Title: Tuesday, September 28, 2004 HIA Review Committee
Date: 04/09/28
Time: 9:02 a.m.
[Mr. Jacobs in the chair]

The Chair: Good morning, everyone. I would like to call the committee to order. It is a couple of minutes past 9 o'clock. A couple of our members haven't come yet, but I assume that they will come soon.

We welcome you all here again on another beautiful day and look forward to the discussion and hopefully can make good progress.

I guess we should start by identifying ourselves for the record, so perhaps, Mr. Broda, you could start.

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

Mrs. Sawchuk: Karen Sawchuk, committee clerk.

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

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

The Chair: Okay. Thank you very much.

As you will remember, yesterday when we approved the agenda, we suggested that the agenda for yesterday would also cover today's meeting. As that stands, we're basically going to just proceed – and I note that Mr. Lougheed has just entered the room; good morning, Rob – with the discussion as per where we left off yesterday.

The committee will recall that yesterday we did defer question 6 and question 11, I think it was, to receive more information. I'm going to suggest that we maybe defer those a little bit longer, until this afternoon at least, because we haven't yet got all the information we need, and I'm going to ask Linda if she will also comment on this item before we proceed.

Ms Miller: Thank you, Mr. Jacobs. Further to your comments we have been doing a fair bit of investigation, and we've been talking briefly to Saskatchewan and British Columbia last night and this morning in terms of ascertaining the situation within their provinces and their perspective on a similar or related matter.

Fundamentally, one of the issues that we really need to look at and analyze further is that the potential for a change if recommended by the committee would be the effect of not having protection of provider information, be it deemed personal or professional. Our concern is that should there be changes made to this legislation, the providers – in this case predominantly the physician group, but it would apply in all provider groups because there is no alternative legislative source where provider information is protected – would become quite significantly concerned about sharing information about their particular practice and therefore would not be in a position to share that information either in the electronic health record world or in other instances where we do require sharing of the information.

As I'm sure you're all aware, this is such a critical issue for us, particularly at this point in time, because we are in the relatively early stages of trying to implement something as fundamental to health reform as the electronic health record. Should there be perceived to be a signal given to the providers that the information is not protected, it may have very significant consequences on the electronic health record because we are in such early stages of getting that information from them, building the trust with the providers that the information we do secure from their records will be shared appropriately and protected appropriately.

So that is really the fundamental concern that we're trying to address here and analyze properly for the committee so that your recommendations are based on a solid set of analysis and policy implications.

The Chair: Thank you very much, Linda.

So I'm asking the committee: allow us at least until this afternoon and maybe even longer. I think it's important we get all the information we can before we make a decision on especially question 6 because it is an important issue.

Dr. Pannu: Mr. Chairman, seeking more information on what Linda just provided. The provider information protection is available only in Alberta at the moment? No other province has it?

Ms Miller: No. Other provinces have provider protection legislation in other forms of legislation, not necessarily in their health legislation. There is legislation embedded in other acts and statutes. In Alberta it's the only legislation that we have, a piece of it obviously, that addresses provider protection.

Dr. Pannu: Has any other province moved ahead with the EHR part, electronic health records?

Ms Miller: Not in our view, and I think other jurisdictions would agree with my point of view on this issue, which is that Alberta is certainly seen to be at least four or five years ahead of other provinces in terms of being able to develop the EHR and roll it out to the number of stakeholders that we currently have at this point in time.

Dr. Pannu: Thank you.

The Chair: Thank you. So we will re-evaluate at lunchtime and proceed on that basis.

I'd also like to welcome Ms Kryczka, vice-chair of the committee, here for the record. Good morning, Karen.

Wendy, are we going to go with number 15?

Ms Robillard: Absolutely.

The Chair: All right.

Ms Robillard: Number 15. The question is: "Is the duty to collect health information directly from the individual except as authorized appropriate?" We have two suggested responses here. The first is a status quo, and the second suggested response is to consider the public health provisions when additional health service providers are considered for inclusion in the act.

The general consensus among the stakeholders is that the duty to collect health information directly from the individual except as authorized is appropriate as written. Existing rules appear to support custodian needs and individual rights. A suggestion was made to consider collection in the electronic environment. Legal review indicates that the act already permits custodians to indirectly collect a wide range of information that is necessary to provide health services. Alberta Health and Wellness will provide clarification of this authority in the Guidelines and Practices Manual. Canadian Blood Services' request for authorization of indirect collection for public health purposes is currently addressed by the provision allowing indirect collection where direct collection would prejudice the safety of another person.

The Chair: Okay. Thank you, Wendy.
So we have the two options under question 15. Do we have any questions or comments from the committee?

Mr. Broda: I'll move that we accept the status quo.

The Chair: All right. I have a motion from Mr. Broda that the committee accept the recommendation on question 15 of status quo.
Are there any questions about the motion? Ms Blakeman?

9:10

Ms Blakeman: No, thank you. I don't have any questions. Call the question.

The Chair: And no recorded vote?

Ms Blakeman: Not necessary at this time. Thank you.

Ms Swanson: Could I just clarify that there are two parts to this particular point, and both of them are being recommended. One is that for the moment we keep the status quo. The other part is that we take a look at the indirect collection for public health purposes down the road as part of the next review in early 2005 through the next committee, because Canadian Blood Services is a service provider and would be one of the potential bodies looked at in that review.

The Chair: Thank you.
Mr. Broda, would you be willing to expand your motion to include that concept?

Mr. Broda: I shall do that, yes. I'll move that

> we accept the status quo and include the review in 2005.

The Chair: Are there any questions or comments on the additional information? Okay. On the motion, all in favour please raise your hand. Opposed? Carried.
Question 16.

Ms Robillard: Question 16.

> Should custodians be permitted to collect information about the individual's family health history without the consent of the family members where necessary to provide health care to the individual? Or should privacy protection of the individual not allow this collection?

The suggested response is status quo. The rationale: the general consensus is that collection of family history without consent is appropriate and essential to provide timely, efficient patient care treatment.

Mr. Snelgrove: I'm sorry if it's in here. What's the definition of family, then?

The Chair: Wow. That's a dangerous question.

Mr. Snelgrove: Well.

The Chair: Never mind.

Mr. Snelgrove: I'm just curious.

The Chair: Wendy, do you want to respond?

Ms Robillard: There is no definition of family in the legislation. Given, though, that we're talking about a family health history, it would have to be some form of blood relative to be relevant.

Mr. Snelgrove: Okay.

The Chair: Mr. Snelgrove, does that alleviate your concern?

Mr. Snelgrove: Okay. If that's cleared up in definitions – and we agreed that there will be changes to definitions – that's fine.

The Chair: Okay. Are you saying that you want the definition clarified?

Mr. Snelgrove: Yes. I presume that a direct bloodline as the definition of family is fine.

Ms Swanson: I just wanted to comment. Blood family would apply when you're collecting history related to genetic predisposition, but it wouldn't necessarily apply to, for example, environmental issues and concerns. I think that might be too restrictive a definition of family as a matter of interpretation. We would probably interpret it more broadly than that.

Ms Blakeman: I'm wondering if we shouldn't be seeking the definition that is used by health providers like the RHAs. They are the front line in collection of the information, so it's likely to be them that would in fact be defining family to collect information. The way we've got it constitutionally now, blood relatives is one thing, but as soon as you get into the married partners, there's a different definition that's now supported by the courts. So you need to know what the hospitals are defining. Who do they let onto the wing during the nonvisiting hours essentially? Who do they define as family?

Mr. Snelgrove: I agree. We are being extremely careful about information collection, with the utmost importance on privacy, and then to just allow them to collect on what someone might consider a different definition of family is a little weird. So I would just like to see them give us the definition of family before we deal with that thing and go back. It's not a big deal, but I would just like to see it done. Maybe it is a big deal.

Ms Miller: I think it is a judgment call that the clinician, depending on the circumstance, does need to make. It is something that will change depending on the situation. Therefore, it would be very difficult to come up with some kind of comprehensive definition of family.
However, in the collection of information, providers are held to the three primary principles. They need to collect it based on need to know, highest level of anonymity, and least amount. I mean, they are held to those three parameters, so in making that respective judgment call, that is what they would be charged to demonstrate that they have done if somebody were to challenge them on that particular issue.

Mr. Broda: I don't know if this opens up a can of worms, but how about adoptive parents that may not want that information released?

Ms Miller: I would think that if a particular person is accessing the health care system, they may be asked about their heritage. The degree to which they themselves would be able to disclose that information would be their judgment call. Certainly, we're not proposing here that somehow the system would have some special access that didn't come from the individuals or from the family member themselves in terms of sharing that information.

The Chair: On this point, Noela?

Ms Inions: Yes, just about a couple of Linda's comments. You'd have to very carefully craft the definition. I was thinking of that same example of adoptive parents or non blood-related individuals.

It depends on what is being assessed. A physician will have a category in a physical history entitled family history, and they're going to make a judgment on the spot about what's relevant in terms of influences and people that may be affecting the individual. Sometimes it's direct ascendants. With descendants sometimes it's not nearly as clear-cut. It's someone that's had a direct influence on the individual or been involved in parenting.

So the definition needs to be carefully thought out, and the word "family" does appear in different places within this legislation both in terms of the disclosure provisions and the collection.

The Chair: Thank you.

Ms Kryczka: Well, I appreciate the discussion, but I think that we do have to respect the use of this with people on the front line and people that are in the health care system. Unless there's been a problem with this in interpretation, I think we should just leave it alone.

Ms Miller: To our knowledge there has not been a problem.

Ms Kryczka: All right. Thank you.

Dr. Pannu: Mr. Chairman, I wonder if it'll be helpful for the committee to in fact seek advice on it from clinicians themselves, either the college or the AMA. One or the other, I suppose, would be appropriate. I'm not sure which group.

It really would be of interest to clinicians as to how family gets defined if we move in that direction. There's some concern here that leaving it undefined would be going too far, but the clinical requirements must be respected and recognized, so advice from representatives of clinicians would be helpful.

The Chair: Okay.

Ms Robillard: In terms of the responses received on the question, there were 10 comments received. One was from a public member, one was from an insurance organization, and the remainder were from clinicians from AARN, from the regions, from the AMA, et cetera, who all concurred with the recommendation, which is status quo. None of them raised any concerns in relationship to defining who a family is or when they would apply the provision. So none of them have expressed any concern about that in their written submissions.

Ms Kryczka: Well, for the record, I would like to reinforce what I just said, and it seems like it's been reinforced across the way. We don't have a problem with this; there's been an explanation. We have more important work to do, and I think we should get on with it.

Thank you.

The Chair: Mr. MacDonald.

Mr. MacDonald: Yes. Could you tell me, please, how an insurance company, a life insurance company, is prevented from getting access to the data that may have been collected about an individual family and their medical history?

Ms Robillard: The way that the insurance industry would access an individual's health information is on the basis of the individual's consent. There are provisions in the act now that protect the information of third parties from disclosure, so when an individual consents to disclosure of their health information, the information of other parties can be protected in the Health Information Act. What should flow to the insurance industry should be about the individual.

9:20

Mr. MacDonald: Thank you.

The Chair: To help the mind of a simple country boy, could someone please give me a practical example of how this would work? Someone comes in, they're ill, and the physician needs to know about their family history before they can do treatment. It's a serious question, I assume. I mean, I didn't just go in with a sore toe, you know; it's life or death. So then the physician needs to know something about my great-grandfather or my grandfather in order to help him with diagnosis. Is that about the way it works?

Ms Miller: Yes, that's about it. I wouldn't say in all but I would think that in many, many cases when you present yourself to the health care system, a family-related question is asked. Where it varies is depending on the nature of the particular reason why you're presenting yourself to the health care system, and that's why we believe the judgment is best left with the clinicians to determine that.

For example, if you were presenting with a symptom where there's a belief or a concern, perhaps, that you may have a particular form of cancer which may be believed to have genetic links, obviously the clinicians will be very interested in your family genetic history as far back as can be traced or remembered. However, if you are presenting for a particular E coli situation as most recently in Calgary, questions may be asked in terms of where you have been most recently and in contact with what kind of family and/or friends in terms of understanding perhaps where you contracted this particular bacteria.

So I'm just using those as two very different examples and examples where the clinicians will want to in their history taking define family in very different ways.

The Chair: So in the first instance, obviously, the physician is only interested in my blood relatives because any other associates or adopted family or marriage or whatever would have no relevance on my genetics.

Ms Miller: Well, I'd even qualify that as well. There's a belief that some carcinogens are environmentally based, so they may well ask in terms of family members that you're in contact with and environmental factors. I mean, there is no black and white kind of answer in this particular scenario.

Mr. Snelgrove: Mr. Chairman, my point wasn't that the doctors or the service provider wouldn't do the right thing with family history. The definition of family could certainly lead to different interpretations. I'm merely trying to say that as we go through this, we don't trust anyone else in the health field to be able to use their judgment to control information. Then we get to the service provider or the doctor, and all of a sudden they've got the God-given gift to understand what information is important, and we'll trust them with it.

I don't have a problem with that, but I'm saying that pharmacists, clergy, nurses, everyone has the best interest of their patient in mind. We're being so restrictive over every other part of this information until we get to the doctor, and then we say: oh, well; he'll do the right thing. That was my point.

Thank you. I'm sorry to take the time, but anyway I think it's important.

The Chair: Well, I think it's a very interesting point, but I guess my question is: so that inconsistency is there; does that affect what we're going to do in this case?

Mr. Snelgrove: I hope not. I just hope it allows us to keep in mind that there's a bigger picture here, and they are health professionals, all of them.

The Chair: Okay. Point well made.

All right. I'm at the committee's discretion here. I don't have any motions. I have a suggestion from one member that perhaps we need more information.

Mr. Snelgrove: Mr. Chairman, I'd move that

> we accept 16 as the status quo.

I don't believe there is a problem, and I believe the system serves us well. My point was probably broader, but I would move that we accept 16.

The Chair: Thank you very much.

So I have a motion to accept the recommendation of status quo on question 16 from Mr. Snelgrove. Are there any questions or comments about the motion? I see no requests for recorded votes, so I will call the question. By show of hands, all in favour of the question? Opposed? It's carried.

Question 17.

Ms Robillard: Question 17: "Is the requirement to inform individuals about collection practices effective or does it create any operational difficulties?" The suggested response is to link this to the pan-Canadian framework and the implied knowledgeable consent and to defer to a committee of the Legislature for consideration early in 2005. The rationale: stakeholders are somewhat divided on whether the requirement to inform individuals about collection practices is effective and about what methods are most appropriate. However, the majority believe it is effective. The issue around consent may in fact impact this practice.

The Chair: So the recommendation is to defer to this committee that we are recommending be struck in early 2005 for the reasons mentioned.

Mr. Broda: I agree with that.

The Chair: Mr. Broda, are you prepared to make a motion?

Mr. Broda: Yes. I move

> to defer it to 2005 as stated for reasons in 17.

The Chair: Thank you, Mr. Broda.

Mr. Broda has moved the recommendation on question 17. Seeing no questions about the motion or about recorded votes, I will call the question. All in favour? Opposed? It's carried.

I never cease to wonder why some members don't seem to vote on either side. It seems to me that we would vote one way or the other. I assume it was a silent vote and I just didn't get the message.

Ms Blakeman: Who are you directing those comments to?

The Chair: Well, I didn't see some members vote. I'm just wondering why they didn't vote either way.

Dr. Pannu: Mr. Chairman, in a recorded vote that's certainly important.

The Chair: Okay. All right.

Question 18.

Ms Robillard: Just for the committee's information, question 18 and question 20 were so closely linked that we moved them into the same issue and dealt with them with one suggested response. So the questions are:

> Are the purposes as currently listed in the Act appropriate for existing custodians? If not, how could these be improved? Is it appropriate to use identifying health information without consent for the authorized purposes stated in the Act?

The suggested response is the status quo. The rationale: with the exception of the AMA, stakeholders generally agree with the current list of purposes for which health information may be used without consent. The AMA continues to object to use or disclosure for anything other than care and treatment without consent and argues that identifiable health information is not required for policy, planning, resource allocation, health system management, and public health surveillance purposes. However, such information must be collected in identifiable form so that it can be analyzed and aggregated for use in statistical form. HIA requires custodians to apply the principle of least amount of information and highest level of anonymity to its use of information. In addition, custodians have many measures in place to restrict access to databases containing identifiable information and to protect privacy and confidentiality.

Ms Blakeman: I'm arguing on the side of the AMA for this. I continue to be concerned about not the initial collection of identifiable information but the tertiary and other exponentially expanded uses of it, especially when it's identifiable, because the original source may well be very careful about things, but we really have only begun to barely understand who else gets access to information in a lot of cases. When people are, for example, signing up for renewal on their house insurance, they're asked in a blanket release to give access to their insurance company, to give access to their medical records, and this information, once they start to get access to it, they use and do whatever else with it, and on and on and on it goes. We really don't know what happens to it, so whenever we allow a situation where the information is individually identified, I think we've got to be really careful. To my eye, this act has far too many opportunities for individually identifying information to be collected and then passed on.

9:30

I understand the argument that has been given to me previously that in order to do certain kinds of research you've got to be able to take the identifiable information, and then you strip off that identifiable information once you know who you're dealing with, and it goes forward, I understand, with anonymity from there. But I think there must be another way to do that or to get access to people rather than collecting information without their consent and then passing it on when it's individually identifying. So I'm speaking against accepting the recommendation that has been made here.

The Chair: Thank you.
Wendy.

Ms Robillard: Yes. I'd just like to point out that the use provisions in the act are strictly within the controlled arena, so we're not talking about information that has been passed on to any third parties. These provisions would not apply to them. They apply only to the custodians and affiliates that are within the controlled arena and bound by this legislation.

The Chair: On this point, Ms Blakeman.

Ms Blakeman: Yes. I accept that, but once insurance companies, for example, have received – and I think the way they're doing this blanket approval to get access to medical records, they could get access to the medical records that are in this arena and then take it beyond that; can they not?

Ms Robillard: This provision has nothing to do with insurers getting access to medical records. This provision is about how those people within the controlled arena who are currently custodians use the information which they now have collected. It has nothing to do with disclosure or use by other parties outside of the controlled arena.

Ms Blakeman: Yeah. See, I think they've got the information and others can now get at it, and that's my issue with it. Thank you.

The Chair: Dr. Pannu.

Dr. Pannu: Thank you, Mr. Chairman. I also find the AMA's position here, at the moment at least, quite persuasive. They talk about the use. AMA does not support health authorities, boards, and AHW using individually identifying information for planning, even within the so-called health arena. Is that what we call it?

Ms Robillard: Controlled arena.

Dr. Pannu: That's right. In their argument they follow it by saying that they believe that identifying information is not required for these purposes and where its use may be justified, approval by the OIPC should be required. Now, that to me seems to be an eminently sensible position to take. If that information is indeed required with identification, then OIPC, the office of the Information and Privacy Commissioner, is the right place to go to get that permission. Unless that permission is granted, I think the information should not be identifiable. Otherwise, the whole issue of anonymity, privacy, confidentiality – those issues are raised by the recommendation that's made. I think physicians have taken, in this case, a position that we should recognize as appropriate.

The Chair: A response, Linda?

Ms Miller: I'd like to explain again the rationale for why Alberta Health and Wellness, as well as other custodians, requires identifiable information to perform the policy, planning, and resource allocation systems. It is the only mechanism available to link data across the various databases. There are 8,000-plus custodians in the controlled arena. If we were to be required to approach the office of the Privacy Commissioner every time for every one of those 8,000-plus custodians for a request to look at information to link it, because somebody has to look at it to link it, I would imagine that the Privacy Commissioner's office would be extremely overwhelmed and unable to – I mean, it would be an administrative overload that would paralyze the system in my opinion.

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

Dr. Pannu: Linda, I need you to challenge the AMA's position here when they say that identifying information is not required for these purposes. They are leaving the door open that in a few cases that might be the case, but for most of the purposes outlined here, identifying information is not needed. I haven't heard any counterargument on that from you or from anyone that that identifying information is not required for most of the purposes outlined here, which are planning, resource allocation, health system management, public health surveillance, and health policy development.

Ms Miller: Dr. Pannu, I believe I've tried to argue that we do need identifying information to do that, to do the linkage. Once the linkage is done, then policy planners, resource allocators can look at the data and make policy resource planning decisions, but the issue is that somebody has to link the data in the first place. To link the data, technically somebody has to look at it, at that form.

My argument is that – certainly within Alberta Health and I have every confidence within the other custodians as well – within those respective organizations there are mechanisms in place that ensure that only those that have to have access to the identifiable information to do their job are granted that access. It is not granted to other than a handful in Alberta Health to look at the information, because it's not necessary for their job. For those that it is, we require them to do that, and to do that they need identifiable information.

The Chair: Okay. Moving on, Ms Kryczka.

Ms Kryczka: Well, I have a concern that the AMA's interpretation as recorded here is very narrow, and I just don't understand that. For instance, policy planning, no question. Public health surveillance purposes, maybe.

I was just thinking as you were having this discussion that with the new veterinary medicine school that has just been approved, it's going to be a province-wide partnership and all of that, but when it was sold in its presentation to MLAs, the two big benefits of it had to do with public health and then the economic side. There is going to be a very strong research component to that that will benefit public health. One of the key points that was made over and over in the presentations and when they had the press release in Calgary is that 80 per cent of viruses originate in animals. They know that, for instance, we have SARS and we have West Nile, but they're talking about public health in the future. I mean, I guess my point for what I want to say is that we need to enable information for research purposes.

My original question I had was on the controlled arena. The Health Quality Council, which is on the document that you people received yesterday, is part of Alberta Health and Wellness, and it's very important work that they are doing. In their submission their concern was being able to acquire information for research purposes. They are not presently in the controlled arena, are they?

Ms Miller: Yes, they are. They are considered, actually, an affiliate of Alberta Health and Wellness.

Ms Kryczka: Okay.

Then my only other comment is that maybe the AMA needs some kind of education or it's an attitude problem I think they may have.

Ms Miller: I have discussed this issue off-line with some representatives of the Alberta Medical Association, although they commented to me that they finally received what they thought was a solid understanding of why Alberta Health needs that. However, they did not change their position in their submission, so I cannot comment further on that issue.

I think one could say that perhaps we need to do a better job in explaining to the Alberta Medical Association why Alberta Health and Wellness does require identifiable information to do its job.

The Chair: Okay. Mr. MacDonald.

Mr. MacDonald: Thank you, Mr. Chairman. I have a question in regard to part 4 here. Now, if the minister or a minister of the Crown or the regional health authority required individual identifying information to manage the health system or develop public policy, before they go to the office of the Information and Privacy Commissioner, how does this ethics committee work? Who is on this ethics committee? For instance, I'm curious to know: if Alberta Health and Wellness were making an application for research, this ethics committee is to glean this application, as I understand in my interpretation of this act. Who exactly is on this ethics committee? Is it people like Robert Hyland who are very interested in the outcome of this consultation process? Is it AMA? Exactly who is it, and how often have they been consulted to date since this legislation has been in force?

9:40

Ms Miller: Can I just clarify? When we say controlled arena, we're talking about custodians. If you were named a custodian, you become a member of this controlled arena; therefore, information is shared without consent more freely than if you were outside of the controlled arena. Ethics boards are not custodians; they're not in the controlled arena; they're a mechanism. I believe there are seven of them established in the province of Alberta.

When a particular researcher wants to access data to answer a particular research question and to do that they believe they need individual data, they must propose their research study to one of the seven ethics boards. Based on the information that the ethics boards are presented from the researcher, which is at this point fairly high level – it's usually articulating the research question and the rationale for it and the expected kinds of data that they think they will need to answer that question – the ethics boards then evaluate that information in terms of the merit of the research question: is it feasible? With the understanding that potentially they will have access to identifiable information, is it ethical for this researcher to proceed?

However, even when an ethics board grants approval for a researcher to proceed, the act states quite clearly that the custodian, be it Alberta Health and Wellness or any one of the 8,000-plus, wherever they want to access data, still has a duty to assess that research proposal in light of the information that's being requested of that custodian to determine whether that particular researcher indeed needs individually identifiable information, or the information can be linked by the custodian who has access to the individual information and then that linked data provided to the researcher.

So that's how the process generally works. Now, in some cases we do have to give identifiable information to the researcher, but when we do that, we also ask the researcher to sign a legal agreement saying that they can only use that information for the purposes of that question and not any further. So that's the general process.

The Chair: On this point, Mr. MacDonald.

Mr. MacDonald: Yes. Again, who selects the ethics boards? These seven different boards that are set up: who sets those up?

Ms Robillard: The organizations that set up the ethics boards have processes in place in terms of how people get assigned to those ethics boards, and Roseanne might have more information about that than I do, but that's primarily how. It's through the association.

So the ethics boards are through the Alberta Cancer Board Research Ethics Committee, the College of Physicians and Surgeons of Alberta Research Ethics Review Committee, the Alberta Heritage Foundation for Medical Research, the Community Health Ethics Research Review Committee, the University of Alberta Health Research Ethics Board, the University of Calgary Conjoint Faculties Research Ethics Board, and the University of Lethbridge Human Subject Research Committee. They are the ones who are charged with appointing members to those committees and determining the issues.

Ms Gallant: I would just add that that's correct. Wendy's comments are correct. Actually, each of them has a web site, and on the web they actually list all of their members and their backgrounds. In general they usually, you know, invite people of varying backgrounds to participate on ethics review boards. So you'll have physicians; you'll have ethicists; you'll have scientists, and so on.

They do list who their current members are, if you're interested in that information. If you're wondering about a member of the public, I don't know specifically, but they may invite. Sometimes they have a member at large, a public member.

Mr. MacDonald: How often to date have these seven boards been consulted in regard to this act since it's come into force? You don't have any idea, eh?

Ms Robillard: You mean how many times have they been approached with research questions?

Mr. MacDonald: Yeah. Sure.

Ms Robillard: It's an ongoing process for them; it's continual. They have frequent meetings. They get approached many times, but I couldn't speak to how many.

Ms Gallant: Within the act the boards are charged with sending us a copy of an approval letter once they have approved research under this act. Some boards do very few a year; the University of Lethbridge has a very low volume. Others do large, large volumes, 400 and 500 requests a year. I don't have the exact number with me, but if you'd like to know what an average year entails with regard to disclosure of health information and approval for research, we can certainly look that up for you. But each one varies.

Mr. Snelgrove: The recent summit on health clearly identified from all first ministers of various parties in every province that reporting and recording health information was absolutely critical to improving the health situation we're in. I don't think that those are the words that the AMA would probably use to say that health information is not required; I think that how they get it they would debate. I find that to be extremely self-serving.

With that I would move that we accept the status quo recommendation for parts 18 and 20.

The Chair: Okay. I have that motion, but I do have some other questions before we get to that. Thank you, Mr. Snelgrove.

Mr. Broda.

Mr. Broda: Very briefly. Thank you, chair. A question. This is already in the act. We're asking to maintain the status quo. Has there been a problem other than the AMA's position?

Ms Miller: Not to our knowledge.

Mr. Broda: Good.

The Chair: Ms Blakeman, did you have an additional question?

Ms Blakeman: I just wanted to request a recorded vote, please.

The Chair: Certainly.
Anyone else? Okay. The motion has been made by Mr. Snelgrove on 18 and 20

> to adopt the recommendation of status quo.

We do have a request for a recorded vote, so I will call the roll.

Mr. Goudreau: I agree with the motion.

Mr. Snelgrove: Agreed.

Mr. Broda: Agreed.

Ms Kryczka: Agreed.

Mr. Lougheed: Agreed.

Dr. Pannu: Opposed.

Mr. MacDonald: Opposed, Mr. Chairman.

Ms Blakeman: Opposed.

The Chair: The motion is carried.
Question 19.

Ms Robillard: Question 19. "If you recommended an expansion of scope [of the act] to include other entities, what purposes [or] set of responsibilities would you change to reflect the mandates of additional custodians?" The suggested response is status quo, pending the decisions on scope through the proposed committee for the Legislature review in 2005. The rationale is that no changes will be required unless private-sector providers or new types of entities are brought within the scope of the act. Canadian Blood Services' request for public health as an authorized use can be considered as part of the investigation of scope changes in 2005.

The Chair: Questions? Comments?
So the recommendation is status quo pending decisions on scope through the committee that is recommended to be convened in 2005. Mr. Goudreau, are you prepared to move that?

Mr. Goudreau: I will make the motion that

> we maintain the status quo pending the decision on scope for review in 2005.

The Chair: Thank you, Mr. Goudreau.
Questions on the motion?
Seeing no request for a recorded vote, I will just call the vote. There were questions last time when I raised the issue of how some members had voted. I guess I would like to be able to see the vote. If I don't see you vote, then I assume that you're not voting, and we are actually supposed to vote, so that's why I made the comment I did. You know, I'm not quite as quick as Mrs. Sawchuk. She sees the votes, but I don't always see them. So if you could make the votes a little more visible for the chair, it would be appreciated.
Okay. On the motion, all in favour? Carried unanimously. Good. Thanks for your co-operation.
Question 21.

9:50

Ms Robillard: Question 21: "Overall, should the listings of authorized uses be expanded, restricted or modified in any way?" The suggested response is: status quo.
The rationale. Although there were two specific additions suggested, both appear to shift the balance too far away from protection of privacy. The first is use in fundraising without consent, and the second is broadening the use provisions from "health service provider education" to simply "education" purposes.

Ms Blakeman: Following the discussion that I put on the record in response to sections 18 and 20, which I won't repeat, I would argue that the listings should be narrowed rather than expanded or left at the status quo. So I would be voting against this motion.
Thank you.

The Chair: Anyone want to respond to that? Mr. MacDonald.

Mr. MacDonald: Yes. I would certainly support what Ms Blakeman has stated. I was just reading in the analysis, for instance, where fundraising by the custodian, in this case the Calgary health authority, is a reason for expanding the list of authorized uses for health information. Now, I'm assuming that they want a list of who comes in the door so that they can send a letter out later for fundraising purposes, which I think is at this time unnecessary and inappropriate. That concerns me.
Thank you.

Ms Kryczka: I move that

> we accept Question 21.

The Chair: I have a motion to accept, as recommended, status quo. Anyone else?
Was that a request for a recorded vote, Ms Blakeman?

Ms Blakeman: Yes, please.

The Chair: Okay. So we will call the roll again on the motion by Ms Kryczka to accept the status quo. I'll start with Mr. Goudreau again. For or against?

Mr. Goudreau: I'm for. Thank you.

Mr. Snelgrove: I'm for also.

Mr. Broda: For.

Ms Kryczka: For.

Mr. Lougheed: Consent.

Dr. Pannu: I'm opposed.

Mr. MacDonald: I'm opposed, Mr. Chairman. Thank you.

Ms Blakeman: Opposed.

The Chair: It's carried.
So are we doing 22(a) and 22(b) as two questions?

Ms Robillard: A single question will work.

The Chair: A single question. All right. Proceed.

Ms Robillard: So question 22: "Are the elements of consent appropriate? Or should consent be allowed to be provided verbally to the custodian?"

The suggested response is to consider with the pan-Canadian framework issue on implied, knowledgeable consent; defer to a committee of the Legislature in early 2005.

Ms Kryczka: I would move that we accept question 22.

The Chair: I have a motion from Ms Kryczka to

> accept the recommendations of deferral until 2005.

Ms Blakeman: Are we in discussion on the motion?

The Chair: We are.

Ms Blakeman: I would tend to have argued again that there are some concerns, I think, around how consent is obtained and especially around the sort of prophylactic or in-advance blanket consent that's being used particularly, in my personal experience, by insurance companies. So I think that there's an issue around consent, but seeing that it's being referred to this committee, which I certainly hope we can have some assurance is going to be struck, then I'm happy to defer the discussion to that.

Thank you.

Ms Robillard: I would just like to comment that the consent issue around the Health Information Act will in no way impact or affect the insurance companies. They are not currently bound by this legislation; this legislation doesn't apply to them. That would be their own legislation or other legislation. So this will not impact that in any event.

The Chair: Ms Blakeman, to your comment about a guarantee that the committee will be struck, of course it will be a recommendation of this committee that it be struck, but I guess that is the only guarantee that we have.

Ms Blakeman: Does the chairperson, then, have some idea what will happen to the recommendations that we've made that are recommending deferral of a number of different topics? If there is no committee struck, what happens to those recommendations?

The Chair: Well, I believe that there will be a committee struck, but I can't guarantee it. Okay?

Ms Blakeman: Okay. I understand that. In any discussions that you've had as chairperson, do you have any idea or do you have a plan B about what would happen with these recommendations if it's not struck?

The Chair: I do not.
Linda, Wendy, anyone want to comment?

Ms Miller: The issue of the pan-Canadian framework and aligning to that is of significant concern to Alberta Health and Wellness. So I believe that Alberta Health and Wellness on behalf of the minister will have to wrestle with that issue very early in the new year. Exactly how that will occur I obviously don't know, but I am quite certain that the issue is going to have to be addressed.

The Chair: Mr. MacDonald, did you have an issue on the motion?

Mr. MacDonald: No. Just a point of clarification. If at some point, regardless of whether there's a committee struck or not, there are draft amendments and then amendments presented to the Legislative Assembly in the form of a bill, there's no reason in the world why any hon. member of that Assembly cannot propose amendments if they see fit.

The Chair: True. Good point.
All right. I don't believe that I have a request for a recorded vote here, so we will do just a hand vote. Again, all those in favour of the motion? Opposed? It's carried.

Mr. Snelgrove: Mr. Chairman, could I make a point that if you are going to recommend that they have this committee, I not be on it?

The Chair: I've already made that recommendation for both of us, thank you.

Mr. Snelgrove: Thank you, Mr. Chairman.

The Chair: All right. Wendy, I think question 23 is okay. It's 25 that you want to break up into bullets; right?

Ms Robillard: No, it is question 23, I believe.

The Chair: Okay. Well, I see 25 down there too.

Ms Robillard: Yes, we incorporated that suggestion as it's linked to disclosures.

The Chair: So you want motions here on each bullet?

Ms Robillard: As we're going to go through a number of quite different scenarios here, it will probably be easier if we deal with each bullet and each suggested response separately under question 23.

The Chair: So on the first bullet then.

Ms Robillard: So question 23 is: "Are the discretionary disclosures without consent (subject to overriding principles) as listed in the Act reasonable and appropriate? Should these permitted disclosures be restricted in any way? Please explain."

The suggested responses are to amend the act to allow for disclosure of individually identifying diagnostic, treatment, and care information without consent to, the first bullet, the collaborative or integrated programs.

I would like to refer everyone to the discussion paper on question 23 that was sent out I believe on Friday by fax.

The Chair: Okay. Will you give us a minute to try to find that one?

Dr. Pannu: Give us some time to look for it.

Ms Robillard: It's a one-page document, 1 of 1.

The Chair: So it is a one-pager, question 23.

Dr. Pannu: Mr. Chairman, can I request a copy of that?

The Chair: Certainly.

Dr. Pannu: I'm desperately looking for it. Oh, here it is. Question 23, is it?

The Chair: Yes.

I believe that we now have copies in our hands.

Ms Robillard: I'll go through this in detail, in any event.

The Alberta Mental Health Board and the provincial diversion program advisory committee requested that HIA be amended to allow the disclosure of health information including diagnostic, treatment, and care information without consent for the purpose of delivering common or integrated programs and services.

The government of Alberta submission requested that the matter be considered. There are some current provisions that enable the sharing of limited health information in a specific situation without consent, and we've talked about these before: to avert or minimize an imminent danger, if the individual lacks the mental capacity to consent, and if the custodian believes the disclosure to be in the individual's best interests, et cetera. Otherwise, consent for the disclosure is required.

10:00

Section 40(1)(i) of the FOIP Act enables the disclosure of personal information without consent "if the disclosure is necessary for the delivery of a common or integrated program or service." Many government departments feel that a similar provision under HIA would greatly enhance the effectiveness of cross-ministry initiatives such as the family violence initiative. Capital health acknowledges difficulties and administrative burdens associated with explicit consent for disclosure but believes it is necessary for transparency.

It has been suggested that parameters could be developed to ensure that an adequate balance is struck between the need to protect the privacy of health information and the need to disclose information in appropriate circumstances. These parameters could include the following: the need for a formal or integrated service framework that clearly identifies the services that are to be delivered, clearly defined membership in the integrated service framework, identification of the organization that has the lead role in the initiative, a requirement that all member organizations be subject to provincial privacy legislation, a requirement for a privacy impact assessment to be completed and submitted to the commissioner for review and comment before the program is implemented, and requirements with respect to how the information would be managed in order to ensure consistency with the intent behind HIA.

It can be argued that the participation and consent of individuals and families is fundamental and required to engage them effectively in collaborative or integrated programs. Some Albertans would make the argument that their health information is more sensitive than other components of their personal information. Therefore, the additional protection of privacy and the requirement for consent-based disclosure may be the most transparent and appropriate for health information.

So the options are status quo or to amend the act to enable disclosure without consent if it is necessary for the delivery of a common or integrated program or service.

The Chair: Thank you. Do we have questions?

Ms Kryczka: If you would like a motion, I would move that we choose option 2.

The Chair: That's a motion for option 2.

> Amend the Act to enable disclosure without consent if the disclosure is necessary for the delivery of a common or integrated program or service.

Dr. Pannu: Mr. Chairman, I have a question.

The Chair: Yes, Dr. Pannu.

Dr. Pannu: In the discussion paper there's a reference at the end of the first paragraph: "Capital Health acknowledges difficulties and administrative burdens associated with explicit consent for disclosure, but believes it is necessary for transparency." Now, I find that position laudable, acceptable, supportable. Is it embodied in option 2?

Ms Robillard: No.

Dr. Pannu: Okay. Thank you.

The Chair: Mr. MacDonald, did you have a question?

Mr. MacDonald: Yes, please, Mr. Chairman. In light of what the Alberta Medical Association states here about the Chief Electoral Officer and fails to see why the Chief Electoral Officer is included – this is on the next page.

The Chair: Well, could we do that when we get there?

Mr. MacDonald: Okay. Sure. If you want to wait, I have a question about that.

The Chair: Very good. So, Mr. MacDonald, are you okay to delay that question till we get to that point?

Mr. MacDonald: I can certainly wait. Sure. You bet.

Ms Blakeman: I'm not in favour of option 2. I think it weakens the legislation, and I am still sitting on this committee believing that we are the only defence on behalf of the public around their identifiable health information. There have been, obviously, some reasonable requests that I've already agreed to, but I just worry that if we continue to allow the erosion of the protection that was in the original act, I'm not serving my constituents well.

I think this weakens the legislation, and I'm concerned about the erosion of the individual control over their ability to give consent. I'm speaking against the motion, and I would ask for a recorded vote.

The Chair: Thank you.

Mr. Lougheed: To the staff. I just wonder if there are any more comments – I see you have comments from the Mental Health Board – from other mental health organizations, advocacy groups, or any other comments?

Ms Robillard: We did have comments, I believe, from the RHAs, but I don't believe we had any further comments from mental health organizations on this issue. However, I can check this quickly.

We had comments from just those people that I spoke specifically to. The regions have not commented specifically, other than Capital health, on the integrated program. The regions are assuming that it would be consent based, as it currently is.

The Chair: Are you okay with that, Mr. Lougheed?

Mr. Lougheed: Yeah. The answer is fine.

The Chair: Okay.
Mr. Broda.

Mr. Broda: Yes. Questions. If it remains status quo, as it works right now – there were statements made in this discussion paper that it would be more effective through cross-ministry initiatives, such as family violence initiatives. However, under the present system it is working; there are some difficulties. If we left it the way it was, how would it really affect – I agree with Dr. Pannu. I agree with the Capital health statement that it is necessary for transparency. If it's working right now with slight difficulties, I think they can be overcome.

Ms Miller: I would agree with your analysis.

Dr. Pannu: I think Mr. Broda has made that point, and I strongly support the position taken by Capital health. I think they're providing leadership here. Therefore, I will be voting against the motion before the committee.

Ms Robillard: I'd just like to correct my response to Mr. Lougheed. The Canadian Mental Health Association indicate that although they've not spoken specifically to integrated programs, their position is that they should require the patient to be notified whenever identifying information is to be disclosed and to eliminate or extremely limit nonconsensual disclosures. So although it was not related specifically to this question, generally that would be their approach.

Ms Blakeman: I was looking for a definition of common or integrated program. Is it appearing on the handout sheet?

Ms Robillard: No. I don't believe it does.

Ms Blakeman: Okay. My specific question then. One of the presenters that we had was a rabbi that was participating in some pastoral care visitation programs offered through the regional health authorities and who wanted access to all admissions, aside from the list he got. Specifically, he wanted to review everybody that was in the hospital in order to kind of pick up some of the people that may not have made it onto his list, which would have told him everyone that was in the hospital. Now, since that's a program delivered by the regional health authorities, is that considered common?

10:10

Ms Robillard: No. That's clearly not a program that's delivered by the regional health authority; it's delivered by a rabbi. There are many clergypeople who do that, but it is not a common or integrated program.

Included in some of the parameters that were suggested for a common and integrated program would be that all member organizations be subject to provincial privacy legislation. What we're talking about here is when different government departments or service providers at the local level want to come together to assist in the treatment of, say, children or families. They see a need as a group to address things like the family violence initiative, and they say: we would like all to share our information for those purposes without consent.

Common and integrated programs may have some definition in FOIP beyond that. I don't have a reference in front of me right now.

Ms Blakeman: But the crux of what we're looking at here is the ability to disclose the information without the consent of the individual whose information it is.

Ms Robillard: Absolutely.

Ms Blakeman: Thank you.

The Chair: Okay. I'm going to suggest that we break at this point, allow committee members to give this some thought. Also, we have some committee members that need to be away for a couple of minutes. Would it be agreeable to the committee that we just take our break now and reconvene at 10:30 and we'll then take the vote on the issue?
Mr. MacDonald.

Mr. MacDonald: Yes. Could I have my concern addressed before we do that, please, Mr. Chairman?

The Chair: All right. Right after the break?

Mr. MacDonald: Right now.

The Chair: Oh, right now. Okay. What is your concern?

Mr. MacDonald: In regard to the stakeholder rationale the Alberta Medical Association states that they fail to see why the Chief Electoral Officer is included. Now, I went over the submissions, and I don't think we've heard from the Chief Electoral Officer. I don't think there's any need to. But if we were to remove that, would that affect the officer's ability to issue special ballots or to provide an opportunity for people in infirmaries to vote?

Ms Robillard: I don't know the answer to that. I see that Noela might have something to say.

Ms Inions: It's my understanding that that disclosure is allowed through specific legislation, both provincial – and there is the federal counterpart as well – and municipal, being able to ask people to vote and contact those individuals. There are provisions that allow that directly in the specific electoral legislation.

The Chair: Okay. I'm going to propose a break at this point. We will reconvene at 10:30. Thank you.

[The committee adjourned from 10:13 a.m. to 10:29 a.m.]

The Chair: I will call the committee back to order. We do have a motion on option 2 of question 23, under the first bullet, and Ms Blakeman has asked to speak to the motion.

Ms Blakeman: Thank you. An additional question has occurred to me. It strikes me that what we're examining here is the ability to disclose individually identifiable diagnostic, treatment, and care information without consent and then to a larger group of people, so if I could prevail upon the staff here from the Privacy Commissioner's office.

It strikes me that this possibility is a back door to information that they wouldn't be able to get through any other door. I note that the suggestions are that additional people who would get access to this information would be covered by FOIP, but could I get the staff to maybe talk about the differences of protection that's available and the opinion of that office on this particular suggestion?

Ms Gallant: I'll begin. Yes, because this is for common and integrated programs, there is the potential to have, of course, large numbers of noncustodians involved in the delivery of these integrated programs and services. For instance, it could have school representatives, it could have police services, and it could have people maybe from the health care service industry involved. So you would have a way of them sharing information from a custodian to a noncustodian that would normally not be done without consent if this provision should be put into this act.

Now, some of those bodies, like police and like the school sector, are covered by FOIP. We know that there are privacy protections within FOIP, of course, but they are different than the privacy protections that are afforded under the HIA. I mean, one of the clearest demonstrations of that would be the privacy impact assessment provision and that it is mandatory under the HIA to do, whereas it is not under the FOIP regime. Therefore, you know, the standard is higher under the HIA, so this disclosure without consent would not be supported by the Privacy Commissioner. We would have difficulty in allowing consent without disclosure to other individuals who are noncustodians.

Noela may want to add something to that.

The Chair: Yes, Ms Inions.

Ms Inions: Yes. I would go back to the purposes of HIA, those purposes being basically the protection of privacy or disclosure for the purposes of delivery of health services or managing the health system. It seems to me that the term "common and integrated programs" is far broader than that mandate or purpose of HIA. There isn't a definition for that term, certainly, within the Health Information Act.

It also would seem odd, comparing the uses that are available to custodians under the Health Information Act, to be able to have a far broader disclosure than the very prescribed list of uses that exists for custodians. One of the reasons HIA works is that there is broad access to information for the custodians, but there are very, very tough, onerous rules imposed on custodians. So this would result in a situation where information is collected under one set of rules and then disclosed with a different set of rules applying to that information after it's been disclosed.

It's my understanding that these programs can work with a consent base, even though that may be an onerous requirement. It seems to me that the individuals would need to be involved in consenting anyway to participate and benefit from these programs, by and large.

So those are just some thoughts on this.

I think that one thing I would say is that these programs are laudatory. They're important programs, and things do happen across departments. The reality is that information and programs aren't just delivered within a single department, so there do need to be ways for information to flow for legitimate reasons. But unless it's clear that this needs to be done on a nonconsensual basis, then certainly the element of choice of individuals and the protection of their privacy I would see as being paramount.

Ms Blakeman: So that sharing in the programs you talked about as being laudable in fact could do this work as long as they got consent rather than what's being suggested here, which is without consent.

Ms Inions: That's one of the options, without consent. I also see the material saying that these programs can work with consent.

Ms Blakeman: Thank you. That's the question.

The Chair: All right. Are we ready for the question? Do we still have the motion on the floor, Ms Kryczka?

Ms Kryczka: Yes. I'd like to leave it on the floor. I've just been reading information in detail on the various submissions in the longer document, so I will leave the motion on the floor.

The Chair: That is the motion to accept option 2?

Ms Kryczka: Yes.

10:35

The Chair: Right. I have a request for a recorded vote, so I will call the roll, and I'll start with Mr. Goudreau.

Mr. Goudreau: I'm opposed, Mr. Chairman.

Mr. Snelgrove: I'm opposed also.

Mr. Broda: Opposed.

Ms Kryczka: Support.

Mr. Lougheed: I'm opposed.

Dr. Pannu: Opposed.

Ms Blakeman: Opposed.

The Chair: The motion is lost. So are we there by process of elimination, or do we need another motion?

Do you want a motion for option 1, Mr. Broda?

Mr. Broda: I'll make the motion that we remain at status quo.

The Chair: Okay. Is this also going to be a recorded vote?

Ms Blakeman: I don't think it's necessary.

The Chair: I agree.

Okay. Any other questions on the other available option? I would think we've basically said all that needs to be said. So I will call the vote by show of hands. All in favour of status quo? Opposed? Thanks for being consistent. [interjection] Absolutely.

All right. Are we going to 25(a) now?

Ms Robillard: We're going to go to the second bullet point under question 23. I'm not sure, but 25(a) comes up in a few bullet points, if that's okay.

Under Suggested Response the second bullet is related to health departments of provincial, territorial, and federal governments for health services provided to those under their jurisdiction. That's to enable the disclosure, and the rationale is that provision of information about their residents to health departments in other jurisdictions is a long-standing practice across Canada to enable home jurisdictions to manage their health systems and develop policy to meet the needs of their residents.

The Chair: Wendy, could you clarify for me the question here?

Ms Robillard: The question came to us from other jurisdictions and from the department saying that they needed to be enabled to share this information, to disclose this health information without consent.

The Chair: So your recommendation here is as stated in the bullet?

Ms Robillard: Yes.

The Chair: Okay. Do we have any questions?

Ms Blakeman: I'm sorry; I just can't find it fast enough. The Privacy Commissioner had a statement on this. Is that correct? It was requested or there was something about information sharing with other provinces that came from the Privacy Commissioner. Is that on this issue or a different one?

Ms Inions: I'm not thinking of something on your point, but the thing that the Privacy Commissioner has spoken to has to do with the extraprovincial powers and the need to co-ordinate provincial and federal commissioners' offices to reduce the duplication and inconsistency in handling these matters. So perhaps that is the press release you're thinking of.

Ms Blakeman: Thank you. Then my question is – am I tracking this correctly? The suggestion is that individually identifying information be granted to health departments in other jurisdictions without consent?

Ms Robillard: Yes.

Ms Blakeman: Okay. Then my question: this may be a numbers game, but why can't it be done with consent?

Ms Robillard: The information flows after the service is provided, after the individual has in many cases left the province already. So somebody could be here visiting our province, end up receiving a medical treatment of some sort, being hospitalized, and then they return home. That province now wants to gather the information about the services provided to their constituent outside of the province. That information has typically been shared back and forth between departments of health for those purposes so they can continue to do ongoing planning and resource management, et cetera, et cetera. This is a long-standing practice.

Ms Blakeman: So has this been an issue, then, in the three years that HIA has been in place.

Ms Robillard: Yes. That's exactly the problem.

Ms Blakeman: Okay. Thank you.

The Chair: Ms Blakeman, Mrs. Sawchuk just made me aware of the commissioner's presentation on August 25, and there is a bullet in there. If you would like, I could read it. It's just a brief paragraph.

Ms Blakeman: That's okay; she answered this. I think she's identified it already; hasn't she?

The Chair: Okay.
Any other questions?

Dr. Pannu: On this sharing of information between provincial departments, what are the various reasons why it is shared? One would be billing, transferring of financial burdens or expenses incurred. What would be the other purposes? You could outline all of them, perhaps, for me.

Ms Robillard: Those are similar to the uses that we put health information to. They do health system planning; they do policy development; they estimate service use for the following years. They do all of those kinds of exercises incorporating the services that their recipients received outside of their provincial boundary, as does Alberta do the same thing.

Ms Miller: For example, Alberta is always interested in knowing the types of services and the quantity of services that are provided to its residents outside the province so that perhaps planning needs to begin to provide that service within the boundaries of Alberta or to make some other form of arrangement. The same would apply to any other province.

Traditionally, although I don't have the specific numbers for you today, a greater number of residents from other provinces come to Alberta for services as opposed to the number of residents that access services outside of the province.

Dr. Pannu: So you're suggesting that some Albertans may go to other provinces to receive a service which is not available here and vice versa?

Ms Miller: Certainly. Absolutely.

Ms Robillard: As Linda has stated, we also provide a lot of services to recipients from northern communities and northern B.C. simply because our hospitals are closer. There's an agreement, so those provinces just want to know what services we're providing, where, and how.

Mr. Snelgrove: Just for the information of the committee, the hospital in Lloydminster is on the Saskatchewan side, funded by Alberta but run through the north prairie region, or region 7. So the sharing of information is vitally important or it's an obstacle to it.

The Chair: How does this work now? Is this a change?

Ms Miller: It's been a long-standing practice, and we have respected that long-standing practice.

The Chair: That's interesting.
All right. Wendy, for identification purposes, I guess, for the motion here we just need to read the statement, because I don't know how else to identify it.

Ms Robillard: Yes. It's the first three.

> To amend the act 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 those under their jurisdiction.

The Chair: Okay. I have a mover. Mr. Goudreau is prepared to move that. Is that correct?

Mr. Goudreau: Yes, I am.

The Chair: Any questions on the motion? By show of hands, all in

favour? Opposed? Carried.
Okay. The next one.

Ms Robillard: The next suggested response is, again, to amend the act to allow for disclosure of individual identifiable diagnostic, treatment, and care information without consent to 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.

The rationale. Disclosures for the limited purposes of determining eligibility for a health service or payment of benefits or a health-related service or benefits are in the interests of the individual concerned. Determination of the jurisdiction responsible is not always apparent at the time a service is delivered, making consent impractical.

HIA currently authorizes the disclosure of individually identifying health information without consent to another minister of the government of Alberta for the purpose of developing public policy. The minister may also enter into an agreement with another minister of the government of Alberta or a minister of the government of Canada or of any other province or territory to disclose individually identifying registration information without the consent of the individual. However, the act does not enable disclosure of individually identifying health information without consent to other government departments or other provincial, territorial, or federal government departments for eligibility review or the payment of health-related benefits or services.

The Chair: Do we have questions, comments?

Dr. Pannu: Eligibility review: would you expand on that? What exactly does that involve?

10:45

Ms Robillard: In some cases, for instance, Alberta Health will fund a certain amount of health service and another government department, typically HR and E but not limited to them, may also fund a portion of a health service. What's needed here is to be able to verify when the first payer has paid and the second payer needs to kick in or, in fact, to verify that both departments are not maybe paying for the same service without the first payer and second payer being aware of who's funding the service. So in those cases the health service providers bill directly for services, and there's a need for the ministries to compare, collaborate, and make sure the services are appropriately covered and paid.

Dr. Pannu: So that was one reason, and there was a second one you gave. The ability to review was one.

Ms Robillard: Yes. Another issue arises with seniors, where Alberta seniors living in long-term care centres are eligible for a number of benefits through other programs. I don't have the wording in front of me, but Veterans Affairs would be one. Again, the custodian needs to be able to disclose some level of health information to another level of government to get hearing aids paid for, you know, other potential medical devices, medical-related services that the individual may be eligible for.

Ms Kryczka: Actually, the Alberta Long Term Care Association's submission, back to the previous question, words it quite accurately; doesn't it? Then they represent so many long-term care facilities in the province. That's exactly their concern.

Ms Robillard: Yes.

The Chair: Is anyone prepared to move this bullet?

Mr. Broda: I'll move it.

The Chair: Mr. Broda. Thanks very much.
Questions on the motion?

Mr. Goudreau: Mr. Chairman, we talk about Alberta entering into some agreements to disclose information to other provinces. Does the opposite happen? Do we have agreements from Manitoba, for instance, disclosing information on their patients to us? Is it reciprocal right across Canada at this stage?

Ms Robillard: I'm not sure about an organization such as the Red Cross. But can other organizations, can other government departments disclose information to us? Yes. My sense is they have been.

Dr. Pannu: Mr. Chairman, on this question of reciprocity between provincial governments do we have reciprocal agreements with other provinces to transfer and exchange this information on a patient?

Ms Robillard: So that's on the previous question?

Mr. Goudreau: We talk about Alberta government departments or federal government departments determining eligibility. We're prepared to do that. Are other provinces prepared to do the same?

Ms Robillard: The issue is related to Alberta government departments and to the federal government department. We've not had a situation come up to date where another province would be funding something provided to an Albertan. That has not arisen. So the issue is other government departments at the federal government because, of course, there are services provided to First Nations individuals that are Alberta residents.

Mr. Goudreau: That's what I was thinking of.

The Chair: Yes. Ms Inions on this point.

Ms Inions: I would just comment and perhaps provide an example. The noninsured health benefits program of the federal government applies to the native community, and that whole program depends on figuring out what's already funded because it's noninsured. If it was not paid for by another source of payment, then that program kicks in and enables benefits to be directly paid, not reimbursed but paid directly to that group of people. So that's an example of the type of arrangement where it's essential to enable the individual to have benefits, to know what's being paid in a copayment basis or by other sources.

The Chair: Thank you.

Ms Blakeman: Let me come at this another way. What are the consequences if we don't approve this?

Ms Robillard: Consequences could be twofold, I think. One is that an individual could not receive a service they should be entitled to receive or could have to pay for it themselves. The second could be that potentially two government departments could pay for a single service provided to an individual.

Ms Blakeman: Thank you.

Ms Kryczka: Related to Ms Blakeman's comment she just made, I go back to the Alberta Long Term Care Association, and that includes, Mr. Broda, how many senior citizens in Alberta? Quite a few.

The government departments need this information to determine eligibility for benefits and services, to distribute benefits or services, and to confirm that benefits or services were received; i.e., Veterans Affairs Canada, Alberta Seniors, Alberta Human Resources and Employment for benefits under the AISH program, et cetera. It's significant in my opinion.

The Chair: Okay. Thank you.

Dr. Pannu: Further to Ms Blakeman's question to Wendy, these two kinds of consequences could result if the amendment is not approved. Over the last three years would you have some idea if these possibilities in fact have become real cases? How many?

Ms Robillard: Yes. I don't know how many, but we have specifically been asked by other government departments to share information relative to specific programs such as dental coverage programs, and the issue around the sharing of information from Seniors to other government departments for health benefits has certainly been raised by those organizations. I don't know how many times, but they've identified it as an issue, an impediment for them.

Dr. Pannu: But has someone been deprived of receiving benefits they were entitled to? That is one of the options that's mentioned.

Ms Robillard: Okay. Because we've not been able to share the information, we cannot confirm that somebody has not received a benefit that they should have, nor can we confirm that services might have been paid for twice, because we're not currently in a position to be able to verify that. Though the other department comes to us, we're bound and not able to disclose. So we've not been able to determine one way or the other.

Ms Kryczka: I move that we support this change.

Ms Robillard: Can I just be clear that the wording that I read this morning is the wording that we would like this to state, and I did add some words. It is: Alberta government departments or federal government departments for determining eligibility to receive a health service or a health-related service or a benefit or for payment purposes.

The Chair: Ms Kryczka, I have to apologize. I did have a motion. The discussion gets so long, and my memory is so short.

Mr. Broda, are you comfortable with the wording?

Mr. Broda: Yes. With the new wording that has been read out, I would support that.

The Chair: Everybody okay with the wording that's now been changed? I don't think I have a request for a recorded vote here, so by a show of hands all in favour of the motion? Opposed? It's carried. Unanimous.

Third parties for payment purposes.

Ms Robillard: Yes. Again a recommendation for disclosure of diagnostic, treatment, and care information without consent to third parties for payment purposes. Disclosures to third parties for payment purposes are necessary for the efficient operation of electronic adjudication of prescription drug claims, and stakeholders who commented were in general agreement with this purpose.

Ms Blakeman: Do we end up with the same situation in this bullet as the office of the Privacy Commissioner outlined for us in the first bullet that we looked at, the collaborative or integrated programs? Can you give us some opinion there? Do you need me to expand?

Ms Inions: I would see this as a very specific purpose, payment purposes being a direct benefit to the individual receiving those benefits and having the direct payment for the service. I would not see this as being very general and not limited, not restricted. I would see this being quite different from the earlier. The collaborative or integrated programs I believe is the other item you're comparing this to.

Ms Blakeman: Yup. Okay. Thank you.

Are all categories of information released here, registration information and health information? Is there any restriction on the information?

10:55

Ms Robillard: There would be some registration information to identify the individual, so presumably it would be name and personal health number. There would be the information about the drug itself, so what drug was there, and from that perhaps one could infer some health information. But there would be no diagnosis or anything of that nature that would flow with that.

Ms Miller: As a qualifier it would have to have, I would think, the drug name to determine, you know, the eligibility for that particular carrier. There may be instances where a particular carrier requires under certain circumstances whether a diagnosis would be required. We'd have to look at that case by case, and I would think that that would be the exception rather than the rule.

Ms Blakeman: Okay. In the bullet that accompanies it is a rationale. We're talking specifically about prescription drug claims, but that's not written into this suggested change. Specifically, this is asking that third parties be allowed to have discretionary disclosure of individually identifiable diagnostic, treatment, and care information without consent to third parties for payment purposes. Although we're talking specifically, as an example, about prescription drug claims and that that would narrow the amount of information, in fact it could be interpreted after the fact to cover additional health services; could it not?

Ms Robillard: It could be other health benefits that were covered on the plan, I assume.

Ms Swanson: I think it could probably include things like the person's share of wheelchair costs, for example. So there could be other kinds of benefits beyond drug benefits.

The Chair: Ms Inions.

Ms Inions: Yes. I would read this on its face as not being limited to prescription drug situations. It could be a billing for physician services, optical, dental. There are a wide variety of services where there would be third parties paying for that service.

The Chair: Thank you.
I do not have a mover for this one at this point.

Ms Kryczka: Yes. I so move.

The Chair: Oh, I do. Thank you, Ms Kryczka. You're prepared to move this?

Ms Kryczka: Yes, I am.

The Chair: Third parties for payment purposes.

Dr. Pannu: Mr. Chairman, could the motion be read again?

The Chair: Is it as stated on the paper, Wendy? "Third parties for payment purposes."
A question on the motion?

Ms Blakeman: Maybe while they're looking for that information, does this include Alberta Blue Cross defined as a third party?

Ms Miller: For the other services than that covered by Alberta Health and Wellness. So for those people that have a plan with them for, you know, other kinds of services, yes, it would. They would constitute a third party at this point.

Ms Blakeman: Alberta Blue Cross would?

Ms Miller: Yes.

Ms Blakeman: So if you had the kind of plan with Alberta Blue Cross that covered, whatever it is, 70 per cent of your prescription costs, because we've changed the status of Alberta Blue Cross now through the Legislature, then they become a third party. Is that what we're talking about here?

Ms Miller: Alberta Blue Cross has basically two lines of business. In one line of business they remain an affiliate of Alberta Health and Wellness, for group 66 I believe it is, which is the seniors' coverage. In that capacity they are an affiliate of Alberta Health and Wellness because they hold a contract with us, so they're part of the controlled arena for that line of business that they incur.
The other lines of business they have in terms of an insurance carrier for other people, employee groups, et cetera – in that capacity, then, they would constitute a third party carrier, if you will. This would apply to them in that instance.

Ms Blakeman: So what's been happening in the three years that HIA has been in place?

Ms Miller: I believe that in some instances that practice has continued with the knowledge of the Privacy Commissioner.

The Chair: Okay. We have a mover. Further questions on the motion?
All right. No recorded vote has been requested. By a show of hands, all in favour? Opposed? Okay. It's carried.
First Nations. No. Excuse me.

Ms Robillard: There's one before that.

The Chair: Yeah.

Ms Robillard: The next issue is to amend the Act to allow for disclosure of individually identifiable diagnostic, treatment, and care information without consent to a successor where the custodian remains a custodian but transfers records. This is a technical change recommended by the Information and Privacy Commissioner to address changes in the mandates of organizations such as the Alberta Mental Health Board.

The Chair: I have a question first, Ms Blakeman. Are you going to be making the motion on this one?

Ms Blakeman: I was going to make the motion.

The Chair: Okay. By all means, Ms Blakeman. I'll certainly take that as a motion from Ms Blakeman, absolutely.
We can do this by a show of hands. All in favour of the motion? Opposed? Carried. Thank you.
Now we'll go to First Nations.

Ms Robillard: Yes. The suggested response is to amend the Act to allow for disclosure of individually identifiable diagnostic, treatment, and care information without consent to First Nations police services for investigating an offence on the same basis as to other police services. The rationale: this is a housekeeping amendment to address an oversight in drafting the Health Information Act.

The Chair: Is that a question, Ms Kryczka?

Ms Kryczka: Motion to support.

The Chair: Okay. Ms Kryczka has moved this recommendation. Are you ready for the question?

Ms Blakeman: I'm sorry; what's the motion again? The second last one? Okay. Thank you.

The Chair: Would read that for us, please, Wendy?

Ms Blakeman: No, no. I'm good. That's okay.

The Chair: I'm sorry; I don't understand your question, Ms Blakeman.

Ms Blakeman: There wasn't one. Thank you.

The Chair: Okay.
So on the motion. All in favour? Opposed? It's carried.
And the last one.

Ms Robillard: The next suggested response is to amend to authorize professional bodies to retain health information used in an investigation or a hearing for 10 years. The rationale: this is a housekeeping amendment for consistency with the Health Professions Act.

Ms Kryczka: Motion to support.

The Chair: Okay. I have a motion from Ms Kryczka – thank you – to support. All in favour? Opposed? Carried.
Next.

Ms Robillard: The following are suggested responses: status quo regarding disclosures without consent to CMPA, Canadian Medical Protective Association, for medical/legal purposes. The rationale is that this amendment is not required. The CMPA wants explicit authority for physicians to contact the CMPA to obtain risk management and legal advice when proceedings are not necessarily threatened or contemplated, when proceedings are contemplated or threatened but not yet commenced, and when proceedings have been commenced. The CMPA "is satisfied that the existing exceptions in the HIA likely cover all three of the above-noted circumstances." Risk management activities can be supported through the disclosure of nonidentifying health information. The HIA does not limit the information otherwise available by law to a party to a legal proceeding.

The Chair: So the recommendation: status quo regarding the disclosures without consent to CMPA for medical/legal purposes.

Ms Kryczka: Motion to support.

The Chair: Motion to support from Ms Kryczka. Questions on the motion? All in favour by a show of hands? Opposed? Carried.

Ms Robillard: The next suggested response is status quo in relationship to the clergy or any person, the presence and location in a health facility unless a patient expressly refuses. The rationale is that no change is required. The act currently enables custodians to disclose information about an individual's location, presence, condition, diagnosis, progress, and prognosis on that day to family members of the individual or to another person with whom the individual is believed to have a close personal relationship without the individual's consent. The disclosure must not be contrary to the express request of the individual. Other disclosures of this information must be consent based. The balance in this circumstance is appropriately on protection of privacy as opposed to access.

Ms Blakeman: I'll move acceptance of the recommendation that we stay at status quo with this.

The Chair: Thank you.
Questions on the motion? All in favour? Opposed? Carried.

11:05

Ms Robillard: The next suggested response: status quo again to any person to address a complaint or allegation made in a public forum. The rationale: no change required, not the right balance between privacy and access.

The Chair: So, again, status quo to any person to address a complaint or allegation made in a public forum.

Ms Kryczka: Motion to accept.

The Chair: Motion to accept from Ms Kryczka. All in favour? Opposed? Carried.

Ms Robillard: Suggested response: status quo regarding suggestions to remove ability to disclose to the Chief Electoral Officer. No change is required. No breaches or problems have been identified to date.

Ms Kryczka: Motion to accept.

The Chair: Okay. Status quo on remove ability to disclose to the Chief Electoral Officer.

Ms Blakeman: Do the staff have any background on why this was being suggested that it be removed? I guess I'm curious as to why the Chief Electoral Officer would need individually identifiable health information. Is that what's currently allowed, or have I got that backwards?

Ms Robillard: No. My understanding is that currently enabled to flow to the Chief Electoral Officer are some individuals who reside in health facilities as opposed to being there for a short period of time, so there may be information that needs to flow. My assumption is that that's the basis on which the authority currently exists.

Ms Blakeman: But if we were talking there about people who reside in facilities, then we're talking about people in long-term care. But isn't their very presence in the facility enough to enable them to exercise their franchise? I'm not understanding why the Chief Electoral Officer needs to have individually identifying health information. Help me.

Ms Miller: I guess it would be best that the Chief Electoral Officer answer that question, but my understanding would be: remember that health information is very broadly defined. So, you know, just by having location and other associated attributes about a person, it then falls into the basket of health information. It is my understanding, although we would have to validate that within offices – it's basically what Wendy has articulated – that especially for those individuals who are residents in such institutions as long-term care, the officer needs access to that information so that his office can enable those people to exercise their voting right. That's my understanding of the extent to which that requirement is needed. There may be others that I would have to look to the electoral office for further direction.

Ms Robillard: I'd like to point out further that the provision is a broad provision, and I'll read it out as it states today. It's "to an officer of the Legislature if the information is necessary for the performance of the officer's duties." So the Chief Electoral Officer is an officer of the Legislature.

Ms Blakeman: The thing is that once that individual is in the arena, they have access to all the other information, and again I'm questioning why they need it. I think they got captured in here because they just listed the five legislative officers and didn't want to be unkind and leave somebody out. But I think that in this case there's a good reason for leaving them out. I cannot understand why they need individually identifying health information when we're talking about balloting. I mean, it strikes me that it's being used to separate something here. That's what's causing me concern.

Ms Robillard: I would just like to be clear that these officers of the Legislature are not within the controlled arena. This is a provision that enables disclosure to them and is limited to what is necessary for the performance of their duties. I would pass it on to Justice to add anything further to that.

Ms Blakeman: Thanks for the clarification.

Ms Gray: I can't clarify, but there may be a need for the electoral officer to make arrangements for people to vote who are not mobile. I'm not sure whether that may be one of the reasons; I'm speculating. But it is something that we could look into and advise further.

The Chair: Yes. Thank you.

Linda.

Ms Miller: Yes. Obviously, we're doing a lot of speculation. I feel very uncomfortable about that. If we could maybe over the lunch hour try to investigate this further so that we bring solid information back.

The Chair: Well, I guess so. It seems like it's a no-brainer to me, but anyway.

Dr. Pannu, did you have a comment?

Dr. Pannu: No. I'm fine now so long as we have time to get the information before we quit.

The Chair: All right. We have a request to table the disclosure to the Chief Electoral Officer till after lunch.

How about "restrict disclosure without consent to purposes related to direct care and treatment"? Can we try that one?

Ms Robillard: Yes. Status quo is the suggested response. There is a need for individually identifiable health information for health system management and policy development addressed in the question about uses.

The Chair: Questions? Anyone prepared to move it? Yikes. It must be bad.

Ms Kryczka: I'll move it.

The Chair: Thanks, Karen.

Dr. Pannu: Mr. Chairman, just for my . . .

The Chair: I do have a motion, but you have a comment. Okay.

Dr. Pannu: Right. A question more than anything else. Direct care: is it care in the hospital? What else could it be?

Ms Miller: Direct care would be direct care in any health service situation. It could be in the hospital, in the community, anywhere. It's back to the point previously made.

Typically, most programs or services offered by Alberta Health are not direct care, although there are programs that would constitute direct care that are operated by Alberta Health directly. But, for the most part, in a policy role you're not providing direct care, so that's back to this particular point.

So direct care means any service provided by a provider to a client or a patient. It could be in the community, in a doctor's clinic, in a hospital, in a long-term care building. Those constitute direct care.

Dr. Pannu: So my visit to my family doctor would be direct care.

Ms Miller: Direct care, yes.

The Chair: Okay. We do have a motion to status quo 1, "restrict disclosure without consent to purposes related to direct care and treatment." Is that correct, Ms Kryczka?

Ms Kryczka: Yes.

The Chair: All in favour? Opposed? It's carried.

Next.

Ms Robillard: The next is a status quo for the suggested response to require the individual to be notified before disclosure without consent. The rationale: no change is required. The balance would shift privacy at the expense of access to health information for authorized purposes.

The Chair: Do I have a mover?

Ms Kryczka: I would move to accept.

The Chair: What a hard-working lady. Okay. We have a mover for status quo on requiring the individual to be notified before disclosure without consent.

Dr. Pannu, did you have a question?

Dr. Pannu: Yes. Wendy's explanation was that to change it to this would mean shifting the balance to privacy and fairer privacy. I think it's a good thing to ensure that privacy is protected.

The Chair: So you support it. Okay.

All right. Anybody else? Okay. By a show of hands, all in favour of the motion? Opposed? Okay; carried.

The last one.

Ms Robillard: Status quo regarding suggestion prohibiting disclosure of psychological raw test and data scores except to those qualified to interpret them. The rationale: this is a matter of professional practice and not appropriate to be addressed in HIA.

Ms Kryczka: Motion to accept.

The Chair: I have a motion to adopt. Are there any questions? All in favour? Opposed? Carried.

So does that include all those under 23 and 25(a)? Number 24 is done. So now we're moving to 25. Is that correct, Wendy?

Ms Robillard: Yeah.

11:15

Ms Swanson: Okay. We're moving on to item 25. The question is around an amendment to specifically reference the triplicate prescription program in the act. The suggested response is to provide explicit authority for the triplicate prescription program. The reason is that stakeholders expressed no opposition to explicit authorization of the TPP in order to prevent a legal challenge.

The Chair: Thank you.

Questions? Comments?

Mr. Goudreau: I'll make the motion to
approve number 25 as recommended.

The Chair: Thank you. All in favour? Any opposed? It's carried.

Question 26.

Ms Swanson: "Should HIA be amended to include stronger provisions to protect confidentiality of genetic information?" The suggested response: to be addressed along with the pan-Canadian framework; defer to committee of the Legislature in early 2005.

Ms Blakeman: I'll move that motion.

The Chair: Thank you. I have a motion from Ms Blakeman
to support recommendation 26 for deferral until the next committee.
All in favour? Opposed? Okay.

Question 27.

Ms Robillard:

> Is an informed/knowledgeable implied consent model for care and treatment appropriate for Alberta's health system? If not, why not? What would be the operational and service delivery implications of an informed/knowledgeable implied consent model for care and treatment?

A suggested response: to be addressed along with the pan-Canadian framework; defer to a committee of the Legislature in early 2005.

Mr. Broda: I move that one.

The Chair: Thank you. Moved by Mr. Broda for acceptance. All in favour? Opposed? Carried.

Question 28. Do you want to do the whole thing at once or by bullets?

Ms Swanson: I think it would be best to do it point by point.

The Chair: Okay. I love those.

Ms Swanson: The question is: "Are the research provisions in the Act reasonable, effective and operationally effective? If not, why not?" The first suggested response is to change the term "research ethics committee" to "research ethics board." This is a housekeeping matter. The standard terminology across the country is research ethics board, and it's the accepted term in Alberta, so that's why we're suggesting that we go with this.

Ms Kryczka: A motion to accept.

The Chair: A motion to accept the housekeeping name change. All in favour? Opposed? Carried. Good.

The next bullet.

Ms Swanson: The suggested response to the next one is to authorize the office of the Information and Privacy Commissioner to publish ethics committee research approvals on a web site after the custodian has considered the request and determined whether individually identifiable health information will be released. This provision will provide greater transparency about research ethics review and release of health information with or without consent.

The ethics approval does not constitute agreement by the custodian to release individually identifiable information without consent. The custodian may decide to release the information but is not required to release it. The custodian is still bound to consider the least amount of information and the highest level of anonymity necessary for the research. The researcher must meet other requirements before a custodian may release the information.

As a custodian Alberta Health and Wellness makes individual-level health information anonymous or aggregates information to protect the privacy of individuals whenever possible. Publication of ethics board research approvals in advance of a decision by the custodian may create unnecessary concerns for individuals who are the potential subjects of the disclosures. So we've modified the commissioner's recommendation slightly.

The Chair: Thank you, Evelyn. Do we have questions?

Ms Kryczka.

Ms Kryczka: Yes. A motion to accept.

The Chair: Okay. It's been moved.

Ms Inions, do you have a comment?

Ms Inions: I would like to speak to the change here. I'm a little puzzled by the comments because the information in a research approval is not individually identifiable health information. It's information that says that there's research study X about whatever drug, perhaps, period. It's a very general kind of thing. This is not about identifiable information of an individual at all. That's not the kind of information that's being published.

If you read it and you say, "After the custodian has considered the request," our office would most times never know whether the request has been considered by a custodian or not. What we get when the research approval is provided to our office – that letter is just a letter saying that the REB has considered a proposal and approved it. Even the researcher may not know whether or not they're going to go to a specific custodian and get information. With this qualification this is quite an unworkable way, I think, for there to be greater transparency about the research projects that have been approved.

There is a requirement for research registries now that's coming through the international publishers of research, and CIHR is now doing this. The information about publishing ethics committee research approvals on a web site is not identifiable at all. Even to a researcher it's not connected at all. It's just a letter saying that we approve ABC research project. That's the type of data.

The Chair: So, Ms Inions, are you saying that we don't need this bullet?

Ms Inions: I'm saying that we need the authority to publish the ethics committee research approvals, but for the qualification after that, where it reads, "After the custodian has considered," I think that if it's to be a workable provision, it needs to end with the words "web site." Authorize the OIPC to publish ethics committee research approvals on a web site.

Ms Miller: We understand that the initial request by the OIPC did not require identifiable information. The only issue that we are basing this modification on is a concern that people not as familiar as many of us in terms of reading a web site and the so-called ethics approved research may lead some people to believe that that research and that data has already been released. So it is just that issue that caused us to propose a qualification to your initial request. We certainly understand that you are not asking to publish identifiable information.

The Chair: Evelyn, did you have additional comments?

Ms Swanson: No. I was going to make the same comment Linda did.

The Chair: Okay. A response to that, Ms Inions?

Ms Inions: I would still just reiterate that the authority to publish an ethics committee research approval on a web site kind of needs to end there. If it has the qualification that the custodian has to have considered the request and determined whether identifiable health information will be released, then it will be unworkable because that is not information that comes to our office and we wouldn't even know where the researcher goes. It doesn't identify the custodians the researcher would go to at all. That is not information that would be available to our office. It would basically kibosh the whole provision.

Ms Miller: I certainly respect your point of view on that and understand the difficulty that that would create. As an alternative we would suggest that there be some sort of disclaimer on the web site that said that this information request, in terms of the status of it, does not necessarily mean a particular custodian has released the data. That would address our concern.

Ms Inions: We would be pleased to qualify that information so that it was not misunderstood by the public.

The Chair: So as a disqualifier you think that's workable, Ms Inions?

Ms Inions: The web site itself does have introductory information, and it could very clearly say that this is just a research project that has been approved, just been received for approval. It does not mean that the research has been conducted.

The Chair: Okay. Does anyone on the committee have questions or comments before we proceed?

Ms Kryczka: I can read a new motion, or you can read it, Karen.

The Chair: Okay. But before you do, I have Mr. Snelgrove.

Mr. Snelgrove: A short question: why does it even go to that? I mean, I don't know the connection between the Privacy Commissioner's office and them publishing research ethics stuff.

11:25

Ms Inions: The connection is through the link to research between our office and the research ethics boards and the information, the considerations they need to consider when they approve a project, because the projects that we see involve health information and a very contentious use of that health information.

The REBs must send our office the approval letter if they have approved the research project. The importance of that is transparency. The importance of that is an apparent oversight and the protection of individuals in Alberta. The whole idea of a registry is transparency: that the public knows certain research is going on, that they know health information is involved in that, and that they know that there is an outside entity – that is, our office – that's receiving these approvals.

The whole area of research has been clouded by suspicion because there's this idea that it's conducted behind closed doors and the public is not told about the research that's going on, the research approvals that have been granted. The REBs themselves are designated under this legislation. They're a creature of this legislation in that they have certain rules that they must follow.

I don't know if that's responsive to your question.

Mr. Snelgrove: I'm just glad I live on a simple little farm, where I don't worry about this kind of crap; I'll tell you.

The Chair: I understand that.

Okay. Ms Kryczka, you were about to say that you're prepared to move an amendment or a different motion here.

Ms Kryczka: Yes. I'd like to present an amended motion to the first one. Do you want to read it, Karen?

The Chair: Sure. Okay. Mrs. Sawchuk has got it. She can read it.

Mrs. Sawchuk:

> To authorize the office of the Information and Privacy Commissioner to publish ethics committee research approvals on a web site.

That's the actual motion.

Ms Miller: With the qualification that an associated disclaimer be also published on the web site indicating that this research has not necessarily been conducted.

The Chair: Does it have to be part of the motion?

Ms Miller: I would ask the committee that.

The Chair: Okay. So she wants a disqualifier. Are you okay with that aspect?

Ms Kryczka: Yes. I had written down "to include a qualifier," based on Ms Inions' comments. I would be very happy with yours.

The Chair: Karen, have you got some idea of what we want here?

Mrs Sawchuk: Yes. We'll grab the wording.

The Chair: Is the committee okay with what's being proposed?

Dr. Pannu: Is Ms Inions okay now with it?

Ms Inions: I think the question is whether the commissioner is okay. But we would provide an explanation so that people would not misunderstand that the information has already been released or that the research has been conducted. We would clearly say: "This is just a research approval. This research has not yet been conducted."

The Chair: Yeah. Is everybody okay with that?

On the amended motion with the disqualifier, all in favour? Opposed? It's carried.

Moving forward on the status quo on request 2.

Ms Swanson: The next one is status quo on clarifying various aspects of the research provisions. We're saying that clarifications can be provided through interpretations of the policies rather than through legislative amendment.

The Chair: Anyone prepared to move that one?

Mr. Broda: Sure.

The Chair: Okay. Mr. Broda.

> To adopt status quo on request to clarify various aspects of research provisions.

All in favour? Opposed? I believe it's carried.

Ms Swanson: The next point. The suggested response is status quo on request to change the ethics committee duties, composition, and number. The reason is that most of the suggestions about the research ethics committees are not within the scope of HIA and are matters dealt with by research funding agencies in their ethics review policies and by bodies that establish ethics committees.

The Chair: I don't think I quite understand what you're doing here.

Ms Swanson: Some of the suggestions, for example, said: increase the number of ethics committees. The department does not establish ethics committees. They're established by bodies that do research or oversee research or want to do research. They establish them according to rules that are provided by the research funding agencies, the research granting agencies. So we don't control the number.

The Chair: Thank you.

Mr. Snelgrove: Because there's not a chance that we need more committees about anything, I recommend that we approve the status quo.

The Chair: Thank you very much, Mr. Snelgrove. I like your rationale. Very, very good.

So on the motion by Mr. Snelgrove,

> status quo on change ethics committee duties, composition, and number,

are you agreed? Opposed? Carried.

Okay. Next one.

Ms Swanson: The next one is status quo on changing consent requirements and allowing surrogates. The Health Information Act specifies requirements for release without consent, including ethics review. Surrogates can consent to disclose for research in the case of adults where the exercise "relates to the powers and duties of the guardian or trustee," and guardians of minors can exercise the rights of infants. Guidelines can be used to clarify these provisions.

The Chair: Okay. On the surrogate bullet, any questions?

Ms Kryczka: I move to accept.

The Chair: Ms Kryczka has made a motion to adopt as recommended, the status quo. All in favour please raise your hand. Opposed? Carried.

Going on to the last one on this one, I guess.

Ms Swanson: Again, this is a status quo suggestion with regard to considering whether custodians should continue to be required to disclose the least amount of information at the highest level of anonymity where there is ethics approval and recommendation that consent is not required. We're suggesting status quo because researchers will still be able to obtain aggregate or nonidentifiable information necessary for the research or to obtain individually identifiable information without consent if approved by the research ethics committee and the custodian agrees that the information is necessary for the research.

Ms Blakeman: I'm going to stay consistent on the concerns I've raised, where I think we need to err more on the side of privacy. I would argue that this should have been more stringent, so I'll be voting against it. Thank you.

Mr. Broda: I move that

> we accept the status quo recommendations.

The Chair: A motion from Mr. Broda to adopt. Is that also a request for a recorded vote? No? Okay. Anyone else?

I have a motion to adopt. All in favour? Opposed? Carried.

Page 10, that new category.

Ms Swanson: Yes, and this we're suggesting status quo as well: a new category of entity with limited defined mandate to receive identifiable information for statistical analysis and research. This was suggested by CIHI, the Canadian Institute for Health Information. We believe it is not necessary. A provision would add transparency to what is already authorized by the act, but it will not affect the data flow.

Dr. Pannu: Then I wonder why status quo. If it doesn't have any negative effects but it adds to transparency, then why not create that category?

11:35

Ms Miller: I guess the rationale fundamentally is that we don't believe it's necessary to have another category that could perhaps be interpreted in some other way. The data flow arrangements have been successful between Alberta Health and CIHI, and we do not see the need for additional categories as special categories.

Dr. Pannu: Mr. Chairman, I submit that increasing transparency is a need that should be recognized in our review, so this explanation doesn't meet the test that I'm applying to it, and that is that we do something that increases transparency. If making a minor change increases transparency, let's go for it. So I can't vote for this.

The Chair: Okay. Thank you.

Mr. Snelgrove: I think the doctor may be on to something, the fact that we might not know we need another entity. With the way the federal approach has been to more information, more shared statistical data, there may be an opportunity or there might be a requirement down the road for a different kind of information. I don't know that. So maybe this should be referred to the committee that's talking about all of those things, the pan-Canadian framework, and maybe that's the way that you access interprovincially or federally. I don't know. We might need a different entity.

Mr. Lougheed: I just wonder about some clarification. It seems some of the comments I've just heard don't mesh with some of the discussion we had yesterday about getting provider information and how that was going to be used for, well, call it transparency, Raj, whatever you want. How do you differentiate between those?

Ms Miller: I'm sorry. I didn't hear the beginning of that question.

The Chair: Maybe a little closer to the mike, Mr. Lougheed.

Mr. Lougheed: Well, we just finished the comments from Raj about transparency being a good thing. Yesterday it seemed the discussion was different than that when we were talking about service provider information being collected and given to other groups for research or, in fact, commercial purposes. As Mr. Snelgrove just said, we don't know what benefits there could be in some of these uses. Seems like we've got arguments on both sides of the fence here.

Ms Miller: I think that certainly when we get into the pan-Canadian discussion and/or the scope questions that have been agreed to be deferred until the January 2005 period, assuming a committee is restruck at that point, there may indeed be a requirement to have additional categories of organizations or persons that have access to health information.

May I suggest to the committee that we defer this item as part of that other debate when we get into the scope and pan-Canadian issues?

The Chair: Okay. The suggestion has been made. Dr. Pannu, do you have a comment?

Dr. Pannu: I think I'd move that we defer this.

The Chair: Okay. I have a motion to defer.

So this is an issue between transparency and data flow. It won't increase data flow, but it will increase transparency.

Ms Miller: I think the argument of transparency is just made on, you know, if it's explicit in the legislation, it offers transparency in that those reading the legislation understand that data is provided to CIHI. Without explicit reference today those that are not familiar with how the system works in terms of sharing information would not be aware of that. So that's the basis for the transparency comment.

The Chair: Okay. I do have a motion by Dr. Pannu to defer this one until the next discussion, which will be recommended to be in January of 2005. All in favour? Opposed? Carried.

Would we like to start 29, part 6?

Ms Robillard: Question 29: "Are the duties and obligations on the custodian appropriate and reasonable? If not, kindly provide your rationale and include any suggestions for improvement." We've also included question 35, "maintaining disclosure of information and notification of disclosures" are part of the custodian duties and obligations.

Some background rationale about this section before we get into suggested responses. Although two custodians noted that the duties and obligations of custodians are reasonable, there were issues around the administrative burden imposed by some requirements and questions about whether the resources devoted to compliance were sufficiently justified by the privacy and access benefits gained by Albertans. Particular areas of concern included keeping records of disclosures without consent, providing notification to noncustodian recipients of disclosures of the purpose and authority for the disclosure, and privacy impact assessment requirements. Custodian obligations in relation to affiliates were a concern. Clarification was requested about information managers, information management agreements, custodians who are information managers, and relationships with affiliates.

So moving into suggested responses: to defer to Alberta Health and Wellness consideration of information managers, agreements, application to custodians who are also information managers, and relationship to affiliates. Deferral is suggested because time does not permit further information gathering and analysis related to the electronic health record. Until a better understanding of legislative requirements can be achieved through increased experience with and evolution of the EHR, issues can be addressed through existing legislation, guidelines, and/or interpretations.

The Chair: So it's a deferral recommendation, a deferral to Alberta Health. Would it ever get to the committee? How would that work?

Ms Miller: I'm certain it would. We likely would need more time than the January 2005 period. Again, it's a reflection of this ever-evolving electronic health record initiative and the direction we're trying to achieve. So considerably more experience and analysis would need to occur to ensure that we had solid policy understanding of what we'd recommend to a later committee.

The Chair: Okay. Do we have any questions, comments, motions? Is anyone prepared to move deferral?

Ms Kryczka: I'll move deferral.

The Chair: Thank you, Ms Kryczka.

Questions on the motion to move deferral by Ms Kryczka? All in favour of the motion? Opposed? It's carried.

Status quo: to keep every disclosure and to retain for 10 years.

Ms Robillard: Yes, the suggested response is status quo. The rationale is that elimination or reduction of notation requirements would remove the ability of individuals to know to whom health records were disclosed without consent. Guidelines can address ways to fulfill the notation requirements, including filing a copy of a cover letter or fax sheet with the individual's health record.

The Chair: Okay. Do we have any questions or comments? Everybody too hungry to move it?

Mr. Broda: Motion to accept status quo.

The Chair: Okay.

It's been moved by Mr. Broda that we adopt the recommendation of status quo on this one. All in favour? Opposed? It's carried.

Moving on.

Ms Robillard: The next suggested response: defer to Alberta Health and Wellness further consideration of the 10-year retention requirement and consider as part of the larger issue of record retention schedules. The change or removal of retention requirements could adversely affect an individual's ability to access information about disclosures. Further review of the retention period is required.

Mr. Snelgrove: Because of the previous motion I think we obviously need to defer this, because we've said, "Yes, keep 10 years, but we'll talk about it." So I would move that we agree to defer.

The Chair: Thank you very much.

Motion by Mr. Snelgrove to defer. All in favour? Opposed?

Modify requirements.

Ms Robillard: Suggested response: to modify the requirement to note information about every disclosure to not require the notation of the purpose of the disclosure when it is disclosed electronically through a system with automated audit capability. The rationale is that the current requirement is impractical and not feasible where disclosure is from the EHR or another electronic system or as part of a batch process. Where the electronic system has automated audit capability, the system can produce a log of every disclosure, including the information disclosed, the person disclosing, and the date of disclosure. However, the log cannot track the purpose of the disclosure. Where systems do not have automated audit capability, the custodian or affiliate will continue to be required to make a notation on the record.

11:45

Dr. Pannu: So you're recommending status quo for the explicit reason that the electronic log does not provide the purposes for which disclosure is made?

Ms Robillard: The recommendation is not status quo. The recommendation is to modify but to modify only the requirement to retain the purpose when it's linked to an electronic disclosure.

Dr. Pannu: Okay.

Ms Robillard: So it's a very minor change.

Dr. Pannu: Right.

The Chair: Anyone else?

Mr. Goudreau: Mr. Chairman, I'll move adoption of the suggested modification.

The Chair: Thank you, Mr. Goudreau.

Mr. Goudreau has moved adoption of the modified requirement on this one. All in favour? Opposed? Carried.

Yes, Linda.

Ms Miller: I'm very anxious to be able to get hold of the Chief Electoral Officer, and it's getting close to lunchtime. I'm concerned that we might miss him otherwise.

The Chair: Is the committee agreed to break for lunch now until 1 o'clock?

Hon. Members: Agreed.

[The committee adjourned from 11:47 a.m. to 1:03 p.m.]

The Chair: I will call the committee back to order with the notation that the dessert is there and that at some time in the afternoon you're welcome to help yourselves.

Also, I would like to apologize for a comment that I made this morning. A point of order has been raised against the chair on a comment that I made about "a no-brainer." Some members have taken offence to that comment by the chair, so I apologize for the comment and withdraw the comment. Certainly it was made sort of in a light-minded way, which perhaps wasn't appropriate. So I withdraw it and apologize. Okay? Any more on that issue?

All right. To get on with important things, Wendy, where are we?

Ms Robillard: We are at page 11 of 13, and the suggested response is: status quo for provisions respecting custodian duties in relation to affiliates. The rationale here is that custodians need to be prepared to accept responsibility for their decisions to contract with affiliates and to be confident that the health information will be adequately protected by their affiliates.

So the issue was around a lesser responsibility in relation to some affiliates, and we're suggesting that the status quo remain.

Mr. Broda: I'll move that it remain the same.

The Chair: Okay. I have a motion from Mr. Broda. Do we have any questions on the motion or on the question? So Mr. Broda has moved

> status quo for provisions respecting custodian duties in relation to affiliates.

All in favour? Opposed? Carried.

Thank you.

Ms Robillard: The next issue is status quo for provisions respecting duties to protect health information outside Alberta. This comes from a request related to the provision to enter into an agreement about information that goes outside Alberta. The rationale is that legally binding agreements are the only way to enforce requirements outside Alberta and are therefore necessary to protect the privacy and confidentiality of the information.

The Chair: Comments?

Dr. Pannu: How in this context are you defining "outside Alberta"? What are the jurisdictions that are referred to if by implication?

Ms Robillard: The regulation says:

> In order to ensure the privacy and confidentiality of health information that is to be stored or used by a person in a jurisdiction outside Alberta or that is to be disclosed to a person in a jurisdiction outside Alberta . . ."

Dr. Pannu: So the concern that I raised here yesterday with respect to the impact of the USA PATRIOT Act, which would it seems compel U.S.-based corporations or their affiliates, if they are doing business here, to disclose that information, that wouldn't be covered by it; or would it? If so, how?

Ms Robillard: This provision has to do with an agreement that a custodian contemplates entering into with somebody outside the province of Alberta to use the data to provide some support to them in relation to the data. So the provision requires the custodian to maintain the data adequately protected and secured even when it's beyond Alberta for the purposes of the Health Information Act.

So, yes, one of our examples would be the Canadian Institute for Health Information, which the department contracts with. In our contract we're legally bound to make sure that the information is adequately maintained private and confidential.

Dr. Pannu: If an RHA contracts with some U.S.-based agency to analyze the data, what then?

Ms Robillard: They would be required to ensure the privacy and confidentiality of the information through written agreement.

Dr. Pannu: Is that enforceable given that the USA PATRIOT Act, as far as we know, would compel the same organizations to render that information available to an intelligence agency in the U.S.?

Ms Miller: We can't answer that question at this time, because we need to hear the report and analysis of the PATRIOT Act.

Dr. Pannu: Okay.

The Chair: Mr. Broda.

Mr. Broda: Yes. Further to that one, just as a question. Say, for example, a radiologist may live in Ireland or may live in India and we're contracting out to have the reading of the ECGs or whatever. How is that protected?

Ms Robillard: It would be protected using this provision. There would need to be an agreement with the custodian in the organization "prior to the storage, use or disclosure of the information," and the written agreement

> (a) provides for the custodian to retain control over the health information,
> (b) adequately addresses the risks associated with the storage, use or disclosure of the health information,
> (c) requires the person [who is receiving the information] to implement and maintain adequate safeguards for the security and protection of the health information,
> (d) allows the custodian to monitor compliance with the terms and conditions of the agreement, and
> (e) contains remedies to address any non-compliance with or breach of the terms and conditions of the agreement.

Mr. Broda: So that's already in place, and that's why you're requesting status quo on this.

Ms Robillard: Yes. We don't want to remove any of those requirements, as we were suggesting.

Mr. Broda: So I'll move that we accept this one as status quo.

The Chair: Thank you, Mr. Broda. Motion to

> adopt the status quo on duties to protect health information outside Alberta.

Dr. Pannu.

Dr. Pannu: Sorry, Mr. Chairman, I'm late. I was going to ask for a recorded vote because I would like it to be strengthened, not just status quo.

1:10

The Chair: Okay. I have a request for a recorded vote. Although it was slightly late, I will take the request for a recorded vote.

So, please, starting with Mr. Goudreau, are you for or against?

Mr. Goudreau: I'm for. I agree.

Mr. Broda: Agreed.

Ms Kryczka: Agreed.

Mr. Lougheed: Agreed.

Dr. Pannu: Opposed.

Ms Blakeman: Agreed.

The Chair: Okay.

Data matching.

Ms Robillard: The suggested response is to maintain the status quo for data matching. The Canadian Mental Health Association requested stricter controls on data matching. Our rationale is that existing provisions adequately protect against inappropriate data matching. Custodians must submit a privacy impact assessment to the commissioner for review and comment before performing data matching, except when the data matching involves information within the control and custody of the custodian. When data matching is part of a research project, the project must have ethics approval and custodians may request a privacy impact assessment as well.

The Chair: Is anyone prepared to move status quo?

Mr. Goudreau: I'll move status quo for provisions respecting data matching.

The Chair: Thank you very much.

Ms Blakeman: I think I'm going to err on the side of saying that the data matching requirement should be more stringent and that the status quo is not sufficient. It should be strengthened. So I would not be supporting a motion for status quo on data matching.

Thank you.

The Chair: Okay. Thank you.

Anyone else wanting to speak to the motion or against?

Dr. Pannu: I just want to seek some clarification on it. The last sentence there under Rationale says that "when data matching is part of a research project, the project must have ethics approval, and custodians may request a privacy impact assessment as well." Why doesn't it put the duty on the custodians to seek privacy impact assessments and say "must"?

Ms Robillard: The whole issue that the ethics board tries to do in terms of looking at research proposals is measure the impact of disclosing an individual's information at a potentially identifiable level against the benefit of the research itself, so a large part of what they do when they review these research proposals is to make a determination about that. If they feel that the invasion of privacy is outweighed by the public benefit that could come from it, they would presumably enable or approve the research project. So there already has been one balance of, you know, public good versus the infringement on an individual.

However, when a researcher comes to a custodian then with the approval of the ethics committee and says, "I would like to do this research project, and I have a requirement to do some data matching," the custodian can then determine whether a further PIA is required. In many instances when researchers come to us, they have identified a target population. They're, for instance, studying the effects of medication X on 35-year-old females who aren't pregnant or something. They've already said as part of their project: we're going to do it based on this information. They may in fact actually come to us with an identified population, so with individuals identified. Obviously we have to data match to disclose what they require.

If the ethics committee has already addressed that, then we wouldn't necessarily require a PIA as a custodian. However, we do have that as something that we can impose. We can impose additional requirements on the researcher, and that's one of them, if we think that what they're asking for might be far too broad a disclosure.

I can give an example where the department did that. A researcher came to us and wanted us to identify the client population. Based on our identification of the client population by diagnosis, they were then going to contact each regional health authority and through a chart review get individually identifying information about those subjects. However, at the end of the day they didn't want to know who the individuals were.

Through a privacy impact assessment process that we entered into with the researcher and which was subsequently reviewed by the commissioner, we were actually able to do that process within the ministry of health, to have the regional health authorities give us the information for us to aggregate it and strip it and provide only nonidentifiable information to the researcher. So we were able to allow the researcher to do the work they thought was necessary but were also able to protect the confidentiality of the individual's health information. We used the PIA to arrive at that conclusion and to get the commissioner to review it.

The Chair: Thank you.

Okay. I do have a motion. Ms Blakeman, are you wanting recorded votes?

Ms Blakeman: No. I've already indicated on the record how I'd be voting. That's fine. Thank you.

The Chair: Very good.

Are you ready for the question? All in favour? Opposed? Carried.

Collection of the least amount of information necessary.

Ms Robillard: We have suggested a status quo for the provision of collection of the least amount of information necessary for the purpose. A regional health authority requested that we amend the requirement so that it not apply for the purpose of providing health services, and our rationale for leaving it at status quo is that the existing provisions allow caregivers to collect the amount of information necessary to provide health services.

The Chair: A motion?

Mr. Snelgrove: It seems like a reasonable statement to me. I move that we accept the status quo.

The Chair: Okay. Moved by Mr. Snelgrove:

> Status quo on collection of the least amount of information necessary for the purpose.

All in favour? Opposed? Carried.

Okay. Privacy impact assessments.

Ms Robillard: We have suggested a status quo response for provisions related to the privacy impact assessments. Issues related to privacy impact assessments can be addressed through guidelines and process improvements where necessary. The Canadian Blood Services' issue related to national databases can be addressed by the next committee of the Legislature in 2005.

The Chair: A motion?

Mr. Broda: I move

> to accept status quo of privacy impact assessments.

The Chair: Thank you. All in favour? Opposed? Carried.

The last one on this section.

Ms Robillard: The next suggested response is: do not eliminate the requirement for written notification to the recipient of the purpose and authority for disclosure of diagnostic, treatment, and care records, but make it explicit that the requirement does not apply where the disclosure is to the individual the information is about. The rationale: the written notification requirement applies to disclosures outside the controlled arena and provides protection for custodians and a notation for the individual's record. It is reasonable that disclosures to the individual concerned, with the exception of responses to an access request, do not require a written notification.

The Chair: Is anyone prepared to move this one, one way or the other?

Mr. Goudreau: Mr. Chairman, I'll move that one to put it on the table for further discussion.

The Chair: Okay. Thank you. It has been moved to accept the status quo recommendation.

Dr. Pannu: Are there some further reasons for not requiring written notification?

Ms Robillard: The current requirement is that the custodian who discloses individually identifying diagnostic, treatment, and care information must inform the recipient in writing of the purpose of the disclosure and the authority. We're suggesting to continue that, not to remove that requirement, except to make it explicit that it would not apply where the disclosure is to the individual the information is about.

Dr. Pannu: So what happens in the case of the individual the information is about? He receives verbal?

Ms Robillard: They could receive the information in written or verbal form, but they wouldn't require a notification on why we're disclosing it to them. They have the authority to receive it under the act.

1:20

Ms Miller: All we're suggesting is that we don't write to the person that we've disclosed the information to. They obviously know they've got the information because we've disclosed it. It just seemed rather strange that we would have a requirement to write to them as well and tell them that we just gave it to them.

Ms Robillard: They have a right to access it already.

The Chair: Okay.

We have a motion on this one from Mr. Goudreau to accept status quo.

Ms Blakeman: It's not the status quo; is it?

Ms Robillard: No, it's not the status quo.

The Chair: Okay. Sorry. It's not the status quo. It is a recommendation. I stand corrected.

Ms Blakeman: Thank you.

The Chair: So, Mr. Goudreau, have we got the motion right now?

Mr. Goudreau: Yes.

The Chair: All right. All in favour of Mr. Goudreau's motion? Opposed? Okay. It's carried.

Part 7, the commissioner.

Ms Swanson: Thank you. In this question we asked whether people had any suggested changes to the responsibilities of the commissioner, and a number of suggestions were made. We are recommending the status quo with respect to some of them.

First, there was a suggestion that there be a penalty for vexatious requests, and we're recommending that we not institute a penalty, the reason being that fines on individuals requesting access to their own information would not appear to be appropriate even though they may be vexatious.

Mr. Broda: Okay. Penalties for vexatious requests. But they could be done by others. It doesn't have to be the individual. Or would it?

Ms Swanson: These would be requests from the individual, I believe, for access to their own health information.

Mr. Broda: Oh, okay. I wanted that clarified. Yeah.

Dr. Pannu: I'd like to move this, Mr. Chairman, the status quo.

The Chair: Okay. Thank you. A motion from Dr. Pannu to accept this one. That is a motion to accept; right?

Dr. Pannu: Yeah.

The Chair: Okay. All in favour? Opposed? Carried.
Next.

Ms Swanson: The next one: we're suggesting status quo to powers related to orphan records. Matters related to orphan records require a discussion with custodians and professional colleges and associations to determine appropriate solutions.

On this one I just want to check. I have a feeling we have said that this is one that would be deferred to the department for additional work prior to the next review, so this isn't quite a status quo.

Ms Miller: I believe we agreed. We modified that to defer to 2005. It's an error.

Ms Swanson: Right.

The Chair: So is everyone clear on that clarification? Okay.
Ms Blakeman, did you have a comment?

Ms Blakeman: That was exactly my point actually. I understood that we wanted to defer that particular section to the committee in 2005, and I'm happy to move that.

The Chair: Okay. Ms Blakeman has moved that deferment until January or thereabouts. Okay. All in favour? Opposed? Carried.
Jurisdiction over entities outside the act.

Ms Swanson: We're recommending there that the commissioner's jurisdiction would extend automatically to any entity included in the scope of the act, but we're not suggesting that it extend outside the act. This was a suggestion from one of the stakeholders.

Ms Inions: Just asking a question of clarification: would this mean that it wouldn't apply, then, to recipients of information or to researchers? These are entities outside the act.

Ms Swanson: We're recommending the status quo in terms of the commissioner's authority over entities. No change.

Ms Inions: Okay. I guess I understand then. The penalty section and offence section certainly include entities outside the act, but you're saying that that would stay as it is.

Ms Swanson: Yes.

Ms Inions: Okay. That answers my question.

The Chair: Okay. It seems to me just not quite clear what the intent is here. Is there a different way to word it or say it? I mean, I think we've got it clarified now, but maybe when we do the draft . . .

Ms Swanson: Wendy is going to read the comment.

Ms Robillard: This is a stakeholder position, a recommendation. It was from an individual Albertan: to extend the commissioner powers to all holders of health information including for-profit organizations such as IT outsourcing or insurance companies. Our suggestion is that we not extend it, that we leave the status quo. If those IT companies are on contract or affiliates to a custodian, they would be caught, in any event, already and the commissioner would have ability to comment on their practices as an affiliate of an organization.

The Chair: Other questions?

Dr. Pannu: What harm would the inclusion cause? Is it difficult to legislatively do that? Is it a question of language? I mean, if the intent is to in fact have them covered through other means, why not put it in the legislation?

Ms Robillard: It's a huge scope issue, where you'd be trying to bind IT companies and all kinds of people who may or may not have health information. We don't want them in the controlled arena, and it gets into a whole lot of other things. So where they perform a service for a custodian on contract, the commissioner has authority to go in and to review their practices, and I suspect they're happy with that.

The Chair: Ms Blakeman.

Ms Blakeman: Wendy said it better.

Mr. Goudreau: Mr. Chairman, I'll move

> the status quo with respect to jurisdiction over entities outside the act.

The Chair: Thank you, Mr. Goudreau. All in favour? Opposed? Carried.
Power to rule on miscarriage of justice.

Ms Swanson: We're recommending the status quo on this issue as well, the rationale being that it's not really an appropriate matter to be addressed by the Health Information Act.

Ms Robillard: I can provide some background if people would like to hear it. This is another question from an Albertan, and the Albertan asked specifically that the OIPC should be asked to intervene or rule on cases where there appears to be a miscarriage of justice with regard to any government act. Clearly, the issue is not relative to the Health Information Act.

The Chair: It makes sense to me.

Mr. Broda: I move that this one stays status quo.

The Chair: All in favour? Opposed? Carried.
Okay. Privacy impact assessment process.

Ms Swanson: Yes. There were some suggestions that the privacy impact assessment process be streamlined, and our rationale for making no changes to the act would be that these matters are not legislative; they're process issues outside the actual legislative provisions.

Ms Blakeman: Could you just repeat that?

Ms Swanson: There were one or two comments from stakeholders about streamlining the privacy impact assessment process. The process itself is not defined in the legislation. That's a matter of administration of the legislation. So we don't feel that any amendments are required.

Ms Blakeman: Because it's not there in the first place.

Ms Swanson: Right.

Ms Blakeman: Thank you.

The Chair: Anyone prepared to move this one?

Mr. Broda: I'll move it.

The Chair: All in favour? Opposed? Carried.

Release name of affiliate who discloses a breach to commissioner.

Ms Swanson: One of the custodians recommended this, and their rationale was that knowing the name of the affiliate who reports a breach of the act to the commissioner would allow them to investigate, but we're recommending the status quo on this item. Right now the commissioner, I believe, doesn't need to reveal that information, and the rationale is that the disclosure of the name of an affiliate reporting a breach would undermine reporting of breaches to the commissioner.

The Chair: Okay. We have a status quo recommendation. Any comments? Questions? Motions?

1:30

Dr. Pannu: Again, clarification. Disclosure of the name of an affiliate reporting a breach would undermine reporting a breach, I'd say. It will discourage the reporters from doing it.

Mr. Broda: Are you moving it?

The Chair: Is that a motion, Dr. Pannu?

Dr. Pannu: I can. Dave just asked me to, so I'll do it.

The Chair: All right. A motion by Dr. Pannu on this one to accept the status quo. All in favour? Opposed? Thank you.

Duty to comply with an order.

Ms Swanson: This was suggested by one of the stakeholders. It was the AMA. What they would like to see is that instead of a stay of the order when the matter goes to a judge or the courts, they would like to see the order stay in effect, at least in certain circumstances.

Our rationale for saying that the status quo should be maintained is that requiring compliance with the commissioner's order to cease disclosures while the matter is before the courts could result in disruption of necessary information with disclosures later found to be consistent with the act.

Ms Blakeman: I disagree with leaving this at status quo. I'm cognizant of the rationale given, that it could disrupt necessary information disclosures, but if there is a commissioner's ruling which then is taken to court and appealed, that can go on for an extended period of time. Particularly in situations where we have people's health information that continues to go out even during an appeal process, that can perpetuate a bad situation over a very extended period of time, so I would argue against this one.

The Chair: Okay. Anyone else?

Dr. Pannu: I have similar concerns.

Mr. Broda: Has there been a problem with this one since it's been in there or any comments from the commissioner's office?

Ms Inions: I do have more questions than answers about this one. First of all, in regard to its legal doability it seems to me that this is kind of a statutory equivalent to a judicial stay and that that is something consistent with an order that was appealed elsewhere. With a court order that was appealed, you can apply for a judicial stay, and that is granted. The practice of the office has just been to say clearly on the web site that because there has been an appeal, the order doesn't come into effect.

So I think this recommendation does require further research and further looking into. That would be my recommendation on it.

The Chair: Thank you.

Mr. Broda: Would it be appropriate to defer it to the Legislature and the 2005 review?

The Chair: Certainly. I would think so. Linda or Wendy, do you want to comment?

Ms Miller: I think we'd like to be able to tackle it next time we meet, if possible.

Ms Blakeman: This round?

Ms Miller: Yes.

The Chair: Okay. The request has been made to do it on the 7th of October, when we meet.

Ms Miller: Yes, if possible.

The Chair: Is that okay with you, Mr. Broda?

Mr. Broda: That's fine with me. Yeah.

The Chair: There seems to be some confusion here and some need for clarification, so you will bring it forward the next time the committee meets, on October 7. All right. Would you include that in your motion?

Mr. Broda: Yes. I would include that

> it be deferred to the next meeting for further information.

The Chair: Okay. All in favour? Opposed? Carried.

The next one is on deferred consideration of the commissioner's request.

Ms Swanson: Yes. This was his request for explicit powers to audit and compel information for an audit. We're suggesting that it be deferred to a committee of the Legislature in early 2005. The rationale is that the commissioner's request for explicit power to conduct audits and compel information for an audit raises a number of issues and concerns that could have implications for custodians and affiliates. The ministry and RHAs are already subject to audits by the Auditor General. The electronic health record is in its early stages of development and implementation, and any audit requirements will have implications for operations of custodians and affiliates.

Mr. Snelgrove: When you use the term "audit," would you not be auditing the system for privacy as opposed to the dollars that the Auditor General would be looking at?

Ms Swanson: Would you like to comment on that?

Ms Inions: I can respond to that question. Yes, that's exactly correct. It's an audit conducted with regard to privacy issues, privacy and security primarily.

Perhaps I'll just make a couple of other comments as well. There's an argument that this power already exists in existing legislation because there's a power to investigate and that sort of thing. The similar provision under FOIP has been used to conduct audits already. There was an audit, a very detailed audit, conducted under that legislation.

But the request here is for that power to be very explicit. Part of the reason is because in comparing HIA to other privacy legislation such as PIPEDA, PIPEDA has a very explicit audit power. So that would be one of the reasons for wanting to make it explicit. When you start comparing the pieces, then people say: oh, if it's not explicit, then maybe you don't have the power.

So the request here is for transparency to make it clear that this power exists, although there is an argument that that power already exists.

The Chair: Does that answer your question, Mr. Snelgrove?

Mr. Snelgrove: Yes, sir.

Ms Miller: One of the rationales, a key rationale for deferral with respect to the needs of the commissioner's office, is that in addition to what is proposed here, the current audit-making powers of the Auditor General's department could also look at auditing for privacy and security reasons. So there needs to be some clarity and understanding and time to communicate this suggestion to impacted custodians to understand the respective scopes and interest areas, and that is fundamentally the reason for deferral.

The Chair: Okay.

Mr. Snelgrove: Do you want a motion?

The Chair: Yes, I do.

Mr. Snelgrove: Could I, at the committee's indulgence, include for both to defer his next request for extraprovincial agreements? I think that basically we have to understand the position of the Privacy Commissioner in this. So with the agreement of the committee I move that

> we defer both of the recommendations to the 2005 committee.

The Chair: A good idea. So we do have a motion to include both of the deferral options in one motion. Are there any questions on the motion? All in favour? Opposed? Carried. Thank you.

Part 8, General Provisions.

Ms Gray: I will speak to that.

The Chair: Okay. Good.

Ms Gray: Question 31: "Is the list of substitute decision makers appropriate? If not, please explain and provide any suggestions for improvement."

The suggested response. If I may, there are two parts to this. This first is to enable a next friend or guardian ad litem to exercise the rights of an individual under the act if the exercise of the right or power relates to the powers and duties of the next friend or guardian ad litem.

There was also a suggestion on the table from the Alberta Long Term Care Association related to substitute decision-makers generally, but perhaps I'll deal with that one next.

The rationale. Although a few suggestions were made to provide for substitute decision-makers, most of these are already covered in the act. They include family members and disclosures without consent if, in the opinion of the custodian, disclosure is in the best interest of the individual. However, the *Alberta Rules of Court* permit a next friend or guardian ad litem to represent infants or adults of unsound mind in litigation proceedings. There is currently no authority for next friends or guardians ad litem to access or disclose health information on behalf of the individuals that they represent in the litigation. A limited authority to exercise the rights or powers of the individual is proposed where the exercise relates to the powers and duties of the next friend or guardian ad litem.

In instances where you have someone who is acting on behalf of an infant or on behalf of a person of unsound mind, they must meet a number of criteria in the *Alberta Rules of Court*, and then the court recognizes them in that capacity. The department is finding that these people are trying to access information in order to conduct the litigation, and there's been an impediment; therefore the suggested response.

1:40

The Chair: Thank you, Holly.

Are there questions, comments?

Ms Blakeman: Is it anticipated, then, that this enabling of a next friend or guardian ad litem would be narrowly restricted to litigation?

Ms Gray: Yes. The notion of a next friend or guardian ad litem – they are basically the same person, but for legal historical reasons they are separated. Next friends can bring an action or a counterclaim on behalf of an individual. The guardian ad litem is someone who is appointed to help someone who is incapable of defending themselves in the litigation. So it is the same person, if you wish, on the different sides of the litigation.

Ms Blakeman: But they only appear in the context of litigation? They don't appear in any other context?

Ms Gray: No. They appear in the context of that specific litigation.

Dr. Pannu: So the scope is quite limited then.

Ms Gray: It is.

The Chair: Holly, the ALTCA item: that's going to be later?

Ms Gray: Maybe we can move on this.

The Chair: Okay. All right. Very good.

Dr. Pannu: I move.

The Chair: Thank you very much. A motion from Dr. Pannu to adopt. All in favour? Opposed? Carried.

Okay. Do you want to do the ALTCA before we go to number 32? All right?

Ms Gray: Yes.

The Chair: Are you going to do that one, Holly?

Ms Gray: I will.

The Chair: Thank you.

Ms Gray: The ALTCA raised the issue of acknowledging a substitute decision-maker for the purpose of accessing and disclosing information on behalf of individuals who are incapable, and in their context it would generally be an adult who is incapable.

The difficulty with simply amending the act to allow for a substitute decision-maker is that in order to ensure that that person has the legal authority to exercise those rights, you generally have to put in place a mechanism to determine who is available to act as a substitute decision-maker, in what circumstances they're available to do that, and what powers they may exercise.

A simple example is that if you have an elderly person who is not capable of making their own decisions, you may have a number of people in a family who wish to exercise that right, so we'll want to make sure from a legal standpoint that the caregivers are in a position to know exactly who can do that. In order to recognize substitute decision-makers, we can't simply amend it and say: a substitute decision-maker.

An example is in Ontario under their personal health information acts. They have, in fact, two pieces of legislation. They have the Health Care Consent Act, which sets out all the criteria and mechanisms for determining when someone does not have capacity and then, in turn, speaks about who can step in and act for that person. There are a number of mechanisms for going through the steps of determining who that is and when they can exercise the rights and what rights they can exercise.

The Personal Health Information Protection Act recognizes a list of people who can act on behalf of a person in respect of health information. It has a hierarchical list that starts with those people who may be appointed under the Health Care Consent Act. Then it goes on to talk about people who can exercise that right only for health care purposes. If there is someone who has not formally been recognized – for example, a comparable piece of legislation is Alberta's Dependent Adults Act. If there's nobody who's gone in and actually been appointed as a guardian or trustee under the Dependent Adults Act, in Alberta there really is no one to step in and take that place unless there's a power of attorney or a personal directive. As I understand it, the ALTCA is talking about instances where there isn't an actual guardian appointed in some manner.

In order to start recognizing a more informal list of family and friends, the Ontario legislation has gone on to list a number of family members in hierarchical order, and in order to exercise those rights, you have to ensure that there's nobody higher up the list who can do that. They also have provisions that say that if you have people at the same level, for instance two siblings, that want to exercise a right and can't agree amongst themselves, there is a dispute mechanism. There is also a board put in place to allow other caregivers who maybe need to step into the gap to get that authority.

I guess the short of all of that is that to put a legal mechanism in place that is workable to provide for a substitute decision-maker is not a simple or easy amendment. It is a very complex process legally, and I suggest that there are a number of policy considerations that have to be carefully reviewed and considered with patients, family, friends, caregivers, and all those people who might interact with incapacitated adults.

One of the options that the committee is looking at today is the status quo, which means that the current substitute decision-makers that are listed in the act stay as they are. They include guardians and trustees under the Dependent Adults Act, an agent under a personal directive, a power of attorney, a nearest relative as defined under the Mental Health Act, and any person with written authorization. Those are the current authorizations, and that's what will be available under the status quo.

The second option is to defer the matter to the 2005 committee if the committee feels that this is of sufficient pressing need that it should be dealt with at that time.

Then the third option is to defer this matter to the next HIA review to be undertaken by the department, going out and talking to stakeholders and consulting.

The Chair: Thank you.

We have a question. Mr. Broda.

Mr. Broda: Yes. I was glad to hear you say maybe defer it, because that's what my thought would be.

You indicated that whether you have a personal directive or you've got a power of attorney, this is fine if you have the individual sign it prior to being incapacitated, but when we look at somebody that has no relatives, period, there is a mechanism right now; is there not? Under the Public Trustee, say, whether it's child or adult, we already have a mechanism in place that they automatically have that right to look after that individual and have the power to look after that child if there's no family member due to an accident and the child is left by himself. Could that not be incorporated into the adult side with somebody that has no family?

Ms Gray: Yes, the Public Trustee and the Public Guardian can step in. I suspect, though, that operationally on a day-to-day basis that is difficult. If you have someone who is permanently incapacitated, that may assist, but there may be instances where perhaps people are not fully incapacitated but need assistance.

So I think there are varying degrees of residents that the Long Term Care Association is coming across, and I believe that they're just looking for instances where there are perhaps family members who wish to step in and be able to disclose and access information, but they either do not have the financial or other kinds of resources to actually become appointed. So you wouldn't want the Public Guardian or the Public Trustee to step in when there are family members who might be able in other circumstances to exercise those rights.

1:50

Ms Blakeman: In essence, then, the Alberta Long Term Care Association is suggesting a less formal process as a possibility here. As the opposition critic for Seniors I hear from people all over Alberta, and the most common concern is around one person involved with a senior or someone in care having an argument or feeling that the person that was appointed is inappropriate. That's within a very formal process, and they would have to follow all of the formal guidelines to resolve it. I think that moving to a less formal process would make that situation even more problematic on site.

So if the Alberta Long Term Care Association feels that this really continues to be an issue and expects it to become a larger issue, maybe they could come back to Alberta Health and Wellness with some statistical information that could be pursued at a later date. At this point I would prefer to keep it in that more formal relationship, which at least allows people the processes to object if they want to. The less formal one I think is problematic.

The Chair: Thank you.

Mr. Broda: A further question. You mentioned that on a day-to-day basis it would be problematic. Do we have numbers? What are we looking at? Are we looking at 20, 30, 10,000? To get a better picture, I would make a motion that we defer it to a later date, possibly into '05 or the next review. Which is preferable? I don't know which way to go. In '05.

The Chair: I'd certainly consider that as a motion, but may I ask a question first?

Mr. Broda: By all means.

The Chair: I'm going to try to simplify the discussion, if I can, so I can understand it. Okay? Am I understanding that under the present scenario a person in long-term care or who is incapable of making their own decisions would have a problem getting one of their family appointed to take care of them? Like, if it was my father and I happened to be the oldest son, what would I have to do to become the guardian?

Ms Gray: Currently under Alberta law you would have to make an application to the courts to be appointed as the guardian and/or trustee of the adult. There is a process in the Dependent Adults Act to follow.

The Chair: Would I have to hire a lawyer to do that?

Ms Gray: Anecdotally, this is the perceived barrier. You are not required to hire a lawyer to go into court and make an application, but it may well be that that formal a process is a barrier to some Albertans for various reasons.

The Chair: Okay. What if some of my siblings – and I do have siblings – wanted to be the guardian?

Ms Gray: They would be required to make the application to the court.

The Chair: Okay. So who's going to win? The one with the most money or the biggest or what?

Ms Gray: It would depend on the facts of the case and who could meet the test. There are a number of factors, but generally it's the best interests of the adult.

The Chair: Why couldn't I and my parents have just decided this before the fact, and then it's all taken care of? Would the courts accept that?

Ms Gray: You can. Through a power of attorney or personal directive that can be done, but there are a number of people who don't do it.

The Chair: I understand that, and I've refereed many of these situations. I guess my bottom-line question is: does deferral present a problem? Do we need to deal with this sooner rather than later? Have we got lots of people out there? Ms Blakeman mentioned that she gets quite a bit of comment as opposition critic on this subject.

Ms Gray: My comment would be that when you're talking about one person exercising the rights of another person, you want to be careful that you ensure that the appropriate legal and policy considerations have been looked at, that you talk to stakeholders and you understand the extent to which you want to allow people to step in and be substitute decision-makers.

The Chair: Why can't we have a provision that would allow a family to work this out on their own and agree that a next of kin such as a son or daughter with the agreement of the siblings would be the guardian without having to go to the courts?

Ms Blakeman: Well, we're talking about this on two levels now, because we're talking generally about being appointed as a guardian for another person or a trustee for another person across the board and the provisions that are available in the Health Information Act about whether you can get information. Your question was: well, couldn't we just work it out as a family? Yes, under section 104(1)(i) you could have any right or power conferred on an individual by this Act exercised "by any person with written authorization from the individual to act on the individual's behalf." So your father could write a letter saying: I appoint you.

The Chair: Without going to the courts?

Ms Blakeman: Yes, because it's already set out in the act. But what's happening is that the Alberta Long Term Care Association is suggesting that we add another clause under section 104(1). They've got a different proposal about what would happen there, a substitute decision-maker. They're asking for another clause to be added into the HIA legislation, and that's the one where I'm saying that we've got enough here and it seems to be working okay. I'm getting dozens, not thousands of people contacting me.

Mr. Broda also questioned how large an issue this is. I think we do have formal legal routes that people can take, and they can take it without a lawyer. So I think everything is there, and maybe in the future if we hear more problems, we can deal with it then. I don't think it's that big an issue right now.

The Chair: Thank you.

Ms Gray: If I can clarify, the provision that Ms Blakeman referred to would be for adults with capacity. You have to have capacity to provide consent. But there is an enactment, the Dependent Adults Act, which allows people to go to court and get an order if there is a real need, so in my view there isn't such a huge gap that it needs to be filled immediately. If we want to move to something that allows family members to step in through a different mechanism than the Dependent Adults Act, that can be dealt with in '05 or through the next review.

The Chair: Okay. Thank you.

Are there other comments or questions?

Okay. I do have a motion. Have you clarified your motion?

Mr. Broda: I would have one more question. I was just wondering whether this is where it should be, under this act. Or are there other acts already in place that can cover this issue?

Ms Gray: That is to an extent a policy decision, about where it most appropriately falls, and I think that would be part of what needs to be considered if the matter is deferred: if we need an extension of the Dependent Adults Act or if it should just be dealt with here.

Mr. Broda: So my motion to defer to the next review stands then.

The Chair: Oh, so not to January of '05?

Mr. Broda: No. Next review.

The Chair: Okay. Motion from Mr. Broda to defer ALTCA suggestions to the next review, not the recommended review in '05 but the next review, which may be three or four years down the road.

Ms Kryczka: Not that I want to disagree with my colleague here, but I'm unsure as to what was in the Alberta Long Term Care Association's suggestion, where they're coming from. My suspicion is about the aging population and the increasing number of people with Alzheimer's when you look at the demographics and aging population. If that at all is the case, I think it should be in 2005 rather than the next review, if that is why they're concerned in the first place, and I can't answer that right now.

The Chair: So your preference would be a sooner review.

Ms Kryczka: Sooner, yeah.

Mr. Broda: Mr. Chairman, I think if we look at it at the next review. If there's a compelling need for it, I'm sure it will be brought up by the department saying, "Look, we have to get this on, whether through this mechanism or another," to bring it into place. So I'd say the next review.

The Chair: So you're changing your motion?

Mr. Broda: No.

The Chair: Okay. Next review.
Okay. Mr. MacDonald. No?

Mr. MacDonald: No. That's fine. Thank you, Mr. Chairman. I was just wondering if that was the review that Mr. Snelgrove was anxious to chair.

2:00

The Chair: All right. So we do have the motion:

> to be deferred until the next general review.

All in favour? Opposed? Well, it's carried.
Okay. Question 32.

Ms Swanson: Question 32 is about whether or not offences and penalties are appropriate. In this case we are recommending the status quo.

There were a number of suggestions: to cap the aggregate amount of fines that could be imposed in a year, also suggestions to increase the fines, and a suggestion to protect custodians from fines in relation to an action by an affiliate.

Our rationale for saying the status quo is that no fines actually have been imposed so far, providing no evidence of need for higher fines, a cap on fines, or protection from fines. Other privacy statutes such as FOIP, PIPA, and PIPEDA do not provide for caps on fines, and the current provisions appear to both provide sufficient deterrence and also protect those who act in good faith but unknowingly contravene the act.

Clarification was suggested regarding when fines will be imposed for violation and whether fines can be imposed on an employee of a custodian. The act is quite clear about its application, and these clarifications can be provided directly to the stakeholder. Clarity was also requested about the line between marketing for commercial purpose and continuing care and treatment. We're suggesting that professionals may seek advice initially from their professional colleges for guidance as to what constitutes professional practice.

So it's the status quo.

The Chair: Thank you, Evelyn. The recommendation is status quo. Questions or comments?

Mr. Goudreau: Mr. Chairman, I'll move status quo.

The Chair: Thank you very much. Status quo moved by Mr. Goudreau on this item, 32. All in favour? Opposed? Carried.
Okay, moving to 33.

Ms Swanson: Question 33 was a request for suggestions for improvements on the rules in the health information regulation. First of all, we've identified a few housekeeping updates, the first being to delete section 1(2) and a reference in section 6(2) to the repealed section 59 of HIA. This is simply to reflect that section 59 of HIA was deleted.

There was one more housekeeping update, to replace in section 2(b) the "Billing Practice Advisory Committee" with the statement "committee of an organization referred to in section 18(4) of the Alberta Health Care Protection Act." This housekeeping amendment is proposed by the department in the government submission because the name of the committee has changed, and rather than changing the name of the committee, we would prefer to reference the statute authorizing the committee.

The Chair: Okay. So you're recommending deleting 1(2) and in 6(2) a reference to the repealed HIA section 59 and replacing the billing practice in 2(b). So both of those.

Ms Swanson: That's right.

The Chair: Do we have comments or questions? Basically a housekeeping amendment.

Mr. Goudreau: Mr. Chairman, I'll move again the updates to delete section 1(2).

The Chair: Thank you very much.
I have a motion to move as recommended. All in favour? Opposed? Carried.
Moving on.

Ms Swanson: Our next item has to do with creation of a regulation respecting retention, disposal, and archival storage of records. Some custodians mentioned this in their submissions. We agree that a regulation should be developed. A regulation under HIA could harmonize requirements across various pieces of legislation and create consistency across the health system, including matters related to the electronic health record. We suggest that creation of the regulation can be targeted for the November 2005 regulation review date. So, basically, it's accepting the advice to create a regulation.

The Chair: Okay.

Mr. Broda: I'll move that we accept this recommendation.

The Chair: Thank you.
Motion by Mr. Broda to accept. All in favour? Opposed? Carried.

Okay. Moving on.

Ms Swanson: The next one is one that we partially addressed previously. We're recommending status quo on the requirement for a written agreement respecting information outside Alberta. A written contract is the only way that we have of ensuring accountability of the party storing, using, or disclosing outside Alberta because HIA itself can't be enforced outside Alberta. This is in line with PIPA, PIPEDA, and the pan-Canadian framework. We think it should be retained.

Mr. Snelgrove: It makes perfect sense. I move that we accept the status quo.

The Chair: Okay.

Motion by Mr. Snelgrove to accept. All in favour? Opposed? Carried.

Ms Swanson: Okay. There are three additional items that were suggested for creation of regulations, and we are suggesting that we not create those regulations, at least at this point in time.

The first one is principles for technical, physical, or administrative security. Our reason is that guidance about issues to consider when assessing the security of information systems is contained in the Health Information Act guidelines and practices manual. There is a step-by-step assessment guide that specifies what must be addressed. That is available on the commissioner's web site. So we're suggesting that this is not really needed at this point in time.

The Chair: Okay.

Mr. Broda: I would agree that we probably don't need it, but so it's not lost, can it be deferred to the next regular review? Simply because something might come out of it, and it's so it doesn't get lost in case it's needed.

The Chair: So your motion is

to include it in the next general review.

Mr. Broda: That's right.

The Chair: Okay.

Any comments on the question? Call the question. All in favour? Opposed? Carried.

Electronic Transactions Act, ETA.

Ms Swanson: Yes. One of the suggestions from the stakeholders was that the regulation contain a reference to the Electronic Transactions Act. In our view it's not necessary to do this. The Electronic Transactions Act provides that any requirement for written records is met if a record is in electronic form and is subsequently accessible. Health information under HIA is not exempted from this provision. HIA's privacy, confidentiality, and access rules are paramount, and if they are met, electronic records are allowed. So the Electronic Transactions Act does apply already without specific reference in our regulations.

The Chair: Seeing no questions or comments, is anyone prepared to make a motion? Okay. There must be some problems with this one because I can't get a mover.

2:10

Mr. Snelgrove: I would move that we shut down that Electronic Transactions Act just as fast we can.

The Chair: Thank you very much, Mr. Snelgrove.

All in favour? Opposed? Carried.

Scope.

Mr. Snelgrove: I move that we don't even talk about this one; we shut it down too. [interjections] We were losing the crowd here, Karen, I'm telling you.

The Chair: I think we lost them.

Ms Swanson: Oh, I'm sorry.

The Chair: Scope. Okay, maybe we should just refer to it quickly. Scope and content of information then.

Ms Swanson: Right. Sorry; I thought there was discussion going on, and I was just waiting my turn.

The Chair: No. Go ahead.

Ms Swanson: Matters respecting information manager agreements are addressed in the guidelines already, and since this area is continuing to evolve, we believe it's better that it not be included in regulations, but we think the regulation power should be retained for potential use in the future. So we have covered this area off with guidelines, and I don't think it's necessary to have a regulation at this point.

Ms Kryczka: A motion to support.

The Chair: Okay. Ms Kryczka has moved agreement, support of the recommendation.

All in favour? Opposed? Okay; it's carried.

Mr. Snelgrove: I'm missing the rest of my pages.

The Chair: You've got more pages?

Mr. Snelgrove: No. But how can that be? Did the machine break? Are we out of trees? What happened?

The Chair: Yeah, we're out of trees.

Question 34. Are there any comments on 34, Evelyn?

Ms Swanson: No, just that we acknowledge that there was a theme about legislative harmonization, and it was addressed at least partially in the discussion around scope and will be addressed in the work on consent in the pan-Canadian framework. Unless you want to vote on it, you know, there's nothing to vote on.

The Chair: I think we're okay here.

Does the committee want to take a break now, or do you want to finish the work here? Okay; I hear that they want to take a break, so we will break until 2:30.

[The committee adjourned from 2:12 p.m. to 2:28 p.m.]

The Chair: Okay. We'll call the committee back into order, back to session. We have a few questions we didn't get finished yesterday or today. I'm proposing that we start with question 11 on page 4 of 13 for further discussion and resolution.

Who's handling question 11?

Ms Robillard: The additional information that was being sought was being sought from the commissioner's office.

The Chair: Okay. Yeah, that's right.

Ms Inions: Thank you, Wendy.

Perhaps I could ask Karen whether the letter has been distributed.

Mrs. Sawchuk: Yes. Right now.

Ms Inions: I have prepared a letter providing the information that was requested by the committee in regard to this number 11. Just to refresh your memory, the questions raised yesterday that weren't able to be answered on the spot were raised by Mr. MacDonald. The first question was: how many applications has the commissioner received to disregard a request under HIA? Secondly, does HIA impose a time limit on the commissioner issuing these decisions? Thirdly, how long does it take the commissioner to make these decisions?

Perhaps you all have your paper now, and we can just briefly go back to the answers to those questions to assist the committee in these deliberations.

In response to the question of how many applications the commissioner has received to disregard a request under section 87 of HIA, we have only received one such application in the three years that the act has been in force, and that request is currently before the commissioner. So they're not a frequent type of request, but they're very serious requests because they involve an individual losing a right that the act creates.

Just as an aside, there have been 10 such applications made under the FOIP Act, and that act has been in place since 1995. The 10th request to disregard under FOIP is currently before the commissioner. So those are relatively small numbers for that time period.

Does HIA impose a time limit on the commissioner for issuing these decisions? No. There's no legislated time limit. Part of the difficulty of imposing a legislative time limit is that it relates to a right of the individual under the act, and what would happen if the commissioner breached the time? What would happen if there was an error and he forgot to extend the time? Then the commissioner loses jurisdiction; the individual loses a right. So it would be maybe not the result you would want in setting out a time frame to handle those kinds of decisions.

The third question: how long does it take? Keeping in mind that these requests arise within the context of an access request and a request to review that access request, the office has given these decisions priority. They've been out generally within 30 days, which is a relatively short time frame as you then need to involve the parties, the participants, in that process.

As a matter of fairness, you must give the individual involved a right to present their side of the case, the custodian that's requesting the request to be disregarded has to make their case, and then they have to be able to respond to what each other has raised. So 30 days is not too long, I think, to respond to those kinds of requests, and in practice they've been dealt with quite quickly through the office.

The Chair: Thank you, Ms Inions.

Ms Inions, under the options we are looking at, one is the status quo. The other one is: amend to "stop the clock." Under option 2, stop the clock, that means everything would stop until the commissioner has made his decision and that there would be no background work done, that people would not be wasting any time on the issue.

Ms Inions: It would be my understanding that stopping the clock would just freeze the time frame at however many days it was from the time the request was made to the time the decision or ruling was given.

The Chair: Okay.

Does the technical team have any additional comments here before the committee deliberates? Do any members of the committee wish to speak, ask questions? We held this one up before just because we had questions we wanted to get answers to before we made the decision.

Mr. Goudreau: Mr. Chairman, I'll move that

> we amend to authorize the commissioner to stop the clock on response time.

The Chair: Thank you, Mr. Goudreau. Mr. Goudreau has moved option 2, "amend to stop the clock." Questions on the motion by Mr. Goudreau? All right. The question then. All in favour of the motion? Opposed? It's carried.

So the next one we'll go to is question 23.

Ms Robillard: Yes. We're revisiting question 23, and that's on page 8 of 13. This was a status quo suggestion regarding removing the ability to disclose to the Chief Electoral Officer.

Dr. Pannu: Mr. Chairman, which document?

Ms Robillard: The three-column document, page 8 of 13.

In discussion with the deputy electoral officer I was able to get some clarification. They indicated to me that their request for information would be focused towards Alberta Health and Wellness. They do not intend to approach other custodians for access to information. The request for information is what they call tombstone data; specifically, the identified name, date of birth, home address, home telephone number, gender, citizenship info, and residency info to try and confirm a six-month residency in Alberta.

Further, on election day they do mobile polling in facilities, but they do not require disclosure of any information from the custodian to do that. The patients present themselves, provide them with the necessary identification or whatever, and vote. So there's nothing requested from the custodian other than to be able to set up a polling station in the facility. As a result of the last FOIP review there was an amendment to the Election Act of Alberta to try to address this. However, the amendment in that act enables that office to seek information from a public body as defined in FOIP. In this case the information is from a custodian under the Health Information Act.

Perhaps I can hand it over to Holly to address that further.

2:35

Ms Gray: I understand that the Deputy Chief Electoral Officer indicated that they would like to retain the ability to access information, the elements that Wendy referred to, under HIA. We would support keeping that reference since the information, when it comes from the department, would be classified as health information, and under FOIP, which is the act which is referenced and allows the electoral officer to get the information at the moment, the HIA is paramount. They could not get information from us under FOIP because health information as defined in the Health Information Act that is in the custody or under the control of a public body that is also a custodian falls under HIA.

It's important to keep the ability to disclose information to the Chief Electoral Officer in HIA, although we have received clarification that diagnostic treatment and care information is not required by the Chief Electoral Officer. It is only registration information.

Ms Blakeman: But there's nothing in the act that is limiting what the Chief Electoral Officer can request. They're just telling you, "This is all we would usually want or usually ask for," but there's nothing in there that limits them to that. They can ask for as much diagnostic treatment and whatever as they want if they wanted to. Correct?

Ms Gray: That's my understanding.

Mr. Snelgrove: In the issues that the AMA brought forward about this, what they said is that they fail to see why, but they didn't have a specific: don't do this. On face value maybe they don't, but when it's presented that this is information they need, there would be no reason for them to want more. So I think we should go ahead with the recommendation that was presented.

Ms Miller: The Chief Electoral Officer or that office would have to demonstrate the need to know more than the registration data, that he has acknowledged that that is what is required. You know, if suddenly Alberta Health got a request from that office for diagnostic care and treatment, we would certainly follow up and try to understand what was the need for the basis of that request and a judgment would have to be made that that was appropriate release.

Ms Blakeman: Did the staff from the chief electoral office indicate whether this was their only access point to the information, the health information that they were seeking, or can they get the information from some other source and this is a backup that they may or may not use?

Ms Robillard: They felt that their amendment to their legislation would also provide access to that information. However, as we've indicated, it relates to the FOIP Act and not to the Health Information Act.

Ms Blakeman: So the final argument, then, is that it's better off to leave them under HIA because the protection of personal information under HIA is stronger than, more thorough than is available under FOIP.

Ms Robillard: Perhaps we'd go so far – and I'd defer to my colleague from Justice – that under the FOIP Act the department may not be able to disclose under their provisions as they're currently stated today.

Ms Gray: Yes. If the Chief Electoral Officer used the FOIP provision to request information from Alberta Health, we would not be able to disclose under FOIP because the information they're asking for has the character of health information and would be governed by the Health Information Act. So there needs to be a provision in the Health Information Act which allows the department to disclose that information to the Chief Electoral Officer.

Ms Blakeman: Thank you.

The Chair: Okay. Are we looking at the status quo recommendation here? Mr. Snelgrove, did you move?

Mr. Snelgrove: You bet.

The Chair: Thank you very much.

Mr. Snelgrove: I forget how eloquently I put it.

The Chair: It was brief though. It was brief, and I like brevity.

Mr. Snelgrove: Apparently.

The Chair: Okay. I have a motion

> to adopt status quo on removing the ability to disclose to the Chief Electoral Officer.

All in favour? Opposed? Carried. Thank you.

Going to 24. Is that correct, Wendy?

Ms Robillard: Yes, that is correct, and it's just below that on the page, page 8 of 13. There was one issue around disclosure to the police that we neglected to touch on yesterday, and that is the second point, the second suggested response, which is to defer consideration of disclosure for the purpose of investigating potential fraud in the health system to Alberta Health and Wellness. The rationale: this requires additional research and discussion with stakeholders to assess the extent of the problem and the potential solutions. An appropriate balance must be retained between protection of privacy and confidentiality and the needs of the health system.

The Chair: So it's a recommendation

> to defer back to Alberta Health and Wellness for more discussion and consideration.

Ms Robillard: Yes.

Ms Blakeman: I'll move that.

The Chair: Thank you very much. All in favour? Carried.

Does that bring us down to number 6, the one we've all been waiting for? Okay. What page is that on?

Ms Swanson: Page 2 of 13.

The Chair: Has everyone found it?

Do you have some additional comments here, technical team? Go ahead, Evelyn.

Ms Swanson: Okay. I just wanted to say that there are three parts to this item, and before we go back to yesterday's discussion, we suggest that we talk about the second part and the third part, and then we'll come back to the other item.

There was a suggestion, which, I believe, was in the government of Alberta submission, 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. Right now that information is not accessible for research purposes, and what we've said as our rationale is that disclosure of identifiable health services provider information for research would be allowed only when there has been a research ethics board review and the board has recommended release without consent and the custodian agrees after considering whether aggregate or nonidentifiable information would be adequate.

This provision was not included in HIA initially as it was felt to be more appropriately handled in other legislation. However, since that time it's been determined that there is no other legislation that contains provisions authorizing release without consent for bona fide research purposes.

The consultation guide did not include a specific question on this topic, and the matter is likely to be sensitive to professionals whose information can be accessed for research. The AMA and CPSA in their initial submissions did not comment specifically but indicated support for disclosure only with the consent of the provider when the information is to go to third parties. That was the AMA. The CPSA indicated support for inclusion of health service provider information in the act.

Now, since that time the AMA did submit the supplementary letter to the committee which was distributed yesterday, and if Wendy can find it, I believe that the AMA has indicated that they don't have a problem with research.

2:45

Dr. Pannu: Was it distributed yesterday, Mr. Chairman?

The Chair: Yes, it was.

What was your last comment, Evelyn?

Ms Swanson: That in this letter the AMA did make reference to use of identifiable information for research.

Ms Robillard: Yes. It's on page 2 of the letter, and they state, "Physicians have always recognized the importance of collecting data for research in order to improve the delivery of care to our patients and the quality of that care."

Ms Swanson: They didn't directly address the matter of release for research purposes of identifiable data, but in general they've expressed support for research.

Our suggestion is that access to identifiable health services provider information be allowed for research purposes on the same basis as it would be allowed for patient information.

The Chair: Evelyn, is that a separate option to the one you have on the discussion guide?

Ms Swanson: It's separate. It's a different issue.

The Chair: Okay. So we still have to come back to the other issue at some point.

Ms Swanson: Yes.

The Chair: Would you tell me again what you just told me?

Ms Swanson: The department proposed that we amend the Health Information Act to allow for disclosure of identifiable health service provider information for research purposes. This would only be allowed where an ethics committee has reviewed the research proposal and concluded that use of identifiable health information, in this case about the health services provider, is reasonable in the circumstances.

The Chair: So what implication will that have to companies that want to buy this information or collect this information for other purposes?

Ms Swanson: It wouldn't impact on those other purposes. It impacts only on research of an academic-type nature as defined under the act.

The Chair: Again, who did you tell me will make that decision that it's for research only?

Ms Robillard: The request comes when the researcher makes the request to the research ethics board. They determine it, and then they come to a custodian, and the custodian considers it for that purpose. When the custodian makes a disclosure under the research provisions in the act, they bind the researcher to use that information only for the purposes specified in the agreement, and they must return it or dispose of it and sign a legal document indicating that they've disposed of the information when they are finished with it. So the information is protected by the agreement from further uses or disclosures.

The Chair: Okay.

Ms Blakeman: I think Ms Robillard just answered the question I had, which is that there is a restriction. If you have a group that approaches them, and they are involved in both research and marketing and ask for permission to use this information for their research portion, they could not then use it for marketing. However, the information horse has left the barn. They are in possession of that. Should they choose to use it, possession being nine-tenths of the law, they have it, and we can't get it back.

Ms Miller: It's true. Well, a researcher would have to sign a legal agreement, and should it be found that an organization or an individual had access and received information for research purposes and later used it for other purposes, there obviously would be follow-up to that matter, but it would have to come to our attention.

Ms Blakeman: Exactly. There's no way for us to know if it got used for something else or if that information granted for research was in fact used for marketing or some other purpose. We have no way of knowing.

Ms Miller: Well, the only way we'd be able to know is if somebody told us, most likely.

Ms Blakeman: Okay. Thank you.

Ms Kryczka: Well, I guess my two questions are around the same. I was going to simply say: who could approach the ethics board with a request? You said: research of an academic nature. That's a fairly strict definition. But then I guess they could turn around and use it for purposes other than for which it was approved.

Ms Robillard: The research ethics committee, as part of their deliberation, must assess whether in the opinion of the committee the proposed research is of significant importance and the researcher is qualified to carry out the research. So there is a test in terms of the researchers themselves and what they're using the information for or how they're proposing to do that.

Ms Kryczka: The second question. These people would be outside the – what did we say earlier?

Ms Robillard: Controlled arena.

Ms Kryczka: Outside the arena. I was going to say the circle. So I go back to the Health Quality Council, who is within. Do they also have to go through the ethics committee if they have a project and they know what they want information for?

Ms Robillard: Yes. Affiliates within a custodian organization can do research, but they must go through the ethics committee as well. Further, I'd like to draw your attention to the definition of research in the legislation. It means "academic, applied or scientific health-related research that necessitates the use of individually identifying diagnostic, treatment and care information or individually identifying registration information, or both."

Ms Kryczka: Can I ask a third question?

The Chair: Certainly.

Ms Kryczka: This is somewhat related but not specifically. Is there a turnaround time when an application or request goes in to the ethics board or committee? Do they try to do it within a week or 30 days? Sometimes the need to do research and have access to information is perhaps on a timely basis. Do you know what their turnaround time is?

Ms Robillard: I'm afraid I can't speak to that.

The Chair: Mr. Broda, followed by Ms Blakeman.

Mr. Broda: Yes. A question here. If I were a researcher and I got all this information, you're saying that after my research is done, I have to destroy it. But as a researcher I may want to hold it for future reference. What you're saying here is that once I use it, I have to destroy it; it's not available any more. Where do I reference it again if I do other research? I might be writing a paper on it, and I refer to research that I've done, and somebody says: I'd like to have that information to verify, quantify. All of a sudden I have to say: I'm sorry; I can't produce it. How reliable would your research then be considered?

Ms Robillard: The researchers are allowed to keep the information they require for as long as they deem necessary to meet their needs. The agreement requires us to have adequate safeguards in place to protect the privacy. So that is worked out between the custodian and the researcher. In the case of custodians the custodians can retain the information in a secure place for an extended period of time, potentially forever should they be able to access it in that format forever.

Ms Miller: Can I just comment further to your question? This requirement to dispose of or destroy the information is similar to any research provision for patient data as well, so it's not something unusual.

Mr. Broda: Okay.

Ms Blakeman: Two clarifications. We are talking about individually identifiable health information disclosed without consent; correct?

Ms Miller: Yes.

Ms Blakeman: Okay. Researchers who, for example, were funded for a particular research – they're a university researcher, and they're funded for a particular research project or receive a grant for a research project through, let's say, a pharmaceutical company. That's still considered research; isn't it? So they could be doing research on behalf of Merck Frosst or somebody, and that product would then belong to the company that paid for it; correct?

Ms Miller: That's correct.

Ms Blakeman: And is the individually identifying information held by the researcher for as long as they want or held by the group that owns the product? It's the same thing: the research is tied to the product; isn't it?

Ms Miller: Typically the product isn't displayed in identifiable format. The researcher has created the product as a result of looking at or examining identifiable information. The custodian that released the information to the researcher holds that data indefinitely, but in terms of the identifiable level of detail the researcher is bound to return or destroy the information.

Ms Blakeman: Except that we just heard that they can hang on to it for as long as they think they need to for backup. Did I misunderstand that?

Ms Robillard: It's at the custodian's discretion in entering into the agreement how long the researcher can maintain it. The custodian can maintain that information in perpetuity.

Ms Blakeman: And they could allow a researcher to maintain it in perpetuity.

Ms Robillard: That would be unusual from my perspective.

Ms Blakeman: Okay.

Ms Robillard: As well, when the agreement is struck between the custodian and researcher, it says:

> If the custodian decides to disclose health information to a researcher, the researcher must enter into an agreement with the custodian in which the researcher agrees
> (a) to comply with
>   (i) this Act and the regulations . . .
>   (ii) any conditions imposed by the custodian relating to the use, protection, disclosure, return or disposal . . .
>   (iii) any requirement imposed by the custodian to provide safeguards against the identification, direct or indirect, of an individual . . .
> (b) to use the health information only for the purpose of conducting the proposed research,
> (c) not to publish the health information in a form that could reasonably enable the identity of an individual who is the subject of the information to be readily ascertained.

2:55

Mr. Broda: Could I ask where she's reading that from? Is it under the HIA? What page is that on?

Ms Robillard: Section 54 on page 37 of my copy.

The Chair: Have we dealt with that issue, Ms Blakeman?

Ms Blakeman: Yes. Thank you.

Ms Kryczka: Can you provide the information on the approximate turnaround time to approve an application, for information?

Ms Robillard: I don't have that information today.

Ms Kryczka: No, no. Not today. But is it possible to get that information?

Ms Robillard: We could make some inquiry and see if we can get that information.

Ms Kryczka: The other question I had, too, is to clarify again. In the application the researcher has to state the use of the results of the research: you know, what is it for? I guess what I'm thinking is that it's all very well and it's admirable, but is there any way of knowing whether they may sell it to a magazine to publish in an article?

Ms Robillard: If the researcher was bound by agreement and limited to not enabling disclosure in a way that would identify anybody, not publishing in a way that would identify anybody, and they willfully went out and published identifiable information or subsequently sold it or gave it to somebody else, the sanctions under the Health Information Act would apply. As well, I presume that there would be fairly significant professional sanctions against the individual.

Ms Kryczka: I guess what I'm trying to understand is the value of doing research. Is the researcher doing it likely for government, for Health and Wellness, you know, for policy, for programs, for a more efficient health care system?

Ms Robillard: All of the above.

Ms Kryczka: All of the above.

Ms Robillard: Absolutely.

Ms Miller: And/or a particular area of interest of that particular researcher.

Ms Kryczka: Yes. A masters, PhD, whatever. In other words, they cannot benefit financially, as in making a profit, from the results of doing the research because then it becomes more of a commercial use.

Ms Miller: Perhaps we're not explaining it well. The researcher could not sell the information in identifiable format to another organization or individual for profit. However, the product of the research, meaning the report, the study, the analysis, which now doesn't identify individuals – it's the analysis result of looking at the data – is typically published in professional journals and the like. A researcher could certainly become known as a particular expert in that area because they've done some fundamental research and, as a result, their particular career be heightened in some capacity. I mean, that can happen.

Ms Kryczka: It's very interesting, because I think that in the future the whole area of research will only take more prominence, if you listen to the leaders at the universities that we have here.

Ms Miller: Certainly research is very, very important for the health of the system. However, obviously appropriate is the disclosure of that information.

Mr. Snelgrove: Mr. Chairman, there appears to be a huge gap between the issues. I don't think that anybody would disagree with the absolute necessity to keep a doctor/patient relationship private, personal. Then it seems that we make the big leap over to the information side of it where the people that want this information appear to suggest that it's not going to affect that relationship. The doctors are very adamant that it will. That's too big a leap.

I can't understand a doctor saying, first: no one in the profession can challenge my relationship. Because it is a publicly funded profession and they need to be held accountable, whether it's by their own professional association or by Alberta Health and Wellness, there obviously has to be in that system somewhere the checks and balances on their professional activities.

That's very different from handling information that comes out of the work that they do collectively. I can't see why the two organizations aren't able to somehow satisfy the absolute right to privacy in a doctor/patient relationship and the ability to take information that we probably need collectively as health care providers and use the information that comes from the services we've given.

So it seems like we've got a square peg and a round hole. It doesn't add up to have this huge difference here. Personally, I just can't see why it's here. Quite honestly, we need to take more time to talk to people in that field or in the department. We have to be very careful that we don't damage that physician/patient relationship and the system, but we don't want to hamstring the groups that do other research. Most of the stuff that we've brought forward – I mean, there are certainly some differences, but there was a relationship in building this thing. These two are here, and I'm certainly not ready to make a decision on this.

The Chair: Thank you, Mr. Snelgrove.

On this point, I would like to add that this is a serious question, a serious issue. I certainly am with Mr. Snelgrove: I don't feel ready to cast a vote yet on this issue. I realize that we're talking about research and that in a few minutes we're going to go into the other question, the other aspect of provider protection or not protection, but to me there's a connection. We run the risk of setting some kind of a precedent.

We have requested some more information as a committee, so I would be much more comfortable if we could defer this discussion for another week, if we could have another week to get that information and deliberate again on this subject when we convene on October 7. In the meantime, some members of the committee want to do some more research and ask some more questions. So, personally, I would be more comfortable with just leaving both these questions unanswered today and deal with them when we get prepared to deal with the full context of question 6.

3:05

Dr. Pannu: Mr. Chairman, I'm thinking along the same lines as you and Mr. Snelgrove, but I think that not only should we defer this very, very contentious and complex set of questions and the resolution of the questions that spring from them to a week from now or 10 days from now, to October 7, but I think we need to give these issues more time. I would suggest that we should defer them to at least a 2005 platter.

I think that that's when they should be addressed, and I would be prepared to so move, Mr. Chairman.

Mr. Snelgrove: Dr. Pannu, would it be fair to say that if we're going to discuss this on October 7 and if at that time there is not a clearing of the mud, then make the motion to defer to 2005? We've done a lot today, so we can spend a lot of time on this issue. At that time, if it's no clearer, then I would be perfectly willing to say: let's put it off.

Dr. Pannu: I think we are moving in the right direction; there is no doubt. But I have been feeling, quite frankly, uncomfortable about having to deal with issues of such significance under such pressure of time that we can't really feel that we have done due diligence as legislators to the matters. We can certainly give ourselves some time over the next 10 days.

I have less time than you. You are part of a much larger team. Remember this. I want to share my constraints in the understanding of it with you. I'm one member of a two-member caucus; my time is much more limited. That's why I'm trying to persuade the committee to give ourselves more time so that people like me could walk out of this room feeling comfortable about what we have done. I'm not feeling comfortable. This is one issue.

The other is related to section 37(2)(a), that the chair has mentioned. My point to you, then, is that we need more time given that not all of us are ready for it now and won't be ready in a week's time.

The Chair: Dr. Pannu, I will not get into a debate with you on who has the most time. Certainly at some point if you want to trade schedules with me, I think I might take you up on that, but that's not relevant.

Ms Kryczka, you had your hand up.

Ms Kryczka: Yes, I did. I would like to look at it the next time we meet, which would be the 7th.

When you look at the long sheets that we got today, if our team could provide us with an overview. Seeing as how we're now down to another layer of this topic and a little wiser, if we looked at the different submissions – like, who were they, what groups of people were they, and what did they say? – because I think there were a lot of things said in the different submissions that came.

Then there were recommendations about revising a section. Wasn't it 37(a) and (b)?

The Chair: Yeah, that's 37. It's on this one.

Ms Kryczka: Just have a presentation that may take half an hour to an hour, whatever it takes.

Mr. Broda: It's actually on 6.

The Chair: That's right; it is on 6, yeah.

Dr. Pannu: Mr. Chairman, I received a piece of paper this afternoon from IMS. I would like to share it with you. I think it should become part of the record. It says corrections. There are some concerns about inaccuracy of information that came before the committee.

The Chair: Could we just have copies made for the committee?

Dr. Pannu: Yes. I think that's precisely why I wanted to make sure that I don't treat it as private information. That adds to the whole complexity of the issues that we have to deal with. You know, the letter from the AMA refers to IMS's positions, and IMS has its own claims. So I think it's something that we need to address.

Ms Kryczka: I understand what he's saying, but I'd like to reiterate my point. There were many submissions that came in other than IMS. It seems like we have a very strong focus here on IMS. If we have a presentation that will come to us where we look at all the submissions and respect who the groups are and what they said – it's not just an IMS issue.

The Chair: Okay. Linda, I guess Karen is asking for a summary of those who presented to us?

Ms Miller: Certainly, we'd be prepared to do that. Yes, that's very reasonable, and we will do that.

The Chair: Okay. I think that some good points have been made. I appreciate Mr. Snelgrove's and Ms Kryczka's points on trying to deal with this on the 7th before we defer it finally till January of 2005. It may be that we can get a resolution with some more information in another seven or eight days. I would certainly consider a motion on this one, but I would hope that we would have one more chance on the 7th before we delay it until January.

Ms Blakeman: Well, I appreciate what Dr. Pannu has offered us in that he has received a mailing that, it seems, possibly only he received. So could we have agreement amongst the committee that if there's any additional information that comes to them either in person or as a document, it will be shared with the whole committee?

The Chair: I don't have a problem with that.

Ms Blakeman: Thank you.

The Chair: So if committee members get additional information from various players, if you want to give me the information, I'll see that it gets copied to all members of the committee. We have tried to do that, Ms Blakeman, with anything that has come to the chair. We have tried to share it. I've taken the position that if someone has something for the chair, it's certainly for the whole committee.

All right. I guess I'm looking for some motion here of deferral to some point, either the 7th or whenever.

Mr. Lougheed: Lloyd already made one.

The Chair: Oh, did you make a motion?

Mr. Snelgrove: I believe Dr. Pannu made a motion.

The Chair: Oh, his motion, yeah.

Would you amend your motion to give us one more chance on the 7th? Would you agree to that?

Dr. Pannu: I'm happy to do that, Mr. Chairman.

The Chair: All in favour? Opposed? Carried.

We have one more item under Other today, I think; do we not, Karen?

Mrs. Sawchuk: Actually, Mr. Chairman, that was the one that Noela dealt with earlier, Information and Privacy Commissioner rules.

The Chair: Linda, did you have something else?

Ms Miller: Not that I really want to get back into it, but the other item under 6. We do have some follow-up information on some of the questions asked yesterday. Do you want to just have us report back on that today or wait till the 7th?

The Chair: Let's go today.

Ms Miller: It might help our thinking over the course of the next week or so.

The Chair: Do we have copies of that?

Ms Miller: I believe that there was an issue paper circulated on the Saskatchewan situation – I know that there was some consideration – and we have a verbal report on British Columbia.

The Chair: Health service provider information, question 6 supplementary.

Ms Miller: Supplementary information, yes. I'll turn it over to Evelyn now. She wrote the issue paper. It's in follow-up to some of the questions from yesterday.

The Chair: We need to make some more copies, so if you'd just hold it until we get them.

Ms Miller: Sure.

The Chair: Were there any other documents, Linda?

Ms Miller: No. We'd also like to give a verbal report on our discussions with the province of British Columbia, but we can just give it to you verbally.

The Chair: Okay. Why don't we go ahead with that one while we're waiting for the copies?

Ms Miller: Okay. I'll turn this over to Holly.

Ms Gray: Thank you. I just want to preface my remarks by saying that I'm not a B.C. lawyer, so I'm not an expert interpreting B.C. law, but I have obtained information about the statutes that govern pharmacists in B.C. I will just give you an outline of what we understand the legislation to be, and because I received this information verbally, we will go and double-check our information to ensure that what we've given you here today is accurate.

3:15

There is a statute in B.C. called the Pharmacists, Pharmacy Operations and Drug Scheduling Act, and under that act all information covered by the act is to be kept confidential unless disclosure is authorized by the act itself, by the bylaws of any particular health profession, or by another enactment.

One of the categories of information that is protected under that act is called patient record information, and it includes various elements, including the name with respect to a prescription, the drug, a prescribing practitioner, authorizing practitioner, health services provided to the patient.

Under the act disclosure of patient record information is only permitted to pharmacists for dispensing, pharmacists and practitioners for monitoring drug use, the college of various practitioners to regulate practitioners, and to federal or provincial governments, payment agencies, or insurers to reimburse the cost of payments for health services.

In addition to that, I understand that the bylaws of the College of Pharmacists of B.C. provides that pharmacists may not release patient record information for commercial purposes if disclosure of that information would permit the identity of the patient or practitioner to be determined. So if it's disclosed in a form where you can discern who the patient or practitioner is, my understanding is that it can't be disclosed in that circumstance.

Under separate legislation, their FOIP legislation, I understand that the colleges do not have access to information that is held by the B.C. government in a database called PharmaNet. That information is not disclosable – it's personal information – if it represents an unreasonable invasion into personal privacy. There is a presumption in the legislation that disclosing a third party's name and address and phone number is an invasion if it's done for the purposes of mailing lists or solicitations by phone or other means. So in that context my understanding is that provider information is also protected.

The Chair: Thank you very much, Holly.

Questions?

I think everyone has the documents now, Linda, so who's going to speak to the document?

Ms Miller: Evelyn will walk us through the document.

The Chair: Okay.

Ms Swanson: Late yesterday we did get in touch with Saskatchewan Health and also did a bit of research on the web and compiled this background for you. It is correct that the Saskatchewan College of Pharmacists is the body now that regulates the practice of pharmacy in Saskatchewan, and there is a second group called the Representative Board of Saskatchewan Pharmacists that also represents the interests of pharmacists.

The College of Pharmacists has on their web site a policy manual, and it includes a statement which I have put in italics in the discussion paper, and I'll just read it to you if you like.

> Pharmacists may disclose to third parties (i.e. a commercial data compiler) prescription information including information concerning the prescriber/ pharmacist/pharmacy, which does not, and may not reasonably be expected to, identify the patient, on the understanding that the third party will not disclose this information with respect to the prescriber/pharmacist/pharmacy except in an aggregate format (i.e., which does not disclose specific individual prescribing or dispensing information), without signed consent from the prescriber/pharmacist/pharmacy. The onus to obtain this consent is on the third party requesting such information.

The source was the web site of the Saskatchewan College of Pharmacists.

The Saskatchewan Medical Association has expressed concerns about the practice of releasing identifiable prescribing information and requested the government to use a regulation-making power under their Health Information Protection Act to protect the privacy of prescribing information. Saskatchewan Health is proposing to create that regulation to prevent Saskatchewan pharmacies from disclosing information about another trustee, for example a physician, that is collected by pharmacies along with personal health information about an individual.

Pharmacies will only be able to disclose information about another trustee, for example a physician, for a purpose that is consistent with the reason the information was initially collected. These regulations will not apply to statistical or de-identified information where the provider cannot be reasonably identified. Saskatchewan Health is currently consulting about this regulation, and it is on the Saskatchewan Health web site.

As additional background, our contact person in Saskatchewan Health told us that Saskatchewan has had a comprehensive database of prescription drugs dispensed to beneficiaries of their Saskatchewan prescription drug plan since the 1970s and that that database covers about 90 per cent of the Saskatchewan population. To improve the completeness of the database in order to support government policy development, quality, improvement, research, and other system functions, their Prescription Drugs Act – and I haven't had time to check the actual name of the legislation or the content – we were told, was amended to require a reporting of all prescription drugs dispensed in the province, and that provision is just in the process of a pilot phase, apparently.

On the web site for B.C. we did learn that they have established a similar database called PharmaNet and that B.C. has legislative protections about its use for service delivery and health system purposes.

So these would be somewhat similar to what we're developing through PIN, and Holly has spoken to the rules that apply.

The Chair: Thank you very much for the information.

All right. I believe that that takes care of our agenda today. I certainly want to thank the committee for their diligence and hard work in moving through quite a bit of material in the last couple of days. Also, I would like to thank the technical staff and the people who advise the committee on all aspects. Your work is greatly appreciated, and without you we would be in deep, serious trouble.

Mr. Snelgrove: If we're not now.

The Chair: Well, it would be deep.

I've been reminded that everyone should take all their materials with them today so that we clear the desks.

Also, I would like to remind the committee that we meet again on October 7 at 9 a.m. I understand that at that point we will have as much as possible a draft document summarizing what you have approved today or didn't approve and, of course, with question 6 on the table to be discussed for possible inclusion in the document on the 15th of October should we get it resolved.

Are there any questions, comments from any members of the committee? If not, I would accept a motion to adjourn. Mr. Snelgrove. All in favour?

Hon. Members: Agreed.

The Chair: We're adjourned.

[The committee adjourned at 3:24 p.m.]