Title: Tuesday, June 1, 2004 HIA Review Committee
Date: 04/06/01
Time: 9:02 a.m.
[Mr. Jacobs in the chair]

The Chair: Well, good morning, everyone. My name is Broyce Jacobs, and I have been asked to chair this select committee to review the Health Information Act. We welcome you all here this morning. We do have a full agenda today, and we'll be disseminating a lot of information, so thank you very much for coming. Certainly it's important that you get the background as we proceed with the review of the health information.

One of the things you'll learn about me as we go is that I believe in starting meetings on time and ending meetings on time. I think there are still one or two that may come, but we will get started. I also would like to note that during the day one or two committee members have indicated that they have to leave briefly for a few moments, so when you have to do that, just go ahead and get back as soon as you can, and that will be fine.

There are two or three things that we need to review with you before we proceed with introductions. You should all have a meeting binder, which was delivered on Tuesday, May 25. Do all committee members have a binder? Okay. You should note that all meetings are open to the public and will be recorded by *Hansard*. Meeting transcripts will be provided to members and support staff, so when you speak, you're on the record. As with past select special committees support staff have been assigned to assist the committee, administrative support staff from the Leg. Assembly Office and technical support staff from Alberta Health and Wellness and from the office of the Information and Privacy Commissioner.

Today's meeting is intended to provide a thorough overview of the Health Information Act and the background necessary for the committee to commence its review. Today we're going to be disseminating information. Next week at the meeting we will as a committee discuss some of the more technical things that we need to do, extensiveness of the review, reference of the review, et cetera. So today's meeting is an information meeting. Next week we'll get into some of the technical and some of the detailed information that the committee will have to make and decide upon to proceed.

All of you, I think, know that the microphones are operated by support staff, so you don't need to worry. When you want to speak, the microphones will be on. We'll be breaking for lunch around noon, and lunch will be available just outside the meeting room. There are coffee and juice and other things available if anyone wants to avail themselves of that opportunity.

So again I welcome you all here, and I think we'll just go around the table, perhaps starting at my left. Would you please introduce yourselves and tell us your role on the committee.

Ms Veale: Good morning. My name is Heather Veale. I'm a lawyer with Alberta Justice, and I'm here to assist the committee with any legal questions they may have regarding this piece of legislation.

Ms Miller: Good morning. My name is Linda Miller, and I am the director of information management at Alberta Health and Wellness. I'm here as a support person to the committee, and I'm responsible for the implementation of the Health Information Act.

Ms Robillard: Good morning. My name is Wendy Robillard. I'm the team leader of the research access and policy support unit at Alberta Health and Wellness. I provide support in implementation policy development around the legislation, and I'm here to provide technical support.

Ms Versaevel: Good morning. My name is Catarina Versaevel. I'm with Alberta Health and Wellness, and I have been working on this piece of legislation and the pan-Canadian framework, which we'll speak to today, for the last number of years. So I'm here today to provide information and background which should assist with the review.

Mr. Goudreau: Good morning. I am Hector Goudreau, MLA for Dunvegan, and I've been appointed as a member to the Health Information Act Review Committee.

Thank you.

Ms Sorensen: Good morning. I'm Rhonda Sorensen. I'm the communications co-ordinator with the Clerk's office, and I'm here to offer communications support.

Mrs. Dacyshyn: I'm Corinne Dacyshyn, one of the committee clerks, and I'll be providing administrative support to the committee.

Mrs. Sawchuk: My name is Karen Sawchuk. I'll also be acting as committee clerk with Corinne, both of us together.

The Chair: As said earlier, Broyce Jacobs. I am the Member of the Legislative Assembly for Cardston-Taber-Warner.

Ms Kryczka: Good morning. My name is Karen Kryczka. I'm the MLA for Calgary-West, and I'll be deputy chair of this committee, working with Broyce and everyone here.

Mr. Lougheed: Good morning. Rob Lougheed, Clover Bar-Fort Saskatchewan.

Mr. Snelgrove: Lloyd Snelgrove, Vermillion-Lloydminster.

Mr. Broda: Good morning. Dave Broda, MLA for Redwater and committee member.

Mr. MacDonald: Hugh MacDonald, Edmonton-Gold Bar. Good morning.

Ms Blakeman: Good morning and welcome to the fabulous constituency of Edmonton-Centre. I'm so glad to have everybody here today. Laurie Blakeman.

Ms Gallant: Roseanne Gallant, health information compliance officer with the office of the Information and Privacy Commissioner and here to offer technical support to the committee.

The Chair: Thank you very much.

You have before you a copy of the proposed agenda for today's meeting. Are there any questions, or is there any discussion regarding the agenda? Yes, Mr. MacDonald.

Mr. MacDonald: Mr. Chairman, would it be possible to add an item to that agenda? It may not be necessary, but I think it's appropriate.

The Chair: What would that be?

Mr. MacDonald: New business. There is no item on that agenda for any new business.

The Chair: Okay. It's been proposed that we add New Business to the agenda. Any objections to that? It's an item, I assume, that just in case something arises, you're covering all your bases; right, Mr. MacDonald?

Mr. MacDonald: That's exactly it. Thank you.

The Chair: Okay. Can I then have a motion to approve the agenda as amended?

An Hon. Member: So moved.

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

Okay. There are seven items for discussion today. It's been suggested that we ask you to hold your questions until after the presentation, so hopefully you'll be able to co-operate with that.

I'm going to invite Ms Catarina Versaevel to start today's presentations. Thank you.

Thomas, would you for the record read your name.

Mr. Lukaszuk: Good morning, everyone. Thomas Lukaszuk, Member for Edmonton-Castle Downs.

The Chair: Thank you, Thomas.

9:10

Ms Versaevel: As the chair mentioned, what we are intending to do today is provide you with an orientation session on the Health Information Act. This orientation is just not on the act per se and what the act is intended to govern but also to provide you with background on the process for developing the act and the issues that we encountered as we were going through the process of introduction and implementation of the act.

Before I start into the content, maybe I'll just highlight your binder and why we included the content we did in the binder that was distributed to you.

The presentation overheads that I'll be using will be distributed to you, and they go into your initial tab. I'm going to be using these overheads today as part of conducting the orientation for you. There's also, as you would have seen, a CD-ROM in the package, and that CD-ROM was there for the interest of committee members who want to get more of a technical understanding of the legislation. It's an interactive CD, and we used it as part of our training and orientation for providers to help them understand the legislation.

Also, the slides that we use to conduct general orientation training on the act are there, so again it's content on the legislation itself.

The public brochures are also included in your binder. At the moment you just have one brochure, but there is also a brochure that was developed by the commissioner's office, which will be provided to you to put into your binder. That will come around shortly. We just didn't have it available at the time the binders went out to you.

Also, there is a document in your binder on how the Health Information Act will work, and that document is very important to understanding how the Health Information Act protects privacy of health information and the duties and obligations of custodians to protect confidentiality and security. We included that to again give you an overview of the legislation itself, and we'll go into some of the detail following up on the content in your binder as we go through the day's session.

Also, the document prepared by the commissioner's office to explain the Health Information Act to providers is included for you.

All of the documents I've just mentioned are in aid of a content briefing on the provisions of the act itself.

The last tab in your binder is a document on the electronic health record. It's a protocol on collection, use, and disclosure within the electronic health record. Again, as part of our presentation we'll follow up on that.

We chose the content for your binder as part of the orientation to inform you on specific provisions within the Health Information Act, and it's likely a reference binder that you will go back to time and time again as you get into more detail on specific provisions and possible recommended amendments to those provisions.

What we'd like to do now is basically the orientation on the act and the process for developing the act, the issues that we heard as we were working on the act, the context for the review. The context that existed at the time the Health Information Act was introduced and proclaimed is different from the context that you have here as you work through a review of the Health Information Act. Even though it's only three years ago that the Health Information Act was put into effect, there have been significant changes, and we will highlight those as we go through the session with you today.

Also, as part of the orientation we're going to highlight and show you a video on the electronic health record and talk to you about some of the issues that may impact your review of the Health Information Act because of the rollout of the EHR, and we're going to highlight for you the issues that we are aware of that likely need to be grappled with by way of review of the Health Information Act.

How we'd like to begin is to show you a video on the Health Information Act. Now, as I mentioned, all of the detail in the binder that you have is intended to explain for you what the Health Information Act is all about. This is a video that we put together at the time the Health Information Act was introduced to explain to the board members of health authorities and the members of executive committee within Alberta Health and Wellness basically at a senior decision-making level what the Health Information Act is all about. We thought that this would be a good way to start our introduction because it does explain the basic tenets and the basic principles of the Health Information Act.

So maybe we'll start with the video.

Video Narrator: Hi. I'm Wendy Theberge from Alberta Health and Wellness.

Alberta's new Health Information Act was passed in December 1999. Everyone who works in the publicly funded health sector, including pharmacists, needs to know about this legislation. This act was developed after three years of consultation with a variety of stakeholder groups and the public.

The Health Information Act meets two needs: the protection of privacy and controlled sharing of health information. Health services are often co-ordinated efforts involving regional health authorities, the Alberta Cancer Board, the Alberta Mental Health Board, other health authorities, and the whole range of providers from physicians to pharmacists. The Health Information Act enables health information to be shared appropriately between these entities and with the Department of Health and Wellness to improve patient care and to implement, evaluate, and improve programs on a regional or provincial level.

The Health Information Act enables the co-ordination of information across regions and the province. It also ensures that Albertans can have confidence the new rules cover the collection, use, and disclosure of their health information no matter how it's stored or transferred.

With the proliferation of electronic systems development, record security, transmission, access, profiling, and so on, people are concerned about the security of their personal health information.

Several reports have recommended greater reliance on evidence-based decision-making to maintain sustainability of the health system. The act puts forward transparent and consistent rules for collection, use, access, and disclosure of health information.

The specific purposes of the Health Information Act, then, are to establish mechanisms to protect the privacy of individuals with respect to their health information and the confidentiality of that information; enable health information to be appropriately accessed and shared; prescribe rules for collection, use, and disclosure of health information; provide individuals with a right of access to their own health information within specific limitations and exceptions; provide individuals with the right to request correction or amendment of health information about themselves; establish remedies for contravention of the act; and provide for independent reviews of decisions and resolution of complaints.

9:20

The scope of the act applies to two dimensions: what type of information is covered and who the act applies to. The act applies to the following types of health information about an individual.

Diagnostic treatment and care information. This is the most sensitive information about an individual's health and the health services provided to that individual, including the cost of those services.

Registration information. This is basic demographic information about an individual: name, address, gender, and so forth. This includes whether or not an individual is eligible to receive health services.

Health services provider information. This is basic demographic information about health service providers such as name, gender, education completed, et cetera. Rules in the act are primarily intended to cover cases where health service provider information is combined with other types of health information. The act also points to other legislation for additional rules that may apply to this type of information.

Now we'll take a look at who the act applies to. The act applies to individuals and organizations who hold health information primarily in the publicly funded health sector like regional health authorities and provincial boards; other hospitals and nursing homes; other boards, agencies, or committees created by custodians; health system appeal bodies as identified in the regulations; pharmacies and pharmacists regardless of how they're paid; fee-for-service Alberta health care insurance plan funded health professionals; and of course the minister and the Department of Alberta Health and Wellness. These groups are called custodians. Custodians are organizations or individual regulated health professionals in the publicly funded health system who receive and use health information, including pharmacists and pharmacies.

The act also applies to affiliates. Affiliates are employees, agents, contractors, and volunteers of a custodian. Affiliates are also physicians paid by a custodian or having privileges with a custodian. What the act does is identify custodians in their role in the health system. Affiliates, on the other hand, have their scope and role defined by their governing custodian. Each custodian must identify its affiliates, who are responsible for ensuring that the act, regulations, and the policies and procedures are complied with.

The Health Information Act doesn't cover services by ambulance attendants, the Alberta Alcohol and Drug Abuse Commission, or persons with developmental disabilities boards. In addition, if the health services are not fully or partially, directly or indirectly funded by Alberta Health and Wellness, then they are not covered under the act. However, a pharmacist is included regardless of how the service is paid for.

Five areas of custodian activities are covered: collection, use, disclosure, right of access to health information, and correction or amendment of health information. Collection is just the initial acquisition of the health information. This is done on an intake form at the hospital or the notes a doctor makes during or following a patient visit or the prescription record at a pharmacy. At the heart of the act is a firm understanding that custodians need information to fulfill their mandates. Without information they're unable to assess the outcomes of their actions, provide quality health services, or meet other expectations and responsibilities. The concept of controlled sharing means that custodians are permitted to obtain and use the amount and type of health information that is truly necessary for them to perform their mandate. This means controlled sharing of an individual's most private and sensitive health information. Custodians will be held accountable for their actions under the act and must demonstrate their need for the information they collect and use.

Generally, custodians are mandated to provide health services; determine an individual's eligibility to obtain health services; investigate, review, or inspect the services provided by health service providers; conduct research into better health practices, services, or management; offer health service provider education; carry out the specific purposes identified in other legislation such as the Hospitals Act, the Public Health Act, the Cancer Programs Act, and the Regional Health Authorities Act; manage internal operations such as planning and allocating resources, quality improvement, evaluation, obtaining payment for services provided, and so on.

In addition, some custodians like the minister and the Department of Alberta Health and Wellness, regional health authorities, and provincial boards have broader regional or provincial responsibilities. These custodians are also mandated to plan and allocate resources on a regional or provincial basis, manage the health system on a regional or provincial basis, conduct public health surveillance to determine and improve the health of the regional or provincial population, and develop health policies and programs on a regional or provincial basis.

Consent for disclosure is a critical consideration for custodians. The act authorizes custodians to disclose health information with the informed consent of the individual. However, the act does list exceptions when a custodian may disclose health information without the individual's consent. Several key examples are continuing treatment and care providers, professional bodies and/or quality assurance committees, researchers subject to an ethics review, those requiring information as specified in other legislation, family members in certain situations, police for investigating a life-threatening injury or for complying with a subpoena, warrant, or court order.

However, disclosure may only occur subject to the considerations of the following: least amount of information, highest level of anonymity, need to know, consent, notation, authentication of recipient, ethics review in the case of research purposes, duty to protect the information, duty to ensure accuracy, and other restrictions as specified by the act. The individual's consent must be obtained if the custodian intends to disclose identifying diagnostic, treatment, and care information through electronic means; for example, through a computer network.

Now let's take a look at access, collection, and compliance. Access is releasing health information to the individual who is the subject of that health information. For example, a person can request his or her treatment file from a hospital or a doctor. If a person believes there is an error in the record, he or she has the right to request a change to that record. The provincial Information and Privacy Commissioner provides for an independent review of

decisions made by custodians regarding right of access to and correction or amendment of health information. The commissioner conducts inquiries and resolves complaints regarding the decisions and actions of the custodians. The commissioner also monitors overall compliance with the act.

In essence, the act builds a controlled arena around this sensitive health information. The controlled arena includes the custodians who are covered by the act. Subject to barriers which control the free flow of information in the act, health information can move from one custodian to another within that controlled arena. Outside the arena health information movement is much more restricted.

There are 10 barriers that are designed to restrict the flow of information within the controlled arena. Custodians are the gatekeepers. They control the passage of health information into, within, and from the organization. Consent of the individual is required subject to identified exceptions. The principle of the least amount of information says that the minimum required amount of information should be transmitted. The principle of the highest level of anonymity says that wherever possible the information should not identify the individual. Everyone requesting information must be able to demonstrate a clear need to know. Every custodian has a duty to protect the confidentiality of this information. It is absolutely essential to obtain consent from the individual before disclosure by electronic means.

9:30

Any time new systems or procedures change within a custodian organization, a privacy impact assessment must be conducted. This is a specific review process to evaluate new procedures against the Health Information Act requirements. Each time a record containing identifying health information is disclosed, a notation must be kept.

Finally, the act specifies offences and substantial fines for violating the Health Information Act. Many of the same rules apply to disclosure of information outside the controlled arena.

The Health Information Act sets the collection, use, access, and disclosure rules for all custodians. Now, these rules address both protection of privacy and controlled access. They also detail the barriers to the free flow of information within the controlled arena. The Health Information Act provides transparent rules for both custodians and clients and in many instances codifies existing practices.

The rules in the Health Information Act are necessary. They are consistent with the fair information practices and rules that currently exist in other jurisdictions.

So that is the Health Information Act. If you need more information, please feel free to contact Alberta Health and Wellness at area code (780) 427-8089, or e-mail us at www.health.gov.ab.ca.

Thanks very much for your attention. [End of video presentation]

Ms Versaevel: Thank you for helping with that video.

May I proceed now with the overheads?

The video is only intended to give you an overview. It's at a very high level by way of its explanation of the Health Information Act, but hopefully it gives you a sense of the scope and the impact of the legislation.

This video was done in early 2000. As we go through the day's orientation, you'll appreciate that some of that content by way of provisions of the act is different than when this video was done. In particular, which we'll talk about more today, the reference in the video to requiring the individual's consent prior to disclosing information by electronic means, which we generally call now electronic health record systems, is no longer required. The Legislature amended that requirement since the legislation was put into effect, and we'll talk today about why that was done while we speak to the electronic health record.

Hopefully, that gives you an overall sense of the act.

Now what I'd like to do is talk about the process for developing the legislation and for introducing and implementing it. We felt that this was important content to talk about as you proceed to conduct a review of the legislation. It took a great deal of time from both people within the department, within the government proper in terms of the legislative review process to arrive at these provisions, and time, of course, was spent by way of implementation, and we'll talk about that. So a great deal of time, as the video pointed out, went into the process for developing this legislation.

In 1996 there was an initial discussion paper that was released to the public generally putting forward issues and perspectives for people to think about and to comment on. How do you strike the right balance between protecting privacy of the individual and protecting the confidentiality of their information? How do you balance that with access to the individual's information that's required to improve patient care and to manage the health system? So throughout the development and implementation of this legislation the word "balance," striking the right balance, has been debated at length.

The initial report, then, was released in 1996, and the summary of public responses was subsequently released in 1997, it should say. In response to that initial discussion paper, as we have found throughout the process of this legislation, we heard from stakeholders, people who are involved with the delivery of health care, not as much from individual Albertans.

Government tabled the Health Information Protection Act, Bill 30, in June of 1997. That bill was a consultation draft. It was intended to say to Albertans: here is a possible approach to health information collection, use, and disclosure rules; what do you think? Responses were received from many organizations, from individuals.

In response to the commentary on the draft bill, Bill 30, the minister at the time established a steering committee, and that steering committee was chaired by Ron Stevens. The committee was announced in December of 1998 and did its work for the next year or so. The work of that committee was to review the responses to Bill 30, the consultation draft, and to put forward recommendations to the minister in response to that feedback. What are the key policy issues? What are the provisions that this act should be containing to primarily deal with striking the right balance, which I mentioned, between privacy and access? Who should the custodians be? What should the duties and obligations on the custodian be to protect information? That committee dealt with all of that. It was a committee of several MLAs as well as organizations like the Alberta Medical Association, the Pharmacists Association, and other stakeholder groups.

That steering committee submitted a report again to the public and to stakeholders letting them know the results of the deliberations, and on most of the recommendations in the report to the minister from the steering committee there was consensus. There were, however, a few issues where there was not consensus, and I'll talk about some of those as I go through.

Based on the report of the steering committee, the legislation, the Health Information Act as it was called at that time and as it is called now, passed in December of 1999.

The reference to amendments from both sides of the House – absolutely, that occurred as the process for introducing the legislation went through the House. The reference to both sides of the House – that phrase "both sides," also speaks to: at the time the Health Information legislation was put into effect, on April 25, 2001,

there were still issues where there were both sides, meaning where there was not agreement on all of the issues. I'll highlight where there was not agreement at the time the Health Information Act was both introduced and then put into effect. I'll also highlight as part of the orientation what has happened to those issues that people commented on back in December of '99, 2000, 2001 and where the perspective on those issues of concern then are now because I think that's also very important to comment on.

9:40

Following the introduction of the Health Information Act in December of 1999, the minister established a Health Information Act Implementation Steering Committee, and that committee was chaired by Marlene Graham. That committee had different organizations, key stakeholder organizations. The organizations at the table for the implementation steering committee were those organizations that were seen to be in the best position to provide commentary to the steering committee as a whole as to the custodian community readiness to implement the legislation and how we assist stakeholders in implementing the legislation. What do they need by way of information, training, materials to help them be in a position to comply with the legislation? So that steering committee's work was very critical to the implementation planning that went on.

One of the recommendations of the steering committee was that a policies and procedures manual be developed for the custodian community, and that was done and was provided to stakeholders three, three and a half years ago now. That manual, of course, will need to be updated following the amendments to come from this committee's review.

A great number of training and support-type materials were developed to assist the custodians to implement the legislation. Training was delivered throughout the province, but as was not surprising, many physicians and pharmacists were not able to come – and we knew that in advance – to on-site training. They're not in a position to leave their offices to come to training. So one of the recommendations we had heard and then acted on was to do a CD-ROM. You have that CD-ROM in your package. That CD-ROM was done so that physicians, pharmacists within their own time, likely in the evening and on the weekend, could review the CD-ROM and get a better understanding of what the provisions in the legislation were all about.

We also worked with the AMA, the College of Physicians and Surgeons, with RxA and the College of Pharmacists on customizing materials for physicians and pharmacists so that we could use best practice examples within the physician and pharmacy community. Those materials we believe are being used. We know that the pharmacy piece certainly has made a difference. What the Alberta Medical Association also has done for their physician community is that every month they release HIA-type questions for the physician community to keep building understanding of the legislation.

Even though this legislation has been in effect since April of 2001, it likely would not be surprising to meet a physician or to meet a pharmacist who may not yet be aware of the provisions of the Health Information Act, because it takes time to become familiar with legislation. We are of the view that that would be an exceptional instance, but it could be the case because, as I say, it does take time to communicate legislation and understanding of the legislation.

Since the legislation was put into effect in April of 2001, there has be ongoing training. The ongoing training is now happening more at the regional health authority level by various custodian organizations as compared to by Alberta Health and Wellness as the key delivery agent although the materials developed by Alberta Health and Wellness certainly have provided the core for the training that has occurred.

Another key activity during the implementation of the act is policy explanation, trying to provide to custodians an understanding of what the policy was intended to be. That is very different from interpreting the provisions; that occurs by the legal advisors within custodian organizations.

I've mentioned the orientation and training materials that were developed for physicians and pharmacists and the ongoing work in that area for physicians and pharmacists. I highlight physicians and pharmacists only for the reason that proper orientation and training need to be different, more customized, for physicians and pharmacists. More support is required because there isn't the same infrastructure as there is for people who work within health authorities, for example, or within Alberta Health and Wellness.

There is also a help desk, which was set up at the time the legislation was put into effect. The help desk is managed within Alberta Health and Wellness, and it responds to questions from the public. It responds to questions from providers on the legislation. There's a lot of communication also on the help desk issues with the office of the Information and Privacy Commissioner. There's ongoing liaison between the department and the office of the Information and Privacy Commissioner on issues that we hear of from both perspectives and that we work on in a common way.

Not to confuse, there is clearly a different role for Alberta Health and Wellness than for the Information and Privacy Commissioner, but there are opportunities, certainly, to assist custodians in understanding the intent of the legislation. I'm sure that as the discussions go on, Roseanne will speak more about the role of the commissioner and issues and perspectives on the Health Information Act from the commissioner's office.

There is also a lot of work and effective liaison with the AMA, with the College of Physicians and Surgeons, with the pharmacist community, with the health authorities' privacy and access staff. There are many vehicles that have been used since the legislation was put into effect and prior that are aimed at explaining the legislation to people, dealing with operational issues. We'll speak more to that as we go through the session with you today.

What I thought might be helpful is to just pause for a moment in terms of the overheads and ask that you take a look at the Health Information Act. I believe that you have received that or did not and will in a moment. What I'd like to do is just bring the Health Information Act as a piece of legislation alive to you, to talk in very general terms, not to walk you through each of the provisions, obviously, but to highlight for you the different parts of the act. Then I'll speak about what some of the key stakeholder issues were at the time the Health Information Act was put into effect.

The first part of the act, called part 1, is basically the introductory matters. This piece of the legislation, as you'll find in comparable pieces of legislation, provides the interpretation. What do we mean by custodian? What do we mean by affiliate? What are the definitions that are there to help explain the rules that are contained within the Health Information Act? Part 1 of the legislation also talks in detail about the purposes of the Health Information Act. The video highlighted those purposes, but the act goes into more detail. So the interpretation is basically to give the backdrop to interpretive matters that help explain the provisions that proceed within the act.

9:50

The purposes of the act are on page 12, and as the video mentioned the purposes, I'm just going to highlight them before I walk you quickly through part 2 of the act: the first purpose, to establish strong and effective mechanisms to protect privacy of the individual and confidentiality of their information, and the second purpose,

which is to enable health information to be shared and accessed where appropriate to improve patient care and manage the health system. Those two purpose statement are where, at the time the Health Information Act was put into effect, it was possible to find views on both sides as to whether the rules within the Health Information Act itself effectively achieved striking the right balance between privacy and access.

That issue, in terms of its debate, is not unique to Alberta. That debate would be found in Ontario as they review their Bill 31, the health information legislation that they have introduced. Manitoba put their legislation into effect in 1997. They, too, would have grappled with the same balance issue. Saskatchewan put their health information act into effect in September of 2003. They, too, would have been grappling with the access and privacy issue. Those four provinces that I've just mentioned, including Alberta, are the four jurisdictions in Canada with health information legislation, meaning sector-specific health information legislation. Other jurisdictions obviously have legislative regimes that protect privacy of the individual and protect their information. It's just not sector specific. They do that through other vehicles.

The third purpose of the act is to prescribe rules, which the act certainly does, for the collection, use, and disclosure of health information. The principles that run throughout the legislation were highlighted in the video for you, and those are that those rules, meaning the collection, use, and disclosure of information, are to be carried out in a manner which ensures the least amount of information, highest level of anonymity that is possible in the circumstances and need to know. A custodian that is using information or a custodian that is receiving information needs to have a legitimate role within the health system in order to have access to that information.

One of the most important things as well as reaching rules to strike that balance between access and privacy is in law to provide individuals with the right of access to their own health information subject to specific exceptions. Now, that right of access, subject to specific exemptions, is basically saying that you may have access unless, and I'll highlight some of those unlesses for you when we look at that part of the legislation.

As well, the act provides individuals with the right to request correction or amendment, and there are a lot of rules as to how that is done. Those you'll find in part 2.

To establish strong and effective remedies for contravention of the act. That, we have found, is a very critical purpose, especially for the public, to ensure that there are indeed fines and penalties for contravention of the legislation.

The last purpose relates to that as well: to provide independent reviews of decisions made by custodians and for resolution of complaints. That's obviously where the role of the office of the Information and Privacy Commissioner comes into play. So those purposes are very critical because they overlay the rules that are in the Health Information Act.

Part 2 of the act basically sets the rules that speak to the individual's right to access their own information and to seek correction and amendment. Part 2 of the act is harmonized to the extent possible with a similar type of section in the Freedom of Information and Protection of Privacy Act. In fact, when we were working on the Health Information Act, we had as one of our operating premises to harmonize the rules within the Health Information Act to the extent possible and appropriate with the Freedom of Information and Protection of Privacy Act. So as we developed the legislation, we worked with officials from Government Services in identifying the rules that were put forward by debate within the Legislature. So Part 2 is very similar to the FOIP legislation.

The third section within the Health Information Act, which is on page 21, speaks to the collection of health information. Basically, what this part of the legislation says is that a custodian may only collect identifying health information if the collection is expressly authorized by an enactment of Alberta or Canada or the information relates directly to or is necessary to enable the custodian to carry out an authorized purpose. In the video you saw the authorized purposes that the act has put forward to say you may use information as a custodian within the controlled arena for those authorized purposes, and that's section 27. That's a very important section to bear in mind, especially as the committee grapples with the issue of scope.

The material that you have in your binder, the document that says how the Health Information Act works, makes the point that the Health Information Act applies itself, as the video indicated, primarily to the publicly funded health sector, except for pharmacies and pharmacists regardless of how they are paid. That document, How the Health Information Act Will Work, indicates that at the time that the legislation was introduced, there were questions as to: why does this legislation not apply to insurers, not apply to employers, not apply to private-sector health entities? That document explains, as part of explaining HIA and how it works, that this legislation is about custodians within the controlled arena, custodians that are part of the publicly funded health system.

So the authorized uses in section 27 of the act speak to what are considered to be appropriate authorized uses within that controlled arena. Once one looks at scope – and we'll talk more about that – if you put different entities as part of the scope, then those uses which are appropriate in that controlled arena context of the publicly funded health sector may not necessarily be appropriate uses in their entirety once you start looking at the possibility of including private-sector health entities, for example. But we'll speak more about that when we go through the scope as one of the issues that the committee does have in front of it to review. I say "does have" because the legislation says it does have, that it must consider, which we'll get into in a moment.

So collection then, part 3, basically says that you may collect as a custodian if it's authorized within a piece of legislation or it relates directly to and is necessary for one of the authorized purposes in the act.

Part 4 of the legislation on page 23 speaks to the use of health information, and again the use has to be in accordance with the Health Information Act.

10:00

Now, the second rule there, use of nonidentifying health information, is probably also very important to highlight as I just give you a quick walk through the legislation. This act says that a custodian may collect, use, and disclose nonidentifying information for any purpose. Basically, what that means is that this legislation is about identifying health information where the identity of you and I as individuals can be readily ascertained.

Now, there are confidentiality protection requirements in the act for nonrecorded health information, but primarily this legislation is about identifying rules for identifying health information. The provision I mentioned to you which is very important – well, they're all important, but this one is particularly important for scope issues – is on page 24, section 27 of the Health Information Act.

Part 5 speaks to disclosure of health information rules. This provision speaks about disclosure with consent and talks about what are the elements of a valid consent within the Health Information Act, and those are highlighted in section 34. As the video commen-

tary indicated, the act requires consent except in circumstances that are detailed in the act, and those are listed in section 35. A custodian may disclose diagnostic, treatment, and care information, the most sensitive type of information, without consent for the discretionary disclosures that are noted in section 35. Again, I'm not going through all of those; I'm just giving you a highlight of where you find different rules within the act, and then we'll speak about some of these more specifically throughout the day.

This section of the act also speaks to the disclosure of health service provider information, and as you'll appreciate from the material in your binder, the Health Information Act is primarily concerned about identifying health information about you and I as individuals. However, it does contain some rules regarding the disclosure of health service provider information. There are only limited rules with respect to health service provider information. Primarily those rules are linked to our identifying health information and also linked to disclosure to health professional bodies who require that information for discipline proceedings or investigations.

Again, we'll talk more about health service provider information as we go through the orientation today. I mention it because it is an issue that we will speak of as part of the review. At the time the Health Information Act was introduced, there was some question in localized areas of inclusion of health service provider information as part of the Health Information Act, but again we'll speak more about that as we go through.

This section of the act also speaks to disclosure by the minister and the department, and it says that the minister or the department may disclose diagnostic, treatment, and care information for the purpose of developing public policy, but again any disclosure that is authorized without consent in the act is subject to overriding principles of least amount, highest level of anonymity, need to know.

This part of the act also speaks to disclosure for health system purposes; i.e., for planning and management of the health system. Custodians like health authorities, the department, the minister are involved in planning and management of the health system, and the rule here basically says that you must be authorized to do so according to an existing enactment or statute, or you must prepare a privacy impact assessment.

As well, the rules for disclosure for research purposes are contained within this part of the act, and as you get further into debate on possible areas for review, the research area has been worked on. Specifically, I would say, Roseanne, that you've had a lot of involvement with the research community on these provisions and issues with the provisions. I don't mean concerns but how to implement, operationalize these research provisions. Wendy as well has had a lot of involvement in terms of access issues in the research area.

Part 6 of the act is also very, very critical. In the terminology that people deal with in health information, they often interchange words like "privacy," "confidentiality," and "security" like they are the same words, like they mean the same thing. They don't mean the same thing. In fact, this section of the act clarifies that the duties and obligations of the custodian are about protecting the confidentiality and security of the information.

When we talk about privacy within health information debates, we're talking about our right as individuals to determine when, how, and to what extent information about us is shared. That's what the word "privacy" generally is intended to mean. When we talk about confidentiality, then we're talking about the obligation of the custodian to protect the information; i.e., to not misuse it and to not wrongfully disclose it. When we talk about security, we're talking about protecting the information by assessing security threats and risks to that information.

The focus groups that we did with Albertans in developing the Health Information Act were several years ago. Probably the last one was done two and a half or so years ago. I may not be correct, since *Hansard* is taking down these words, about the exact timing there, but a while ago. The focus groups with Albertans put forward that often people are not really aware of what is happening to their health information. They go to the doctor, as I have recently done, or spend time in a hospital, and you're there to receive care and treatment. What is happening to your health information is not exactly what you're thinking about when you're lying in emergency or having someone operate on you.

Even when we're not in a hospital setting, what is happening to our health information – focus groups at the time advised us that they weren't necessarily aware of collection, use, and disclosure practices or rules and that they generally had confidence in their health provider to protect their information.

What they were generally concerned about was unauthorized access by hackers. Especially as one spoke more about the technological environment, some Albertans had concerns about unauthorized access, that someone could get into their electronic medical record or into the EHR, which Wendy will speak about later on, concerns about an employer finding out information which may impact their employment or insurance companies. But, generally within the health system, people had confidence that the health system used information to improve care. As time has gone on and there have been more articles, more discussion about technology, and more recent polls done of Canadians' expectations and attitudes, generally there is still that comfort, but there are more issues being raised because there are more issues put into the public debate to have commentary on.

What this part of the legislation, part 6, does is deal with those concerns that we certainly heard of through focus groups, that there needs to be a duty on custodians to protect confidentiality and security of the individual's health information. So here's where you find the rules about highest level of anonymity, need to know, least amount of information. In this version of the act you'll see on page 41, at the top of the page, "59 Repealed 2003." This is the provision I was mentioning to you, section 59 of the Health Information Act, which required a custodian to obtain consent prior to disclosure of electronic means, which was repealed with agreement of all the stakeholder community. They supported and requested that change, and that change, indeed, was made.

10:10

The duty to protect information, that the custodian has to take reasonable steps to maintain administrative, technical, and physical safeguards, is part of confidentiality and security. It speaks to transborder data flow as well as information manager agreements, and it speaks to data matching. We'll speak about that as the review of the Health Information Act proceeds.

Part 7 deals with the review by the commissioner. Part 7, again, is very similar to the provisions within the FOIP legislation. This piece also at the back has for you the designation regulation, which basically speaks to the custodian; i.e., those panels, committees, and boards that the video mentioned were also part of the custodian community. It also lists in detail what is contained within registration information, that second type of information that was mentioned, and it also includes rules around transborder data flow and fees. Again similar to FOIP, the Health Information Act allows fees to be charged in terms of access to information.

So not to lose you in a mire of detailed provisions within the

Health Information Act, but I did want to give you a sense of the act. It is a complex piece of legislation. Not that there's complexity in the drafting or complexity in putting the rules together, but collection, use, and disclosure of health information is a complex issue. It's an issue where there are many points of view, and I'll highlight some of those in terms of what we heard from stakeholders at the time of proclamation.

Do you think it might be time to have a bit of a break for people?

The Chair: Agreed. Perhaps before we do, let's just see if there are any questions to this point. Ms Blakeman.

Ms Blakeman: Are you able to tell us who were the opposition MLAs that were on Mr. Stevens' steering committee or on the implementation steering committee chaired by Ms Graham?

Ms Versaevel: The implementation steering committee, chaired by Marlene Graham, consisted of Marlene Graham and stakeholder organizations. There were no other MLAs on that committee. On the Mr. Stevens-led steering committee, Gary Dickson was at the table.

Ms Blakeman: Thank you.

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

Mr. MacDonald: Yes, please. You spoke about the Health Information Act and how it relates in Alberta and also in Canada, and you were talking about transborder issues. In May of this year a government member asked the minister of health a question in regard to the potential of having X-rays or other medical exams read in India, for instance, because, of course, this is a practice that's going on in America. Many people in this province are amazed to find that when they dial a phone and ask for consumer information, they're talking to someone in India. Now, what authority does this act have to prevent or enhance that practice if it were to go forward in this province?

Ms Versaevel: What I'd like to do is just take that question, and I'll provide you with comments a little later if I may.

Mr. MacDonald: Sure. Thank you.

The Chair: Mr. Goudreau.

Mr. Goudreau: Thank you very much, Mr. Chairman. I'm just wondering and following up a little bit on the previous comments about the Canadian legislation – no doubt there would be some legislation that is similar to this particular one – and the legislation in other provinces and if there was an attempt in the past to harmonize all of this and to get a free flow of information amongst provinces?

Ms Versaevel: As we carry on with the orientation, I will speak to you today about an initiative which is intended to do exactly that: to harmonize collection, use, and disclosure rules.

Ms Kryczka: I don't need a whole lot of explanation at this point, but you talked about division 3 on page 35, disclosure for research purposes. I'm just wondering if that is going to be one of the issues around the implementation of the act as we review this, the availability or the access to information for research purposes.

Ms Versaevel: There may be stakeholders who will present issues to the select committee for commentary on the research provisions in the legislation. We have not identified a series of research issues for you today that we have heard of, but that does not mean that you may not hear some of those issues from your stakeholder community that will be providing submissions to you.

Ms Kryczka: I had a bit of a heads-up there, so I thought I'd raise it right initially.

The Chair: Other questions?

Catarina, you've done an excellent job in a comprehensive way of giving us a tremendous amount of information. I just hope we can all remember it.

May I suggest that we take a brief break and reconvene. Would 10 minutes be appropriate given the length of information we have for the remainder of the day? We'll recommence at 10:30 then. Thank you.

[The committee adjourned from 10:17 a.m. to 10:31 a.m.]

The Chair: We will call the committee back to order. Catarina just suggested to me that at some points during the presentation at the appropriate spot she will stop and take questions, or if you have a really burning question that you would like addressed, she said that would be okay too. We're mainly concerned here with – it's not that we want to inhibit information, but we do want to make sure that we move forward here. We're still working on a 4 o'clock adjournment, so if we get into a lot of discussion about process, it could – we will do that next week.

Having said that, Catarina, we'll again ask you to proceed.

Ms Versaevel: Thank you. The information I'd like to provide to you now is: what issues did stakeholders raise at the time the Health Information Act was put into effect? The development, the introduction, and the implementation planning for this legislation created the opportunity to meet with several stakeholders to try and explain and address what the provisions were about. Certainly, that did occur during the introduction phase and during the preparation for the proclamation, but we thought it would be of interest to you to know what issues were raised as we proceeded to introduction and proclamation.

One issue that was raised by some groups was the number of disclosures of diagnostic treatment and care information that were in the legislation without the consent of the individual. That issue is one that was certainly raised in other jurisdictions as well. The response, generally, to that comment and issue was that in the majority of instances the disclosures without the individual's consent that are detailed in the legislation tend to codify existing practice. They are types of disclosures that were occurring within the health system at the time. Putting them forward in legislation made those types of disclosures more transparent both to the provider and to the individual. It is important, though, to highlight for you that that was an issue.

That issue also linked to the issue on disclosure to police services, so the debate from the police perspective was that there was not sufficient disclosure without the individual's consent to the police. The Health Information Act in the disclosure section does speak to disclosure to the police. It allows disclosure to the police in several instances: for the purpose of complying with a subpoena, warrant, or order; to a municipal or provincial police service for the purpose of investigating an offence involving a life-threatening personal injury

to the individual if the disclosure is not contrary to the express request of the individual. A third potential ability in terms of discretionary authority to the police is for any person if the custodian believes that the disclosure will avert or minimize an imminent danger to the health and safety of any person.

So those three provisions address disclosure to the police. However, it is important to explain, I guess, that in the interest of identifying the issues at the time of proclamation, disclosure to police services was an issue on behalf of police. Police service organizations came forward to say that with their mandate, which is to protect the public and ensure public safety, then having to rely on a subpoena, warrant, or court order was not sufficient for them to do their role. That issue was debated at length, and the conclusion at the time the Health Information Act was introduced and then proclaimed was that the health system's view, that it is important to protect the privacy of the individual in the context of the health service, was what was important and that the police would be able to have information disclosed to them in the instances that I mentioned. However, that was an issue, and we've been doing survey work with health authorities and police services since the Health Information Act was put into effect to help inform on that issue at the time of the review.

The other issue, moving back to the second bullet, is potential access to patient files in physician offices. There was a concern raised – and it was in the media at the time – that it would be possible for the department, for example, to go into a physician office and get access to patient files. This was an opportunity, of course, to clarify that the Health Information Act does not allow that to happen. There has to be a need to know, and there would be no need for a department or an official to go into a physician office to get access to patient information. It would not be permissible, appropriate. Nonetheless, that was an issue and a concern and one where a lot of discussion did indeed occur.

Another issue at the time of proclamation of the act was the administrative burden on custodians to accommodate the provisions within the Health Information Act. Although the rules were intended overall to codify existing practice, they did put additional duties and obligations on providers within the health system to protect confidentiality and security. An example is the requirement to do a privacy impact assessment for new administrative practices or systems. That is an example of the issue of administrative burden that was raised and one, again, that was attempted to address by working with organizations like the Alberta Medical Association to put forward ways in which to do that which could be shared across physician sites. But the issue of administrative burden is obviously an issue any time that legislation is put forward which requires a change in practice in terms of collection, use, and disclosure. We have not heard that issue to the extent we heard it at the time the act was proclaimed, but it was an issue when we were introducing and proclaiming the legislation.

10:40

Another issue that was certainly there at the time of the proclamation of the act is again in the context of disclosure to police. That was a request by pharmacists, meaning on behalf of pharmacists by the Pharmacists Association, that they should be able to contact law enforcement if they suspected fraud. The legislation allows a custodian to disclose to another custodian in the instance of suspected fraud but not to the police. Again the balance stayed with the protection of the privacy of the individual.

However, as you get into the debate on the review, you will likely have an issue brought to you on triplicate prescription programs, and a recommendation likely will come forward that a custodian should be able to disclose without consent when we're dealing with triplicate prescription programs, basically narcotic types of issues. The act does not currently say that. A lot of work has been done with the assistance of the OIPC to enable that to occur within the act, but the act does not clearly state that at this time, and it would certainly be helpful to consider that type of issue at the time of your review.

The other issue at the time the Health Information Act was introduced – and again this is an issue that was in the media – came from the Canadian Mental Health Association, the Alberta chapter, as a potential for a Charter challenge, that the Health Information Act did not sufficiently accommodate the Charter. Again many, many, many, and then a few more discussions on that issue to try and grapple with that. That did not proceed, but what it reflected again, I think, is a view among some stakeholders at the time that the act did not appropriately strike the right balance between privacy and access in terms of privacy of the individual and access to the individual's information.

Another issue at the time of the Health Information Act proclamation, as I mentioned when I spoke before the break, was on health service provider information and the inclusion of health service provider information within the Health Information Act. The rationale that was presented for including health service provider information within the act is to ensure transparency, again to the provider community, that health service provider information was used for resource allocation, for management of health service provider issues within the health context. So the rules are there for that purpose. As I mentioned, there are limited rules within the Health Information Act for health service provider information, but that was an issue. It was grappled with by the Ron Stevens steering committee, and the recommendation from that committee was that if there is a rationale to include it, it is appropriate. Indeed, there was a rationale, and that type of information in a limited way was included, but there certainly was discussion on that.

Those are the high-level types of issues, meaning those are thematic types of issues that were raised at the time the Health Information Act was introduced, and they were very important issues. They were issues that required good debate at the time the legislation was put forward.

What's interesting as we worked on implementation of the legislation is that many of these types of issues are not the issues that you're going to see us highlight when we identify the issues for review as we experience the Health Information Act in the year 2004. Not that there aren't issues; there are other types of issues that will be put forward. These issues have been impacted by experience of the Health Information Act, by actually working with the provisions. I think these issues have also been impacted by the working relationship with the various stakeholder organizations.

Does that mean that the police issue has been resolved? Likely not, and it is an issue that we'll identify for you today. Has the issue of consent for care and treatment been resolved? It may be resolved within the Health Information Act, but we'll present it to you as an issue for discussion because of the pan-Canadian harmonization initiative that is underway.

So maybe I will stop just there on the issues that we heard about and worked on at the time of introduction and proclamation, because what I'm going to do is move from the 2001 time frame, so to speak, and where we are now and what we see as the context for the review of the Health Information Act, the context that you'll more likely be facing than what we were facing at the time the legislation was introduced and proclaimed.

Ms Blakeman: I'm sorry; I think I was momentarily distracted. When you talked on page 8 about the potential accessibility by others to patient files and physician offices, I think I heard you say that there really was no reason that this would be occurring and it in fact did not turn out to be an issue. Did I hear you correctly?

Ms Versaevel: Yes. The issue that was raised was the potential of the department or the minister going into a physician office and being able to access patient files.

Ms Blakeman: Okay. But that doesn't cover, you know, other staff that are in the doctor's office accessing files and doing things they shouldn't be doing.

Ms Versaevel: No, and that's not what this point is about. Within the Health Information Act we talk about custodians and we talk about affiliates, which are employees or nurses or others working within the physician office that are affiliates of the custodian physician, and they indeed would be able to access information.

Ms Blakeman: This was about the ministerial staff accessing. Okay. Thank you.

Ms Versaevel: This was about the department. This was about those without a need to know the health information about the individual to provide care and treatment; that's correct. Thank you for that question to clarify that.

The Chair: Other questions? Very good.

Ms Versaevel: The situation in the year 2004 is clearly different than in 2001, although when the Health Information Act was proclaimed, we had reference to disclosures by electronic means, and that was intended to address some of the earlier Alberta Wellnet applications that were being developed. It reflected the department's understanding of electronic means at that time, four years ago or so.

When the requirement to obtain the individual's consent prior to disclosing diagnostic treatment and care information by electronic means, i.e. within an EHR environment, was removed at the request and with the support of the stakeholder community, i.e. the provider community, what that reflected was an argument from the stakeholders saying that the way in which you disclose information should not be subject to different types of disclosure rules, meaning that if you're disclosing information by a fax or by an e-mail or through an EHR, the individual should not have the right to say: you can disclose it by a fax, but I don't want you to disclose it through an EHR, and I don't want you to put it in the mail.

10:50

The argument was that the way in which information is stored and the way in which it's disclosed, i.e. the vehicle, the mechanism, should not be a right, so to speak, that the individual has. The stakeholder, the provider community, argued that what is important is that the privacy protection be there for the information, not how it is disclosed, that the confidentiality and security protection must be there. In fact, the Health Information Act, when it removed section 59, put in a new provision in terms of the electronic health record, that the security issues within the EHR had to be adhered to. The act already by implication said that, but it made it very transparent that that indeed was required.

Now, why is the electronic health record an issue for the HIA review? It becomes an issue when we talk about scope of application of the Health Information Act. As we go through the EHR issue, Wendy is going to, after we show you a video on what the EHR is all about – and some of you may indeed have seen that video already, but I think the majority likely will not have seen that video. Hopefully, the majority has not seen that video. I think you'll find it instructive because it explains what the electronic health record is all about and will come back to the issue of the scope of the Health Information Act challenge that is created by the EHR. That certainly is a new contextual challenge that this review committee will have: the electronic health record and what impact that has on scope and on disclosure.

The other very important impact on the review of the Health Information Act, which was partly there when the Health Information Act was introduced and proclaimed but is very critically here at the time of the review, is the federal legislation, the federal Personal Information Protection and Electronic Documents Act, called PIPEDA. That legislation probably will become part of what you end up talking about within the review. That legislation became applicable throughout Canada to all private-sector organizations that collect, use, and disclose personal information in the course of commercial activities. Several years ago it impacted us in terms of the context of this review; it impacted personal health information as of January 1, 2004.

As of January 1, 2004, the federal legislation impacts custodians, in our language, that are also subject to the Health Information Act. The impact of the federal legislation being in effect to entities engaged in commercial activities within this province means that health-sector entities like private pharmacies, laboratories, and health care practitioners in private practice became subject to PIPEDA, because what PIPEDA says is that unless you have legislation that is substantially similar to the federal law, then the federal law has what is called primacy. It is paramount.

Now, with this federal legislation and our Health Information Act what is understood in terms of the day-to-day practice within our province is that physicians, pharmacists, laboratory physicians are subject to our Health Information Act. This becomes an issue as we review the Health Information Act, but it is not a day-to-day operational issue for physicians and pharmacists. They are proceeding under the Health Information Act, and there have been discussions with organizations like the Alberta Medical Association, the colleges, and RxA on the work that is underway on the federal legislation. Why we're raising it as part of this orientation is because of the work that is happening within health jurisdictions across Canada as a result of this federal privacy legislation.

A year or so ago the deputy ministers of health across Canada made a submission to the federal government putting forward the argument – so that's provinces and territories – that PIPEDA was drafted for regulating trade and commerce and does not adequately reflect the unique attributes and complexities of health care delivery and that it should be the health jurisdictions that appropriately determine the collection, use, and disclosure rules for health information and that it was very difficult to apply the federal trade and commerce law to collection, use, and disclosure, that in fact those rules did not reflect health care delivery. So an argument was made at that time, i.e. a year ago, to exempt health organizations from the application of the federal law. Obviously, since the law became applicable in January 2004, that argument was not able to be successful.

However, what was understood by the federal level was that health jurisdictions would attempt to harmonize collection, use, and disclosure rules and thereby have a solid argument that with an appropriate harmonized privacy and confidentiality regime in place

for health information, indeed there would be a solid argument to exempt health organizations from the application of PIPEDA. This work resulted in something called the pan-Canadian privacy and confidentiality framework. Does that work have status? In terms of formal status it does not. It is work that is underway by jurisdictions, by people like me who work on these types of issues, people like Wendy and Linda who try and grapple with these issues across jurisdictions.

We're going to talk about the pan-Canadian framework with you today so that you're informed of it, but it likely will not be until near the end of June or so, July, that we'll be able to advise you what the status of that work is. We felt it important as part of the orientation to explain that work to you, but I just want to underscore that it has no formal status. It is work at an official level only at this time, so I won't say any more about that. We'll get into more detail shortly on this pan-Canadian framework, but it is very critical to this work given that people are attempting to commit to harmonized rules.

When we worked on our Health Information Act back in '97, '98, '99, 2000, et cetera, we did so based on what is happening within Alberta, and what is happening within Alberta is of course very important. What is different about this time of the review of the act is that there's also a challenge to look at the collection, use, and disclosure rules that are being worked on to be harmonized in other jurisdictions.

11:00

Now, that's critical work not only because of the federal privacy law, and most health jurisdictions would argue that we would rather have our own legislative regime to govern our collection, use, and disclosure practices rather than a federal law. That's not unique to health information. I think that argument is there also given the proclamation putting into effect the Personal Information Protection Act in January of 2004.

Why that harmonization is also critical takes us back to the electronic health record. In order to have an interoperable EHR across the country, we need to be able to harmonize rules, especially in the area of consent for care and treatment of health information. So that pan-Canadian view is a very, very important view. It is put forward for you to think about as part of the review of the Health Information Act, but we'll bring that more alive as we talk about the framework. Right now I'm just highlighting the contextual shifts since the act was put into place.

The other is public expectations. One of the initiatives that may take place – I say may because the work that we're doing on the pan-Canadian framework again is work at an official level – is to look at public opinion in this whole area of expectations around confidentiality and security. That's not public opinion in the context of our review of HIA. I'm not speaking about that. I'm speaking about this pan-Canadian work and at a federal level.

What we do know that is different in terms of attitude is that more and more people are talking about health information than they did when the Health Information Act was put into effect. That's for several reasons. One certainly is the technological advancements and some of the work we've done on EHR, both in terms of a very short video that we will show you and in terms of brochures that we will provide to you. People are talking more about health information and raising more questions. Everything, though, that we continue to hear from the public has to do with keeping information confidential and secure, not controlling who sees what information about us. But there is more dialogue at a public level.

Another contextual change from the Health Information Act introduction to the review is the engagement of the stakeholder community. We worked with stakeholders at the time the Health Information Act was being developed and introduced, but the involvement and the work with stakeholders over the last three or four years has significantly increased. There are solid working relationships with the stakeholder community through groups like the EHR Data Stewardship Committee, which Wendy will speak to you about later on today. There have been many opportunities to work with stakeholder communities on the training materials, and there is a better understanding of the issues because we do have a very solid working relationship.

I think that working relationship is also true with respect to OIPC and the stakeholder communities. There has been a lot of engagement with stakeholders in trying to understand the Health Information Act and its implementation. So at the time of the review the stakeholders who are very engaged in health information issues are very evident, and there are ready-made vehicles to meet with those stakeholders.

One example of that, in addition to the publicly funded health-sector stakeholders, is an ad hoc task group of private-sector health entities that we've been working with for about four or five years. We started working with private-sector health entities prior to the introduction of the Health Information Act in 1999 because the intent had been that the Health Information Act, initially way back in '97-98, would also extend to private-sector health entities. The initial steering committee, chaired by Ron Stevens, in their report to the minister recommended that health information should be subject to the same type of protection; i.e., there should be a level playing field whether information is in the publicly funded health sector or within private-sector health entities.

At the time the Health Information Act was introduced, it was not possible to proceed with that for three reasons: one, the federal privacy legislation not being clear in December of '99 and until, well, recently how the PIPEDA legislation would impact health information. So to include private-sector health entities when that vehicle for protecting information in private-sector entities was not clear made it questionable to expand the legislation in that way.

Secondly, government departments other than Health and local public bodies like municipalities and schools were just then becoming subject to the FOIP legislation, and they were already faced with the challenge of trying to understand: how will this impact record management? How will this impact our information practices? So Alberta Health and Wellness was requested to not expand the scope to other government departments and to local public bodies. So the Health Information Act, as you know, applies primarily to the publicly funded health sector and to pharmacists and pharmacies regardless of how they are funded.

Why I am lingering on this point for a bit is that the mandate of this committee will be addressed at the June 8 meeting, as I understand it, as part of your review of the terms of reference. Those terms of reference make reference to a point that I want to speak to as part of the private health sector context for the review. The mandate of the committee, in accordance with the Health Information Act, states that the committee must review the application of the act to other government departments, to local public bodies, and to private-sector health entities.

Even though the legislation at this time does not apply to private-sector health entities and is subject to review based on this provision in the act what will occur, of course, with private-sector health entities, we have maintained because of this intent the working relationship with this ad hoc group of private-sector health entities. That group has insurers operating within Alberta WCB, Blue Cross, all types of private-sector health entities. So in terms of discussing

the impact on private-sector health entities of future collection, use, and disclosure rules, that vehicle certainly is there.

The other context is government departments and expanding the scope to other government departments. From our work – and, again, we have continued to meet with other government departments – the other government departments of Alberta are likely of the view that the FOIP legislation provides proper protection for health information in the custody and under control of those entities. We're going to speak more with you in terms of the other government departments when we talk about issues, but that is a contextual issue as we look at the review of the Health Information Act, the experience of other government departments and the impact of expanding the scope to other government departments.

So those are some of the different contextual issues that we have now as compared to what we had back in '98-99 when the provisions of the act were being drafted.

11:10

I guess the other thing I would add is that we also have a very active community of advocates. I think that's probably the best way to say it. There is a community of privacy advocates that speak to privacy and confidentiality of health information, and those advocates, in terms of organized advocates, aren't necessarily within Alberta, but they are part of the broad Canadian community. I guess it again speaks to the fact that we are reviewing these issues within Alberta, but because of the Internet commentary comes from all types of venues which are not Alberta based, and that is very different again from when the legislation was introduced. The information that people are grappling with is from just so many different sources than what we had. So we have a very active community of interested parties in this review.

Do you have questions on any of those comments or any comments I haven't made?

Ms Blakeman: Can I just get clarification? Could you provide an example of a private pharmacy? Is that one that would exist, like, in a long-term care facility, where they're not in fact providing to the public but only to an enclosed group?

Ms Versaevel: Most pharmacies are likely private pharmacies. The only pharmacies that are not private likely tend to be hospital based, so most pharmacies are community based and tend to be private pharmacies.

Ms Blakeman: So "private" is not referring to who they're serving but how their economics work.

Ms Versaevel: No, no. It's the funding base. It's whether they're publicly funded or not.

Ms Blakeman: Okay. Thank you.

The Chair: Further questions?

Wow. Everybody is getting everything. Very good. Good job.

Ms Versaevel: I'm not so sure we could conclude that, but that's a good comment.

Mr. Lukaszuk: Underestimating us.

Ms Versaevel: Not at all.

Now, just to break from speaking words, we would like to now – I said that I would do a hand sign; I did it a little slow, my hand sign – show you a video on the electronic health record development. It's very short; it's about six minutes long. As this video is getting set up, Rhonda, may I have the brochure? I'm just going to hand them around.

The reason why the video and this EHR brochure were developed was that there was increasing media commentary on EHR, electronic health records, and questions coming as to: well, what is this? What is government intending to do with respect to electronic health records? What are they, what are their benefits, and how does the Health Information Act protect or speak to the collection, use, and disclosure of that information? This video was done for service site offices, like in physician offices or pharmacies or hospital waiting rooms, to run in that service site to explain to the public what the EHR is about and how the Health Information Act impacts the collection, use, and disclosure of information within the EHR.

We want to show you this quickly to just talk in general terms about the EHR. Then Wendy is going to talk more specifically about what's happening within the EHR development now, what is intended, and we'll speak to you about the role of a group called the EHR Data Stewardship Committee. Then we'll go back into HIA-type issues again. But we thought it would be helpful to just bring EHR alive to you.

Have many of you seen this video?

Ms Kryczka: Can I ask a question?

Ms Versaevel: Of course.

Ms Kryczka: I just wanted to ask a question around permanency of data in records. Was that at all covered? Is that an individual discretion, say, in a doctor's office. Can you clean out records? I'm just imagining that it must be building and building; right? Then when someone passes away for instance, what happens?

Ms Versaevel: A great deal of work was done in preparation for the Health Information Act on the retention, storage, and archival of information, and the Health Information Act speaks to the future potential of enacting a regulation to look at that. Wendy was involved subsequent to the proclamation of the act in looking at retention issues with health information. So maybe, Wendy, you could respond to that question.

Ms Robillard: Certainly. As records retention rules apply today, different custodian groups and organizations have their own rules. Some are established on recommendation through their professional associations and some through legislation. So there is some requirement to maintain certain records for a period of time but not all of the records.

The Health Information Act does enable the establishment of a regulation, and we did work with stakeholder groups just after the legislation was enacted to try and set a similar expectation for the whole health sector as we know it today. At the time when we were working on developing that and reviewing all of the various pieces of legislation and recommendations from different professional groups, we were in the development of the EHR, which is intended to be a longitudinal record of a person over time. We were grappling with issues about records retention and trying to establish minimum platforms for destruction at the same time as we were creating what we were hoping would become a longitudinal record. So we agreed in discussion with the committee to put aside our discussions and allow the electronic health record to come to life and to understand and grapple with some of those issues as well.

It's clearly something that needs to be revisited. It didn't make sense to say to dispose of things after, for instance, 10 years if we were trying to create something that would be maintained over a person's lifetime. We needed to get some more experience and let the EHR unfold and understand what that would mean, and we need to consider all those things together. So that issue clearly needs to be revisited.

11:20

Ms Versaevel: One moment, please. We're having technical difficulties here. I think that while we figure this out, we'll just speak to the brochure, and then Wendy will start describing some more detail in terms of our current functionality within the EHR, what's planned, and the data stewardship committee mandate and role. So I think I'll do that. I'll just carry on, and then once it begins working, we'll just stop and go to this.

The brochure that you have on the electronic health record speaks, again at a general level, to the fact that information technology obviously is impacting how health information within Alberta and other jurisdictions is being stored, used, and disclosed and that Alberta as well as other jurisdictions are looking at and developing a provincial EHR.

What the video, when we see it, and what the brochure talk about in terms of what we mean by an EHR is basically a collection of our health information that's gathered by different health professionals over time, and Wendy will speak a bit more to this in a few minutes to bring that more to life for you within the Alberta context. But right now within Alberta we're talking about applications such as the PIN, the pharmaceutical information network lab test history results application. So the EHR is basically built by information gathered from different health professionals.

The exchange of health information from provider to provider is obviously not new. That has happened to provide us all with care. That happens right now through paper-based medical records, through electronic medical records within some physicians' practices, through faxes, through e-mail, but it's the view certainly that the electronic health record medical system is going to improve the quality and safety of Albertans' care by making quality information readily available at service sites, which is seen to be obviously very, very, critical and will be in support of the providers' decision-making. Having information within the EHR both accessible for use and able to be disclosed and shared among health professionals is going to enable and streamline the sharing of health information to improve patient care.

The other benefit of the EHR is that it's going to give health professionals a common understanding of our health conditions, thereby preventing unnecessary treatments as well as avoiding duplication of tests that we receive.

Of critical importance as well is that the EHR is going to improve the accuracy of our health information that is maintained by our provider and obviously will improve the efficiency of the health system. Wendy and Linda are very involved in the electronic health record implementation within Alberta and will be in a position to answer any questions after Wendy gives you more of a detailed presentation.

I'm just trying to speak like the video right now. I know that it's not quite the same, but I just wanted to cover what the video covers to help provide the background for what Wendy is going to speak with you about. If we do get to see the video, what is interesting about it is that it shows you what an EHR potentially looks like. So it gives you a visual sense of the EHR and the access to information within the EHR, which makes it more dynamic than what I'm able to do by talking to you right now.

The other thing that the video speaks to is how the act protects health information. So the rules that we have talked about in terms of collection, use, and disclosure for health information are the same rules for the paper-based as for information within the EHR, and just as the health provider within the EHR and with paper-based must consider our views in terms of determining how much information to disclose, they have to consider those views within the EHR and within our paper-based record, within fax mail type of transmissions. Basically, the rules are the same within the EHR as they are for paper-based records except for the heightened focus on security of the EHR.

Here we go.

Video Narrator: Information technology is improving the way your health information is stored, used, and disclosed by your health provider. Alberta along with other Canadian jurisdictions is developing a provincial electronic health record.

What is an electronic health record? It's a collection of your health information gathered from different health professionals over time. When required, other health professionals can access this information through a secure computer network. Examples of this type of information may include information on your lab test results, your prescriptions, and a list of your allergies.

11:30

While visiting Edmonton, Ted Smith experiences shortness of breath, dizziness, and a rapid heartbeat. He is taken by ambulance to the local emergency department. The examining physician, Dr. Brown, determines Mr. Smith's lungs are congested and his blood pressure is elevated. Dr. Brown asks Mr. Smith if he is currently taking medication for any conditions. Mr. Smith has difficulty answering. ER nurse Dorothy accesses Mr. Smith's electronic health record. She sees that he is taking medication for heart disease. Mr. Smith is admitted to the hospital, and a series of diagnostic tests are ordered which reveal new conditions that become part of Mr. Smith's electronic health record. New medications are prescribed for Mr. Smith. These are now also part of his electronic health record.

Mr. Smith is discharged from the hospital two days later with a referral to a cardiologist and orders to follow up with his family physician. The following week Mr. Smith sees Dr. Green, his regular physician, in Grande Prairie. Dr. Green accesses Mr. Smith's electronic health record to view the results of his most recent tests and his new prescriptions. Dr. Green assesses Mr. Smith. Two weeks later Mr. Smith has his first appointment with a cardiologist. The cardiologist reviews Mr. Smith's electronic health record and is immediately up to date on Mr. Smith's history, test results, and prescriptions.

Health professionals support the move from paper health records to electronic health records. Electronic health records will improve the quality of your care by making quality information readily available at all points of care; reducing delays in treatment and supporting your provider's decision-making; enabling the sharing of health information to improve patient care; giving health professionals a common understanding of your health condition, preventing unnecessary treatments and adverse events such as harmful prescription drug interactions; reducing unnecessary duplication of tests such as lab work and X-rays; improving the accuracy of personal health records; streamlining the exchange of information; enabling the sharing of information to improve the efficiency of the health system.

Alberta's Health Information Act establishes strong and effective mechanisms that protect your privacy and the confidentiality of your information. Violating the rules in the act is a serious offence.

The act requires health providers to only collect, use, and share the least amount of information they need to provide you with your care and treatment.

If you have questions or concerns, you can learn more about electronic health records and the Health Information Act on-line at www.health.gov.ab.ca, by calling the Health Information Act help desk at (780) 427-8089, by contacting the office of the Information and Privacy Commissioner at (780) 422-6860 or dialing toll-free at 310-0000. [End of video presentation]

Ms Versaevel: So the video, as you will appreciate, just gives a good sense, hopefully, of why EHR developments are being pursued across the country and in particular the focus within Alberta Health and Wellness work. Wendy is going to speak about that and talk about the current functionality within the EHR. So we'll go from broad to more specific information for you that we're going to hear.

Linda, would you say that in terms of the EHR development Alberta is moving well ahead in terms of other provinces? Or where are we at in Alberta compared to what's happening in other jurisdictions?

Ms Miller: In our discussions with other jurisdictions I think it is reasonable to say that Alberta is considered to be about four to five years ahead of other jurisdictions in terms of achieving an electronic health record. We call this generation one because it is a long journey. We started populating the electronic health record with drug and laboratory information because that was clearly the priority area of information that our providers told us they really needed to have. If they had lab and drug information, that was 80 per cent of what they needed to make a good diagnosis.

So that's where we started, and indeed it has put us far ahead of the other jurisdictions. In fact, I think it's fair to say that we're the envy of the country at this point in time.

Ms Versaevel: So, Wendy, I'll just change these for you?

The Chair: We do have one question, Catarina, if we could take that first.

Ms Versaevel: Of course.

Mr. Goudreau: I was just wondering if everybody is participating now in the electronic health record in terms of the list that's identified and if there's a minimum amount of information that needs to be provided. If we're starting to become very dependent on electronic health records, it can be just as dangerous not to have the information as to have too much information.

Ms Versaevel: Thank you. I'll have Wendy or Linda reply to that.

Ms Miller: That's very true. In fact, as we've been able to be fairly successful, our providers are also at the same time telling us that they need more information, more complete information, because as they become familiar with using, it they say, indeed, just that: there is then a safety issue should the information not be made as available or as complete. We're working towards that end, but it will take us several years because it's very complex. It's about knitting together a number of information systems that were built many years ago, have different standards and different information collection practices. We need to bring that information together by either trying to standardize that information or replacing those systems, and it takes a large investment and time to do that as well.

The Chair: Thank you very much, and I certainly appreciate the information, Catarina, you've given us.

Wendy, we would certainly be happy to have your presentation now. Thank you.

Ms Robillard: Thank you. To talk about information technology in the health care system and the provincial EHR is really important. Obviously, the provincial EHR is very recent, and information technology has been used in the health system for some time, so it's important to know what's different.

Well, when information technology systems are used within custodian organizations, for instance within a regional health authority, they may have a certain database, but that data was contained within the health authority, and nobody else had access to it. If, in fact, there was a need for that information to flow from the regional health authority or the hospital to a physician office, for instance, there was human interaction that made that happen. There was information that would likely be put onto a piece of paper and mailed or couriered to the physician office, and that's how the information flowed between the systems. So that information was still used in the health system, but its method of transmission was quite different.

11:40

With the development of the provincial electronic health record, clearly what we have not done is create a single database of all health information. In fact, the electronic health record is intended to link multiple databases where they reside, and that's an important point to note. But what is different is that custodians, once they get access to the provincial EHR, then can actually access health information without any human intervention. They can go, then, to the regional health authority to get information if it's within the provincial EHR and if they have that access. There's nobody saying: yes, that information can now flow. They actually just go get the information they require to do the work they do, so that's important to note.

As well, quite clearly not all the health information that's held within databases is available through the EHR. It's sort of like the concept of an iceberg. It's the key component, the top piece, which is available, and there's still much more information than is available through the provincial EHR.

The development of the provincial EHR has been stakeholder driven. So the stakeholders are at the table; they're helping us determine what pieces of information should flow, what pieces of information are important from different aspects of the health system. The current functionality within the EHR, as the video talked about, is really allowing physicians, pharmacists, and health care providers, primarily in the first instance through web-based applications, web browsers, to access information such as the drug and allergy information, such as the lab information, and in fact the client registry, so a listing of primarily Albertans who are registered with the health care system and those who interface with the health care system. So that's what's currently enabled.

The access is a role-based access, so not everybody who has access to the provincial EHR has access to the same amount of information. It depends on what your role is and what your need is to know that information. In terms of how we've tried to follow the rules in the legislation, we have looked at security, so we've secured the system to the best of our ability today. In terms of privacy, we've done our privacy impact assessment. That has been forwarded to the office of the Information and Privacy Commissioner for their review, and we're trying to respect confidentiality of information through the role-based access.

The current functionality within the EHR is fairly limited, but we have on the next slide, then, the vision going forward for the next three years. The IM/IT strategic plan, which again has been established through stakeholder consultation, has identified with us where they would like to see the electronic health record move in the future. We are moving towards system-to-system interface, so moving away from web browser and actually allowing the systems to interact with each other in a more direct fashion. We have the three – client registry, drug and allergy, and lab results – still there, but moving towards diagnostic imaging, additional registry information about providers and about facilities, and clinical text reports. So reports that are generated in many areas of the health system would be available through the EHR; for instance, discharge summaries or operative reports, those types of things.

As we move more to system-to-system interface, there is a higher need for security, not only for the systems within the ministry but also for all of the players at the table who are accessing the provincial EHR. In terms of some of the privacy and confidentiality issues, we have established the Electronic Health Record Data Stewardship Committee, and I'll speak to that momentarily. Obviously, the review of the legislation will also enable EHR, and there will be some issues coming forward, no doubt, relative to the provincial electronic health record that will need to be tended to in this review.

We have developed a number of tools that the stakeholders are using around assessing their security, privacy, and confidentiality requirements. We're continuing to develop better systems to authenticate and authorize individuals to access the system and building more infrastructure within the systems. So there's work going on on many fronts in terms of where the EHR will be going in the near future.

One of the key points is the Electronic Health Record Data Stewardship Committee. With the information that is accessible within the provincial EHR, some of it is within custody and control of certain organizations. So, for instance, regional health authorities, physician offices, even the ministry have certain databases or at least components of that information that people can access. But there are also components of the system, such as the pharmaceutical information network, which was built to support the work of the physician and pharmacy communities primarily within the health system, that are not clearly owned by any physician organization or any pharmacy organization.

So, in fact, there was a need to develop a data stewardship committee to help us develop some oversight rules around access to that information, so that EHR Data Stewardship Committee was formed by ministerial order. Membership on that committee includes physicians and pharmacies, both the colleges and associations, the health authorities and boards. There are public members on that committee, as well as an ethicist and the department.

The committee was established to oversee the management of the provincial EHR, so they follow the rules within the Health Information Act but clearly go beyond those rules. They provide advice to the IM/IT Governance Council, which is a council chaired by the deputy minister with representatives from organizations at the CEO level, the same organizations as on the data stewardship committee.

The committee guides the development of standard information management rules through the management of the information exchange protocols and the information manager agreements. The information manager agreements are used as a tool for a custodian to enable another organization to provide IM/IT services on behalf of the custodian, so the agreements are set in place to provide direction to that organization that's supporting a custodian in regard to the collection, use, and disclosure of health information. So within the provincial EHR there is a need to have an information manager overseeing the provincial EHR itself, and in this case it's the department and Alberta Wellnet who provide that support.

Custodian organizations that wish to participate in the provincial EHR must sign an information manager agreement and must agree to abide by the information exchange protocol rules before they can access the provincial EHR. The information exchange protocols – and you have a copy of those – address collection, use, and disclosure issues. The protocol builds on the Health Information Act but clearly goes beyond that in terms of how information can be used and disclosed, so in some cases it sets a standard perhaps even higher than the Health Information Act itself.

That protocol is really in its infancy. It is there. It is in place. It is being followed. But the data stewardship committee and their subcommittees are working very hard at expanding those rules. For example, one place where you may see clearly that the rules are fairly limited is in the area of research and accessing the provincial EHR for research purposes.

So while all of the stakeholders agree that that is an intent and that that information can be useful for research purposes and to improve the health system itself, we've not yet had enough deliberations to arrive at what those rules will be. We are engaging many stakeholder groups to develop those protocols now, and those protocols will be vetted through the stakeholder communities as well before they are implemented. So lots of work yet to be done by the data stewardship committee.

Ms Versaevel: Thank you.

The Chair: Thank you very much, Wendy, for your report.

Are there any questions to this point? Yes, Mr. Broda.

Mr. Broda: Just looking at the EHR, you indicated, Wendy, in regard to a regional health authority that doctors can access back and forth. Can you do it interregional as well right now? What happens in the film that we saw here? What if I'm in the U.S.? Does a U.S. doctor have a reciprocal agreement to check my records here?

Ms Robillard: Right now the EHR is provincially based, so it's within Alberta. Clearly, though, the pan-Canadian framework expectation is that EHRs will be linked across Canada and perhaps even through other countries. So I think that's the vision for the future and part of the rationale to establish rules across Canada that are similar so that we can have confidence when we make that information available to physicians practising in another jurisdiction that they apply the same rules and security, et cetera, to that information. So we're not there yet, but clearly that is a vision.

11:50

Mr. Broda: Okay. In your understanding, is the U.S. doing something similar to this, or have they got legislation, or are they doing it within their own country so that we could tap in or vice versa?

Ms Robillard: In the States they do have health information protection legislation. That is there. However, their health system, as I understand it, is quite different than ours. So I'm not sure they're as far along in the development of the EHR, but Linda may have more up-to-date information on that than I do.

Ms Miller: It depends on where you talk about in the States. I believe some of the HMOs, health maintenance organizations, like

Kaiser Permanente and such are very much advanced in this endeavour and other areas less so. So it varies significantly.

Mr. Broda: Okay. Thank you.

The Chair: Mr. Goudreau.

Mr. Goudreau: Thank you very much. I guess I'm a little confused in terms of ownership of information. Often a doctor will die, or he will set up a practice and build up a whole pile of files and will retire, and all of a sudden the practice is up for sale. Quite often he'll say: "Well, I've got a thousand files, and they're worth $500 per file or $5,000 per file. That's the value of my practice." How much information on those files is actually owned by the doctors? If we're going to start transferring information back and forth, is there an effect there in terms of the information that they have?

Ms Robillard: In terms of the records that physician offices hold, they do have what the act calls custody and control of those records, so they are the ones who manage those records for all intents and purposes. Obviously, the individuals whose information it is have the right to access that information. In terms of the information that will flow from physician offices to the provincial EHR, in fact, they will largely be the stakeholders who help us to determine what pieces will flow within the provincial EHR and which pieces will remain within the office itself.

The Health Information Act also talks about when physicians retire or sell their practices and how that information can flow to another custodian so another physician who might purchase that practice can actually have access to those records under the legislation. Their profession also provides guidance to them in terms of how they should deal with records when they retire or cease to practise, and it's largely through their professional association that those rules are established and access to those records continues to follow.

As well, there is ability for physicians to transfer records from one physician to another. So if I should choose to see a different family physician, I can request that my records be transferred, and that typically is done now today. The rules and expectations around that are established, in fact, by the AMA.

The Chair: Thank you.
Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. Mr. Goudreau touched upon a matter that I was just dealing with recently. Am I correct to understand that the information in a doctor's office is owned by the patient, and the doctor's office manages that information on behalf of the patient? If and when there is a change of ownership of a practice, the doctor is selling just goodwill; he is not actually selling the information. The patient owns his or her own information; don't they?

Ms Robillard: The whole issue of ownership is an interesting one, and perhaps my colleague with Justice might even speak to some of this. The records as we talk about it in the Health Information Act are in the custody and control of a custodian, so the custodian actually manages those records. The individual has complete access to the records under the auspices of this legislation. Even prior to this legislation it was a common practice that individuals had access to their records. However, the legislation for all intents and purposes doesn't actually speak to who owns the record itself.

The Chair: Heather, do you want to add to that?

Ms Veale: I don't have too much to add to that. The legislation itself does not speak to ownership, the concept of ownership of information versus having custody and control. Really, the legislation thinks of it in terms of custody or control.

The Chair: You still look pensive, Mr. Lukaszuk.
Catarina, then, and we'll go to Mr. Broda.

Ms Versaevel: This afternoon, when I speak to the pan-Canadian framework issues, I will touch again on that question about the term "ownership." As Wendy and Heather have both pointed out, the act does not speak to ownership. At the time the Health Information Act was being developed, there was a lot of debate among legal people and among policy people on the whole issue of ownership. What was clear at the time the Health Information Act was put forward was a recent Supreme Court case, I believe it was, that made it very clear that it was the individual's information. So it was not like owning it or selling it in terms of where the question went but that it was the individual's information, that they had the right of access to their own information.

So although the act does not deal with ownership in terms of the legality and the legal issues associated with ownership, it clarifies the intent that it is our own information. We have a right of access to that information. It's the custodian that maintains the record, but we have a right of access to our own information within the record.

It does have a lot of legal nuance to it, I think, Heather, at least as I recall the debate among people when we put the rule forward. So Wendy is quite correct: there is no ownership reference, but the intent is that it's our own information, and we have a right of access to it.

The Chair: Mr. Broda on this point before we go back to Mr. Lukaszuk.

Mr. Broda: If I recall correctly – this would be several years ago, before health information records were available – when there was a transfer of a physician to a physician in my community, because I as an individual might not want to go to that physician, those records were transferred to the hospital and were kept there until such time as the individual went to see the new physician. Then he could access them and bring them back to the office. So I don't know how that's happening now, but that's what happened, say, 10 years ago.

The Chair: Thank you.
Mr. Lukaszuk.

Mr. Lukaszuk: Thank you. When I was using the term "ownership," I didn't necessarily imply that there would be an economic value attached to it. What I meant by ownership is: is any patient at the present time in Alberta in a position to withdraw his records as if it were a file from a doctor's office and then himself or herself obtain the custody and control of those records? That, in my mind, is more of a definition of an ownership without attaching a dollar value to it.

Ms Robillard: Under the legislation as it currently is written, the individual has a right to access that record. So the individual would likely at their request receive a photocopy of the record. The original record itself remains with the physician who provided the practice. Even if the record is transferred, it does not necessarily

mean in every instance that the record moves from one place to another or ceases to exist. That raises all kinds of questions in terms of legal issues and all of those things, which have nothing to do with, primarily, the Health Information Act.

The Chair: I'd like to thank the committee members for their questions and the answers and the presentations that have been made this morning.

I suggest at this point, unless there are objections, that we break for lunch – it's now here and prepared – and reconvene at 1 o'clock.

[The committee adjourned from 11:59 a.m. to 1:01 p.m.]

The Chair: We will call the committee back to order and thank everyone for coming back this afternoon.

This is an important committee, and the subject is really important to many Albertans, especially when you consider the context of necessity of divulging information and protecting privacy. So we need this information for background, and we'll get into more detail later.

Catarina has just suggested to me that we proceed and that if you do have questions as we go forward, she would be happy to take them. So with that, Catarina, we would invite you to proceed with the next step.

Ms Versaevel: Thank you. The content for the remainder of this orientation session is on the pan-Canadian framework that we made reference to this morning as well as to discuss with you those issues that we do anticipate likely should be subject to review in the Health Information Act. Reflecting upon the content provided this morning, we do appreciate that that is a lot of information to absorb. I don't think the intent is that every provision in the Health Information Act be reviewed in detail. I think the intent, although it's a comprehensive review, is more to review the issues that through experience people have raised in working with the Health Information Act. That's where the issues that we'll present to you this afternoon will focus, but providing you with the landscape of information by way of the review of the Health Information Act is just to help set a context. There is a lot going on out there for sure as it relates to health information, but it's not as though all of that information has to be grappled with in detail as part of the review. It is indeed to help set the context.

In the interest of providing you with background and context for the review, I'd like to talk now about the pan-Canadian health information privacy and confidentiality framework. Again, just to emphasize, the information I'm going to provide you now is information that is being worked through at the official level. There is no status to this information. It's not as though a government in a particular jurisdiction has said, "We're going to do A, B, or C," or that Alberta has said: we have taken a position on these issues. That is not the case. This is official information, but it helps convey what a framework that is harmonized might indeed look like and why it is important.

The people who are working on this pan-Canadian health information privacy and confidentiality framework have put forward several reasons why Canada needs to look at harmonized rules in core areas for the protection of privacy and confidentiality. One of those reasons we talked about this afternoon, and that is the existence of federal privacy legislation and putting forward the argument that if we have harmonized rules in place for the health system to protect privacy and to address collection, use, and disclosure of health information, then jurisdictions have a solid argument to request exemption of health organizations from the application of PIPEDA; i.e., that argument could be reviewed and could be warranted at the federal level.

The other reason for the health system arguably needing this type of framework is because of the investment that jurisdictions have made given the benefits of the electronic health record across the system.

The third reason is that jurisdictions who have health information legislation in place or in development have all learned from each other, and the rules naturally have tended to be harmonized. Although there are differences across jurisdictions, there is a natural harmonization that occurs because people share their thinking and their work and share the law in these areas. So there's also a natural evolution of harmonization that does occur.

The provincial and territorial ministers of health except for Quebec in 2001 signed what was called a harmonization resolution. That resolution committed jurisdictions to harmonize principles to look at common collection, use, and disclosure rules, and the ministers in that harmonization resolution identified the types of areas that should be looked at. So the work on this framework is also a natural outgrowth of the harmonization resolution commitment that was made, as I say, in 2001.

Those are some of the key reasons why jurisdictions have been working on this framework.

By way of background and as part of the work of the group of people who have developed potential harmonized rules for further discussion, we also looked at the existing health information regime in Canada. What is very clear and has been clear for a number of years for sure is that all levels of government – federal, provincial, and territorial – do recognize the central importance of protecting privacy and protecting confidentiality of information. The legislative vehicles that jurisdictions use do vary. However, if you were to review all of those different vehicles, you likely would see a reflection of what people tend to call fair information principles reflected in that legislation.

As I mentioned to you this morning, four provinces in Canada have health information in effect or are in the process of enacting health information legislation, and those jurisdictions have had a lot of discussion back and forth. Even though I mentioned that those pieces of legislation are generally harmonized in many areas, there are differences. For example, in Alberta the legislation applies to the publicly funded health sector including pharmacies and pharmacists regardless of how they are funded. By comparison, British Columbia in enacting their Personal Information Protection Act, which also applies to health information – it's not sector specific – includes as well private-sector health entities such as insurance companies and employers. Our health information rules, as we talked about this morning, do not.

So there are differences among jurisdictions, but as I say, all privacy laws in Canada do incorporate fair information principles. In doing this review, we looked at all of the different vehicles in all of the different provinces trying to see where harmonization across the system is possible, what is critical in terms of those core areas to argue for the potential of looking at exemption from the federal law.

With respect to what exists in Canada in terms of privacy and confidentiality regimes in provinces and in territories in particular, there are many common elements, and I just want to highlight a few of those common elements before I talk specifically about the framework itself. Most legislation in Canada – i.e., a regime for health information – puts forward strong mechanisms to protect privacy. That you will see when you look at legislative vehicles or

policy. Some of these elements that I'm mentioning to you are not necessarily in legislation; they are in policy statements that jurisdictions have in effect.

1:10

Another common element is giving people the right of access to information about themselves and the right to request correction. We have that; other jurisdictions have that as well.

The duty on providers to collect, use, and disclose health information at the highest degree of anonymity possible for the intended purpose of using that information is a typical element that you'll find in other regimes for health information. The duty to consider the express wish of the individual on how much information to disclose and to enable individuals to determine the extent of information subject to limits like emergencies, bodily harm, safety, that type of thing, most jurisdictions would see as an element that is important.

The user access rules defining who can input, who can modify information, who can use it under what circumstances and to what extent: most health information regimes grapple with that issue and look at the health care provider as being the key role where access to information is important in terms of providing care and treatment for the individual.

The other common key element that we identified would be found is security provisions to protect against unauthorized access, use, or disclosure. That recognizes what we've already talked about, that when Canadians have concerns, what they have most concern about is unauthorized access to their information in ways that could end up jeopardizing and compromising their livelihood, their reputation.

So those are some of the common elements that we found to be in place in terms of health information privacy and confidentiality regimes.

The other, although that's not necessarily always in law, is an independent oversight function in each jurisdiction to ensure that there is redress for individuals if their rights or a piece of legislation or policy has been violated with respect to confidentiality and security.

The other and final common element that I'll mention at this stage is sanctions for noncompliance: fines and penalties.

So even as we proceed with the work on looking at harmonized rules, we do so from a base of key elements that generally are to be found in jurisdictions given that every jurisdiction has to grapple with collection, use, and disclosure of health information.

We do not have sector-specific legislation in each jurisdiction for health, and there are jurisdictions who likely have no intention of going there, like British Columbia, for example, and there are other examples. So this work on the framework that we're doing at the official level is not arguing that each jurisdiction should adopt sector-specific health information legislation. Rather, the discussions that are going on are more: here are harmonized rules that might make sense for consultation purposes to adopt in whatever legislative vehicle makes sense within that particular jurisdiction.

As people work on the framework at the official level, everyone does so recognizing that this is content for discussion and for further debate. It's up to the Legislature and the legislative review process to determine what legislation would be in effect or what types of rules that legislation might contain.

By way of another point of background on the framework development, we have looked at what is happening with electronic health record developments in Canada. Clearly, a pan-Canadian system of EHRs is seen as a priority of the ministers of health and the deputy ministers of health. EHRs are seen as well as a key pillar to improve patient safety and the quality of health care and as an innovative vehicle. That has been talked about. That has been spoken to in the media as well.

The types of EHR developments. As we have done preliminary work as a context for the rule development that's underway, with respect to EHR activities across Canada, jurisdictions are focusing in on different areas. Nonetheless, everyone has recognized that harmonization in the interest of an interoperable EHR is certainly very, very important, and we already have spoken to some of that in our orientation content this morning.

So that's some of the background that the people who have been working on drafting these proposed rules have looked at.

Now I want to talk about the scope and the principles of the framework rules. In what I'm providing to you by way of information on the framework, I'm highlighting that content in the framework work that is likely going to be relevant within the review of the Health Information Act, recognizing that the review is arguably broader than our experience in Alberta but is looking at what's happening in other jurisdictions as well.

The harmonization thinking that has been going on is saying that the framework rules should be set for any organization that collects, uses, and discloses health information for the purpose of providing care and treatment to us as individuals and for the purpose of management of the health system and health research, and we're talking, then, about providers within the health care system. It's also recognized that some jurisdictions may choose to include provisions that cover health service provider information such as we do, for example, in Alberta. Some other jurisdictions may not choose to do that. So the framework is grappling with many issues. Those are some in terms of who the framework rules should apply to.

It also talks about what type of information, potentially, should the harmonized rules apply to, and certainly the rules that are being grappled with would apply to what we call diagnostic, treatment, and care information; i.e., health information about the individual, registration information.

The whole topic of genetic information likely will come to this table for some discussion, and this is also different than when we were working on the Health Information Act in the first instance as part of the background analysis prior to putting forward health information legislation for introduction. There has been a lot more work done on genetic information in the last few years. There's been a lot of research done at the federal level on genetic information and understanding the implications of genetic testing and uses for genetic test results. Some of the thinking and work on the framework is looking at that genetic information.

Now, most people who speak about genetic information would likely argue, at least people I've heard arguing on this – that doesn't mean some people wouldn't argue what I'm about to say – that genetic information should not result in having special legislation for genetic information. There should not be exceptional legislative regime; rather, genetic information should be viewed as a component of personal health information, but it may need to be looked at very critically, meaning there may be some unique attributes of genetic information which may require some different types of provisions, in particular to protect against the potential discriminatory aspects of genetic information, again in relation to insurers or employers, as some have argued in the material that has been developed in this area.

1:20

Another issue that's raised in the area of genetic information is familial access. We talked this morning about the individual's right to access their own information, and when we get into genetic information, the literature is starting to grapple with: "Well, should

genetic information also entitle familial access? Is there a community interest in this type of information?"

So genetic information is an important issue. It's one that the people working on the framework are grappling with, and some of that work will help inform in terms of background discussion that this committee indeed may have on genetic information.

The work on the framework to date has also recognized that when we look at First Nations, Métis, and Inuit people issues, there are unique cultural issues that occur that may not be experienced by other communities, not that there are not other communities who would argue that they have unique cultural interests, but there are particular cultural interests that have been also grappled with in the framework development.

The people working on this have identified purposes, meaning what are some common purposes, similar to what we spoke of this morning in section 7 of the Health Information Act in terms of here are the purposes that underlie the rules. A similar type of work has been done and also on underlying principles that should be looked at.

The work underway has also looked at what some definitions are that potentially could be harmonized, not the exact wording but rather: what is the intent of some definitions that could be common across jurisdictions that would help with arriving at harmonized collection, use, and disclosure rules? Again, as with any rules that this framework is grappling with, it's the intent of the rules and it's the intent of the language, not saying to a jurisdiction, because one couldn't – it's the Legislature and the legislative drafting process that determines what actual words would be in legislation. But the framework debate has been about: what is the intent of the definitions that would be good to harmonize, and what is the intent of some duties and obligations that should be harmonized?

There's been discussion on rules around privacy impact assessment, discussion on rules around cross-border transfers. As Wendy mentioned this morning, the framework work is grappling with that, and there were some questions this morning on transborder data flow issues. This framework thinking is attempting to grapple with that.

Policies and procedures. Our act requires that custodians develop policies and procedures to reflect the rules in compliance with the act. That's something that is in existence in many jurisdictions and potentially an area that could be harmonized.

Information manager, those entities that store information on behalf of custodians. Those types of rules potentially could be harmonized.

Transforming identifying personal health information. Our act enables that regulations could be set for transforming, encoding, stripping health information to make it nonidentifying. We have not to date developed regulations in that area for good reason. It's an area that evolves quickly. So, rather, policies and procedures have been put forward.

Another area that has been looked at is: what are physical, technical, and security safeguards that potentially could be harmonized? As well – and we had a question on this this morning – the retention and the storage and the destruction of personal health information. The accuracy and authentication is another area that has been looked at in terms of potential harmonization.

Personal health numbers. A critical issue for us working on the Health Information Act is that only certain individuals should be able to access an individual's personal health number; for sure providers and custodians under the Health Information Act who provide care and treatment, but our regulation also lists certain other entities that may require an individual to produce a personal health number. Those are a limited number of entities because of the privacy issues around someone's personal health number. So the framework is grappling with that as well.

Fines and penalties. Right now, interestingly enough, we have a huge range of fines and penalties in this country. They go from $10,000 to $50,000 for individuals and up to $500,000 for corporations. The harmonization discussion in that area is more around ensuring that there are fines and penalties, not to try and identify a number necessarily. We do have a number in our Health Information Act of up to $50,000.

Another area – and we're still just talking about the duties and obligations area – is immunity from suit. Again, we have a rule around immunity from suit, and that basically talks about people acting in good faith. When people are trying to do their job, they should be protected from suit.

So those are some of the duties and obligations, and in terms of those topics we generally address those in part 6 of the Health Information Act, that I highlighted for you this morning.

Another is the right of the individual to access their own information, and we spoke about that this morning. That's in part 2 of the Health Information Act. We also spoke about the collection of personal health information, and again the framework discussions are looking at what rules could be harmonized in that area.

Where there has been a great deal of debate within the various groups and discussions attempting to look at what rules could be harmonized is in the area of duty to protect the individual's privacy, and there's a lot of debate in this area. There's a lot of debate on: what are the appropriate rules to protect the individual's privacy? That debate has been polarized in different jurisdictions. It's been polarized around what constitutes consent. What is it? What are the elements of consent that people can agree with? When is the individual's consent required for collection, use, and disclosure?

What people have come to in this debate is that the goal, obviously, is to provide Canadians, including us as Albertans, with knowledge of what is happening to our health information. The federal privacy law indeed in its interpretation requires that. It requires that Canadians be informed about the collection, use, and disclosure of their information. So the goal certainly is to provide Canadians with that knowledge while not interfering with the legitimate exchanges of information that are required to provide health care and to manage the health system, recognizing again that when you're managing the health system, the argument for needing identifying health information, likely for planning and management of the health system, generally is at a level of anonymity in general terms.

There are exceptions, too, to every comment however, and there are instances where that is not the case, but that is where protection is required. This framework also grapples with that. When you're dealing with information for planning and management of the health system, you need legal authority in legislation, whether that's at the provincial, territorial, or federal level, or you need privacy impact assessment issues. So the framework is grappling with some of that.

1:30

The privacy protection issue, then, which is basically the consent issue – I mentioned this morning that privacy is about our right as individuals to determine to what extent our information is shared with others. That's the privacy issue that people often synonymize with the consent debate. Confidentiality and security are more what people grapple with when we talk about the duties and obligations to protect privacy and confidentiality of the individual's information. So when we're talking about duty to protect the individual's privacy, we're grappling generally with the consent rules.

Within our country we have a very interesting situation in terms of care and treatment to the individual and consent rules. In Alberta

in our Health Information Act, subject to all the overriding principles – least amount, highest level of anonymity, need to know – subject to other barriers on the free flow of information, those different constraints that we've talked about like privacy impact assessments, the video talked about notation, making a note when information is disclosed, when it's not about care and treatment. There are a lot of duties that restrict the flow of information.

Within that context our Health Information Act says that you may disclose and use diagnostic, treatment, and care information for the purpose of providing care and treatment to the individual. So information may flow from the physician to the specialist for the purpose of care and treatment. There is not a consent step that occurs with the individual.

Our Health Information Act also says in section 58(2) that the custodian must consider our expressed wishes in determining how much information to disclose, along with other factors that the custodian considers relevant when they make that determination. So we've got what some people call no consent for care and treatment, with the obligation on the custodian to consider the expressed wish of the individual in deciding how much information to disclose. But when we make that statement, one has to keep remembering all the other principles and overriding obligations on the custodian. That's still not free flow of information; it's just not a consent requirement for the individual.

In Saskatchewan they have a different approach to grapple with the consent question on care and treatment. They have a deemed consent with no opportunity to withhold or withdraw. So that's different again than what we have in Alberta.

In Manitoba – and as I mentioned, they've had their legislation in effect since 1997 – they also have a no consent approach, plus they have in law something that is termed a lock box. An individual can lock their information, not make it accessible. However, Manitoba's experience is that that provision, although it is in law, has not been used. So basically they have a similar approach in practice to what we have in Alberta.

In Ontario Bill 31, the health information legislation that has been introduced – it's not in effect; it has been introduced – has what is called a knowledgeable implied consent model. That model basically says that a custodian is entitled to assume that they have the individual's consent for collection, use, and disclosure unless the individual provides notice to their provider that they withhold or withdraw their consent.

By summarizing those four consent models just like that, I'm not meaning to do disservice to the complexity of any jurisdiction's legislation. I just wanted to illustrate that there are different models in place for consent for care and treatment. We are grappling with that within the framework work, and I would suspect, since likely there will be a need to look at some of these framework rules once they are complete, that if that indeed proceeds, meaning that that's the plan, it will require that the committee, too, look at some of those models and the recommendation coming from the framework. It's been a very interesting debate because of all of the different approaches and because consent is an interesting debate.

The other areas that are being grappled with are those collection uses and disclosures that require expressed consent. For example, if information is already out in the media, is it appropriate for a hospital or a physician to talk to the media and say, "Yeah, I can confirm that that person indeed has that condition"? Likely, one would argue that that isn't really appropriate even if it is in the media. So those types of issues are potential examples of where an individual's expressed consent is required.

The other area that's grappled with is disclosures without consent. We've talked about the section of the act, section 35 of our Health Information Act, which is the disclosures without consent. When you look across the jurisdictions that have health information legislation, they're fairly common. We're not that unique. We have some unique aspects, but we're not that unique. We also have grappled with purposes with no right to withhold or withdraw consent.

There are arguably purposes which can be argued to be in the public good or required for management of the health system; for example, determining eligibility and payment. Likely, one would not say to the individual: you have a right to not provide that information in terms of determining eligibility and payment. That's an example of just enabling the system to manage itself. So the framework debate – and it was true, too, for the Health Information Act debate – has grappled with the consent issue probably more than any other issue because it is the critical privacy protection issue.

Our Health Information Act in section 104 talks about rights being exercised by other persons. Similarly, the framework has grappled with substitute decision-maker rules. In the health system, when we are ill and dependent, we do have situations where we need a substitute decision-maker. So who might they be? What kind of right can they exercise on our behalf? Those types of issues have been grappled with in the framework deliberations as well as use and disclosure for research purposes – what constitutes research, and what are the duties of a research ethics committee? – those types of issues, similar issues that we grappled with in putting together the rules in the Health Information Act.

The other rule that has been grappled with is the commissioner process: what's the oversight and redress? We have variation across the country. Some jurisdictions give the commissioner the ability to do an order. Other jurisdictions do not. Some jurisdictions don't have what's called a commissioner. They have an ombudsman like in Manitoba. Other jurisdictions don't have what's called a commissioner. They have a review officer.

So this pan-Canadian framework has put together core rules in these types of areas for consultation and debate. The intent is that at the time of the review of the Health Information Act and looking at specific areas that could be subject to amendment, it will be important to take a look at the harmonized rules that have been put forward so that Alberta, too, is in a position to be harmonized with core rules that are being looked at to harmonize across jurisdictions.

1:40

We're not there yet. We likely will not be in a position with the content on the framework to say, "Well, here are the rules, and we can grapple with those as part of the three-year review," until likely the third week of June, the fourth week of June. So pretty soon but not quite. But I wanted you as part of the orientation to be aware of the types of rules that are being grappled with and that in these areas there has been work done to harmonize rules.

Actual rules have been written and developed and are ready for consultation. The consultation that is being looked at for the framework is with privacy commissioners, with ombudsmen and review officers, and in fact there already has been conversation with privacy commissioners. The other part of the consultation process would be with national provider organizations: the Canadian Medical Association, the Canadian Nurses Association, those national provider bodies that work with our AMA, with our College of Pharmacists, for example. There's also the potential of doing a survey of other providers to ask them what they think some of the operational implications of these framework rules might be.

Manitoba and Alberta are currently going through a review of their

legislation. Manitoba is doing a five-year review, given that it was put into place in '97. We're doing a three-year review. So Manitoba, too, will be grappling with some of the framework issues once we're in a position to proceed, and as I've mentioned, likely this select committee, too, will need to reflect upon the pan-Canadian proposed framework rules.

There may be a public opinion poll conducted by Health Canada. Certainly, there will be an analysis of the proposed framework rules by Health Canada. We have already done a review of the framework rules vis-à-vis our Health Information Act, and other provinces and territories will be doing that. So by the end of June we will know whether we're in a position to proceed to consult on the framework rules and how to weave that into, so to speak, the three-year review that is being conducted of the Health Information Act.

What has been very significant about this work is that due diligence has been done looking at the rules in these areas that I mentioned to you in all of the jurisdictions but also in the United States, in New Zealand, in Australia, and in the United Kingdom. In terms of all of that research, should the committee in the future have a question on what's happening in other jurisdictions, in particular areas, we can certainly draw upon that information for you by way of comparison should your debates and your discussions take you there.

This framework has been worked on for the last nine to 10 months, so there's been a lot of work done on it, but that's just to bring the framework alive to you and what its potential impact might be on the three-year review.

So, again, I'll stop there and ask if there are any questions, if I may.

The Chair: Thank you very much. Certainly you may.

Questions? Yes, Mr. Snelgrove.

Mr. Snelgrove: I was just wondering. If Manitoba is doing a review and we're doing a review, do you have people that would sit with them and talk about the common – you know, what I'm saying is that it doesn't make sense to have both doing them in isolation.

Ms Versaevel: Manitoba has distributed their discussion guide, and in drafting our consultation guide for your review, we are very aware of the areas that they're focusing on in their review. We work closely with their legislative planner who is looking at the review. Although we don't necessarily sit together, we work together, indeed, on the issues that they're grappling with and the issues that we're grappling with so that we learn from the experience of each other, absolutely.

Mr. MacDonald: There seems to be a need to harmonize these rules across the country. How much health information is being transferred from one jurisdiction to another now?

Ms Versaevel: I will let Wendy speak to that. That question I think has potentially different components because certainly when we are receiving care in another jurisdiction, information about us may be sent to that provider. That's not a huge statistic in terms of people who end up receiving care in another jurisdiction, but there is information that flows across jurisdictions.

Ms Robillard: Yes. There are some provisions for information to flow across jurisdictions. However, as Catarina has mentioned, for the purpose of continuing treatment and care that would be one-off. So if you happened to receive a service in another province – for instance, were there on vacation, got sick – there might be information that flowed, but it would be very specific to you and between the care providers providing your care. So that information flows today.

There are some pieces of information that flow to national organizations such as CIHI. For the most part they're aggregate components of information that do some comparators so that everybody in the health systems across the country could compare a health region in Alberta with a similar health region in another province in Canada. So that kind of information flows.

Then there's also aggregate information that flows back and forth between the ministry of health and the federal jurisdiction around communicable diseases, those types of things, typically at an aggregate level: how many immunizations are we doing, what's our incidence of disease, that kind of information. So there is information that flows but at an individual level fairly limited, I would think, at this point.

Mr. MacDonald: So if CIHI and all these different organizations are getting their information now on specific regions of the country and they've got their national database, which is public information, what's the driving force behind this further harmonization? Is it research with the potential for commercial purposes?

Ms Robillard: No. I think a lot of the drive around the federal, the pan-Canadian, framework is around provision of care and services beyond borders. So, for instance, to enable a provincial EHR to be linked nationally, if you were in another province and needed a health service, they could access that information for treatment and care purposes. But Catarina can speak to that more clearly than I can.

Ms Versaevel: The drive to harmonize collection, use, and disclosure rules in core areas such as I've listed in the overview of what the framework is grappling with has to do in part with working on the commitment that the ministers made back in 2001 to harmonize collection, use, and disclosure rules. Some jurisdictions would argue that they don't want to reinvent the wheel; they want to build on the practices and the rules that exist in each jurisdiction. It's been viewed for a number of years prior to this framework work that I'm mentioning that it is in the interest of the health system to try and harmonize these rules in core areas because we have individual health systems, but we also have what people think of as a Canadian health system, and that we try and strive toward common protection of health information for Canadians.

The second reason, most certainly, is that because of the federal privacy law, jurisdictions want to ensure and see harmonized rules as a solid argument that we have an existing health information privacy and confidentiality regime in place across this country: "Look here at these harmonized rules." This reflects a solid argument to exempt us as health organizations from the application of the federal privacy law.

The third reason is the one Wendy has mentioned: looking at an interoperable EHR. It's very difficult to design the EHR without common rules, especially in the area of consent for care and treatment.

I'm not sure if that answers your question properly.

Mr. MacDonald: No.

Ms Versaevel: Perhaps you could rephrase your question.

1:50

Mr. MacDonald: Well, private health care providers, many of them American based, not only in this jurisdiction but in other jurisdictions in Canada, have expressed a desire to increase their market share. The first ministers' conferences, if I understand them, were talking about the standard of care, standard of training across the country for medical staff. Who was the driving force behind this harmonization of health information?

Ms Versaevel: The ministers of health made a commitment to harmonize rules in 2001 when they signed the harmonization resolution. So that was the initial commitment, and the work that has occurred on the framework that we're discussing at the official level flows from that commitment and has been exacerbated, so to speak, in terms of the need to do this by the three reasons that I just mentioned.

[Ms Kryczka in the chair]

The Deputy Chair: Okay. Are there any other questions that you want to direct towards Catarina? No?

Ms Versaevel: All right then. I won't answer any more.

Where I'd like to move now as part of the orientation is to talk about the preliminary issues that we have identified for review. Now, what is in your overhead package says: Key Issues for Review. If you could just scratch that out, because it should say: Preliminary Issues for Review. We do not know at this stage whether these indeed are the key issues. These are the preliminary issues that we have identified.

One we have talked about today, so I'll just quickly summarize it in the context of these key issues, and that is scope. This is an issue for review partly because the Health Information Act, as I mentioned this morning, has made it so. It says clearly in the Health Information Act that

> a special committee of the Legislative Assembly . . . must include a review of the application of this Act,

i.e., to consider expanding the scope of the act,

> (a) to departments of the Government of Alberta,
> (b) to local public bodies as defined in [FOIP], and
> (c) to any other entity that is not a custodian and has information about the health of an individual in its custody or under its control.

So basically the Health Information Act has said that this committee must consider the application of this legislation to other government departments and to local public bodies and to private-sector health entities. I think we covered that sufficiently this morning as to why that is also critical now given the federal privacy law.

With specific reference to scope we are working on a series of issue background papers for your consideration as the review carries on. What we're attempting to do is focus in on those issues that we've identified here as preliminary issues and issues that in working with the Health Information Act have come to our attention. So we're doing issue background papers for you on those areas, basically defining the issue, providing you with background, and looking at possible ways to address the issue. So we're doing that with respect to the application of the act to other government departments and local public bodies. What is the issue? What are the implications? You'll likely hear from other government departments, certainly, with their views.

The scope in terms of WCB and Blue Cross. We will specifically do an issue piece for you, but that is certainly a scope issue in terms of expanding the application of the act.

AADAC and community boards or facility boards, i.e. persons with developmental disabilities. You heard in the video that those two entities are not part of the Health Information Act scope at this time. Those two bodies, AADAC and Persons with Developmental Disabilities Provincial Board, in terms of government structure sometimes move from one entity to another. That's why looking at the scope of those entities given the government structure and also given the health information in their custody and control will come back to the table, and we're planning to do, as I say, an issue piece on that.

Another is ambulance operators. The Health Information Act does not apply to those operators. They are currently covered by the confidentiality regulation through municipalities, and given the review of ambulance services in the province, that issue is a scope issue for the Health Information Act and would come to you for your consideration.

[Mr. Jacobs in the chair]

Mr. Broda: Can I ask you a question on the ambulance operators? With the regional health authorities now taking the ambulance over, where you have municipal bodies that they'll be contracting out, under whose jurisdiction would they then be if they had a municipal law and then we have a regional health authority jurisdiction? When the region contracts some of the services, they may be municipally owned. So where would the ambulance operator fit in that group then?

Ms Versaevel: That's a good question, and it's part of the issue paper that we are pulling together for your review. We need to have more discussion with people in the department who are responsible for the ambulance area and with their municipal colleagues so that we can provide you with a more informed response.

Mr. Broda: Good. Thanks.

Mr. Goudreau: Before we move off the scope, I'm thinking about other associations or organizations such as the CNIB or the Red Cross or the diabetic association where I've shared some of my information on my health through those particular groups, or a lot of people have, with bracelets and the impact on that information and how they share or use that information.

Ms Versaevel: So are you asking whether the scope of the application of this particular should extend to those types of bodies?

Mr. Goudreau: Should be extended to those groups. Uh-huh.

Ms Versaevel: I don't have a response for you. That's part of the scope debate, meaning it's part of the debate at this table.

I think that if you start from the principle that there should be a level playing field for health information in the custody and control of an individual – meaning that it doesn't matter what the entity is; it matters that they have health information in their custody and control – that's one perspective that would take you down a certain line.

Once you start looking at including all entities that might have health information about us within the Health Information Act, one has to look very critically at that because with ability to use information comes responsibility in terms of other duties and obligations, and it may not be appropriate to include all types of entities even though they might have information in their custody and control.

It's a very important question and one that we will grapple with when we give you a more informed piece of the scope of application, and we will ensure to address your question as well, but I think it will require a significant amount of debate at this table.

Mr. Goudreau: Okay.

The Chair: Those are good points, and as has been pointed out, we will have to debate those items as we go forward.

Any other questions?

All right. I think there's still some more information coming, so, Catarina, we'd invite you to go ahead.

2:00

Ms Versaevel: Again, these are preliminary issues that we're identifying for you at this stage which likely would need to be grappled with by the select committee.

On the application of the Health Information Act to private-sector health entities, as I mentioned, the act already states that this committee must consider, must review the application of the act to any entity that has information about the health of an individual in its custody or under its control. It's important here to just highlight a nuance. It says in this overhead: "in its custody and control." What the act says is "in its custody or under its control." I just wanted to mention that because the act doesn't say "and control." It says "or under its control."

Now, the private-sector health entities, as noted from the question just now at the table, will be a very important debate, because it's not about should an entity be part of the scope – that's part of the question – but what's the impact if that entity is part of the scope? That will be the fuller debate that ends up, I think, happening at the table, because once it's part of the scope, then one has to look at all the rules that would end up impacting that entity.

In our work and meetings with this ad hoc private-sector group that I mentioned, we've been talking for the last four or five years to one thing that that group has said. Many people in that group have operations in Alberta, but they are companies, insurers for example, that work across Canada. They made it very clear at the beginning of those meetings and since that they are interested in seeing harmonized rules because it's very difficult for them, they argue, to do business, so to speak, from one jurisdiction to the next when the rules vary as they do across jurisdictions. That is just a comment made from that ad hoc group.

Another key issue that we will do an issue paper on for you for your review and deliberation as you proceed with your work is an area we've already talked about, and that is the electronic health record. What's the impact on scope in terms of who the act applies to? What's the impact on some of the rules when we move as a system from paper-based records over time to electronic medical records, to EHR? What does it mean when you no longer have health information in the custody or under the control of one provider but you have information that is accessible to several providers through the EHR? What does that mean for our Health Information Act rules?

Another issue that we are doing a piece on in terms of an issue piece is the inclusion of health service provider rules. As I mentioned, that was an issue at the time the Health Information Act was introduced. There was a rationale for including health service provider information rules, and those are in a limited way addressed. Most of the disclosure rules for health service provider information are not in the HIA, and as I say, we'll put forward an issue piece for you because we expect that you will hear on that particular issue.

We'll also do a piece on another issue that we anticipate will need to be grappled with, and that is the impact on health information that is information on a reserve, information in other places but regarding First Nation and Métis people and how the federal Privacy Act intersects with that and how our EHR implementation drives a need to look at that issue as well. So that is another issue.

I've already mentioned genetic information and unique rule application potentially depending upon the attributes of genetic information. So we're doing an issue piece on that. Now, let me just use that example to stop for a moment. That genetic information is an example of an issue that you may not hear about from a stakeholder group, but we believe from an Alberta Health and Wellness perspective, given that that issue is being grappled with across the system, that it's an issue we likely need to grapple with within our Health Information Act. So these preliminary issues for review are not necessarily only issues that you can anticipate stakeholder groups might raise for your consideration; they're also preliminary issues, from our experience with the act and what's happening with health information legislation, that we would suggest need to be looked at as well. As I say, genetic information is an example of that.

We're also doing an issue piece for your review, consideration, and deliberation on PIPEDA, the federal privacy law. We will not include within that a debate on PIPA because the Personal Information Protection Act is not part of the scope or terms of reference of this committee, but it links in when we talk about arriving at harmonized rules and substantially similar legislation. That's not to suggest that we're looking at PIPA. The terms of reference, when you review them, clearly indicate that that's not part of the terms of reference, so it's more as part of the broad context.

We'll also do a piece for you on use and disclosure for research purposes, and that fits into an issue that you've been advised you indeed might hear from. Disclosure to police services is certainly another issue that existed, as we mentioned, at the time the act was introduced and likely will continue to receive commentary. We'll do a piece, following up on the presentation today, on the pan-Canadian framework because that likely is an issue and part of the terms of reference for the committee.

We anticipate in terms of the review that based on our feedback on the issue – and maybe, Wendy, you can speak to some of this from the help desk perspective as well. We did preliminary work within the business units, within Alberta Health and Wellness, with several stakeholder groups and asked: given your experience with the Health Information Act, if you had an ability to make amendments, what would you amend and why would you amend it, based on your experience with the legislation? So we spoke to different groups in preparation for thinking through how best to prepare support material from a technical point of view for this committee, and through those discussions we certainly heard about the issue of scope. We heard from other government departments and on their behalf local public bodies that they likely would not be very inclined to see the scope of application of this legislation expand to other government departments or local public bodies. They feel that there is ample legislative protection of privacy within existing legislative vehicles.

We certainly heard that we do need to grapple with the issue of ambulance operators. We heard many other specific issues. Many of those had to do with understanding the Health Information Act and a need for further training, orientation, and interpretation. I think the best insight we have to the public in terms of the issues that the public might experience or be experiencing with the act has to do with what Wendy and her staff hear in terms of the help desk. Maybe you could just bring some of that a bit to life, Wendy, and then I'll carry on with some of the issues.

Ms Robillard: The primary issues that we hear from the public at the help desk are about access to their information. They understand that they have a right to access information; they're just not certain how to exercise that right. So we do a lot of education of the public in terms of whom they need to approach, where their service providers might be located, about, you know, documenting things in writing, and then the ability to go to the commissioner's office if they're not satisfied with the information that they get. Those are the primary concerns that the public raise.

2:10

Mr. Lougheed: Could you sort of generally summarize for what purpose people would be seeking access to that information, their own information?

Ms Robillard: Actually, I probably am not a good person to answer that question. The act doesn't require individuals to provide a rationale or a reason for wanting their information. It simply is theirs, and they have a right to it. For custodians trying to respond to the individuals, it might be useful for them to understand what it is they're looking for so that they can ensure they get what they want. In other words, if you have hundreds of pages of documentation if you have some chronic condition, is there something specific that you're looking for so that we can make sure you get that? But beyond that, when the public phone us at our help desk, we don't get into their reasons why they want the information. We just provide them with information on how to access it.

Mr. Snelgrove: Just a suggestion. If I were moving from the Maritimes to Fort McMurray, I might want to take all my information for my family and bring it.

Ms Robillard: Absolutely.

Mr. Snelgrove: I think that would also explain why we want to have the same kind of reporting. Portability of your information would be one of the best reasons.

Mr. Goudreau: I'm just trying to put all of this in perspective, and I guess I've got three questions. We're talking about reviewing the files and the requests. How often does it happen in relation to our population base? When we want to respect the balance between privacy and access, has that been challenged by anybody in terms of saying, "Well, my privacy has been breached"? Is there a big issue out there in the province? Are there some main concerns that have been identified over the last three years with the existing health act? The final one. We've got fines and penalties. Have those been issued to anybody in the last three years or since the health act has been in place?

Ms Versaevel: I'll speak generally in response to your question and then ask Roseanne a question, which I think will help answer your question as well. With respect to the Health Information Act and its provisions, we have not heard a lot of issues and difficulties with the Health Information Act's specific rules, so no. We have certainly seen and tried to respond to interpreting, explaining what the Health Information Act is all about. That's why the issues that I raise for you, in terms of issues that we've identified in a preliminary way to be issues that likely need to be focused on by the select committee, come from what's happening, what's changed in the context. Ambulance issues have changed. EHR has changed. There's a mandate for the committee to review expanding the scope to these other entities, and looking at the implications of doing so is part of that review.

The preliminary list of issues is in relation to what we have heard about, so police, health service provider issues, what's happening with the pan-Canadian framework. Here's our best assessment at this time as to what needs to be grappled with, but we have not heard – here are 20 issues that we've been able to summarize, which we attempted to do by talking to different people in preparation for the review. A lot of the input was needing further clarification or very specific things rather than thematic issues, which is more where we're focused on.

Roseanne, with the commissioner's office, is in a position to explain or respond as to what type of review or reviews in response to the Health Information Act might have been undertaken as a result of collection, use, and disclosure by custodians under the act, because there have been a few.

Ms Gallant: Yes, certainly. There have been a number of requests by individuals to the commissioner for him to review decisions that were made by custodians in regard to their access to their health information. For instance, if they've been denied access by physicians, then they have the right to complain to the commissioner, which they then do. We have a number of reviews of that nature open.

I thought what I might do for the next meeting, if that's appropriate, is bring our current list of statistics that would give you a bird's-eye view, currently, of how many requests for reviews we have, how many of each style are open. The majority of our work in this area hasn't necessarily been in requests for reviews. It's been more in the privacy impact assessment review area.

However, as well, maybe to address the second part of your question with regard to fines and penalties, to this date, no, a fine or a penalty has not been levied. However, we have had the occasion to indicate to an individual that we would indeed recommend to Justice a fine or a penalty in one instance where they were reluctant to discontinue the practice that they were proceeding with. When our office became involved, then they were aware and followed what they needed to do.

Ms Versaevel: The other point to add, I think, Roseanne, to what you're saying in terms of the commissioner is that early on in the implementation of the Health Information Act there was an approach through the commissioner's office and through others supporting custodians to understand the provisions in the act, to take an educative and explanative approach that it takes time for people to understand the rules and that when there was a potential contravention, it was understood that that may be because people may not yet be familiar with the rules. We're at a different stage now, but I just wondered if you wanted to comment on that, and then Wendy has a comment as well.

Ms Gallant: Sure. That's indeed the case. My role specifically when I was hired as health information compliance officer was indeed to assist with the education and awareness of all of the issues that related to the act and to assist custodians and stakeholders in interpreting those rather than from a punitive position but to try and assist them. Of course, now as time is moving on, we are moving more into a compliance role. So, yes, that's quite correct.

Ms Robillard: I guess I'd like to add two comments. One is around the custodian role. So many custodians are large and have lots of health professionals working for them, and there are many avenues of sanction that may not require fines or penalties under this legislation. In fact, their professional practice is dealt with by the colleges and the associations. So that's one route. We have heard of

situations where concerns that may be raised relative to health information and its perhaps inappropriate use or disclosure have gone that route, so we wouldn't necessarily know about them other than we hear from some organizations that they have used that.

In terms of the number of requests to access health information, we don't track the number of requests in the province. That in and of itself would be a huge undertaking. But one must remember that there are both formal and informal processes, so any time you have an interaction with a health care provider, they're probably providing you with access. They're probably talking to you about your lab results, and you may not take a piece of paper away, but you get lots of information back and forth that way. In fact, it may be common practice for you to even receive copies of some of your health information, whether you ask for it or not, you know, that it is available. So there are informal routes where people get lots of information, but for those people who want, you know, full access to their record or multiple copies of records, then we do advise them to use the more formal route under the legislation. It's hard to really track that, but I assume that lots of people are getting lots of information.

Ms Gallant: If I may, I might also comment on the earlier question about why individuals want to access their health information. A number of the reasons, when I used to work in a health record department, that were common were for medical/legal reasons, so for interactions with legal, or for their own interest, just that they wanted to have their own health information.

Perhaps a third reason. Now, of course, I can't remember what my third reason was. Isn't that helpful? It'll come to me.

Ms Blakeman: Right after coffee.

Ms Gallant: Yeah. That's it.

The Chair: Any other questions? Yes, Mr. MacDonald.

Mr. MacDonald: Yes. Thank you, Mr. Chairman. Earlier you stated that there was an ad hoc private-sector group, the collective you have been talking to for the last five years. Would it be possible, please, to provide the names of those that are on that ad hoc private-sector group that you've been conversing with for the last five years?

2:20

Ms Versaevel: Yes. I was mentioning that we've been talking to them for the last four or five years. We don't talk to them all the time, about twice a year. I'd be happy to provide you with the list that we send invitations to to come to the meetings. Those are not necessarily the people who end up coming, but, yes, for sure we can do that.

Mr. MacDonald: Thank you.

The Chair: We're nearing the end of the presentations, so with the committee's permission I would suggest that we forgo the break. I think we can be finished Catarina's presentation in about 10 or 15 minutes. That would only leave us the last couple of items on the agenda. Would the committee be in agreement to proceed?

Hon. Members: Agreed.

The Chair: Anybody object? Okay. That's sort of what I thought you'd do.

Ms Versaevel: Just carrying on with the issues, we've summarized what we see as the preliminary issues from our perspective based on our experience with stakeholders and our experience in working with the act. So these are thematic issues at a broad level.

There are other issues as part of the amendment process to the Health Information Act which have to do with drafting and needing to clarify certain points. For example, in the information manager provisions likely comments might come forward from the department to clarify drafting, an "and" or an "or" in certain places, so we haven't gone through that type of thing. I'm sure that will be coming to the table as well. We've spoken more in this orientation of those thematic broader issues that likely we'll be here to grapple with.

Wendy, do you have other issues to identify than those we've highlighted?

Ms Robillard: No, I don't have any.

Ms Versaevel: Then that is it for now.

The Chair: Do we have any questions?

I have one question, if I may, Catarina.

Ms Versaevel: Will it be hard?

The Chair: No. Well, I don't think so. Given the information that you've presented today and the information that we're going to need as we go forward – I know that we'll be getting a copy of everything that was said today – will you be giving the committee members any summaries of what you have said, or will you be presenting other information that they can actually put their hands on and read as they further deliberate?

Ms Versaevel: I had no intention of summarizing what I've said because I really just talked. The overheads, hopefully, will serve as that, so I wasn't intending to summarize what I said today. That doesn't mean that I could not attempt to do so.

In terms of other information, yes, for all of the issues that we've talked about, the preliminary issues, we do intend to provide you with background papers. As you go through the review, we will ensure that you have the necessary content background to conduct the analysis. So from a technical point of view those issue papers will be there for review in preparation for discussion. I would imagine that there'll be an agenda. It'll be determined that these three areas are going to be focused on, and there will be background papers to support the analysis.

As soon as it is possible, by the end of the third week of June, the last week of June, with respect to the confidentiality framework, then indeed it should be possible to provide the content that I went over quickly in terms of the framework, so that will be other material in follow-up to the orientation today. It should be possible to provide that if we get agreement to do so.

In terms of the other comments, in terms of going through the overheads, if a summary of what I said is required, then I can attempt to do so with the assistance of Wendy and *Hansard*. Absolutely.

The Chair: Comments from the committee? Yes, Mr. Snelgrove.

Mr. Snelgrove: I hate it when you call me mister. You know that.

The Chair: Okay. Lloyd, go ahead.

Mr. Snelgrove: The review of this act deals with electronic

information basically. Is there a part of it that requires the people in the medical field to use this? I mean, in many little communities we have doctors who are still all pen and paper. You know, is there a part of it that says that you must sooner or later be a part of this?

Ms Versaevel: The type of information that the Health Information Act applies to is recorded information, so that's information in a record. Within our health system we have information in paper-based records, and that's primarily at this stage where health information is. Most of our providers have paper-based records, although more and more there are physicians with electronic medical record systems within a clinic, and more and more of that is happening through the physician office support system.

Then, as Wendy has mentioned, we're moving, as are many jurisdictions, to an electronic health record system as compared to an electronic medical record, which we do have on several physician sites. This Health Information Act applies to health information in the custody or under the control of a custodian. It is not about information in an electronic health record or about information in a paper-based file. It's about any health information about us that's in the custody and control of a custodian that's governed by the Health Information Act.

Why we have provided information today on the electronic health record is that we felt that it was important as part of the orientation to understand where we were going with the EHR. As part of the review we'll have to grapple with the scope of the act as a result of the EHR development and some of the rules because information more and more will be in an electronic health record format. So, indeed, this information applies to health information, regardless of the format that it is contained in, as long as it is recorded information.

Mr. Snelgrove: Thanks.

Ms Versaevel: You're welcome.

The Chair: Yes, Dave.

Mr. Broda: Okay. Thank you, Chair. These preliminary key issues that we're going to be reviewing again provide us with background paper. We will also have an opportunity to request some other background information as we go along, as the issues arise.

Now, we briefly went through the act this morning. We went section by section. There are various sections in here, like disclosure of health service provider information. There have been some questions on that. Will we be getting into some of the meat of this, or is that an issue that should be reviewed or anything like that?

Ms Versaevel: It depends on the committee's wishes once you review the terms of reference. The terms of reference to be reviewed next week focus the committee on particular areas. For example, it is very unlikely that you would need, because there haven't been issues raised unless we're not aware of them, the individual's right to access their health information. So part 2 likely is not something where one would be looking at amendment issues. Part 7 of the act, which is the commissioner's duties and powers, again is not anticipated, so that's why we didn't do a detailed review of each part of the act but rather would focus you in on the provisions of the act that are critical to review given the issue. So we were going to do provision related to issue rather than, "Let's discuss every provision in the act," but more, "What are the issues, and what provisions in the act currently address those issues, and where might you want to consider change?"

Mr. Broda: Thank you. I might be jumping the gun. I mean, this is an orientation given as an overview of where we're heading, and of course as we go along, we'll see how it all develops. Thank you.

Ms Kryczka: I'm trying to think of something simple in my mind in terms of what the act is for and also the electronic health record as, I guess, a subsection of that. Is the ultimate goal of this so that if the individual that the doctor has the medical record for should move anywhere, there is key information that is portable? Either the person takes the paper file with them, the doctor sends it, or it's an electronic health record. So if they're being assessed for something that developed, you know, when I'm living in Ontario, say, there's a history so that a new doctor is able to understand my history.

2:30

I guess I'm just saying: why are we doing this? What is the key so that there are all these rules and guidelines, et cetera, around? As an individual citizen who's going to benefit ultimately from all of this?

Ms Versaevel: Are you asking – and excuse me if I'm not understanding – what is the goal of an electronic health record, or what is the intent of the Health Information Act?

Ms Kryczka: Of the act itself. I'm sorry. I missed the electronic health record part. I know that some medical offices and labs and that have gone to electronic health and the PIN and that, but it's a record. Whether it's paper or it's electronic, there's a record. I guess what I'm just saying is: as we go forward, is that what we're thinking of ultimately for individuals so that they ultimately will have better health care?

Ms Versaevel: In terms of why we have a Health Information Act and why we're reviewing it?

Ms Kryczka: Yeah. For better assessment?

You know, if you were having memory problems suddenly or Alzheimer's, was there anything in your records in the past that the doctors recorded that it looked like you had some problems or you were put on some medication, et cetera? I'm just saying: is this ultimately to benefit the citizen or some system out there? You know what I'm saying? I'd like to personalize this, I guess, to be honest with you.

Ms Versaevel: My understanding of why the government introduced and proclaimed the Health Information Act is to ensure that providers within the system who have health information about Albertans in their custody or under their control have rules which say: "Here is the standard. Here is the law in terms of your collection, use, and disclosure of health information about Albertans in your custody and under your control."

Government introduced the Freedom of Information and Protection of Privacy Act, and it set the rules for access to personal information. It talked about providing us with the right of access to our information, and it had a different focus than the Health Information Act. It focused in more on the area of access.

This Health Information Act was put into place as sector-specific legislation to govern personal health information, to say to the provider: "You may collect information about the individual under these circumstances. You have to give the individual right of access to their information, or here are some circumstances where you don't need to do that. Here's how you are able to use the information and to disclose it." The act was about making it transparent to providers

and to the public about: here's how your health information is handled or needs to be handled in the province of Alberta.

It was not about trying to say to a custodian: here's the type of information that you must have in the health record. It wasn't grappling specifically with physician practice and what information they put in a file and what information they didn't put in a file. It was more about: "Given the information that you have as a physician in your custody and control, here are the rules. Here are transparent rules that the Legislature has said govern the collection, use, and disclosure of your health information."

When we talked this morning about the electronic health record, then government is saying that we are interested in Alberta – and other Canadian jurisdictions are as well – in investing in a province-wide electronic health record system, which is different than the Health Information Act discussion, that we're interested in investing in this electronic health record system on a province-wide basis because we believe it will have great benefits to us as Albertans in terms of improving our care, minimizing duplication of time when we have to repeat provider-to-provider information about ourselves, when we end up duplicating lab tests. Indeed, the electronic health record investment is about intending to improve our care, as we highlighted in the video and some of the comments we have made.

So there are two different discussions. One is on the Health Information Act, and why it's of interest to Albertans as individuals to review the Health Information Act is again as part of saying to the public: we've had these rules in place; we have an obligation to review them and to ensure that they are still appropriate for providers and for the public.

Thank you.

The Chair: Yes, Linda.

Ms Miller: Just to add to the comment, how the Health Information Act has helped is that prior to having this piece of legislation, when we were asked to share information between hospitals, say, and home care places, there were different pieces of legislation that we had to look to in terms of having the authority to share that information, and we were dealing with a lot more conflicting legislation in terms of: could we release this kind of information to that kind of a provider? By having a Health Information Act within the province of Alberta, it has made that much more straightforward. We go to the Health Information Act first and foremost. So that has added to the puzzle as well.

I would just like to also add a comment about the EHR. Is it relevant to this discussion? When a provider wants to share information with another provider, it's called point-to-point sharing of information. So I'm Dr. Black, and I know Dr. Green. Dr. Green phones me up and says: you have information on this patient; can you send it to me? There's typically a trusted relationship between Dr. Black and Dr. Green, as an example.

What an EHR does that makes the world different – and that's why the rules are challenged in today's Health Information Act – is the patient's information is posted in a central repository. So although Dr. Black's information will go to the repository, he doesn't necessarily know who's going to be pulling down information on that patient. He doesn't know necessarily who that patient also goes to. Because there's not necessarily a trusted relationship any more between two providers, because it's getting posted in a database, another provider can at any point in time, as long as they have the appropriate access, pull that information down.

That creates some concerns for providers, and that's the reason why they have asked us to establish the electronic health record stewardship committee. They want reassurance that anybody that has access to the electronic health record is abiding by the same collection, use, and disclosure rules. Those rules are defined in much greater detail than in our current legislation.

I just wanted to add how the EHR changes this kind of communication that happened prior to an EHR.

The Chair: Thank you for those comments.

Before we go to the last two items, the first of which will be the date of the next meeting, I'd like to thank you, Catarina, for a very excellent presentation – wow, you have this information down pat, and we appreciate that – and also our support staff: Wendy and Linda and Heather and Roseanne. Karen and Corinne and Rhonda, thank you very much for your help today and your support.

We just needed to say a couple of things about next week's meeting, which is June 8. I think you've all already been notified of that one. What we'd like you to do for that meeting is bring your calendars for June and July. We have some work to do ahead of us, which will take quite a bit of time.

We acknowledge the fact that we're in a time of the year when people go on vacations and take time off, so we probably need to look at maybe booking one or two or three weeks off, but if we could agree on some dates when we could maybe even have two meetings a week, we could maybe move forward with continuity. We will talk more about this next week, but we probably don't have a year to do this review given the fact that there could be a provincial election before the full year is out, so it would be sort of nice to get this done before, if you know what I mean.

2:40

What I'm saying is that if we could move forward as expediently as possible. We don't want to go too fast; we want to do the job thoroughly. We will need to do some consultation with some groups out there, so we'll need to talk about that next week and also terms of reference. So if you could bring your calendars with you, we'd appreciate that very much.

You should also note that the binders for the next meeting will be delivered tomorrow, and you will get the copy of *Hansard* of today's meeting on Thursday.

I see we have a question.

Ms Blakeman: Why aren't we doing the scheduling now? Why are we waiting a week?

The Chair: We just decided to do orientation today, and next week we'll talk about terms of reference. The committee will need to decide how extensive they want to do the review, so we thought it would be more appropriate to do calendaring next week. I don't think everyone has their calendars.

Ms Blakeman: It's just that I'm booking up really fast, so a week is going to make a difference. But that's okay.

The Chair: I understand. Yeah.

Mr. MacDonald: Mr. Chairman, do we have a budget for this committee, and if we do, how much is it?

The Chair: We do have a budget. I'm sorry; I don't have that number. Does anyone?

Mrs. Dacyshyn: We're dealing with that at next week's meeting.

The Chair: It's not a huge budget, but it is a budget.

Mrs. Dacyshyn: The budget for this committee was approved by the Members' Services Committee in December.

Mr. MacDonald: So probably the committee will not meet outside Edmonton. Are there going to be hearings across the province?

The Chair: We will decide that next week, Hugh, but if I may hazard a humble opinion, I would guess that we may have to have the odd meeting outside of Edmonton. You know, we may have to look at some of the other centres. If groups want to present from let's just say Calgary, Medicine Hat, Lethbridge, Grande Prairie, we may have to do some travel. That's a decision the committee will need to make, but it's certainly a possibility.

Mr. MacDonald: Fair enough. Sure.

The Chair: Okay. Any other questions? Did I miss anything on next week's meeting?

Mrs. Sawchuk: New business.

The Chair: Yeah. I'm going to go there. I got it. I'll never forget that.

Ms Kryczka: This is not a new item here. I just want to confirm. *Hansard* is coming out what day?

The Chair: Thursday. You'll get a copy.

Ms Kryczka: And it goes to our office?

Mrs. Sawchuk: Yes, Mr. Chairman, it does. The *Hansard* transcripts will be sent to your Legislature office, and staff can forward them on.

Mrs. Dacyshyn: If I can add something there, it will be posted on the Assembly web site at the same time as the hard copy comes out, so if you choose to access it that way, if you need to know where to find it, you can give us a call. We'll show you. But they do get posted on the web site pretty much the same moment they're done in hard copy.

Ms Kryczka: Good.

The Chair: Any other comments or questions on next week's June 8 meeting? Have we missed anything on that?

Mrs. Sawchuk: No.

The Chair: Okay. New business, an item we added to the agenda today. Does anyone have anything to bring up under the item of new business? Okay.

Mr. Goudreau: I move that we adjourn.

The Chair: All right. We have a motion to adjourn. All in favour, say aye.

Hon. Members: Aye.

The Chair: Opposed, say no. We are adjourned. Thank you very much for your attention today and your willingness to be here.

[The committee adjourned at 2:44 p.m.]