in their opinion and because this whole electronic health record is new for them as well and they have concerns notwithstanding anything that we're talking about today – because now we're talking about sharing information in much different ways than they've been used to all these many, many years. I believe their concern would be that should this provider protection be removed, because by taking it out of HIA there is no other provider protection, they will be reluctant to share it, or if it is mandated that they share it, the quality of the information may be affected.

Ms Blakeman: It strikes me that what's really at the heart of this issue is use of the information for marketing and sales. Nobody seems to have trouble, during the discussions we've had, with use of the information for research if it's for pure research. There may well be difficulties with members of the committee having this identifiable information used under the guise of research when it's really marketing.

I'm just wondering: if we remove the protection that's here, would we then be facilitating marketing and sales possibilities by those who wish to use that information in that way? Is that the job of this committee, to facilitate private-sector marketing and sales strategies? I guess that's a question I put out there. I don't think that ultimately the request to remove the protection of health service provider information is about better health care; I think the request to remove that protection is about better sales and marketing.

During the questioning that we were able to have with people that appeared before us, the concern was always about being able to get at prescribing information. It took me a while of digging to find out

what they actually wanted, and my understanding was that it would be used for marketing purposes. Does that really help Alberta health care? If we're worried about the amount of money that we're now spending, particularly on pharmaceuticals – and everybody seems to understand and agree that the higher cost of new drugs is part of what's causing us problems – do we really want to be facilitating something that gets us into even more marketing of new drugs?

I mean, we're now in a situation where the public is being convinced, certainly attempting to be convinced by television commercials out of the States, that we should now get a prescription for things that are, well, troublesome and inconvenient, basically facts of life. So we've now got all kinds of purple pills and erectile dysfunction pills and all kinds of other things being marketed to us as a must-have drug. Ten years ago those drugs didn't exist and we all got along fine, but now they're a must-have drug, and they're costing the health care system a lot of money.

So the question that we're looking at here is: are we facilitating something that in the end will cost Alberta health care and the taxpayers of Alberta more money? I would argue that it is, that the protection of the health service provider information, while not something I'm particularly keen on for any other reason, I think ultimately is still keeping us in a position where we have some control over that.

The Chair: Okay. Thank you. Any technical staff want to respond to that?

Ms Miller: No comment.

The Chair: Okay. Mr. Broda was next, then Dr. Pannu and Mr. Lukaszuk.

Mr. Broda: Thank you, Chair. A question comes up, and I hate to categorize only one group. We're talking physicians. What other providers would be opposed to it? We talk about trust issues. When we talk about prescribers, there are other prescribers besides physicians. Have any made any comments in this regard?

Ms Miller: To my knowledge, no, but I don't believe we've pursued it. Predominantly, though, it is physicians that prescribe.

Mr. Broda: A trust issue: I'd like to know what you're referring to. How would it affect? What trust are you talking about?

Ms Miller: The trust by the providers.

Mr. Broda: The physicians in this case, because you said that there haven't been any other providers that you're aware of.

Ms Miller: Oh, in terms of the trust issue. We hear that comment from other providers, as well, but more predominantly with the physician community; that's correct. But we do hear the trust comment from other providers.

Did you want me to explain about trust?

Mr. Broda: No. That's fine.

The Chair: Dr. Pannu.

2:00

Dr. Pannu: Thank you, Mr. Chairman. Two issues that in my mind are paramount when considering this issue are patient safety and quality assurance. What I've read and heard here and received as information tells me that having section 37, part of which protects provider information, does not negatively affect either of these two key concerns that I as an MLA have with respect to how legislation should be shaped.

Then there's the evidence of some other provinces doing certain things and perhaps some of them doing it in a way which helps cut down the overall costs of drugs, pharmaceuticals. As far as I know, B.C. is the only province which, with the legislation that they have, protects provider information and prohibits the use of that information for marketing and for commercial purposes. It also has instituted a sort of drug purchase plan in the public system, a reference-based drug purchase plan, and they have been able to control to some degree the escalating costs of drugs as part of the overall costs of health care provision in the country.

When you go to Manitoba and Saskatchewan, Saskatchewan is moving in the direction that we are already at, from what I've heard, from what I understand. Manitoba, in fact, has chosen the path of what Linda called trust, what I call collaboration, you know, between different health care providers. It's really a collaborative model where pharmacists, nurses, doctors work together to provide the best care at perhaps the cheapest possible cost.

Ontario is the one case where there is at this stage no protection, according to the report that we received. I'm not sure if that information is comprehensive and complete, but that's the information that we have before us, and I'd like to know more about it.

Quebec in many ways, through different acts and legislation and the regulatory system that they have, provides more or less the protections that prevent the use of health care provider information for commercial or market purposes. It gives highest priority to the protection of both privacy and confidentiality, two principles that are the driving force behind our act.

So I think, Mr. Chairman, the case has not been made according to the information before us for the removal of that section. At best, what we can do is seek more information, bring this matter up hopefully in the spring, and deal with it then. It's a crucial issue; it's an important issue. It deals on the one hand with the questions of patient safety and quality assurance. On the other hand, it deals with our ability to control costs, particularly of one health item; that is, drugs. I therefore would submit to you that the committee should consider revisiting this issue – another committee will do that – but that it be done in the spring of 2005. This is an argument that I made I think last week: that we postpone this or defer this for further and closer examination in the spring. That would be the position that I am taking here.

The Chair: I assume you're prepared to move that. I would like to take the other comments that are on the speaking list before we do that, before we take motions.

Mr. Lukaszuk.

Mr. Lukaszuk: Thank you, Mr. Chairman. Interesting comments. I would agree with Dr. Pannu that, indeed, patient safety and quality assurance are pivotal here. That's the only reason that we would make changes, if any. However, my outlook on how removal of section 37 from the act would affect patient safety and quality assurance differs significantly from Dr. Pannu's, and I'll give you some examples why.

First of all, as a committee we have heard from the department that currently the information that is available to the minister and the department for their ability to make policy decisions, drug coverage decisions for the Minister of Human Resources and Employment, who deals with Alberta Works and AISH and widows' benefits and all the other programs, and decisions on what procedures or what

medications are covered all stems from a database which is as inaccurate as a database could ever get.

All we know about medical procedures and about medications is what we pay for under the medical services card. We don't know what doctors prescribe. We don't know what procedures they do unless they're covered by what we pay for. What we pay for is a segment of Albertans, as I said earlier, who don't necessarily reflect the cross-section of utilization of health services. Usually those individuals are either older or in ill health, particularly in the AISH component, which now is about 35,000 Albertans, who utilize the health care system at a rate that is significantly higher than the provincial average, so it sways the averages tremendously.

Now, about quality assurance we know very little. I'll tell you an example. Prior to my life here in the Legislature, as many of you know, I was dealing a great deal with individuals who were injured, with the Workers' Compensation Board. In an unofficial manner very often case managers would advise me: "Send your client to a particular doctor. When he does a surgery, clients tend to return to work much faster. When this other doctor does a surgery, they tend not to return to work as fast." There are differences in procedures that doctors have. There are differences in methodology. There are differences in the medications they use. The differences in infections that they have in their offices postprocedure are tremendous. They're all over the scale.

Those are things that I think we should know, not only as government but as members of the Legislature, so that we can make decisions on what we should pay for, what we should encourage, what education there should be for the public and for physicians and also for average Albertans.

When the AMA was here, I asked them a question. "Why don't you want to disclose that information to me? If I'm going for a medical procedure, particularly something of a surgical nature, I want to know what methodology the doctor uses, what medications he's going to put me on and everything before I allow him to carry out the procedure." Their answer was: well, then, go and ask him. But that would mean that for me to have an informed decision, I would have to book appointments to five or six different doctors, ask them, and then pick the one I feel most comfortable with. I'm not sure if Alberta health care would like it very much if I was doctor shopping in that way.

Why can't Albertans access that information to know which doctors do what procedures, how efficiently, how effectively, what their recovery rates are, what medications they use? That's information that should be available to Albertans. We don't need to know patient information; it's aggregate. Doctor X does so many surgeries in such-and-such a time, those are the outcomes, and those are the medications he uses. There's nothing secretive about it. They do it under a publicly paid service. Why should those who pay for it not know about it?

The Chair: Okay. I would like to remind the committee that many have suggested that we try to be through here by 3 o'clock today or before because of other events. Do I need to give my brevity speech again?

Ms Blakeman: Consider it done.

Can I question him?

The Chair: On that point, yes, and then Mr. Broda.

Ms Blakeman: I'm just wondering. On your desire to have a situation where you could go somewhere and find out which doctor did the best knee surgeries or had the best recovery rate from heart surgery or whatever, who would do the analysis on this? What we're talking about is not removing a section which protects the identification of the doctor that does something. You were talking about things like, you know, Dr. X does a certain kind of surgery and there's a certain kind of outcome. Where are you getting the additional information about the outcome? That requires a level of analysis; doesn't it? Who is the intermediate here or the end run in this? Who is analyzing this information that you're now pulling from these doctors if we don't protect the health service information? What's the missing link in this?

2:10

Mr. Lukaszuk: Obviously, at this point we don't have a system that will allow for us to do that, but if you were to disclose that information, you would be able to find out which doctors do what surgeries how often. I suggest to you, Ms Blakeman, that if you were to have heart surgery, you would want to know how many of such surgeries the doctor has done. Hopefully, you're not his first one. Those are things you would be able to find out.

If and when the ministry or some other body or health authority chooses to then compile the information and process it into further information, they could, but at this point you can't find out. You don't know whether, for the doctor who is going to carry out your heart surgery, you're going to be his first one or his thousandth one unless you go to several of them and ask them.

The Chair: Mr. Broda.

Mr. Broda: Thank you, Chair. Further to Dr. Pannu's comments, I didn't have the opportunity to speak to the new Ethics Commissioner in Saskatchewan. You indicated that they're tending to move in this direction. My understanding is that Gary Dickson, one of your colleagues, the new Ethics Commissioner in Saskatchewan, has made a comment that he does not think it should be in the Health Information Act. I didn't have a chance to speak to him.

Further to your comment about delaying it, I would say that it's probably a good idea, Dr. Pannu, to delay it for further review.

In the meantime I would like to make a motion or an amended motion that in section 37(2)(a) instead of having the word "or," change it to "and" and to have a further review at a later date.

The Chair: Okay. You want to make a motion to change wording in the act?

Mr. Broda: That's right.

The Chair: And then a further review as part of your motion?

Mr. Broda: Yes. To cover Dr. Pannu's request.

The Chair: Yeah. Well, I'm going to take all comments that want to be made before I accept any motions. I've already asked Dr. Pannu to wait, so I guess he gets first dibs on this one, to be fair.

Mr. Snelgrove, I'm looking for your enlightened comments.

Mr. Snelgrove: Well, this is an extremely interesting point. I guess that why I would have to agree with Mr. Broda is that our system right now is not broken; it is slightly off-kilter. There is a lot of good in the way they've balanced the act, and I think the interpretation in section 37, that was left up to the Ethics Commissioner, put him in a position of having to err on the side of more privacy is better, which is fine when they're put in that position.

By changing the wording that Mr. Broda has talked about, I think you're leaving all the protections in there, but you're putting a level of responsibility for that decision on it. We don't need to review

everything, and unless the information being reviewed will have damage, then it shouldn't matter. I would like to see this proceed with his slight change and then be reviewed in a bigger context in the spring.

The Chair: Thank you.

Ms Miller: It is our view – and I'll turn it over for more technical identification or discussion if necessary – that that one-word change will substantially affect the privacy protection as it currently exists.

The Chair: Okay. As I listen to the debate and the information that the committee has reviewed and discussed, it seems clear that there is definitely consensus about the importance of health information. You know, I don't think you can argue that information is good for the system, valuable to the system, and that we need the information.

I think the point has also been made that, you know, we do have to worry about the collection of the information, who does it, and how it might be perceived by those who actually generate the information, namely the providers. The word "trust" has been thrown around. I can understand why doctors might have this concern, because the doctors I've talked to don't seem to have a problem with information being collected. It's that the information is being collected for commercial purposes and the fact that, you know, clinics and individual doctors are sort of identified in the information that's found. So I understand why they have their concern about trust and why they are reluctant to agree to the collection of information as it presently is being done.

We have a pan-Canadian discussion ongoing, and I guess one of the questions I have to the technical team is again: how will that affect . . . You know, we have apparently some inconsistencies in some of the provinces at the present time on this subject, so will we all sort of fall into what the pan-Canadian group recommends, or will each province have its own act and its own method of dealing with this problem?

Ms Miller: I believe the discussions thus far in these pan-Canadian tables, if you will, have agreed that this has to be at the discretion of the province.

The Chair: Okay. So we would still have the discretion?

Ms Miller: Yes.

The Chair: Okay.

Ms Blakeman: Isn't it also the case that most of them talk about not having this information released to be used for – and the wording's been different – commercial purposes, marketing purposes, sales purposes? Almost every one of them has a clause on that; am I not correct?

Ms Miller: Yes, that's true.

Ms Blakeman: Thank you.

The Chair: So the committee has an interesting challenge before it. Does anyone else want to make any final comments?

Okay. I've already referred to Dr. Pannu's motion, asking him to hold that motion until we had given everyone at the table a chance to speak. So in fairness, Dr. Pannu, I guess that you have heard what Mr. Broda would like to do. If you do propose a motion, and it passes in the form you discussed, I guess that would end the debate at this point. So I guess I'm going to come back to you and ask you what your intent is here in regard to your earlier comments.

Dr. Pannu: Thank you very much, Mr. Chairman. I would like to make a motion in a moment but give us a bit of a background to it.

The Chair: Could it be a brief background?

Dr. Pannu: One of the compelling reasons, quickly, for a motion to defer, which is what I'll be making, is that I think we have not as a committee had a chance to look closely at the relationship between removing the protection and confidentiality of provider information and the costs factor that I've talked about. In the committee we haven't really taken a closer look at what might be the link between the two. I have no doubt that all of us, regardless of party labels or whatever, are committed to doing everything that we can to control and reduce overall costs. As I said, drug costs are the one most rapidly escalating factor. So we need to have a chance to ask the fundamental question: what will be the impact if we make some changes along the direction of that?

The second small comment that I want to make. I just want to share with you very briefly, Mr. Chairman and the committee, a book that I used to use in my course on the sociology of professions in the late '60s and early '70s. The title of the book was Radical Professionals, storefront lawyers and doctors, you know, who went out into the streets and all of that stuff. Their interest was in empowerment of the patient, for example, in the medical context. That's the kind of concern that I hear here from my colleague across the way, Mr. Lukaszuk.

I think the relationship between a patient and a doctor is I submit different from the relationship between me as a customer and a Wal-Mart clerk. It's very different. The Wal-Mart model of medicine does not work. The difference in the amount of knowledge that a patient has about his or her own medical condition and the treatment that is needed is very great as compared to the level of knowledge the doctor has. Doctors deal with each as a unique case. They don't invent widgets. They give you the kind of surgery that they think is best for you rather than one standard surgery for everybody.

Having said that, Mr. Chairman, I would like to now move that the committee recommend that

> we defer the decision on this matter until the new committee to be struck in the spring of 2005 has an opportunity to take a closer look at the whole issue of provider information protection.

The Chair: What would be the rationale for that, Dr. Pannu?

2:20

Dr. Pannu: So that we have more time. I said, you know, the cost issue. Any changes that we make, I think we should ask: what are the consequences insofar as we're able to assess that?

Just a last point on this, Mr. Chairman: even in the IMS paper before us – that is, the newest one – their first choice is to see the committee defer the discussion. If we are not willing to do that, then they say: go the route that Mr. Broda is suggesting. They're not suggesting to do both. They're saying: do one or the other. Their preference is that the matter, in fact, be deferred, so another ground why.

The Chair: Okay. I will accept the motion, but before I have further discussion, I want to go back to the technical team. We did not include research in this discussion yet.

Ms Miller: Yes. We'd like to do that first because I believe many of the arguments being made in terms of understanding the costs and other impacts to the health care system can be addressed through

better research provisions. That is a goal that we would like to achieve with this review.

The Chair: Would I have the committee's permission to spend a few minutes on the research aspect before we vote on Dr. Pannu's motion? Would that be agreeable?

Hon. Members: Agreed.

The Chair: Okay. Who's going to handle that, Linda?

Ms Miller: I'll turn it over to Evelyn to explain.

The Chair: What page are we on on that one?

Ms Miller: It starts with 20 of 28.

The Chair: Okay. Thank you.

Ms Swanson: I'm thinking we should maybe stick to the health service provider component of it.

The Chair: Evelyn, can you hit your mike?

Ms Swanson: Sorry.

Ms Miller: And we'll stay with the provider component of research for this discussion.

Ms Swanson: As we mentioned a few minutes ago when discussing the health service provider information, the technical support team did make two recommendations that would work together, one being to retain the current provisions and protections for health service provider information.

The second part would be to look at allowing for disclosure of health service provider information, identifiable information, for research purposes. The release of this information for research purposes would be subject to all the protections that we already have in the legislation for patient information being released for research purposes. This would allow for some research and some of the benefits that have been discussed around the table to occur through research that has been through an ethics review, research that has disclosed the information at the highest level of anonymity and the least amount of information.

We see a lot of value in having research done in this area but probably not the commercial aspect of it. The question that we've highlighted at the bottom of the page would be whether or not the committee would like to make a recommendation prohibiting the commercial use of the information and disclosure for commercial use.

We circulated earlier this morning a sheet of paper with a suggested response. We took into account a number of questions that the committee raised at its last meeting about the protections that are available.

The Chair: All right. Has everyone now got the copy in their hands? They have. Go ahead, Evelyn.

Ms Swanson: This suggested response is from the technical team. It does take into account some of the questions that were raised by committee members at the last meeting, asking about the provisions and what kind of protections there are for that identifiable health information. What we're suggesting is that we

> allow access to identifiable health services provider information for research purposes on the same basis as access to identifiable health information about patients, subject to
> - the addition of a prohibition against the disclosure of identifiable health information for purposes of commercial and marketing research, and
> - a review of the research provisions by Alberta Health and Wellness to ensure there are sufficient post-disclosure protections and safeguards for identifiable health information.

This suggestion would work in harmony with retaining the current protections but allowing disclosure in certain circumstances for research purposes.

The Chair: What did you just say?

Ms Swanson: This recommendation works together with our recommendation about retaining health service provider information in the legislation with the current protections but then allowing for disclosure for research purposes for research projects that have been through all of the hoops, the protections that are in the act.

The Chair: So research but not commercial?

Ms Swanson: Not commercial and marketing-type research.

The Chair: Okay. All right. I've got some questions.

Ms Blakeman: I'm directing this toward Ms Miller. I'm not making her speak for the physicians around the trust issue she'd raised, but does she have an opinion on whether this proposal might assist us with the problem she was presenting around trust?

Ms Miller: I can't speak for the physicians, quite clearly. I believe there is growing comfort amongst the provider community, including the physician community, that the rules around disclosure of information for research purposes are reasonable. I believe that if we were to reassure the provider community that those same rules and processes would be applied in the instance when the information is provider information, that would support their notions of the importance of research and ability to support what we're proposing here today, although I can't obviously speak for them.

Ms Blakeman: I know. Thank you for your best attempt.

Mr. Lukaszuk: This recommendation made by the department makes me wonder primarily because of the fact that it is the department, the ministry, that is a large purchaser of private, for-profit research. Correct?

Ms Miller: Yeah. For nonidentifiable research.

Mr. Lukaszuk: That's right. I'm sure you're purchasing information continuously from various commercial research companies who utilize information, and now you want to cut them off from that information.

Ms Miller: No. That's not what we're suggesting.

Mr. Lukaszuk: Well, you're buying it.

Ms Miller: In nonidentifiable form, yes. But we're not intending by this phrase to cut that off.

2:30

Mr. Lukaszuk: So it's okay for them to sell it to us but not to anybody else?

Ms Miller: We buy, I believe, nonidentifiable forms of research. The issue that we're seeing that should not occur is research that's in identifiable form.

Mr. Lukaszuk: So Alberta Health and Wellness at this point is not purchasing any identifiable research information.

Ms Miller: To my knowledge, no, but I could verify that.

Mr. Lukaszuk: So who would you allow access to identifiable information then? Not-for-profits? You would allow access to identifiable only for research purposes; correct?

Ms Miller: Yes.

Mr. Lukaszuk: So who would be doing this research? If they can't commercialize it, who would be doing it? A charity?

Ms Miller: Oh, I see what you mean. There are many research organizations out there that do it: not-for-profits, independent researchers, academics, universities.

Mr. Lukaszuk: When they do it not-for-profit, it is us the Alberta taxpayers that cover their expenses and the costs of research. They don't do it for free. I imagine their salary – they do it except the dollars come from the Alberta taxpayer as opposed to a corporate structure. Isn't that true?

Ms Miller: Well, we all know there's nothing for free, but it's not for the resale.

Mr. Lukaszuk: What I'm seeing over here now is just a nucleus of setting up a new government industry of researchers who would now take over the research as a not-for-profit except it is for profit because it's paid by taxpayers. So we're going to put companies that do their research currently on a commercial basis out of business and replace the research that they do with not-for-profit research agencies.

Ms Miller: I can't speak for for-profit commercial agencies, clearly, but there are, I'm aware, commercial agencies that do research on nonidentifiable information. There are different kinds of research. There's research on identifiable information, and there's research that can be done on nonidentifiable research. Our information and what we're proposing here is special protection when identifiable information is being used for purely commercial purposes. That's all we're proposing.

Mr. Snelgrove: I'm not sure of the difference, to try and make someone define what is a commercial or marketing research, be it a not-for-profit or a government agency or a university. I guess from an individual point of view if after all of the protocol has been followed, information about me or whoever has gotten into this area where it can be used for research, then I quite frankly don't care who gets it if it can be used by a commercial firm to improve drugs or service providers. I'm not sure who you're going to put in a position to determine, then, what is commercial or marketing research, and I'm not sure it's important.

If the walls around the information, the identifiable information, are there and we ensure that part of it, then I don't understand why we would be so leery of commercial ventures or marketers. I'm just not sure that it makes a difference.

The Chair: Is there a response to that? If not, I have comments from Mr. Broda.

Mr. Broda: Yes. My question comes back again. I don't know. For some reason we're just stuck on this commercializing end of it. It's research. It's information that's gathered. On that chart over there the patient's identification is not even there, so it's protected. So I just can't understand why. Is commercializing, profit a dirty word? I don't know.

On that chart alone it says that, yeah, the information is gathered, but it's not patient information; it's information. Why is a physician opposed to providing information that does not include any patient information?

The Chair: I think physicians would not be opposed if they were asked.

Mr. Broda: Obviously. They don't want to include it.

The Chair: Because they want to be able to control or give permission to the people who want to use the information for commercial purposes.

Mr. Broda: My next question would be then: if they were paid for the information that they're opposed to providing, would they be opposed to it?

The Chair: Well, I'm not even going there. I don't know.

Okay. Was there response from the technical team on either of those two questions, comments, or whatever they were?

Ms Miller: The concern is that the providers feel, I believe – we've heard this in many forums – that because the service information we're talking about is of interest typically for commercial purposes and reveals details about various providers' practice patterns, they're very concerned that without the appropriate context around that in terms of explaining those practice patterns on an individual basis, it could be interpreted inappropriately and used for purposes for which it was never collected.

The Chair: Okay. If I could philosophize for one moment. If this were a family situation and I was the father and one of my children was representing the commercial interests and the other one was representing the doctors, I would lock them in a room and tell them they couldn't come out until they came up with a solution. This is a win/win for everybody. We need to get the information out. It's of benefit to Albertans.

I am sympathetic to what the doctors are saying to a certain extent. I think they have a point. If I were a doctor, I think I would understand what their concern is. As Linda explained on the chart, but as Mr. Broda and others have pointed out, it's hard to say that this is identifiable information.

Again, I wish the two players in this game could resolve this, but they apparently have been unable to do that. So now I've got a motion on the floor, and I've got the suggestion here about the research aspect. I don't know. If the motion passes, then where is this at? Does the technical team need this dealt with today, or would this also be tabled until next winter or spring?

Ms Miller: The department sees the need to have the ability to do research relevant for provider information as being very important because it has presented challenges for us as a department to understand certain factors that are going on in the health care system.

It is our preference, however. Certainly, it's the committee's decision.

The Chair: So, I guess Linda, my question is, before we go to Mr. Snelgrove, if the committee were to agree to this, would we still be able to have the other debate by the other committee on the other aspect?

Ms Miller: Yes, most definitely. This is just about the research part of it.

Mr. Snelgrove: It would be helpful even if we can agree. I don't disagree with this, if that's truly political. I don't disagree, but I'm not sure how it shakes out. Could you have for us, possibly for next meeting, a typical organization that might be using information now that wouldn't be if we went to the research limitation or some organizations that are doing it that won't be affected so I can just in balance think: okay; what does this really mean to what level of organization? Straight across the board.

Ms Miller: We'll certainly attempt to do that: maybe draft some scenarios and real-life scenarios to the best of our knowledge.

The Chair: You know, I think that's a fair point that Mr. Snelgrove makes. I'm trying to figure out how we're going to deal with the motion and also the comments about the research one. My inclination is just to table everything until next week, but I don't know whether the committee will . . .

Dr. Pannu: Mr. Chairman, I had looked at this this morning and then forgot about it. I'm willing to have the matter tabled until next meeting.

2:40

The Chair: Everyone knows, as I do, that that is the last meeting. The nice thing about that is that we won't be able to defer any more.

Mr. Snelgrove: We talk about groups that use nonidentifiable information, and I can understand that. I need to know who that affects when you're identifiable as opposed to nonidentifiable. That's a huge difference to me, much, much more critical around identifiable in my opinion.

The Chair: I think that is a good solution to wait one more week, Dr. Pannu, but I think to need to point out to the committee that next week being the last meeting, you know, if the committee agrees to whatever, then that will be – I don't know how we'll get that in the final draft, because next week is the final draft. How will we work that out?

Ms Miller: We work on weekends and at lunch hours.

The Chair: Yeah, but the committee will come in here next Friday, you'll present the final draft, and you can't obviously incorporate into that the issues that the committee hasn't yet decided on.

Ms Miller: No. We'll just leave a place holder for that piece, obviously.

The Chair: So then the committee would make a decision next week, whatever that decision might be, and we'd just trust you to put it in there the way we direct you to. I don't have a problem with that.

Ms Miller: I would anticipate we could discuss it first thing, and then maybe at a break we could take a few minutes to draft what we believe we've heard the committee recommend, and then bring that back for your review before you agree on the whole report.

The Chair: All right.

Dr. Pannu, did you say that you would be prepared to change your motion to

> table these items, the disclosure including research, until October 15?

Dr. Pannu: Mr. Chairman, yes. I am agreeable to.

The Chair: Thank you very much.

Agreed?

Hon. Members: Agreed.

The Chair: Okay. So that concludes the discussion on the draft document. I think this morning I gave my word that we would allow a brief discussion on preamble. Did you still want to pursue that?

Dr. Pannu: Mr. Chairman, I have a motion which has two sentences of preamble and then a motion on that.

The Chair: All right. Let's hear it.

Dr. Pannu: So with your permission, may I go ahead?

The Chair: Proceed.

Dr. Pannu: Mr. Chairman, thank you for the opportunity for allowing us to revisit an issue that I raised this morning. My motion is as follows. It is prefaced by two whereases. I'll put them in the record.

> Whereas the USA PATRIOT Act grants American law enforcement agencies special powers to violate privacy rights that could include accessing the personal health information of Albertans held by American companies or affiliates of American companies, and whereas Alberta's Information and Privacy Commissioner has informed the committee by the way of a letter dated September 24, 2004, that he's unable to provide comment on this important matter until after the end of October, be it resolved that the committee recommend that the B.C. commissioner's report on the implications of the USA PATRIOT Act for privacy rights and confidentiality of personal health information forms an integral part of the review of this act when a legislative committee in spring 2005 resumes its review of the Health Information Act.

The Chair: Dr. Pannu, do you have a copies of that for the committee?

Dr. Pannu: I don't, actually, but they could be made very easily.

The Chair: Are there questions on Dr. Pannu's motion? No questions? All right. The question has been called. All in favour of the motion, hold up your hands. Opposed? It's lost.

Any other items today?

I'll accept a motion to adjourn.

Mr. Broda: So moved.

The Chair: All in favour? Agreed.

[The committee adjourned at 2:45 p.m.]