



Legislative Assembly of Alberta

The 27th Legislature  
First Session

Standing Committee  
on  
Health

Wednesday, January 21, 2009  
8:32 a.m.

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First Session**

**Standing Committee on Health**

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Pastoor, Bridget Brennan, Lethbridge-East (L), Deputy Chair

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Denis, Jonathan, Calgary-Egmont (PC)  
Fawcett, Kyle, Calgary-North Hill (PC)  
Notley, Rachel, Edmonton-Strathcona (NDP)  
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**Bill 52 Sponsor**

Rogers, George, Leduc-Beaumont-Devon (PC)

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Linda Miller	Deputy Minister

**Office of the Information and Privacy Commissioner**

Frank Work	Information and Privacy Commissioner
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[Mr. Horne in the chair]

**The Chair:** Good morning, everyone. I'd like to thank you all for coming and call this meeting of the Standing Committee on Health to order. A couple of notations before we begin. Ms Blakeman will be substituting for Dr. Swann for the duration of Bill 52. We're also expecting Mr. Mason to join us, and he will be substituting for Ms Notley for this meeting. Attending the meeting via teleconference we have Jonathan Denis. Are you there, Jonathan?

**Mr. Denis:** Good morning.

**The Chair:** Good morning.

The deputy chair, Ms Pastoor, will be joining us by teleconference from Lethbridge within the next little while, I do believe.

We have a number of officials from the Department of Health and Wellness. I'll introduce them in a few minutes, when we get to the point on the agenda where we begin the technical briefing. We have another presentation this afternoon, as you know, so we'll introduce those individuals at that time.

Just a few housekeeping items, particularly for people who are here presenting to the committee. The microphones are operated by *Hansard* staff, so it's not necessary to push any of the buttons on your console to turn your microphone on or off. That'll be done automatically. If you do have a BlackBerry with you, please keep it off the table so that the receiving/transmitting function doesn't interfere with the audio system. Thank you.

We have a number of items of business to complete before we get into the main point of the meeting, which is the review of Bill 52. I'll ask, to begin, for approval of the agenda. Can I have a motion to approve the agenda, please? Mr. Dallas. Any discussion? Those in favour? That's carried. Thank you.

Actually, just before I go on, I neglected to ask the members to introduce themselves for the record, so we'll just go around the table, starting with Mr. Dallas, please.

**Mr. Dallas:** Good morning. Cal Dallas, Red Deer-South.

**Mr. Vandermeer:** Good morning. Tony Vandermeer, Edmonton-Beverly-Clareview.

**Mr. Olson:** Good morning. Verlyn Olson, Wetaskiwin-Camrose.

**Ms Blakeman:** [Remarks in Vietnamese] Welcome to Edmonton-Centre, celebrating Vietnamese Tet and Chinese lunar New Year. My name is Laurie Blakeman. Welcome to my fabulous constituency.

**Mr. Fawcett:** Kyle Fawcett, Calgary-North Hill.

**The Chair:** If the staff would introduce themselves as well.

**Ms Dean:** Shannon Dean, Senior Parliamentary Counsel.

**Ms Friesacher:** Melanie Friesacher, communications consultant with the Legislative Assembly Office.

**Ms LeBlanc:** Stephanie LeBlanc, legal research officer with the Legislative Assembly Office.

**Mrs. Kamuchik:** Louise Kamuchik, Clerk Assistant, director of House services, LAO.

**Ms Norton:** Erin Norton, committee clerk.

**The Chair:** And on the phone Mr. Denis.

**Mr. Denis:** Yes. Jonathan Denis from Calgary-Egmont.

**The Chair:** Thank you. I'm Fred Horne. I'm the MLA for Edmonton-Rutherford and chair of the committee.

We'll move, then, to item 3 on your agenda, the review and approval of the minutes of our last meeting, November 24, 2008. Can I have a motion to approve the minutes, please? Mr. Fawcett. Any discussion, corrections, or other changes? Seeing none, all those in favour? Mr. Denis?

**Mr. Denis:** In favour.

**The Chair:** Opposed, if any? It's carried. Thank you.

Item 4 relates to a number of decision and information items that we need to address in order to facilitate our review of Bill 52, the Health Information Amendment Act. I'd like to begin by just explaining a bit, provide some context for the review, and talk a bit about work that was done in preparation for this meeting. As I think the members are aware and for the record, the bill was referred to the Standing Committee on Health on November 27, 2008. It was referred following second reading, and we'll have a discussion in a few minutes about the implications of a second reading referral. The last bill that we reviewed, Bill 24, you'll recall, was a first reading referral, so the situation is a little different in this case. Ms Dean will help us with that.

As well, given the difficulty with scheduling meetings over the holiday period, the chair and the deputy chair worked together to communicate with members, and we have scheduled three meetings between now and the commencement of the spring session. I believe everyone has those dates: today, obviously; the next meeting is January 30; the third meeting is scheduled for February 4. Those are scheduled currently as all-day meetings. Obviously, if we don't need the entire time, we don't need to occupy members for the entire day, but we'll make some decisions, I guess, here in a few minutes that will determine the time requirement.

The deputy chair and I proceeded to schedule a technical briefing on a bill with department officials, which is what we have today, and it's similar to the process used in the review of our last bill. We also invited the Information and Privacy Commissioner to appear at today's meeting. He had expressed verbally to me an interest in doing so and also issued some public communication on the bill, I believe, prior to the holiday period. He's appearing this afternoon. The other thing that we did was ask staff to prepare a draft stakeholder list, which was precirculated. That was to aid members in the discussion we're going to have here in a few minutes about determining which stakeholders on this list and, perhaps, ones that weren't on the list we would like to invite to appear.

I'd like just to move, then, to a discussion of second reading referral and also a peculiar situation that we find ourselves in because of the fact that the House was prorogued. So I'd like to turn it over to Shannon to address those two issues.

**Ms Dean:** Sure. Thank you, Mr. Chair. The nature of the committee's review of a bill is different when the bill has received second reading in the Assembly as compared to when the bill is referred following first reading, which is what happened last fall with respect to Bill 24. Essentially, second reading means that the House has agreed with the principles of the bill, and under Standing Order 78.3 what the committee is empowered to do is recommend one of three

things: that the bill proceed, that the bill proceed with amendment, or that the bill not proceed. This is different from a review after first reading, where the committee is permitted in its report to comment on the bill in terms of opinions and recommendations. So one could say that the scope of review after first reading is broader than what you're faced with with respect to a second reading referral.

If the committee wants to consider amendments to Bill 52, it's important to take note of the rules governing admissibility of those amendments. Essentially, any amendment that you're considering should be consistent with the principles of the bill that have been approved at second reading. Now, we can get into a more detailed discussion if that subject does arise later on during deliberations, but I just wanted to flag that issue at the outset.

Relevant citations for this principle are found in *Beauchesne's* 698 and *House of Commons Procedure and Practice* 653 to 658. The point here, again, is that amendments should be within the scope of the original bill and consistent with the principles approved at second reading. Now, in this case we are dealing with an amending bill, so an amendment would not be appropriate if it amends a statute that's not before the committee or a section of the parent act; that is, unless it's already in the bill that's before you. Essentially, you can't bring in new concepts that weren't approved at second reading. Again, we can go back to this discussion if and when you want to consider amendments later on.

Unless there are any questions, I'll just move on to the issue of prorogation.

8:40

**The Chair:** Any questions on this point?  
Go ahead.

**Ms Dean:** Given that the committee's work on Bill 52 will probably continue through the spring, there are some issues that you need to be aware of given that the Assembly will be proroguing before the throne speech in a few weeks. I think there is an increasing familiarity surrounding the term prorogation given the events in the House of Commons last December. But for the sake of completeness, it's an act of the Crown, and it's the formal ending of a session. All business of the Assembly is suspended. In fact, not only is it suspended, but it's quashed. Hence the familiar phrase: bills dying on the Order Paper.

Now, prorogation is different from the adjournment of a session or a sitting. For instance, when the House adjourned last spring, the bills carried over for consideration in the fall session. The practice in our Assembly is typically for prorogation to occur the day before the start of a new session. I don't know for sure, but I anticipate that prorogation will take effect on February 9, and the throne speech is scheduled for February 10.

What does all this mean in connection with the bill that's before you? Well, technically speaking, Bill 52 will die. That doesn't mean that your work can't continue because there is a tool in our standing orders for that bill to come back. It's through a process called reinstatement, and it's provided for under Standing Order 51. That standing order has been in place since 2001. In Alberta we haven't utilized it, so we're still working out some of the details, but I think it's important for the committee to consider the reality that the bill, when it's reinstated, may in fact have a different number, and obviously the title to the bill, which right now has 2008 in it, would be corrected to read 2009. So at the end of the day I'm asking the committee to put this on their radar when they're considering placing advertisements if the committee's decision is to proceed with public input, because I think it would be important to err on the side of caution and not place those ads until the bill has in fact been reinstated by the Assembly.

Those are my comments, Mr. Chair, unless there are any questions.

**The Chair:** Mr. Fawcett.

**Mr. Fawcett:** Thank you, Mr. Chair. When the bill is reinstated, is it reinstated at its same progression in the House? Would it be reinstated in second reading, or does it have to be reinstated and started over?

**Ms Dean:** The bill would be introduced. Then there would be a motion that would be made, presumably by the Government House Leader, that would ask that it be reinstated at the same stage that it was at the time of adjournment, which would be: referred to this committee. Again, you need the Assembly to bless that reinstatement.

**The Chair:** As well, the bill may come back with a new number, and it will definitely come back with a new year attached to the name. In practical terms, we probably don't want to be issuing an ad requesting public input for a bill that's not going to exist in its current form when it comes back.

**Ms Blakeman:** Ms Dean, could you tell us if the expected government motion to reinstate at the same stage is debatable?

**Ms Dean:** It's not.

**Ms Blakeman:** Thank you.

**The Chair:** Any further questions, then?

Thank you very much, Ms Dean, for explaining that.

We'll move then to item 4(c) on the agenda, consideration of the stakeholder list. As I mentioned, the list was circulated some time ago. First of all, I guess I should say that the intention here is for the committee to have a discussion on which groups it might like to invite to present to the committee. This is separate from the discussion of public input that we might solicit through advertisement or other means. For purposes of identified stakeholders the list that was precirculated was prepared for us by the LAO staff. The following are the names of organizations that have come forward from members so far as organizations they would like to hear from: HIV Edmonton, the Canadian AIDS Society, the Sheldon Chumir ethics foundation in Calgary, the University of Alberta Faculty of Medicine and Dentistry, the Health Quality Council of Alberta, the Alberta Medical Association. We had a direct request – I think the clerk will circulate a copy of the e-mail from the Consumers' Association of Canada – to appear.

In addition to this, I just wanted to mention that the deputy chair and I had a discussion. If you're familiar with the Health Professions Act, you'll know that there are in the order of, I think, 21 professions now that are regulated under the act. Each has its own – they're called colleges. One of the suggestions that came from our discussion was that there is an organization in Alberta called the Federation of Regulated Health Professions. One option for the committee to consider, rather than trying to invite each individual college to speak, might be to approach that association and invite them to make a presentation to the extent that they can on behalf of the professions. There may be areas of common interest that the professions have that they'd like to discuss with us. I'm sure there are. There may be areas of difference, where individual professions might like to present to us, and that's fine as well. But that's a suggestion from the deputy chair and me just in terms of how to make efficient use of the time available that we have.

That list that I just read includes eight organizations. If I could ask at this point, are there others?

**Ms Blakeman:** A number of the ones that I was concerned about you've already listed. Thank you. But I'm most concerned about vulnerable people or anyone whose disclosure of health information could cause extreme problems in their personal and working life. I'm wondering if any representation has been asked for from groups representing people dealing with mental illness, which is another group of vulnerable people that I think is not represented here yet. The last one is in STDs. You've picked off HIV Edmonton, but I think we also need to look at organizations that are working in a wider context with STDs.

**The Chair:** Is there one in particular, Ms Blakeman, that would fit the bill?

**Ms Blakeman:** I just don't have the resources to go through the names, but, I mean, there are a number. They're available through Capital health here. There's an STD clinic. There are agencies that are operating throughout the province. I'm sure you would be able to find out who they are.

**The Chair:** If I could, just on your point about mental illness. I'm not sure if they were on the list, but I'm wondering if the Alberta Alliance on Mental Illness and Mental Health might be an organization.

**Ms Blakeman:** I would think so, and Canadian Mental Health is an obvious one because they're pretty active.

**The Chair:** With the meetings that we have scheduled – we have the two full days – you know, we have the opportunity probably to accommodate all the groups that have been mentioned so far.

**Mr. Denis:** Mr. Chair.

**The Chair:** Yes, Mr. Denis.

**Mr. Denis:** Just on that note about reasonable accommodation. It's my understanding that it has been the past practice of this committee to allow people a fixed time each of 30 minutes just to ensure fairness and consistency. It's my suggestion that we follow that as well.

**The Chair:** Okay. You're referring to the process that we used for Bill 24?

**Mr. Denis:** That's correct, yes. It's my suggestion – and I don't know if people want it as part of the motion or not – that we follow the same process. It seemed to work last time.

**The Chair:** Any discussion on that point? Just for information, we provided a general parameter of 30 minutes: 15 minutes approximately for a formal presentation and then at least 15 minutes for question and discussion with the committee members. So that would make us consistent with our past practice.

**Mr. Vandermeer:** I would agree with that. I think it's consistent with past practices, and it's a very efficient use of our time.

**The Chair:** Okay. Any other comment on that point?

Ms Blakeman, if we did a bit of research, we could find, perhaps, well, at least one representative group on sexually transmitted

diseases, that aspect, and one on mental health, perhaps with a consumer perspective. Both the groups we mentioned, I think, would fit the bill. I think, then, with the numbers that we've got here and using the parameters for 30 minutes, it's realistic that we could accomplish hearing from these groups in the two subsequent meetings.

**8:50**

**Ms Blakeman:** I'm sorry. Those meetings are to be the 30th of January and the 4th of February?

**The Chair:** Correct. One is a Friday, and one is a Wednesday.

**Mr. Vandermeer:** Another stakeholder group that I know has said that they had interest in coming before this committee was the Glenrose Rehabilitation Hospital Foundation and – I'm not sure of the proper term – the Cancer Foundation.

**The Chair:** The Alberta Cancer Foundation?

**Mr. Vandermeer:** Yeah. Their interest would be in regard to fundraising.

**The Chair:** Any discussion on that point?

**Mr. Vandermeer:** I'm not sure. Maybe Ms Dean would know better if that would pertain to this bill for privacy issues with getting names of past patients so that they can do fundraising. Currently they can't do that.

**The Chair:** I'm sure we'll get the answer to that one in the technical briefing.

**Ms Blakeman:** Yeah. It changed. When this act came in, the foundations could no longer access patient records to then do an ask letter following somebody's discharge from hospital. I think there's an expressed interest – it's been in the newspaper – from some of the hospital foundations that want access to those patient records, again, for the purposes of sending people an ask letter to raise money. It's part of this discussion about: where does people's personal health information go? Who has access to it?

**The Chair:** So you would support this?

**Ms Blakeman:** Well, I think it's going to be part of the discussion, so we'd probably better either revisit the decision or uphold the decision that was made earlier.

**Mr. Dallas:** Mr. Chair, I would just concur that we should add one of those organizations to the list. I think, generally speaking, we have a list that brings a perspective from a group, and we should probably, as best we can, try to stay to that because, as you had stated earlier, this list could be broadened to hundreds of potential stakeholders. I think that if we brought a perspective of a foundation to the group, that would be good.

**The Chair:** Mr. Fawcett.

**Mr. Fawcett:** Thank you, Mr. Chair. From what I understand, this bill is not proposing to make any changes in that area, is it?

**The Chair:** I don't know. I wouldn't consider myself qualified to answer, but we will have the opportunity in the technical briefing to ask about that if we wish.

**Mr. Fawcett:** I'm not saying that it's not an important issue. I'm just wondering, because the bill has gone to second reading and we are limited in our scope as to what changes we can bring forward, if this isn't contemplated in this bill, whether it would be appropriate to have this group in front of us knowing that there is really very little that we can do as a committee to bring forward those changes. That would be my only concern.

**The Chair:** Well, I'll just ask the clerk. Is it preferable to have a motion and name the organizations in this instance? Okay. We'll do that, then. I'm going to ask for a motion that the following groups be invited to make a presentation to the committee using the 30-minute parameter.

We'll get some better wording here, but I'll just name the groups again:

HIV Edmonton, the Canadian AIDS Society, the Sheldon Chumir ethics foundation, an organization to be determined representing the perspective of Albertans with sexually transmitted diseases and the health providers which serve them, an organization to be determined which represents the interests of health care foundations.

**Mr. Denis:** Mr. Chair, just a quick question: is this to be an exhaustive list?

**The Chair:** It is, yeah. For the purposes of the next two meetings it is.

**Mr. Denis:** Okay. I just wanted to be clear on that.

**The Chair:**

The University of Alberta Faculty of Medicine and Dentistry, Health Quality Council of Alberta, the Alberta Medical Association, the Federation of Regulated Health Professions, and the Consumers' Association of Canada.

**Ms Blakeman:** I'm happy to make that motion.

**The Chair:** Thank you, Ms Blakeman. Any discussion? Those in favour? Mr. Denis?

**Mr. Denis:** Yes, in favour.

**The Chair:** Thank you. That's carried. Okay.

Thank you very much. The chair and the deputy chair will undertake to schedule the groups that we discussed, then, for the next two meetings.

**Ms Blakeman:** Did mental health stay on that list?

**The Chair:** Did I miss that? I apologize.

An organization representing the interests of Albertans with mental illness.

**Ms Blakeman:** Thank you.

**The Chair:** Sorry. Thanks.

Okay. I'd like to move on, then, to 4(d). This is a discussion of research requirements. I wanted to let you know that the deputy chair and I had some discussion with staff prior to today's meeting. One of the likely needs that we thought the committee would have is for a cross-jurisdictional comparison of the provisions in this legislation with other provinces and territories and beyond Canada if appropriate. I'll throw that out as one of the things we might want to consider and then just invite a discussion. Is there any other?

**Ms Blakeman:** I'm particularly interested in Manitoba's set-up for

the repositories and how the oversight works on the repositories there. That seems to be the one that's most successful in Canada or the one that people are keenest to talk about. Sorry. I have to look at the rest of my notes, but that was one that came up for sure.

**The Chair:** Are there any others? Obviously, we're free to ask for additional research as we may require it.

I'll look to Ms Blakeman for some advice on this, but the select special committee that reviewed the Health Information Act originally would have had a number of recommendations. Would a summary of those, do you think, be helpful to this discussion?

**Ms Blakeman:** Yes because there's a summary of the recommendations we made. Then I think it's also helpful to know which ones progressed, because some of them were encapsulated in Bill 31 of 2006. Some, in fact, moved forward, and there was a series of others that were to be recommended to a second review committee that was to be put together that never happened. There was some decision-making that was passed on to another committee that was never put together. There's a series of sort of dangling issues out there that have never been addressed, and some of that stuff arises in what's inside this Bill 52. So yes.

**The Chair:** Ms LeBlanc is the person who's going to provide this for us. Do you have any thoughts or any additional suggestions of things you think might be helpful?

**Ms LeBlanc:** No, Mr. Chair. I don't know of any additional suggestions at the moment, but we're happy to help with any research requirements that the committee desires.

**The Chair:** Okay. Just to review, then – and we'll ask for a motion on this at the end – we have the cross-jurisdictional review. We have the summary of recommendations from the select special committee on the Health Information Act. I'm sorry. I've forgotten exactly the year there. We have a summary of, we call it, the legislative and regulatory environment in the province of Manitoba that governs health research.

**Ms Blakeman:** Yes but specific to the oversight of the repositories.

**The Chair:** Anything further?

Could I ask, then: would someone be kind enough to make a motion

requesting that LAO staff prepare that research for the committee?

Mr. Fawcett. Discussion? We can come back to it, Ms Blakeman, too.

**Ms Blakeman:** I think the one other thing – and maybe it's coming in the briefing from the department staff – is some additional information on how all of the platforms work, on how those electronic health records are currently out there in cyberspace. There were a number of different – and I don't have the right language to use, so this is indicative of what kind of help I need. There was a different system started by the Edmonton regional health authority, a second one by the Calgary regional health authority, and a third one by everybody else. There was this different series, and I'm interested in how this all works and how they work together.

**9:00**

**The Chair:** I believe it's included in the briefing that we're going to have, but if it's not sufficient, we can add to our list.

**Ms Blakeman:** Terrific.

**The Chair:** I'll call for the question, then. Those in favour of the motion? Opposed? That's carried. Okay. Well, thank you very much. I think that gets us off to a good start.

There is one other area where we need to have some discussion, and that's around communications. We alluded to this a bit earlier this morning. Melanie Friesacher is here from LAO communications. Melanie, my understanding is that you're going to prepare a draft communications plan for the committee to consider at the next meeting.

**Ms Friesacher:** Correct.

**The Chair:** But I did want to ask if we could deal with this question of advertising for public input today so that we can have some discussion around the costs of sort of where we want to target and, above all, make sure that we can buy the space that we need should we decide to proceed with public advertising. Based on, you know, the counsel that Ms Dean has given me, particularly the issue of this bill needing to be reintroduced in the House, if we are proceeding with some advertising, I have two suggestions. One is that we aim to place the ad probably no earlier than February 13, assuming we're going to have an Order Paper published before session begins and assuming that we can get a motion from the government side to bring back the bill in that first week, and that is to avoid advertising sooner and having the wrong name and so on. That would be one suggestion from the chair.

I guess the other one I'd like to make is that you'll recall in our review of Bill 24, we elected to advertise only in the dailies, and that decision was based in large part on the information from the department that talked about a year and a half to two years of consultation previously. There was a much greater awareness of the bill. From what I've been able to determine in this case, that's probably not true for the purposes of this bill. Certainly, people are aware of the bill. We'll have the opportunity to talk with the department about consultation. In this case I think we might want to consider advertising in the weeklies as well. I'm going to ask Melanie to sort of outline some of the options, then, for us.

A question, Ms Blakeman?

**Ms Blakeman:** Just a third item to be considered. When the committee – and it may have been this one – dealt with the bill around mental health and the changes to the Mental Health Act, there was a phrase that was used in the advertising that indicated that people could have their information protected. I'm struggling for the exact words, but I'm sure you can find them for me. Subsequent to that a number of the policy field committees have decided not to use that phrase unless they really needed to. We ended up with a situation where people could apply and say: "I'm giving you this information. I want the committee to be influenced by it, but I don't want it published." So then we were making decisions as a committee without anyone else being able to examine the information we based the decision on.

I think we have somewhat of the same struggle here. I've already been contacted by individuals who have important things to say about this act but need to protect themselves, and I am struggling in a way to make sure that the final decisions the committee produces are transparent in that anyone from the public can figure out how we reached the decision and based on what information and at the same time offering a level of protection to individuals that need to come forward and tell us what's wrong with the system or how it needs to be fixed or protected. I don't necessarily have a solution to this problem, but it is something I think we need to deal with, and the first place it comes up is the advertising.

**The Chair:** Thank you. Maybe what I'll do is ask Melanie to sort of outline what some of the options are. We can come back to this question. We did deal with it under Bill 24 as well.

Melanie, could you take us through this, please?

**Ms Friesacher:** Thank you, Mr. Chair. As you mentioned, the subject of health information and the impacts the bill may have on Albertans both receiving and providing health services is extensive, so we want to advertise to the largest audience possible. To do so, it's recommended that we advertise in the weeklies and the dailies. Now, to run an average-size ad, which is about a 5.5 by 5.5 black-and-white ad, in approximately a hundred weekly publications costs about \$24,000. The same approximate size ad running in nine Alberta dailies costs about \$6,500. What you get for that is a reach of 700,000 Albertans for the weeklies and over a million Albertans in the dailies.

It's recommended we go to the weeklies simply because weeklies do have a longer shelf life. People tend to keep the weekly around – they're quite popular in especially the rural communities – whereas the dailies you tend to read and get rid of right away.

**Ms Blakeman:** Recycled, of course.

**Ms Friesacher:** Recycled, hopefully.

I'm looking for direction from the committee to advertise in both weeklies and dailies. What I can come up with is a draft ad with more definite costs for the next meeting.

**The Chair:** Okay. Just for purposes of clarification, these are funds that are already provided for in the budget of this committee, and in the case of the last bill we used the lesser amount because we only advertised in the dailies, right?

**Ms Friesacher:** Correct. We used the lesser amount.

**The Chair:** Any further discussion on dailies, weeklies, or both in terms of the target? I think we have consensus that the committee would want to advertise in both. Please chime in if you have a concern on that point. Okay.

In terms of the timing, if the committee would be in agreement with the suggestion around issuing the ad on or around February 13, after the motion has come back through the House, then there's the question of, you know, a deadline for submissions to be received. If we chose something in the order of a month to five weeks later, it would give members the opportunity to have all of the submissions before the two-week break at the end of the month. So it's just a thought, but there's an opportunity then, that we don't have when we're sitting in the House, to review them perhaps in more detail. Our practice with the last bill was to actually have the clerk post the submissions to the internal website as they were received so that members could pick them up as they came along and review them at their leisure rather than providing you with a small book at the deadline. Would you be in agreement? A month would be March 13.

Then the third – the members will know this, but I just want to fill Ms Blakeman in. What we did on Bill 24 was that the advertisement invited written submissions, and in the advertisement people were asked to indicate if they were willing to appear if requested by the committee. So we had some indication of their interest and their willingness, but not necessarily was there a commitment by virtue of sending in a submission that you would appear before the committee. This was useful to the committee in terms of making sure that different perspectives were represented in the deliberations.

So a suggestion would be to follow the same practice as last time: invite written submissions, have people make that indication if they would appear if requested. They're not obliged to, but it gives us some indication. That positions the committee, then, to discuss who else they might want to speak with in person.

**Ms Blakeman:** Based on the people I've already talked to from across Alberta, what we need to offer people is an opportunity to share their life experiences and the concerns that have arisen from that without publicizing who they are or where they could be found. I think what's happened to them is important, and we need to know it, and we need to consider it as part of what we're doing in this committee. Others need to be able to see that information as well, but I think we have to protect the individuals who in some cases would have their work lives or personal lives significantly imperilled if their personal information was released.

So there are two criteria I'm trying to achieve here. One is a transparency of the material that the committee examines in order to make their decisions – others should be able to examine that same material – and, secondly, to be able to protect people whose life circumstances are placing them in a position where they need to keep their personal information confidential.

9:10

**Mr. Olson:** Well, I totally agree with the concerns that Ms Blakeman has. It just strikes me that I don't know how we will ever be able to achieve that if the person is going to walk into this room and make a presentation to us. If they have the option of submitting a written document that will become part of the record and they can put in or leave out whatever information they choose, I think we need to give them the responsibility in that context. I don't want to become the editor and decide, you know: I don't think they should have said that. I want them to provide me with the written information, and it'll become part of the record, and we can make a decision. We don't ever need to know their name, as far as I'm concerned.

**Ms Blakeman:** I agree. My hesitation is in somehow putting more or less weight on somebody's written submission because they agree or don't agree to appear in person. I think this is a different circumstance because I can tell you right now that these people won't even give me their personal information, and they won't give me any way of getting back in touch with them. They'll only contact me so far. If I'm trying to draw them out and get their written submission in front of us – and I agree: we should not be the editors. They should be clear that whatever they send us will be public. Their information needs to get out, but I don't think we should be putting weight on whether or not they agree to appear before the committee as an indication of how serious they are of what they're presenting to us.

**Mr. Olson:** If I could just respond to that, I also don't disagree with that, except that if we receive five dozen letters that seem to be strikingly the same story and they're all anonymous, I don't know necessarily that I would give them all the same weight as I would somebody who gave me their name. One letter might be more compelling than something that looks like it's a kind of an organized campaign to write a bunch of letters. I'm not anticipating that, but I'm just saying that I don't want to make any commitment that I'm going to give equal weight to something that I think is maybe not a legitimate concern.

**Ms Blakeman:** Well, I think those kinds of form letters become pretty obvious to all of us pretty quickly.

**Mr. Olson:** Yeah. Exactly.

**Ms Blakeman:** I just don't think we can use whether or not they've agreed to appear in front of a committee as criteria for deeming someone's story or information important. We can't use that as criteria in this instance.

**The Chair:** In fairness, it was not applied that way in Bill 24. It was just, frankly, for the purposes of the committee trying to determine who might be interested.

**Ms Blakeman:** I'm sorry. I don't know what Bill 24 is.

**The Chair:** Sorry. That was the Adult Guardianship and Trusteeship Act.

**Ms Blakeman:** Okay. We renumber them every year, so there's been a different Bill 24 since that one. Sorry. That was guardianship and trustee?

**The Chair:** Yeah. I think I'm speaking for the government members as well, my colleagues that are here. There's no problem with omitting that, asking for people to make an indication of whether or not they'd be willing to appear. There's no problem with omitting that from the ad content.

**Mr. Dallas:** Well, Mr. Chair, just to refresh my memory. The material that was submitted to the committee was posted on the website. Is that not correct?

**The Chair:** Except where there was an express request on behalf of the submitter. I don't know if we had that situation, Melanie, but I believe we made provision for it if they requested that the information not be made publicly available.

**Ms Friesacher:** Correct. For those individuals that requested it, we removed the personal information on the public website.

**Ms Blakeman:** But the information still went up there without their personal information on it.

**Ms Friesacher:** Correct.

**Ms Blakeman:** Okay. I'm okay with that. I think the public still has to be able to see what influenced us in our decision-making. Their information still has to be public but not their personal stuff.

**The Chair:** I think we all share the same concerns that Ms Blakeman raised. Ms Dean was kind enough to give me, you know, the citation for the most recent change in the standing orders. It's 65(1)(c). So the committee can go in camera with unanimous consent. We also have the option for people to appear before the committee on an in camera basis.

**Ms Blakeman:** Yeah. Good point.

**The Chair:** Okay.

With that in mind, then, what I'd like to suggest is that we ask the staff to proceed with drafting an ad. We've got two meetings before the 13th of February, so we can review the ad at the next meeting of the committee, the specific content, and then we'll have our plans in place to issue it around the February 13 date. I don't think we need a motion on this. Are we agreed? Okay. Well, thank you very much.



That still gives us plenty of time for the presentation. I'd like to invite the officials from Alberta Health and Wellness to come forward, please, and make themselves comfortable. Just while you're getting seated, I'd like to welcome Linda Miller, the newly appointed Deputy Minister of Alberta Health and Wellness – welcome, Linda – Mr. Martin Chamberlain, Queen's Counsel, corporate counsel to the department; Mr. Mark Brisson, who is the acting assistant deputy minister of information strategic services. Do we have Wendy Robillard joining us as well? Wendy is seated in the gallery, and she is the senior manager for health information.

I just wanted to mention that the materials are going to be circulated now and that we're going to be taken through slide by slide. As an added convenience for members we posted them to the website yesterday. It wasn't necessary to review them in order to get the information today, but we thought it would be helpful. Normally we try to have any briefing materials that you need to read posted a week before the meeting.

What I'm going to do here is make a suggestion. Your presentation is divided into a number of different components. The first part, I believe, is kind of a health information 101, if you will, for the committee. What I'll do is perhaps pause after that section and ask for any questions of clarification from the committee. Then I believe what you're going to do is take us through the act piece by piece. You've divided it – I think there are about five sections here – and I'll do the same thing. At the end of each section I'll just ask for a pause and see if there are any clarification questions from the committee. I'm also going to probably try to work in a short break at a logical point, somewhere around 10 o'clock or so.

Thank you very much for being here. Please proceed.

**Ms Miller:** Thank you, Mr. Chairman. Indeed, it is a real pleasure for us to be able to present today at your first meeting with respect to Bill 52. We have outlined our presentation fundamentally in three parts, as Mr. Chairman has indicated, the first part being a very brief overview of the Health Information Act as it exists today, outlining some key concepts that we believe are a critical part of our language and probably a lot of terms that you will hear in subsequent presentations.

The second part of our presentation will highlight very briefly the provincial electronic health record and, I believe, answer some of the questions that Ms Blakeman has raised in terms of: how does the electronic health record work? I'd suggest that that may be the best time for a logical break, Mr. Chairman.

Then the third part is concluding, again, with some of the key rationale for the challenges we have faced since starting the journey of e-exchange, electronic exchange, in the health care system, thus the rationale for some of the proposed HIA amendments.

I'd like to begin by laying some fundamental constructs and understanding in terms of what has happened in Alberta over the last number of years since 2001, when the HIA was initially proclaimed. In my opinion, this piece of legislation has served Alberta very well. It has enabled us to share information with thousands of health providers in a very secure and appropriate manner. I believe it is also fair for us to say that when we drafted the legislation, many of the ideas were built on what we knew at the time, how to manage a paper-based system.

9:20

Providers shared information primarily with those they personally knew and with whom they personally built relationships over time. The act has enabled the health care system to notice a notable shift in the paradigm of how information is shared. This is undoubtedly a great achievement. As well, we have much more work to be done.

HIA continues to be the foundation on which we share all personal health information in the province of Alberta. It has been instrumental in laying the groundwork with core providers of the system, such as the physicians, the pharmacists, and the health regions. It has taught us such important rules and practices. We have introduced concepts and mechanisms such as the privacy impact assessment, security audits, and promotions of best practices in the electronic world. But along the way it has also enabled us to understand that it is time to change some of these practices beyond the paper world and to put into place mechanisms that make sense and are viable in an electronic world when you're sharing thousands and thousands of records on any given day.

Today's scope of the Health Information Act includes provision of access to the electronic health record to over 20,000 individual providers. However, they do, based on the scope of the act as it is defined today, represent what we commonly call the more traditional provider groups, that being the physicians and pharmacists and some of the key employees within the health regions. As we know, many of the health services in the health system are provided by other health providers, and many other so-called health services are not necessarily publicly funded, so we believe it is time to extend the scope in a measured way as we move forward to such organizations as the Workers' Compensation Board, the dentists, the chiropractors, et cetera, all of this, of course, contingent on them meeting the same set of access standards and security requirements that any other provider group does today. Alberta Health and Wellness believes it is time to broaden the definition of what are considered health services as defined under the Health Information Act.

The second area I'd like to briefly overview is the protection provided to health service provider information. Today the Health Information Act is quite unusual relative to other information-sharing legislation in other provinces in Canada in that we have very special protections for health provider information, some arguably even greater than that when it comes to personal health information for average Albertans.

I believe that at the time of drafting the legislation, the rationale for that, based on extensive stakeholder consultation, was based on the need to build trust within the health care system. As I mentioned previously, at the time of the HIA being proclaimed and developed, we were looking at the health care system exchange of information based on those that knew each other and the trust that they had built up individually. We believe we have built some foundations in improving that trust. We still have some ways to go, but it is now time to extend that paradigm and enable information sharing and start to focus the Health Information Act on the personal health information protection, all of this in recognition that provider information remains protected appropriately within other legislation such as FOIP and PIPA.

The electronic health record. As I've mentioned, we have already provided well over 20,000 providers access to the provincial electronic health record. That means thousands and thousands of records in a given day are collected by providers and made available to other providers who have the given role to look at that data and secure measures with the understanding that every time they touch that record, be it to view or download, there is an audit of that occurrence. That activity is not possible in a paper-based world, and thus I believe that an electronic health record is much more secure than a paper-based world can ever become.

Last but not least, I'd like to comment on the concept of research. Today the Health Information Act is essentially silent on the idea of facilitating research. As a result of the journey we have taken in the electronic health record over many years at a considerable cost, we have been able to amass large amounts of very valuable information

for researchers, policies, and those that need to manage the system better. It is time to have mechanisms in place, in our opinion, to enable that asset to be utilized for what it was intended to be. We need the necessary mechanisms and tools to enable that access, and thus you will see some recommendations and amendments in terms of research access.

What we have amassed on a population basis is without question the envy of the country and the envy of the world. It is our belief that it is now time for us to leverage that investment and continue to position Alberta in its leadership position and provide the best possible care to Albertans.

With that, I'd like to turn it over to Martin Chamberlain, who will overview the current Health Information Act and then, following that, Mark Brisson in terms of a very brief overview of the electronic health record.

Thank you.

**Mr. Chamberlain:** Thank you, Ms Miller.

Mr. Chair, thanks for the opportunity to speak on this matter. As Ms Miller indicated, we're going to start with a very brief overview of the current scheme under the act just so everybody is familiar with the terms because it helps, when we get into the changes, to understand what we're affecting, to the extent we're affecting anything. I appreciate that for those of you who are quite familiar with the act, this will be elementary and rudimentary. I apologize if I'm doing this at a level that is well beyond what most of you understand, but I want to make sure we've got the basic principles in place.

Now, what we have provided to the committee are a number of pieces of paper. I just want to make sure that everybody has gotten and seen the paper. One is a written submission, that I believe was distributed, which I'm not proposing to go through line by line at all. It follows to some extent the PowerPoint that we'll go through later with respect to the changes to the act, and it's something we want to leave you with because it outlines the key objectives for the changes in the policy and the rationale for them. That's something we want to leave you with. Obviously, if there are questions on it, the department is always available to address questions through the chair.

We're also providing for information some pieces of paper that may be of assistance. One is some information from the office of the Information and Privacy Commissioner that outlines basic roles and responsibility for custodians under the Health Information Act. It addresses some of the basic principles, and quite frankly it's a good summary overview of what the act does and how it operates.

Another piece that I provided the chair this morning – I don't know if it's been distributed yet – is a brochure on Alberta Netcare, which is a very brief overview from the department on what the EHR, Alberta Netcare, is, and Mr. Brisson will go into a little greater detail on how that operates.

Finally, what I am proposing to go through is a PowerPoint presentation. With the chair's indulgence, I prefer not to work in the dark, so if everybody has got the copies, I'll just work through the hard copies. This is not a particularly good room for PowerPoint presentations in my experience, so I'm planning on going through it on that basis. I'm on page 3 of the PowerPoint, Mr. Chair.

Essentially, what we want to do is explain the current purposes of the HIA, which quite frankly aren't being affected by any of our changes, but it's important to understand the changes in the context of the current scheme. The key purpose of the Health Information Act, which came into effect in 2001, was to provide a statutory scheme for the protection and confidentiality of health information. Prior to that, there was no specific legislative scheme dealing with

health information. It was covered by fiduciary arrangements between providers and patients. It was provided by common law. The attempt was to actually codify a scheme that provided basic protections for health information.

At the same time, though, there was a recognition that health information operates historically in a slightly different world than other personal information. It's routinely shared between health providers. It is used for research purposes to better health care. It is used for health system management purposes. There was a need to enable sharing of information, so the act allows that. It also sets out specific rules for the use, collection, and disclosure of health information. It provides for a right of access so that a patient has the right to access their health information and a right to request corrections to their health information if they believe it's wrong. It sets out a process for doing that, and none of those provisions are being affected by the amendments that are proposed in Bill 52.

It also allows for a scheme for dealing with contraventions and for oversight of the act. Essentially, the office of the Information and Privacy Commissioner, who, I understand, you're going to hear from this afternoon, is charged with overseeing, monitoring, administering the act, and in that act he's given a number of powers to investigate matters, to hear complaints, to issue compliance orders, and to lay charges. There are fairly significant fines in the legislation for contravention of the Health Information Act.

So that's the general scheme and the purposes of the act.

**9:30**

What we want to do – because this is how the act is changing. Some of the changes get at the type of information and who's covered by the act. The act addresses and imposes a number of obligations on custodians. Custodians are defined in the act. There's a long list of organizations that are custodians. There's a brief overview in that information from the Privacy Commissioner. Essentially, though, they are the organizations that provide health services: the Alberta Cancer Board, the Mental Health Board, the regional health authorities, hospital operators, nursing home operators, and health service providers.

Now, one of the key pieces – and this is one of the key changes that we'll talk about later – is health service providers who are providing services in the publicly funded system. That's one of the key hooks, and it flows through various definitions in the act. It's in the definition of health services; it's in the definition of health service providers. Essentially, it applies only to those health providers who are providing publicly funded services.

There's another term which comes up which we're trying to do some clarification on – we're not actually changing things, but we are trying to do some clarification – which is "affiliates." Affiliates are persons, organizations that are providing services for custodians, essentially. They're employees, they're agents, they're contractors of custodians who are working in their arrangement. For example, the Department of Health and Wellness is a custodian. I would be an affiliate. A nurse in a hospital: the regional health authority is a custodian; the employee would be an affiliate.

There's an important distinction there. A custodian is primarily responsible for complying with the act. An affiliate is responsible for complying with the act as well, but their acts – their use, collection, disclosure of information – are the acts of the custodian. The custodian is responsible for making sure that the affiliate is complying, and the affiliate is actually responsible for complying with any policies around the health information of the custodian.

There's another term which isn't in the PowerPoint, but it will come up later, and that's the concept of information manager. Information managers are organizations or individuals who, in

agreement with a custodian, are providing information services. It might be that a primary care network of physicians is utilizing a data manager to manage their information, their records, and they're doing that under contract. There are rules in the legislation that set out the requirements for that. The Department of Health and Wellness is the information manager for overseeing the electronic health record, the Netcare.

So those are the basic parties who are covered and dealt with by the act.

The information covered by the act falls into a couple of different schemes. Firstly, health information is covered by the act. Health information is made up of two basic components. One is diagnostic, treatment, and care information, and those terms are defined in the act. Essentially, though, that's your patient record. That's the information of the patient. So the doctor's diagnosis, the lab records, anything to do with the treatment and care of the patient is the diagnostic, treatment, and care information. It's what most people would understand as being their health information. It also includes their registration information, which is their name, their address, their Alberta health care number, their birthdate, those pieces that put them on our system so that we know who they are, can publicly fund their services, and know whether or not they're eligible for services.

The other piece, that Ms Miller touched on, that's covered by the act is health service provider information, which is, again, a defined term in the act, a long list of information with respect to providers, including their business card information, but goes on to talk about their professional credentials, any terms and conditions on their ability to practise. Quite a significant piece of information that's covered under the health service provider piece. What it doesn't include are pieces that are not funded by the Alberta health insurance plan. Dentists who are providing normal dental services are not covered. For health providers who are not custodians because they're not providing publicly funded services, that information isn't caught. They're not caught because they're not custodians with respect to that information.

Now, just to go through – and I'm on page 6 of the PowerPoint, for those who are following – the sort of fundamental areas that the act deals with and some of the key pieces that we want to touch on . . .

**The Chair:** Excuse me. I just want to acknowledge that I believe the deputy chair, Ms Pastoor, has joined us.

**Ms Pastoor:** Yes. Thank you very much. Good morning, Fred.

**The Chair:** Good morning. We're on page 6, Bridget.

**Ms Pastoor:** Yes. I've got it. Thanks.

**Mr. Chamberlain:** As I indicated earlier, the act sets up rules with respect to collection, use, and disclosure of health information, and there are parts in the act dealing with each of those. Essentially, a custodian is limited in the manner and the type of information they can collect. They are limited in the way they can use that information, and there are specific rules around the disclosure of that information. Now, those rules work quite nicely for paper-type records and direct dealings. They don't work as well for electronic health records, which is something we'll talk about later.

The concept that we use to describe the act is this concept of a closed arena. Essentially, the rationale is that your health information can't be disclosed without your consent, except that that doesn't work in the normal doctor, specialist, nurse, patient world, where

information needs to be shared sometimes on a very fast basis. So we have this concept of a closed arena within which information can be shared without consent among custodians, provided they comply with the rules of the act. There are some very specific lists, primarily in section 27, which is the use section, which are factored into both the collection and the disclosure provisions of the act, that set out when you can use information. I'll look at section 27 in a minute.

Essentially, there are some high overarching principles that apply to all aspects of the act which relate to and govern custodians when they utilize the information. Those, in a nutshell, if anybody is interested, are set out in sections 56, 57, and 58 of the Health Information Act. Basically, they are rules around using only the least amount of health information you need in order to provide whatever services you're providing. The act talks about things like using only that that is essential to carry out the intended purpose. You can imagine all sorts of scenarios. If you're talking to a dermatologist about skin conditions, he may or may not be concerned about your psychiatric condition. He may be, in fact, but you can imagine that there are lots of circumstances in which a health provider may not need to know information in order to deal with your common cold or whatever he or she may be dealing with.

That's the sort of fundamental, overarching principle, which, quite frankly, we're not changing in any way, shape, or form with these amendments. A health provider must only collect, must only use, and may only disclose the least amount of information that's necessary, and there's a high degree of anonymity in that. So if that information is being used or disclosed for health system management purposes or research purposes, there's a requirement that the highest degree of anonymity as possible be utilized. If there's some research that has been approved by a research ethics board and it can be done with aggregate nonidentifying information, the requirement is that that be done. Those are the sort of fundamental, overarching principles that apply to all aspects of the act.

Now, there is another one, which is in section 58(2), which is with respect to disclosure, and it applies only to disclosure. A patient's wishes are to be considered when a custodian is determining whether or not to disclose and how much information to disclose, and the custodian can consider that along with whatever other factors the custodian has to consider. Those are the overarching pieces. The Information and Privacy Commissioner has a role overseeing all of those pieces. A violation of those fundamental principles is a contravention of the act, and the commissioner can lay charges if appropriate.

On page 7, Mr. Chair, is sort of an overview. This is actually a summary of what section 27 provides, which are the use provisions. It's actually the key piece of the act with respect to even collection and disclosure because you can collect for section 27 purposes and you can disclose for section 27 purposes.

These are the fundamental purposes of the act: the provision of health services; investigating health service providers – if a college has a concern about what a particular health service provider is doing, they can access and use health information for purposes of pursuing that investigation for research, and there are a number of provisions in the act that set out when and how research can be done; there's a research ethics board requirement, and there are a number of provisions that deal with that – and also for managing internal operations.

There are actually a couple of sections that deal with management. One is for all custodians, so a primary care network, a physician running his practice, or a hospital operating their practice can utilize health information for management purposes. They need to know how many beds they need; they need to know whether or not their

chronic disease management programs are working properly. That type of management information can be used under section 27.

**9:40**

The other one is for the department and health authorities primarily, which is the ability to use the system for management purposes. That includes policy development, public health surveillance, planning, and resource management purposes. Health information can be used for those purposes, again always subject to those overarching principles that you use the highest degree of anonymity and the least information necessary for the intended purpose, whatever that might be.

In a nutshell, Mr. Chair, that's sort of an overview of the key principles of the act.

Now with the chair's indulgence I'd like to turn it over to Mr. Brisson to give us a bit of an overview on the electronic health record.

**The Chair:** I think we'll just pause for a moment and ask for any questions for clarification. Ms Blakeman.

**Ms Blakeman:** I have a couple of them. Could the individual explain exception-based legislation and how that applies in this particular case to the Health Information Act? That's the first question. The second one is this distinction between individually identifiable health information and anonymous health information, or stripped information, how that applies to this particular Health Information Act.

**Mr. Chamberlain:** Let me try and deal with the second one, and then I'm going to ask Ms Blakeman to clarify the first one for me because I'm not sure what she's getting at. The act does make a distinction between identifying information and nonidentifying information. Essentially the difference is that if it's identifying information, a person's able to determine that it is your health information. Where that becomes a potential issue is if you're doing aggregates and small samples. So if in a very small town you're doing research work and you're looking for 16-year-olds who have certain conditions, it may be possible, even though you've taken the identifiers off the information, that it is identifying. There's always a bit of a determination when you're utilizing aggregate information as to whether or not specific information is in fact identifying. The act does not preclude the disclosure or use of nonidentifying information at all. So it becomes a bit of an issue occasionally of determining whether or not a particular sampling is of sufficient size that it is nonidentifying.

Your first question with respect to exception-based . . .

**Ms Blakeman:** Well, I guess what I'm getting at is that in section 27, which is talking about the uses, everything that is referred to is in fact talking about the use of individually identifying health information, all of it.

**Mr. Chamberlain:** Yes. That's, again, going back to what I just went through, because there are no restrictions on the use of nonidentifying health information, the provisions around it, and section 27 and the other provisions in the act that deal with use and disclosure deal with that without consent. If there's consent, then the patient has consented to the use and disclosure of the information. But the controlled arena concept in utilizing the information for health service provisions and research management purposes relates to utilizing that information when that information can be used without consent, and there are a few places in some of those

hooks where the consent requirement comes back in; for example, in some of the research provisions. If a research ethics board determines that actually there should be consent before that information is used, the research ethics board could impose that as one of the terms and conditions of proceeding with the research. Does that answer your question?

**Ms Blakeman:** Yes. For the most part, if information is inside the arena, it is identifiable to an individual. It is readily shared between any of the custodians that are in the arena, but it's individually identifying information.

**Mr. Chamberlain:** That's correct. The proviso I'd put on that is that you still have that overarching principle of the highest degree of anonymity. For example, if the department is using health information for policy purposes, if we can make that nonidentifying or as nonidentifying as possible, then there's an obligation on the department and any other custodian to do so.

**Ms Blakeman:** Yeah. My first question was really to confirm that essentially you cannot share people's personally identifiable health information – that's the law – except in the following situations that are outlined in this act. So this is exception-based legislation, is it not?

**Mr. Chamberlain:** That's correct, Ms Blakeman. Yes.

**Ms Blakeman:** Thank you. That's what I was looking for.

**The Chair:** Any other clarification questions at this point? I have one. Those exceptions that Ms Blakeman just referred to, those are noted in section 27 only, or are they to be found elsewhere?

**Mr. Chamberlain:** I focused on section 27 because it's the key use piece, and it factors into the collection provisions, which are actually in section 20, which says you can collect for any of the section 27 purposes or as required or pursuant to any other enactments. So if there's a legislative requirement somewhere to collect health information, that's caught by section 20.

Section 35 deals with the disclosure provisions. There are actually a number of sections after section 35 that deal with specific disclosure provisions; for example, disclosure to the Attorney General if there's a suspicion of fraud, public safety disclosures that happen in there. But section 35 starts out with the provision that you can disclose for the section 27 purposes, the key one obviously being provision of health services, and then goes on to add a number of other provisions. Another one that's actually in section 35, for example, is the disclosure of health information to another province for purposes of reciprocal billing. That type of disclosure is actually there.

So there are different rules for each of collection, use, and disclosure, but the fundamental rules are the use ones in section 27.

**The Chair:** Okay. Thank you very much.

**Mr. Brisson:** Since a lot of the amendments that are being proposed to the act will have an impact on, as we move forward, the provincial electronic health record, we thought we'd put together three or four slides to give you an overview context of really what our provincial electronic health record is, which we've called Alberta Netcare.

On slide 8 is a strong example, kind of the business driver as we've moved towards an electronic health record, some of the reasons why. It's a case study on an elderly diabetic patient as they

move through the health system. As you can see, as a patient moves through the health system, they move across different facilities, they'll work with different custodians, different providers will provide service to them, and at each point of care health information is collected, and it is used to help with the care and treatment of each of those patients. You'll also, I think, from this diagram observe the sharing of information across each of these different facilities or custodians. In some cases we have that sharing of information in today's environment. In other cases in the electronic world we don't. That's where the true benefits of a province-wide electronic health record do come in.

Furthermore, if I take us to slide 9, the health system traditionally has been really based on the providers providing care. Large, acute hospitals have been the deliverers of care over time, and it really hasn't been, necessarily, patient focused. The previous example as well as this slide, where we are trying to move towards in the health system, is a patient-focused health system. As those patients move across these different providers and work with different providers in the health system, as they navigate through the system, how we share their information effectively is very important. The electronic health record itself is an attempt to do that. As a patient shows up in each of these different custodians or provider organizations, we're able to access their information at point of care. Each provider has that complete patient record of key information so that they can provide that service back to the patient.

If I take us to slide 10 and just dive down one level deeper, we look at the architecture behind the provincial electronic health record. This is a very simplified diagram that we're providing to you, but it has some key points that really will help with why we're making the changes to the Health Information Act. On the bottom of the slide you'll see a number of systems – source systems we would call them – that are in the community in physician offices. They will be in Alberta Health Services in the different health regions. They will be in ambulatory care settings. They will be in some private settings in the continuing care world.

Very much we've put together a simplified view, but those number of boxes you see on the bottom, there are many of those right now in the current health system. These are used at point of care for health care providers. Recently we've completed a strategy with Alberta Health Services to start to reduce the number of those systems and move to single systems on the basis of functionality, so one acute care system or reduced acute care systems, diagnostic imaging systems, pharmacy ones. The intent is to reduce the number of those, to reduce the complexity, and also increase the information sharing across.

9:50

The real benefit of the electronic health record is that the systems that you see at the bottom are source systems which each of the providers use, but as a patient moves across each of those, we want to be able to have that one complete record. We have some repositories right above that where we aggregate some of this information across all of those systems, and then we present it in the box above, which is called Alberta Netcare. That's the provincial electronic health record. What it does provide is the key health information of each of those patients at point of care as they cross each of these different systems. One thing to be sure what we're doing with Alberta Netcare is we want a complete record. A lot of the changes you'll see in the act are a movement towards that.

One of the key changes in there, as we've discussed, is with respect to masking. Masking right now within Alberta Netcare only takes place in that top box. It does not take place in all of those boxes at the bottom. There are various reasons for that. One would

be the technical complexity of doing it. Many of the systems you see below are legacy systems that may not have the technical complexity, or the cost to do it would be not insurmountable but it would be great. Many of these systems are built in the U.S. and some in Europe, where the masking principle isn't necessarily as widely agreed to as we have here. Therefore, it really isn't available in this system.

When we look at global person-level masking as part of previous changes to some of the regulations within HIA, we did that within Alberta Netcare. We have not made those changes down at the bottom for those various reasons, and ergo many of the providers will be able to see all of the information in each of those systems without it being masked. It really is only masked above.

Do you want me to complete or take a question?

**The Chair:** We'll pause and take a question, sure.

**Ms Blakeman:** A couple of questions have arisen from what you've said. Can you tell me whether we are still making a distinction between electronic health records and electronic medical records? My understanding of that previously was that the electronic medical record was the information that was being kept in a local physician's office. Your GP's information used to be in a paper file. Some of them still keep it in a paper file. That information was called an electronic medical record and was not part of this sharing of information. But once you moved outside of your physician's office and you got a test or you got a drug from a pharmacist or you were in the hospital for some kind of treatment, all of those were part of the electronic health record. That's my first question. Maybe you could answer that.

**Mr. Brisson:** Very correct. Electronic medical record does refer to the physician office system in each of the clinics. It is part of the entire electronic health record initiative. At this point in time, though, we don't have information coming from the private clinics, those systems, into Alberta Netcare. That is part of the, I'd call, next phase of where we're moving with electronic health records: not only to supply results and tests to those physician systems but also to have some information come from those physician clinics to help with the completeness of the record in Alberta Netcare.

**Ms Blakeman:** Okay. When you're talking about masking, are you talking about lock boxes, or are you talking lock boxes of information, or are you talking about masking some information on the health record from providers who somehow it's deemed they wouldn't need access to it, which is back to the example of the dermatologist not needing to know that you had bronchitis last year?

**Mr. Brisson:** I'm not referring to a lock box. I'm referring to global person-level masking where the entire record with the exception of a few data elements, like your name and some of your demographic information, your clinical information, will be masked. The record will be masked. As a provider . . .

**Ms Blakeman:** But only at the Netcare level, not in all of the other levels. So those can easily be sharing information back and forth. Your pharmacist is able to see that you had bronchitis and that you went to a dermatologist.

**Mr. Brisson:** Your pharmacist will be able to see in their own pharmacy system the information that they have collected in that system. If the pharmacist signs on to Alberta Netcare and a mask is placed on Alberta Netcare, they can't see the information in Alberta

Netcare unless they, in the accessing of that, ask to break the glass – that is the type of functionality that exists in Alberta Netcare – which poses a question to the provider: “This record is masked. Do you have a reason to see this information? Would you like to break the mask?” They can break the glass, and the mask is then taken over, and that record of them breaking the glass is audited. So they can see the information.

**Ms Blakeman:** Is the individual aware that that is taking place?

**Ms Miller:** Certainly, on the very rare occasions when people have asked for information to be masked, it is explained to them that that can happen. Whether or not that’s fully understood at the time of the explanation, I can’t comment on that, Ms Blakeman. Certainly, we have provided information to all of the providers to ensure that they explain that to each person that has asked, but very few people overall have ever asked for that.

**Ms Blakeman:** So if I asked for information to be masked but my pharmacist went onto Netcare and said, “I want to see beyond this; please break the glass,” it would be done even though I had requested that the information be masked.

**Ms Miller:** Yes.

**Ms Blakeman:** Okay. That’s where the problem starts.

**Ms Miller:** The provider is not bound to honour the masking. They must consider the masking, but if they feel that it’s in your best interests for the provision of care to look at that data, they certainly have the ability to do that. However, that specific audit does occur in a very special audit file in terms of those that have chosen to unmask information, if you will.

**The Chair:** Any questions from other members at this point? I have one as well. The subject we’ve just discussed, then, in terms of the requirement for consent or nonrequirement for patient consent to unmask a record: is that a consequence of the proposed legislation, or is that already the case under the existing legislation?

**Ms Miller:** It’s already the case under the existing legislation.

**Ms Blakeman:** But you’re looking to take this a step further, are you not?

**Ms Miller:** Yes.

**Ms Blakeman:** So it’s an expansion of how much information is out there, who else can get at it, and how much they can unmask it. That is what we’re considering.

**The Chair:** That leads to my second question. Correct me if I’m wrong, but this has to do with fundamental changes in the service delivery model for health care as well and, specifically, the move to an integrated model where we have multiple providers on different sites who are in fact working as part of a multidisciplinary team to address not necessarily one specific concern of a patient but a range of what could be some fairly complex problems. We’re not just automating old processes here; we’re enabling new processes. Is that a correct understanding?

**Ms Miller:** Absolutely. If I could just elaborate on why we’re asking for this masking provision to be removed. As Mark has

described, it only exists at that one tool level, the very top, called the Netcare portal. It does not exist in any of the other feeder systems or point-of-care systems, as we call it. Because of that, it is a superficial protection that we believe the public may be believing is far more extensive than is actually capable. Whether or not the information is masked, when the provider looks at that information, an audit occurs. If a person has a concern about some sensitive information, they can at any point in time go to any person or provider that has access to the electronic health record and ask for their full record.

There are proactive audits done on those that are looking at the electronic health record, looking for outliers in terms of unusual volumes, you know. So if a particular provider seems to be doing some scanning or what appears to be scanning of records at a larger than anticipated volume, that is picked up through our proactive audits of the system. Our concern is that the expressed wish of masking or the ability to mask is, as I’ve said, not really a true reflection of what happens in the electronic health record.

10:00

In the spirit of being transparent to all Albertans, we believe it is more important for them to be reassured that there are appropriate security measures put in place to audit who has access to what, when, and where. Even before providers are provided access, they must meet very strict security provisions and demonstrate the need to know based on their scope of practice, et cetera. Those kinds of measures are much more reflective of the true way we are sharing the electronic health information here in the province of Alberta. That was the rationale for our proposing a change to that amendment, basically.

**The Chair:** Okay. Well, let’s proceed with the rest of your presentation, Mr. Brisson.

**Mr. Brisson:** Just to recap, in essence, the benefits of Alberta Netcare and the way we’ve rolled it out here are that as we move across all those systems and those providers, we are able to share that information at point of care effectively for the patient as they present.

I’m just going to provide some usage statistics for you on the scope of the electronic health record as it has been deployed to date. We have over 22,000 users of provincial EHR. The breakdown of the users I’ve described here in a few bullets. As you can see, it’ll be those main providers that we all think of in the health system when we are at a point of care where we provide those services.

Looking at some of the changes being proposed, it’s for expanded use of Alberta Netcare. There are over 1,900 unique sites for accessing a provincial EHR. I’ve listed some there for you as well. It’s those acute-care centres, emergency departments. It’ll be physician clinics, community pharmacies that supply data back to the repository as you go fill your prescriptions at different pharmacies in the community, continuing care, public health, and new urgent care and advanced ambulatory care centres. So we’ve seen a successful deployment of provincial EHR across multiple settings. Going back to that original example of, as we move forward, really trying to solve that business case of that elderly diabetic, that’s the reason we’re moving with some of these changes, to try to realize the benefits from them.

**The Chair:** Great.

If you’re in agreement, I think this is probably a good point to take a short break. I suggest we break until 10:15 if that’s acceptable to members. Thank you. So we’ll reconvene at 10:15.

[The committee adjourned from 10:03 a.m. to 10:17 a.m.]

**The Chair:** I think we're all here. We're ready to reconvene. I believe, Mr. Brisson, we were on page 12.

**Mr. Brisson:** Yes. I've completed the HR portion. I'm going to pass it back over to Mr. Chamberlain to continue with our proposed HIA amendments, starting with the scope changes as the first section.

**The Chair:** Thank you.

**Mr. Chamberlain:** Thank you, Mr. Brisson and Mr. Chair. What we wanted to do, rather than trying to go through the legislation line by line, which isn't particularly productive and, given the bill amendment form, is actually very difficult to do in any event, is highlight the key objectives that the bill is trying to accomplish. These objectives are basically similar to the same scope that's set out in the written submission we provided to you, but we wanted to give sort of an overview of what they are and an explanation as to what the bill is attempting to accomplish.

The first one we've touched on a little bit. It's with respect to expanding the scope. That deals with a couple of provisions. The first one is getting rid of the publicly funded requirement. The rationale for doing this is that right now we have a real dichotomy. This is one of the overarching principles in the act: a custodian has an obligation to make sure that the information they collect is as accurate and complete as possible. Certainly for purposes of having health information, having an emergency room doc accessing records, it's imperative that the information they access is as complete and accurate as we can make it. That's the ultimate goal that Mr. Brisson is trying to get to as he expands on the electronic health record work.

That record is not complete if it doesn't include all health information. Easy example: if you go to your dentist with a root canal, and he prescribes you with antibiotics for potential infection and with painkiller, and a day later you end up in an emergency room, the emergency room doc needs to know that you're on antibiotics and painkillers. If that information is not treated in the same form, is not dealt with under the same legislation, is not accessible in the electronic health record in the same way, you've got a risk; you've got a concern.

The intent is to have a single, statutory scheme that applies to all health information, and that's done in a couple of ways. One is by getting rid of the requirement for the publicly funded piece, and the other is enabling us to add custodians, add health professionals by regulation. The intent would be that we start with the current scheme we've got. We don't want dentists, day one, to suddenly be in a new regime. We need to transition that. So as it makes sense to bring providers in, we would add them. It's not actually a change; it's just creating the ability to add other providers and additional health information through regulation to the current scheme so that we actually move towards a complete, more accurate record of health information that's all governed under one scheme as opposed to the current scheme of common law, of PIPA, of Health Information Act.

The other piece that we deal with that's part of the scope change is actually making the legislation patient focused. We want to move towards health information of patients. That's what this is about. As Ms Miller indicated, originally health service providers were provided with protection under this legislation. Now, this legislation predated the Personal Information Protection Act, which does provide protection for business-type information, for personal

information held by organizations and individuals. The intent is to remove the health service provider stuff so that the legislation is specific to patient health information, and that's what it deals with, and that health service providers are subject to the same rules that every other professional, every other businessperson, every other individual will be subject to, which are FOIP and the Personal Information Protection Act.

We're also as part of the scope changes – and this is one that the Privacy Commissioner has requested. What we're finding with patients moving from jurisdiction to jurisdiction, with health providers operating in multiple jurisdictions, and particularly with TILMA facilitating AIT, the agreement on internal trade, facilitating more movement between health professionals, is that the Privacy Commissioner needs to have the ability to work multijurisdictionally so that if he's got a complaint that may impact on a B.C. physician or on health records that are in B.C. and Alberta, he can co-ordinate his activities and any complaints with his colleagues in those other provinces. That's one I think Mr. Work would support because, quite frankly, I think it's one he's been asking for.

Certainly, the two major changes are the scope change that we just talked about and the changes to the electronic health record. As Mr. Brisson indicated, the electronic health record has evolved over time, and we've now got a lot of experience, as do health service providers, with working with Alberta Netcare, the electronic health record.

One of the rationales for basically carving out a separate scheme for the electronic health record is to recognize that it's a unique, new model for storing information. It really is. The traditional collection-use disclosure rules work quite nicely when you have a doctor dealing with a patient, collecting a paper record of his information, sending on a referral to a specialist, and sending a copy of an X-ray or a lab report or whatever else. Then there's a discrete collection of information used for a specific purpose and then disclosed on. That doesn't work particularly well when you've got a system that stores electronically thousands and thousands of pieces of information that are accessed daily by physicians, labs, pharmacists, putting information into the system to make health information records complete and providers accessing it for multiple purposes.

Again, I go back to the emergency room scenario. An emergency room physician has a patient arrive as a result of a motor vehicle accident or a heart attack or whatever. They need to access information now. They're not going to find out who the GP is, call the GP, and ask him to fax over copies of the medical records. There's no discrete disclosure and consideration by the original physician of whether the information is required by the emergency room doc. The obligation is going to be on the emergency room doc to satisfy the overarching principles of the act, to figure out what information he needs, the least information he needs, and to get it quickly in order to provide appropriate health services. So that ability to store information in a unique network is quite a change from the traditional paper file and a change from the traditional electronic medical records that Ms Blakeman referenced. This information is now available in the arena as necessary, as essential.

**10:25**

One of the key pieces I want to make clear is that those fundamental, overarching principles continue to apply, so notwithstanding that we've set up a separate scheme to deal with the electronic health record and recognize its uniqueness, it enables a number of regulation-making powers to enable us to put rules around who's entitled to access over and above just custodians, authorized custodians, so that we can set requirements, make them sign appropriate agreements, set additional requirements if we need to, address through regulations any audit requirements, the log require-

ments that are appropriate to make sure that the information is kept secure but at the same time make sure that information is as complete and accurate as possible and available to health service providers within the arena who need to use it when they need to use it.

The change that has been referenced. Ms Blakeman was talking about the masking requirements. The reality is that the masking requirements in the act are not changing. Section 58(2), which sets out the provision for expressed wishes, consideration of expressed wishes, isn't changed by this. The change that's affected by the legislation is indicating that utilization of an electronic health record, putting information into that storage regime, accessing that regime to determine what information is there and what you need to pull out of that in order to provide the health service that you're performing is what Bill 52 proposes is a use.

Section 58(2) is one of the very few overarching principles – I think it's the only overarching principle – that only applies to disclosure. That consideration is not in the use provisions, which means that when putting information onto a system, a custodian would no longer have an obligation to consider the expressed wishes of the patient when putting the information on, and the rationale, again, is that we still have all of the overarching principles with respect to least information, essential only for the services you're providing, and we also have the overarching obligation of making sure that that information is as complete and accurate as possible.

One of the examples that came to mind when I was listening to Ms Blakeman is that one of the things that is sometimes requested in masking is communicable disease status. The reality is that if an emergency room doctor is treating a patient who comes in with a number of wounds, that's information that they would need to know in providing treatment and making sure that there are proper security and safety measures taken for the health service providers and other patients in the emergency room. That information is necessary because the physician needs to have a complete and accurate record. The intent is to have an electronic health record that is complete and accurate. There is no change in the consent provisions. The use of that information in the controlled arena right now can be done without consent. Information is put onto the electronic health record without consent, so there's no change there.

The only change that's effected is with respect to consideration of expressed wishes. That does continue with respect to the physician who uses the information on the system, accesses that information about the communicable disease status. They can then not disclose that information to other professionals, to whoever without considering the expressed wishes. So 58(2) continues to apply. It's just discrete utilization of the electronic health record where the department has determined that it makes the most sense to classify that as a use and to make sure we have a complete and accurate record.

I'm flipping through my PowerPoint. I'm on page 15. Sixteen. I can't read it without my glasses, Mr. Chair. I want to mask that, by the way.

The sections with respect to electronic health records recognize that we need to be flexible. The electronic health record has evolved significantly since the act was put in place in 2001. We anticipate that it will continue to evolve. One of the things Mr. Brisson's team is working on is patient portals so that patients could in theory access the electronic health records themselves. That's a long time off, but you can imagine the security rules that we'd need to put around that, the protocols that would need to be in place, determinations about which portions of the electronic health record a patient may be able to access, how they'd do it, whether they'd do it directly or through their custodian. There are a number of things to consider,

so we need the flexibility through regulations to create those rules and to modify them as technology changes. That's the rationale for creating a fairly broad scheme of regulation powers, to enable us to properly manage the electronic health record world.

Moving on, Mr. Chair, the other series of changes are not that significant, quite frankly, but they deal with research issues. I'll start with the easy one. We've had some issues around whether or not certain language in the act actually enables a custodian who's providing information to a researcher to collect from the researcher information in order to do some data matching and to limit the information the custodian provides back. There's an issue about whether or not that custodian can actually collect the information and whether that's authorized by the act. We believe it is, but there's some ambiguity around the language. One of the clarifications is to allow a custodian to actually ask the researcher to provide some of the information to them so that they can properly define what information to provide back, which is again consistent with making sure that for the researcher they get the least information necessary to perform the research that's been approved by a research ethics board. So that's really a clarification provision.

The other change is the addition of some sections enabling health information repositories. These would be authorized by regulation, so they don't exist unless a regulation designates a particular organization as a repository. There are a number of changes throughout the bill which deal with the research provisions and allow a health information repository to be part of the research process so that various data sources could be provided to a health information repository to facilitate research, to facilitate management purposes. The rules around those would be set out in regulation although they would also be governed by the same overarching principles, by the same research rules that are in the act currently, and they would still be subject to Information and Privacy Commissioner oversight, who has oversight over the whole piece of legislation.

The other piece is a bit of a grab bag, sort of clarification of some definitions and rules. Most of these things are, in fact, more housekeeping than anything else. We have identified over time some ambiguities in some of the legislation. I'm on page 18 of the PowerPoint. There are a couple of sections, 46(3) and 47(5), that actually authorize disclosure of information acquired by the department and by health authorities. They overlap the general disclosure requirements with slightly different language. They've created some ambiguity and uncertainty, so we're simply proposing to delete those sections, which means that disclosure rules apply and that all of the same overarching principles apply, but we eliminate the ambiguity.

The other piece involves various changes, and if you look at the bill, there are various changes that affect this. It's trying to clarify the role of affiliates and custodians. There are issues like whether or not an information manager is actually an affiliate. We have other issues. For example, the easiest one is a physician who has privileges in a hospital. The regional health authority is a custodian; the physician is a custodian in their own right. When they're dealing with hospital records, are they doing it as an affiliate or a custodian? The distinction is that the custodian is the one who's primarily responsible for compliance with the act, and the affiliate is responsible for complying with the policies of the custodian. It's important to clarify in those circumstances whether or not you're doing this as a custodian or as an affiliate and a recognition that you might be wearing two hats. You may actually be an affiliate for certain purposes.

That is what those sections are deemed to do, with some additional reg power so that the minister can, if necessary, designate somebody as an affiliate in certain circumstances, to actually address



problems if they arise and make it clear who is primarily responsible, whose policies would apply.

I've just flipped through. It's the same issue on the information manager and clarifying whether the information is managed as an affiliate, and there are a number of sections that deal specifically with that.

**10:35**

I'm on page 20, Mr. Chair. The last couple of pieces are some clarification and cleanup, if you like. We're anticipating that responsibility for providing health services in correctional facilities will be transferring from Solicitor General to Alberta Health Services, and they'll actually be primarily responsible for ensuring health services. One of the issues that has come up with respect to correctional facilities is that if you have a nurse or a physician in the facility, they may or may not historically have been caught as custodians because if they weren't providing services under the health care insurance plan because they were being paid directly by the Solicitor General, they might not have been custodians, which means they may not have had access to health information and to the electronic health record for that patient. So we're trying to clarify that through the other scope changes.

We also have issues where guards, the warden, who are not health providers themselves, are responsible for making sure that an inmate is getting their medication. They need to know whether an inmate is diabetic, whether an inmate is prone to seizures so that they know what to look for and to provide care, not necessarily health services. A guard needs to know if an inmate is diabetic, that they may actually be in a coma if they appear to be in a diabetic coma. We want to make it clear that that information can be provided to the correctional facilities for the purpose not only of health services but for continuing care and treatment. That's a fairly minor amendment, but it's fairly important to the safety of both guards and inmates.

The other change – and this is a minor one – has come out of a few specific examples. Currently if a college is investigating a professional, they can access health information for purposes of pursuing that investigation. It's unclear under the act whether or not a professional who is lodging a complaint with a college can utilize health information. For example, if a pharmacist becomes concerned about the prescribing practices of a specific physician or a nurse practitioner or whoever is actually issuing prescriptions, it's not clear that they can actually provide the health information to the college for purposes of them determining whether or not there's unprofessional conduct, whether an investigation is required, whether practice visits are required. We want to clarify that a custodian can in fact provide health information for purposes of lodging a complaint with a college.

Mr. Chair, subject to questions, that's an overview of the key objectives that we're trying to accomplish through Bill 52.

**The Chair:** Well, thank you, everyone, for the presentation. I expect we have several questions for you.

**Ms Blakeman:** I actually have four questions, so I'll be guided by the chair. If he'd like me to do one and then go to the end of the line to ask others, I'm happy to do that.

**The Chair:** How about two at a time, Ms Blakeman?

**Ms Blakeman:** Sure. Happy to.

I'm wondering why we don't just remove the masking provisions because it's striking me that this is offering a protection that, in fact, is not a protection. It can be seen as being misleading, and I'm

wondering why we're not just removing it. You gave a perfect example: someone, for example, who has an STD who's asked for information to be masked, and for the first person that asks for it to be unmasked, it is. There you have an individual thinking this information is protected, and it's not. Why don't we just not have it, and then everybody would know that that information is not protected? That's question 1. Do you want to answer that, and I'll go on.

**Ms Miller:** I'll start. We want to change the definition of use. Fundamentally, if you're in the arena, that becomes a use, so it wouldn't exist in that environment if the amendments go forward as recommended. We have still included it as a disclosure because that would be outside of the arena of custodians, fundamentally.

For example, it would apply still to the paper records. There's still lots of paper exchange that does go on in the health care system. It's not completely electronic yet. It is more readily achievable to ask the individual or for that individual to express their wish and that it be acted on in a thorough way based on that paper record when it is taken from one custodian to another. It is part of that maintaining both worlds. I guess that would be part of my answer to you, Ms Blakeman.

With a broadened definition of use it becomes most of the exchange. The disclosure is outside of the arena. In that way, most often that disclosure is paper based.

**Ms Blakeman:** Just for everybody else, there's collection of information, use of information, disclosure of information. We're talking about leaving the masking provisions in the disclosure provisions.

**Ms Miller:** It's the expressed wish, not the masking.

**Ms Blakeman:** Sorry. The expressed wish that their information not be shared in the disclosure section, which offers a small amount of protection but not a whole bunch. Has it been your experience while the act has been operational that individuals grasp, comprehend the fine distinctions of this?

**Ms Miller:** Difficult to understand how much is grasped. I know there have been letters written to the minister asking that information be protected. I believe from the tone and the frame of questioning that we read in those letters that people are of the understanding that it is masked throughout the system. Although our answers, obviously, are very correct in the ministerial responses, I suspect that probably not a full understanding is out there in terms of what is really capable and what is not.

**Ms Blakeman:** Well, that's an area to work on.

I used my two questions in doing a supplementary, so I'll go back on the end of the list.

**Mr. Vandermeer:** First, I want to commend you on doing an excellent job of explaining the bill to us. My question is fairly simple. The reason I'm asking it is that I'm on the board of a credit union, and at times we need board approval for certain mortgages and so on. It comes before us, but we don't know who we're giving the mortgage to. It comes in the form of a number, and it explains, you know, that it has been approved by CUDGC and Credit Union Central and all these things, and then it gets final approval by us. Why can't we just use a number for patients and not have names attached, too?

**Ms Miller:** Are you talking for care purposes? It wouldn't support care. When the provider looks you up in the electronic health record, or portal as it is often referred to, it is important that they see up front that it's Linda Miller. There is a number attached with every person or most persons that access the health care system today. That's how we track data between different databases collected in different systems. But the name of the person that the provider's record is looking at is critically important for another step in validating that they've got the right person and the right information associated with that person. Did that answer your question?

However, for administrative purposes, et cetera, clearly it is a rare occasion when from an administrative or a management perspective we need to know individual names attached to those records. There are likely only a handful of people in Alberta Health and Wellness, as an example, that ever look at identifiable information based on the principles that Mr. Chamberlain has outlined for you today.

**Mr. Vandermeer:** Okay.

**The Chair:** Anything further? Others?

Ms Blakeman, and then I have a couple as well.

**Ms Blakeman:** Okay. My understanding is that in your request to widen the scope to have custodians added by regulation – therefore, it's not in the act; therefore, it's not subject to public scrutiny – that allows new players into the arena and would also allow commercial entities, if they're providing health services, to be in that arena and have access to that information. Correct?

**Ms Miller:** If they were agreed to as being a custodian, but just being a custodian does not automatically provide you access to the electronic health record. It kind of lays the groundwork that you can be considered. Clearly, you still need to demonstrate a need to know and the highest level of anonymity. It's set to three principles that have been outlined as well as meeting the same security provisions as providers that do have access. It's not that automatically you're in the arena, shall we say.

**Mr. Chamberlain:** If I could supplement, Mr. Chair. The reality is that the legislation currently authorizes custodians to be added by regulation. That's not a new concept. We've combined it and reworked the sections to get rid of the publicly funded piece, and the intent is to utilize the regulations so that we can phase that change in because it has a fairly drastic impact, obviously, on the number it provides and the amount of health information. We need to have the ability to phase that in, so the regulation piece has been reworked in conjunction with the other amendments, but it's not a new piece.

10:45

**Ms Blakeman:** I agree, but I think the concern is that as soon as we move away from the proviso of publicly funded, we open it to the commodification of personally identifiable health information and commercialization of it. Those are the concerns that people have. So they want to know: how do they get protected from that? HRG, for example, is a commercial entity, a very successful one, that also provides health services on a contract basis to the Alberta government. If they now have information and decide they're going to do a helpful health promotion, contact everyone that got a new knee through their service to let them know that there's a brand new knee out there, a new, updated, fancier knee, and, you know, it's been three years or five years, and they should contact HRG about coming in to get a new knee, that information would be available. HRG would have access to that information.

**Mr. Chamberlain:** And they would still be bound by the same overarching principles. Although they have that information and to the extent that they have custodians operating for them now who may have access to some of that information, they would still be bound by the use provisions of the act. So they couldn't use it except for one of those section 27 purposes.

**Ms Blakeman:** But it strikes me that what we're doing here in this expanded scope is moving less from protection of information, more towards expanded uses of information if I'm understanding where your expanded scope is moving.

**Ms Miller:** I think protection stays at least the same. If not, we continue to strive to improve it. We are trying to expand the definition of the use provision. The rationale for that is because of the manyfold number of exchanges of information that happen on a minute-by-minute basis within the health care system.

The electronic health record is a compilation of records put together visually so that there's one view that may have come from a diagnostic physician, a radiologist, a lab doc, your visit at the emergency department, your home care. I mean, it's all put together, critical pieces of that, in one view. As we expand the number of people that have access to that based on very strong security provisions, the way the act is now, technically, one could argue that those are all individual disclosures. It's not a manageable, feasible way to move forward because it happens on such a regular basis with such a volume.

The piece that we're trying to change is to recognize that in the electronic health record you need, it is the basis of the collection of all that information. It's not one to one; it's one to many. But many, obviously, still means that I have access to those providers and want them to access that collective record. So it's just not feasible to view each one of those thousands and thousands of records exchanged as individual disclosures under the act. It's just not a manageable situation as we move forward. However, anybody that's deemed to be in that circle of trust – i.e., using information – must meet very strict security provisions. We're not proposing for a moment that those provisions be relaxed at all. In fact, they should be tightened as we learn more on how to do that in such a large, complex system.

**Ms Blakeman:** Okay. I'll go back to the end of the line.

**The Chair:** If the members will indulge the chair, I'm going to ask a couple of questions as well. The first has to do with just trying to clarify what information would be accessible through Netcare, going back to your original point that Netcare functions as a portal for a number of subsystems that are available. Would I be correct in saying that unless you are a health practitioner who's operating in an environment where Netcare is used at the bedside, so a clinical information system in a hospital or other acute-care setting or perhaps a pharmacist who's part of the pharmaceutical information network, by and large, unless my family doctor has got some special set-up that connects directly to Netcare, only the information that my doctor chooses to feed into the electronic health record is going to be available to be viewed?

I'm thinking of things like written chart notes that my physician may have, things beyond sort of the usual scope of lab tests, perhaps, you know, a referral to a psychiatrist or another mental health professional. Is it correct, then, that it's still up to the individual practitioner in terms of what information they put into the EHR and that my expressed wishes are still binding on that professional in terms of what I may or may not wish disclosed?

**Ms Miller:** We've been working with the physician community for years in terms of defining what we call a minimum data set. Of all the data that doctors collect in their electronic medical record, we're still working, getting closer to an agreement on what out of all that is absolutely critical that needs to be shared on a routine basis from the EMR. That hasn't happened yet, but we anticipate that will happen in the near future. Once that so-called minimum data set is agreed to, that set of data, then, will become routinely extracted, if you will, from the electronic medical record to the broader electronic health record.

Now, I think the second part of your question, Mr. Chairman, was: is there going to be an ability for a particular physician at a particular time to say that for this particular person we don't want to share X, Y, Z? That's a use provision, so that would not be available once the minimum data set has been agreed to. That would require system changes on a one case by one case basis, fundamentally, if you will. But a lot of what we're talking about with building this minimum data set does not include what we often think of as the very sensitive information like personal notes or informal comments that a doctor may make on your record just based on some observations. We're talking at this point in time about very factually based data in terms of, you know, the diagnosis that you're presenting with, your key symptoms, et cetera, those kinds of very critical pieces of information and not the very sensitive stuff that we all think about and get quite worried about in terms of being out there for broad distribution.

**The Chair:** Okay. So it's primarily the quantitative information, the status, lab results, that sort of thing.

**Ms Miller:** Yeah.

**The Chair:** Okay.

The other question I wanted to ask. I'm not familiar in detail with the legislation, but what about provisions in other statutes that protect information? For example, in the case of mental health I believe that a patient must provide explicit consent to one of a number of designated mental health professionals – say you use a psychiatrist, for example – in order for that person's medical records from the psychiatrist to be released to another professional. Would that protection still apply? Perhaps based on your earlier answer it would because we'd be talking about in-house records of a physician, but I wanted to make sure, particularly in the case of mental health.

**Ms Miller:** We treat all records the same with the same degree of protection. We have been reminded many times by providers that what one views as particularly sensitive may be viewed very differently by another individual, so our approach has always been that we treat all data the same, be it mental health data or sexually transmitted data or my lab result. Often you can look at a lab result and determine many things without having an official diagnosis of a sexually transmitted disease, as an example.

If I understood your question correctly: are there going to be any special provisions for mental health data?

**The Chair:** Well, are any existing special provisions for mental health information untouched by this legislation? Perhaps I'm wrong – Mr. Chamberlain will correct me – but do I not need to sign a release form for a psychiatrist in order for him to release my patient records to another professional?

**Mr. Chamberlain:** To be honest, Mr. Chair, I'm not familiar with

the specific sections you're referring to. Mental health information to the extent that it's provided by publicly funded psychiatrists or in RHA facilities is caught by the Health Information Act. The changes we're proposing are not making any consequential amendments to any other provisions, and the HIA rules are subject to any other enactments. So if there are provisions like that, we're not purporting to affect them. But I'm not familiar with the specific one you're referencing, Mr. Chair.

10:55

**The Chair:** Thank you.

**Ms Blakeman:** Picking up on that, then, if someone was privately engaging and not paying for this through the public system right now, their records would not be even sought to be put on an electronic health network. However, once this change in scope goes through, for example, a privately paid-for psychiatrist's records would be sought to be put on, and the individual's request that their psychiatric records not be disclosed is only going to be in play if they actually disclose outside of that arena, but that information will be shared widely with any custodian that's in the arena.

**Mr. Chamberlain:** Just to clarify, Ms Blakeman.

**Ms Blakeman:** Please do.

**Mr. Chamberlain:** You're correct in that that information, that increased scope, would bring that privately paid health information, assuming we expand to include that information by regulation, within the Health Information Act, so it would be governed by all of those overarching principles we've spoken of.

There is a distinction between the act, the Health Information, and what goes on to the EHR. Whether or not that information is actually put up on the EHR would depend on the psychiatrist determining whether or not it was appropriate to have that information put up on the EHR and whether or not the ministry determined that that was essential information that needed to be put on to make the record complete and accurate. But there is a distinction. The fact that they come under the Health Information Act does not necessarily mean that the information goes onto the electronic health record.

**Ms Blakeman:** Okay. At this point I would find it very helpful to get some kind of listing of what would be considered and would usually be put onto a health record because we're now digging deeply enough here that I don't understand what you're talking about anymore, and I need some clarification.

I'm wondering also if you can explain data matching, particularly around individually identifying health information.

**Ms Miller:** I'll give a deputy minister's answer on data matching. It's a very technical undertaking. Basically, it's typically done for either management or research purposes. What has to occur is that if we do the most simple form of data matching, you have two databases that will have been managed for whatever reason, under separate custodians perhaps, or it could be under the same custodian, but there are simply two databases. Because every person has a health number, hopefully it has been recorded in each of the databases. In some cases not because of some of the old environments we're dealing with, but let's assume they are. So what you have to do is match Linda Miller's record in database A using variables such as my age, my sex, my name, if all of those things are in a particular database, with like variables over in the other database.

Now, often you'll find that because we're dealing with two, and often it is many more than two, what has been collected in this database versus that database is not consistent, so you look at the different variables to make those connections. The person building that what we call crosswalk has to do that on an identifiable basis. Therefore, it is done with the closest of scrutiny in terms of who has access to do that. But once they've done the match, we then have the ability to anonymize that matched data, if you will, and then often that is the data that is released for research purposes.

**Ms Blakeman:** The anonymous information or the matched information?

**Ms Miller:** It's matched, but it's anonymized.

Now, there are cases where identifiable data has to be released based on the research question and the approval of ethics boards, et cetera. But most research, we believe, can be undertaken through an anonymized process.

**Ms Blakeman:** In other words, it's taking identifiable information about an individual in one database and finding the same individual on a second database and putting the information together.

**Ms Miller:** And then anonymizing it before it's released wherever possible.

**Ms Blakeman:** Can you also explain the lockbox concept?

**Ms Miller:** Do you want to go ahead, Mr. Brisson?

**Mr. Brisson:** The lockbox in the concept: within masking, I guess, is one example we could use. We would lock the record for you based on some sort of identifier or some sort of acceptance to open it only based on this categorization. Let's just say that in some jurisdictions in the world we've seen them use cards where if you lock your record, that provider can only open that record with your consent. You'd have to swipe that card on a machine, and they would swipe on the same machine to open the box. It would mean that any provider using the information without the patient in their presence would not be able to open that record and ergo would not be able to see the information. That has administrative issues for physicians, other providers, and administrators within the health system that would make it very impractical.

**Ms Blakeman:** But it does actually lock off people's information without their being present to be able to give permission for it to be used and disclosed.

**Mr. Brisson:** Correct from a technology perspective, although depending on how the policies or regulations are developed, that still technically could be opened depending on how you implement the solution. But, yes, that would be the intent where lockboxes were originally considered.

**Ms Blakeman:** Thank you.

**The Chair:** Other members have questions? Any members on the phone?

**Ms Pastoor:** Yes. Via mike Bridget speaking.

**The Chair:** Could you speak up just a little more, please? [The

teleconference connection with Ms Pastoor was lost] Maybe we can try to get her back.

I wonder if I could just ask you to comment generally on this, if you will. When you consider the development of data repositories and the opportunities that would present, it would seem to me that one of them that would be very important is the ability to identify population health trends within specific parts of the province, say, perhaps ideally even within a primary care network.

I'll use chronic disease as an example, diabetes. We know, for example, that Capital Health, I believe, over the last couple of years has had the ability to monitor A1c levels, which is an indicator for type 2 diabetes, in the lab results for people who have received those blood tests. That, in turn, has potentially given them the opportunity to intervene with those patients at an earlier stage and in many cases prevent them developing full onset type 2 diabetes. Is part of the intent behind this to allow us to identify other population health outcomes and to perhaps intervene sooner and thereby reduce the incidence of some chronic disease or at least the severity of it?

**Ms Miller:** I'll start the answer. Absolutely. I mean, the scenario you have is currently defined as more of a use provision. Just to take that one step forward in terms of our wanting to facilitate greater access to the data for research purposes, the ministry receives a number of requests every year for access to data for strong research reasons. For the ability to respond to those requests, the first place we go to is the Health Information Act. In some cases we're not able to respond as fully as they need because, one, they maybe have a database that's very relevant to their research question, but we the ministry cannot collect that data within our environment, yet they want to use the database that they have collected or know somebody else has and access several databases within Alberta Health and Wellness.

**11:05**

That continuum of care, those longitudinal studies for research purposes where you could do the matching and then anonymize the data across the different databases, needs to be facilitated so that we can do population-based research.

Also, the concept of introducing research agencies will in our minds facilitate in the future allowing certain organizations to help Alberta Health process the number of research requests that are out there and reduce the time that it has taken to date in terms of being able to respond to research questions. Many other provinces have an ability to do this, such as Manitoba, and I know that a number of researchers in this province have been searching for models like that so that Alberta's wealth of data we've collected can be leveraged and used to improve the health system and the outcomes for individuals within Alberta in a much more timely way, shall we say.

**The Chair:** Thank you.

I think we have Ms Pastoor back on the line now. Bridget, are you on the line now?

**Ms Pastoor:** Can you hear me now?

**The Chair:** Yes, we can.

**Ms Pastoor:** Okay. Sorry. I thought I had it on hands free, but I guess it wasn't.

Is it my turn?

**The Chair:** Yes, it is.

**Ms Pastoor:** Okay. Thanks. A couple of concerns. Say I'm in a

car accident, and I end up in ER. I'm just not sure how much time that ER doctor is going to have to check through this massive amount of information that's going to be in my complete record. I don't think that the holistic approach is actually taken in the ER. I think they deal with what they're looking at at the time. All of this other information is now out there; I'm just not sure that I really understand why that would all be necessary.

The other thing is that when you speak of research agencies, what would an insurance company be considered when they need that research to do their amortization rates, when they need that information?

**Mr. Brisson:** Within the ER context Netcare right now has that key information you need on an individual. It won't have everything for the past 20 years on the record there; it'll have the last, for example, four to six months of your key lab results, some of your diagnostic imaging, up-to-date demographics, and your drug interactions. It has that key information. When we talk about completeness, we talk about the robustness of the data in there and additional information that'll go in that'll help with the completeness of that record, perhaps around immunizations, where you'd have reactions to them, increasing along those areas. The 20-year history would not be in Alberta Netcare in the portal view. We could go back to some of the other source systems to pull more information.

From an ER context, when they do come in there, they look at: do I have the right person? They look at drug interactions, reactions, if you had a lab test in the last two weeks, those types of things, so that they're not redoing some stuff. It's that key information right away at point of care; it's not everything of all time.

**Ms Pastoor:** Could I just pick up on not redoing lab work within two weeks? Is that what you're saying? I probably could support that from some point of view, but I'd just like to use a personal example. I went from one dentist's office to the other, and within 10 minutes I had two X-rays because the other dentist didn't like the X-rays that I got from the first dentist, which to me was bizarre.

**Ms Miller:** That's one of the reasons we'd like to expand it to other providers, such as dentists, so that we can reduce the amount of duplication. It will never eliminate it.

**Ms Pastoor:** Well, I'd taken the X-ray with me.

**Ms Miller:** Oh, I see.

**Ms Pastoor:** I know it's another whole issue, but I mean it's this business of redoing a lot of stuff for nothing.

**Ms Miller:** Yeah, a lot of duplication does exist in the system. It does, I suppose, speak to the matter of trust between providers and just past practice. I can't comment further on that, but I think we have found evidence – many providers that have had access to the electronic health record for some time have spoken quite eloquently, in my opinion, in terms of how it's changed how they practise on a patient-by-patient basis and look at the most recent history of a record and only dive deeper if they need to. It has avoided repeat tests and the time lag that that creates when you're waiting to get the next result in. If we've got the most recent result there, many providers that have experience with the electronic health record would look to that result rather than reorder it.

**Ms Pastoor:** Okay. My other question was regarding research agencies. Insurance companies could then well be considered

research agencies because they need that information to do their own research in terms of amortization: how much it's going to cost, et cetera, et cetera. That goes back to a comment that Ms Blakeman made about the commercialization of information.

**Mr. Chamberlain:** If I understand the question correctly, it's about insurance companies doing research. Insurance companies do research now. There are research provisions under the legislation. If they are doing research for amortization purposes or otherwise, they normally use nonidentifying information, in which case the act allows custodians to provide them with nonidentifying information. If they're utilizing identifying information, requesting that from custodians, like any other organization doing research they would have to go through the research ethics board provisions in the Health Information Act. So there's no change there. Insurance companies do a lot of their own amortization work with their own clientele's information, which they do through consent that they get when you sign up for an insurance policy. I'm not really sure that there's any change at all here with respect to insurance companies and the activities that they currently conduct.

**Ms Pastoor:** Okay. Let's reverse that, then. Would the medical side be interested in accessing the insurance companies' databases? Some of that would be, you know, maybe across provinces, et cetera. Then is this reciprocal, database exchange?

**Mr. Chamberlain:** The insurance companies would be bound by different legislation. So if a primary care network or whoever was looking to get information from an insurance company, they would have to comply with the Personal Information Protection Act requirements. To be honest, I can't speak to those specifically off the top of my head. To the extent that it's nonidentifying information that a physician or a researcher was looking for from an insurance company, there would be no restrictions on it.

**Ms Pastoor:** Okay.

I'm sorry, Fred. Do I go back to the bottom of the line now? I can't see sort of what's going on.

**The Chair:** No. Go ahead.

**Ms Pastoor:** I just have one more. I spoke with a chiropractor this morning. One of his concerns was that as a chiropractor he had identified what he felt was a medical condition and the patient had said: yes, here's my doctor. So he phoned the doctor, but the doctor said that he couldn't discuss anything. It left two professionals unable to speak to each other because of freedom of information and client privilege. If this doctor now thinks, "Okay; well, maybe there's something I should be looking up," would he be able to punch in to his machine and pull up his patient? What would he pull up? Would he pull up anything from the chiropractor?

**Mr. Chamberlain:** I can't comment on the specific scenario and why the physician felt he could or couldn't discuss specifics with patient consent. They certainly could have. You've actually highlighted one of the problems that we are trying to address, which is that chiropractors operate both in the publicly funded and in the privately funded world. The Alberta health care insurance plan does provide some basic chiropractic coverage, which would make it a publicly funded service, but a large chunk of the work chiropractors do is in fact private. It's paid by private insurance or by patients directly, which means that it's outside the Health Information Act world. So when you have a physician dealing with a chiropractor,

his concern, I suspect, is that he's not dealing with somebody who's working in the same arena he is because for the information he gathered, if it was done on a privately paid basis, the chiropractor was not a custodian for those purposes. So he's not within the arena. That's the concern we're trying to address by getting all of the health information into a common scheme so that whether or not this doctor was correct in not discussing, we make it clear to all professionals that they're all operating under the same legislative scheme.

**Ms Pastoor:** Okay. That's it for now. Thanks very much, Mr. Chair.

**The Chair:** You're very welcome.

Mr. Fawcett, followed by Mr. Olson, please.

**Mr. Fawcett:** Thank you, Mr. Chair. I have two questions, and one of them has to do with what Ms Pastoor was just talking about or is similar in scope. We're talking about expanding the scope of the act, I guess, to allow for a more complete electronic file of individual patient records. What does that do, I guess, from a liability standpoint? Is there an expectation on health providers that they're looking at these to make their diagnosis, and if they're not, is there any sort of liability now that they do have access to this expanded scope of information?

11:15

**Mr. Chamberlain:** Just to clarify, there are two distinct pieces. The electronic health record information you're speaking of is a subset of health information, but there's a determination by the providers and by the ministry on what information needs to be put on an electronic health record. That's somewhat distinct from the scope expansion, which would bring the chiropractor, that we just talked of, within the health information world for all of his data so that he is now bound by the same rules as the physician. That doesn't necessarily mean that the chiropractor's information is placed on the electronic health record.

As for liability, I can't provide legal advice. Certainly, that's something the colleges are going to have to consider, as to what appropriate standard of care is. If a physician or a pharmacist or whoever is considered by the courts to be negligent for not taking advantage of information sources that are now available to provide better health care, then certainly there's a possibility that there could be liability flowing from that, no doubt.

**Ms Blakeman:** But not specific to this legislation.

**Mr. Chamberlain:** Exactly. This legislation doesn't create that, and you'd get the same argument now if you have a pharmacist who's not taking advantage of the resources that are available on PIN. If a court were to determine that that was not meeting the required standard of care, that may expose them to liability. The intent here is to provide a more complete and accurate record so that we get better patient care, that we do address adverse incidents, that we don't get confusion around identification or the drug interactions that Mr. Brisson talked about in place. So there's a balance: better care, yes, greater liability. That's because more information is available to provide that better care.

**Mr. Fawcett:** My second question is just more of a clarification. Essentially, one of the purposes is, as mentioned on page 12 of your presentation, to refocus protection on individuals' health information. It talks about removal of health services provider information from the act. You mentioned that that would be covered under the

Freedom of Information and Protection of Privacy Act and the Personal Information Protection Act. Everything that is being removed will be encompassed or is encompassed within those acts already, so it's more of a redundancy that we're removing than anything.

**Mr. Chamberlain:** The Personal Information Protection Act and FOIP cover personal information in the hands of public bodies for FOIP and other organizations. So to the extent that those do provide protection for personal information of professionals, whether they're health professionals or other professionals or individuals, those provisions are there. Are they exactly the same as the Health Information Act? No. But the intent was to make the act focus on patient information because that's the scheme and to ensure that health providers get the same protection that every other individual and professional would have.

**Mr. Fawcett:** Okay.

**The Chair:** Thank you.

**Mr. Olson:** My question is, I think, just at a very practical level, but it's something that occurs to me as being a person who's always a little bit nervous about not having a piece of paper in my hand. Maybe the nature of my concern isn't because of the amendment. It probably would be there even without the amendment. What are the protections in place in case the system fails? If all of this information is stored electronically somewhere, you know, how are we protected from that information being lost in some sort of a catastrophic incident?

**Ms Blakeman:** Lost rather than accessed.

**Mr. Olson:** Yeah, gone.

**Mr. Brisson:** To try and not get too technical, in the architecture diagram I provided you, I showed you a number of systems and a number of databases. All of those databases are backed up in secondary data centres. We provide a certain amount of redundancy in the system such that as these are clinical systems, they need to be available 24/7. All of the changes made to applications are done through different what we would call change windows such that we have them backed up each time. So if one part of the system goes down, the other part of the system is brought up from that backup or secondary data centre. Without getting into more technical context, that's the approach we've put forward. Included in there would be that all of the audit and security provisions are backed up as well in each of those different systems.

**Mr. Olson:** So if there is a huge storm that wipes out all the power in the centre where this stuff is located, somebody elsewhere in the province is still going to be able to access the information they need?

**Mr. Brisson:** That would be leaning me towards more of a disaster recovery plan. If all of the power in a certain grid of the province goes out, if you don't have power coming into your systems, they're not going to come up. However, if other parts of an integrated health system are working, if we have telephones backup from disaster recovery, we should be able to access that electronic information if it is stored and integrated across the whole system. So there's backup and redundancy of your information, and then there's disaster recovery, both of which are tied together, but it would depend on the instance that you're faced with.

**The Chair:** Thank you.

Are there any other questions from members here in person or members on the phone?

**Ms Pastoor:** Yes, if I might. It's Bridget again. Who actually is doing this system? Who at this point in time is in charge? Let's just pick two or three. You're saying that you're trying to merge these different data systems. Which companies are actually in charge of doing this?

**Ms Miller:** Many. The ministry is responsible for the strategic plan. The ministry also provides core systems to the provincial electronic health record, such as the registries, for all Albertans that have access to the system, a provider registry, all providers that have access, et cetera. We also manage the pharmacy information network. However, Capital health does manage on our behalf the portal, that top picture, the one provided by Mr. Brisson, but they do that on our behalf and under contract. The various databases that are in the middle part of that diagram may be held by either Capital or Calgary for the most part. The point-of-care systems, the line at the very bottom, are held now by the Alberta Health Services organization for the most part or the pharmacists or the physicians within their own particular environment. So there are multiple people working on this, shall we say.

**Ms Pastoor:** Okay. What are the companies that have the contracts?

**Ms Miller:** I can speak to the ones that have contracts predominantly with Alberta Health and Wellness. In terms of new development it's CGI at this point in time. IBM has had contracts for major development in the past.

**Ms Pastoor:** Are these strictly in Canada, or are we talking American companies as well that go across the border?

**Ms Miller:** Many of them have an American base. Not all do, though.

**Ms Pastoor:** Then my next question would be: does the PATRIOT Act cut in, the information that they have access to in another country?

**Ms Miller:** I'll let Mr. Chamberlain answer that question.

**Mr. Chamberlain:** The PATRIOT Act is the PATRIOT Act, and it does apply. Changes were made to the Health Information Act and FOIP in I believe it was 2006, based on recommendations of the Privacy Commissioner, to amend the legislation to provide that disclosure of health information pursuant to a court order had to be a court that had jurisdiction in Alberta, to try and provide some protection with respect to the PATRIOT Act. These amendments don't impact on that issue at all.

**Ms Pastoor:** So, in fact, the Americans actually would require a warrant to be able to access our personal health information.

**Mr. Chamberlain:** I don't want to pretend to be an American expert. The PATRIOT Act allows orders to be issued to companies with American bases to provide information to the government for security purposes.

**Ms Pastoor:** Without warrants, right?

11:25

**Mr. Chamberlain:** I believe that's the case. There is a court oversight provision in there somehow, but I'm not an expert on it. The Health Information Act amendments provide that in order to disclose information pursuant to any kind of order like that, it has to be an order that's recognized by the courts in Alberta. That was the privacy commission's recommendation, to try and provide some Alberta oversight in that regard.

**Ms Pastoor:** Right. Okay. So even putting the PATRIOT Act aside, how does NAFTA fit into that when, in fact, some of the rules of NAFTA would certainly overrule anything that Alberta would try to legislate?

**Mr. Chamberlain:** I'm not sure that NAFTA has any particular application in this sense.

**Ms Pastoor:** Okay. All right. Thank you.

**Ms Miller:** Could we just expand? We have contracts with those companies, and in those contracts we require them to do the work locally, i.e. in Alberta, and access the data and keep it in Alberta.

**Ms Pastoor:** Thank you.

**The Chair:** Thank you.

I don't have anyone in addition on the speakers list unless you have any further questions, Ms Blakeman.

**Ms Blakeman:** Well, as part of some of my questions I'd asked for some information, but I'm aware that individuals cannot request information and that it needs to be a committee decision to request information, so if you're about to release these good people, I'm wondering if, before they leave, we could decide whether they can provide us with the information that I requested.

As a reminder, the information I was looking for was a much more detailed description of what kind of information gets loaded onto the electronic health network as compared to what's actually in existence in the various databases. There were a couple of conversations about: well, they may have that information, but it may not actually get loaded onto Netcare. I'd like to get some idea of the difference and what steps or protections are in place to decide whether your example of information, a psychiatrist's records, gets onto that electronic health record that gets brought up in the ER when the person has a car accident. I don't understand how that works, so I'm trying to get an idea of a listing of how they choose or what tends to get on that list in the electronic health record.

**The Chair:** Okay. Certainly. The way we'd like to proceed is that the committee's research needs are serviced, as you know, by the LAO research staff. The staff are free to request information from the department, so my suggestion was going to be that we come back to the research list under other business, and then we could add to it at that time.

**Ms Blakeman:** Okay. Sorry.

**Ms Miller:** Mr. Chairman, could I just add that we can certainly provide a list of the kind of data elements today that are put on the provincial electronic health record. What we can't provide is an exhaustive list of all the data that's out there in existence.

**Ms Blakeman:** No. I just need to know some sense of what's there.

**The Chair:** Yeah. We'll have the discussion, and we'll refine our request, and it will be forwarded to you through the LAO research staff.

**Ms Blakeman:** Okay.

**Ms Pastoor:** Mr. Chair, I'm sorry. Just another question has come to mind. Might I ask it?

**The Chair:** Absolutely.

**Ms Pastoor:** Okay. Thanks. My question is that the other day – it would be about three weeks ago – for some reason something popped onto my computer asking if I wanted to check my credit rating, and I thought: why not? Clearly, I had nothing to do that day. Anyway, I thought: "Okay. Fine. Why not?" because I haven't done it. I couldn't believe the inaccuracies in there. For this health record will I be able to however say, "I want to look at the data you've got to see how accurate it is"?

**Ms Miller:** Yes. I mean, that's the personal health portal, which is our next stage of evolution, that we want to and are beginning work on so that every Albertan can in reasonable time look at the data that the providers are looking at, although presented in a view that's understandable, and then, obviously, make a notation when you're concerned about something that may be there or not or some perceived inaccuracy.

**Ms Pastoor:** And I would also, then, have access to who had accessed my record?

**Ms Miller:** We haven't worked that through, but yes, you have access today. As I commented, you can ask . . .

**Ms Pastoor:** But would it tell me who accessed my record if it wasn't me, who else has used it? You know what I mean?

**Ms Miller:** Yes, I understand. You can do that today. It would be provided to you, though, in a paper copy. If your question is "electronically can you one day take a look at exactly who has accessed your record?" yes, probably to the degree of the type of custodian that has looked at your record. Would it be by every individual's name; i.e., every nurse in the hospital on ward whatever that you were admitted to? Likely not. We would likely provide it at the custodian level.

**Ms Pastoor:** Right. Thank you.

**The Chair:** All right. Well, on behalf of the committee I'd like to thank you, Ms Miller and Mr. Brisson and Mr. Chamberlain and Ms Robillard, for being here today. The briefing, I think all the members will agree, was extremely helpful, and I appreciate the very detailed answers to our questions. Thank you again. Thank you for your time.

It's 11:30, and I understand that lunch is already here. Our next scheduled presentation, as you know, is at 1 p.m., so we'll stand down, then, until 1 p.m., at which time we'll reconvene. Thank you very much.

[The committee adjourned from 11:30 a.m. to 1:03 p.m.]

**The Chair:** Good afternoon, colleagues. We'll call the meeting back to order. I believe we're still waiting for Ms Pastoor to join us. She indicated she'd likely join us in progress.

I'd like to welcome Mr. Frank Work, Information and Privacy Commissioner for the province of Alberta. Good afternoon, Mr. Work. Thank you for being here. Also, welcome to Mr. LeRoy Brower, director of the Health Information Act. Mr. Brower, it's a pleasure to have you here as well. Thank you for coming.

Mr. Work's presentation, I think, is going to run in the order of 15 minutes or so. Following that, we'll have an opportunity for questions and some dialogue with the committee.

Mr. Work, just before we start, I'll ask my colleagues and the staff here to introduce themselves, beginning with Mr. Dallas.

**Mr. Dallas:** Thank you. Cal Dallas, MLA, Red Deer-South.

**Mr. Vandermeer:** Tony Vandermeer, MLA for Edmonton-Beverly-Clareview.

**Mr. Olson:** Hello. Verlyn Olson, Wetaskiwin-Camrose.

**Ms Blakeman:** Laurie Blakeman. I'd like to welcome you all to my fabulous constituency of Edmonton-Centre.

**Ms Friesacher:** Melanie Friesacher, communications consultant with the Legislative Assembly Office.

**Ms LeBlanc:** Stephanie LeBlanc, legal research officer with the Legislative Assembly Office.

**Mrs. Kamuchik:** Louise Kamuchik, Clerk Assistant, director of House services.

**Ms Dean:** Shannon Dean, Parliamentary Counsel.

**Mr. Fawcett:** Kyle Fawcett, MLA for Calgary-North Hill.

**Ms Norton:** Erin Norton, committee clerk.

**The Chair:** I'm Fred Horne. I'm the chair of the committee and MLA for Edmonton-Rutherford. On the phone: Mr. Denis, are you there?

**Mr. Denis:** Yes, I am, Chair. Thank you.

**The Chair:** Okay. Jonathan Denis is the MLA for Calgary-Egmont. Our deputy chair is on the phone, I think, as well.

**Ms Pastoor:** Yes, I am.

**The Chair:** Bridget Pastoor, MLA for Lethbridge-East. Please proceed when you're ready, Mr. Work.

**Mr. Work:** Thank you, Mr. Chairman. By way of preliminaries, two things. First, let me say what a pleasure it is to be here and to participate in this process. I've been associated with the Legislative Assembly since 1991, and the process that you're conducting with respect to this bill I just think is outstanding. I'm delighted to see Alberta proceeding in this direction; that is, having committees like this review legislation like this. Whatever misgivings I may have about the particular subject matter, I welcome this process heartily.

The second thing is that I just returned from holidays on Sunday, and my staff were a bit behind the eight ball. They prepared a written presentation for me, but I wasn't able to review it and give them final instructions in sufficient time to give you advance copies, so I apologize for that. But I will make my remarks, and then with



your permission, sir, we'll leave copies with you for the committee. I do apologize for not being here to get those out in advance.

I was actually going to more or less read my presentation into the record, but just on the way over here I had a bit of a change of heart. I'd like to talk to you a bit about the Health Information Act and my experience with it. This will encompass the concerns I have about Bill 52. I'm troubled by Bill 52. I'm deeply troubled by Bill 52 in a lot of respects.

In 1999 Mr. Halvar Jonson was minister of health, and they brought in the first draft of the Health Information Act. He wisely brought it in, introduced it, and then referred it to a steering committee, knowing full well that this was a huge step for Alberta. I mean, we've always described the Health Information Act as creating the arena whereby health information goes into the arena and the ticket holders that get into the arena are the health care providers. Once inside that arena, health information moves very, very fluidly. There are really very, very few impediments or checks and balances on the flow of Albertans' health information inside that arena, so that arena has to be a guarded place. It just has to be, both for reasons of security – you know, you don't want leaks in that arena – but also for reasons of confidentiality and privacy. This is relevant, Mr. Chairman, most of all for the confidence of Albertans.

After Mr. Jonson introduced the first iteration of the bill, it was sent to a steering committee that was chaired by Mr. Ron Stevens, and the then commissioner, Bob Clark, asked me to sit on the steering committee. The steering committee was quite interesting. It had some MLAs, had some docs. I think there were some pharmacists. There were some health care administrators; you know, people that were running health boards and stuff. We reviewed the bill, the Health Information Act, very thoroughly. We all knew that this was pretty radical stuff, and there weren't a lot of other provinces that had gone this step at the time.

We knew the importance of it to the health care system. Someone somewhere who initiated this legislation knew enough that electronic health records and electronic patient records were going to be critical to the maintenance and the efficiency of our health care system. I believed that to be the case then, and I still believe it to be the case. The use of electronic technology to facilitate the necessary information flows in our health care system is critical.

But, as I said, there was a leap of faith there. Suddenly the kind of control that you as a patient could exert over your health information when it was a sheet in a filing cabinet was quite different than the kind of control that you can exert when your information is a bunch of ones and zeros that can be instantaneously transmitted to a million different places. So it was radical.

#### 1:10

It was radical. In fact, I remember that after the Health Information Act was passed on the recommendation of the committee, the Privacy Commissioner, Bob Clark, for my sins made me assistant commissioner, and one of my responsibilities was the Health Information Act. I did a lot of speaking, and there was a lot of interest across the country about this fairly bold, new step that Alberta had taken. I'll tell you that I would do presentations across the country, especially in B.C. and Ontario, and on occasion there would be people in the audience when questions would come. One chap I remember in particular got up and said, "You sir," speaking to me, "are an accomplice in the theft of Albertans' health information, and you should be prosecuted." This guy wasn't a loony-tune. He was a very educated, knowledgeable individual, and he was mad. He said: you are an accomplice in the receipt of stolen goods, and that is the health information of Albertans. I often heard that.

Now, this is 2001, 2002 kind of time. Over the years the rest of the country more or less caught up with Alberta, and most of the other provinces either have or are bringing in specific health information legislation. I tell you this, Mr. Chairman, because at the time the HIA was innovative, but it was radical and it was hot. A lot of people were worried, frightened, you know: "What does this mean? Is everyone going to see my information? Is everyone going to know that I'm on medication for this? Is everyone going to know that I tried to commit suicide?" Now, I guess, people maybe are not as concerned about those things generally. Some probably are, though. I think we understand better the way the Internet and things like that work, so we're sort of less concerned that once your information goes into a database, it suddenly goes everywhere. We know better now, but there still is the concern.

The office of the Information and Privacy Commissioner not only went along with the HIA by being on the steering committee. Also, in I think 2003 there was a provision in the act that said that before you can disclose someone's health information by electronic means, you had to get their consent. In 2003 Alberta Health and Wellness and other people said to us: "You know, this is really unworkable. It means that to create an electronic patient record, we have to get everyone's consent, and our focus groups and so on indicate that most people are okay with this," and that made sense.

I wasn't commissioner at the time, but we went along with that, and I fully went along with that because we understood the importance of the electronic records to our health care system. But we also knew that this was one of the provisions that did give people a little bit of control over the act. It was a tough trade-off to say: "Okay. Let this consent provision go." The consolation was that there were still other provisions in the act that gave people a role, and it is a role. I mean, there is no doubt about the needs of the system; you know, that *Star Trek* thing that the needs of the many outweigh the needs of the individual or the few or something.

There is no doubt that for the most part we exert very little day-to-day control over our health information, and I still believe that is as it should be. I go to my GP. He orders tests. He shouldn't have to ask me for my consent to order the test or for my consent for the test results to come back to him or for my consent for the test results to then go to the specialist or to the surgeon. I mean, I don't see the need for individual control. Some people still do, mind you. I still get fingers shaken at me when I go places. But for the most part we've relinquished control for the good of our own health and for the good of our system.

But we still need to be more than numbers. I really believe, Mr. Chairman, that there still has to be some element of control in this, even if it's just for one or two people, some way of recognizing individual sensitivities and sensibilities. We can't all just become numbers here. I'm very concerned that these Bill 52 amendments will remove, really, the last two vestiges of individual – and I almost hesitate to use the word – "control." They'll remove the last two means by which an individual in Alberta can assert their wishes over their electronic patient records, electronic health records. That really troubles me. That really bothers me because we've had the faith and the good will of Albertans to date, and we've done amazing things. My office has been involved throughout the development of, first, Wellnet and then Netcare. Alberta I think is acknowledged nationally as the leader in terms of developing the electronic health record, the electronic patient record.

We have had the goodwill and the trust of Albertans to date. I mean, part of that is because we've traditionally done the right thing. Part of it is because – I like to take some credit – my office has performed its job as watchdog. We hear the complaints that people have or their fears that their information has been misused. Two

years ago we prosecuted, for the first time, an individual that had surfed another individual's health records, and we obtained a conviction and a hefty fine. I mean, we've won the trust of Albertans in that regard. I honestly believe that we need to maintain that trust. Both for actual reasons but also for symbolic reasons we have to be able to tell Albertans: you still have a role in this, you still have a place here, and if your concerns are serious enough, there's a way you can assert them. One of the main ways is section 58(2), which simply says that a health care provider must consider the wishes of a patient before making a disclosure of their health information.

After my office got a complaint last year, Leahann McElveen, one of my investigators, did a report. It involved a patient and a pharmacist. The patient didn't want the pharmacist to disclose some information of hers. It's a very good investigation report. If you're interested, it very thoroughly describes how Netcare works. The pharmacist basically said to the patient: "I'm sorry. I can't help you. There's nothing I can do. I have to disclose your information as required by the minister."

Now, remember that the act doesn't say that the doctor or the pharmacist in this case has to do what the patient wants, right? It's not a matter of that. You just have to take that into consideration. Our investigation report determined that the only way a health care provider can take someone's wishes into consideration – and, again, they don't have to. The health care provider could say: well, I hear you, but all things considered, I can't do as you want. If they do want to accede to the patient's wishes, the only way they can do that is through masking. That's it. As far as we can tell from the act, the only way that section 58(2) can be given effect is if the health care provider can then put a mask over that piece of information. If the masking goes, it's our view that section 58(2) becomes meaningless. You might as well repeal that, too, because it's a hollow promise, then.

I'm not sure what the rationale is for wanting to repeal this. I haven't heard whether it's money, administrative convenience, exactly what it is. On the basis of what we know about health information technology, this can be done, and it is done in many of the systems that are operating in doctors' offices today, this masking feature. So I'm waiting to hear a really strong argument about why this masking feature has to be taken away, but I can think of a whole bunch of arguments why it shouldn't be taken away. I'll come up for air.

*1:20*

The other piece that troubles me greatly in Bill 52 is sort of a simple change. The bill will simply change that when health care providers exchange information, instead of being a disclosure – like, for Mr. Brower and I, I'm the specialist and he's the GP. When he gives me patient information, right now that's a disclosure, so it has to be logged. The patient can ask for a list of the disclosures of their information. What Bill 52 will do is turn that transaction into a use. There are some logical reasons for that, but by turning that into a use, it means that that event, that exchange of information will no longer be available to the patient. So what? Will most patients care? Most people in the health care system just want to get well, right?

You know, I've been a patient, as probably most of us have, and when I'm a patient, I'm not worried too much about where my information is going. I'm more worried about my outcome. You know: "Make me well. Tell whoever you need, but make me well." That's true, but after the fact and on a day-to-day basis the ability of the individual, if they want to or if they're suspicious, to find out who has had transactions with their information I think is very critical.

I foresee that losing that ability for an individual to get that disclosure log could increase the work for my office considerably. Right now if someone has a suspicion that someone's been surfing their records improperly, they can ask for a log – right? – and say: "Okay. Yeah, those are all right. I went to that doctor and so on." If that's not available, their only recourse is to come to us and lodge a complaint based on whatever vague suspicion they might have. Then we will investigate it, and we will get the information because by statute we can have access to that. But I foresee this causing not only issues for patients but also for my office in terms of work.

I've gone over the time I said I would take. The last thing is with the repositories. I'm less foaming at the mouth over those. Well, I'm not foaming at the mouth over anything here, but the concern we have about the repositories is that health research is good; health research is critically important; health research saves lives and saves a lot of money. To the extent that these data repositories can do, you know, longitudinal kinds of research with a very healthy, full set of data, it's a good thing, but these repositories have to be accountable. I mean, they will be in a position to get huge amounts of Albertans' personal information, and to do a lot of this research, it won't just be health information. Of course, the researchers want to link occupational issues or social issues or education to health. This is the way the world is: you try to get as broad a look at the causes of health events as you can. So these repositories will be in a position to have a tremendous amount of information.

I just feel that the state of Bill 52 in terms of dealing with these repositories is not satisfactory. Too much is being left to regulation. I'm not opposed to the notion of the repositories, but I'm very concerned that a lot of the aspects of these repositories, their accountability aspects, should be in legislation and not done by regulation. So, not opposed to the repositories in principle but concerned that a lot of what they do should be governed by statute, not by reg. As Bill 52 stands, almost everything to do with them will be done by regulation.

I think that if I said anything more, it would just be bludgeoning the subject to death. I'll thank you again for listening to me and be happy to take any questions.

**The Chair:** Thank you very much, Mr. Work. I think we have a number of questions for you.

**Ms Blakeman:** The issue of masking came up this morning, and I actually asked the question: well, why don't we just dump it? What I'm finding out is that although the masking provision exists, the way it is currently implemented, or my understanding of this – and I could be corrected – is that almost any request by a health service provider to unmask the information is acceded to. I believe that people can be misled as to how much their information is actually protected with this masking procedure. That's my problem. I'm going back and forth between your point of view, which is where I originally came from, and going: well, are we just misleading people by leaving that provision in place right now? The way it is, anybody that asks to, in quotes, break the glass and see that information is evidently being granted that information, or access to that information. People think their information is protected, and it's not. Are we misleading people there? I don't know if you have a comment on that, but one of the concerns I'm seeing is that dilemma.

**Mr. Work:** I'm in somewhat the same boat you are. Well, I am in the same boat, not somewhat. I am in the same boat you are in that I don't have first-hand knowledge of the technology, but my understanding is that the masking feature can be what the system

designers, administrators want it to be. The system can be set up so that only a physician with certain credentials can break the glass, or it can be set up so that anyone can break the glass. I'm not aware that doing it one way or the other makes a significant cost difference. Someone else would have to speak to that. I don't know. But I do know that the masking can be adjusted to the needs of the system. You just have to tell the system: okay, the following people are the ones that get to take the mask off. That list can be long or it can be short, and you can set criteria for the individuals. You know: here's when you are allowed to take the mask down.

I think that typically, as it stands now, if a physician wants to break the glass, so to speak, they just click on the piece of information, and a little dialogue box comes up and says: "Are you sure you want this unmasked? This event will be logged." You know, something like that, just a caution, and then if they want to proceed, they click through again, and the mask comes down. I think that who gets to break the glass is entirely within the control of the people building the system.

**Ms Blakeman:** Thank you.

**The Chair:** Others?

**Mr. Vandermeer:** You mentioned that the paper system as opposed to the electronic system was a safer system. I think that, you know, if you leave paper around or it's in a file somewhere, anybody can peek in and there's no accounting for who looked at it, whereas with this system of masking it's logged every time somebody does it. They have to be accountable for that. In an emergency situation where a doctor needs to know if this person has a communicable disease or something, he can unmask it, break the glass, and find out what the information is, but he has to be accountable for that, right?

**Mr. Work:** Correct.

**Mr. Vandermeer:** So if a pharmacist does that or a caregiver does that, then you find out and you say: well, why did you break the glass? Then maybe your office would be getting busy because they would be going after people that shouldn't be breaking the glass, right?

**Mr. Work:** Yes.

1:30

**Mr. Vandermeer:** In my opinion it would be a system that works and is more accountable than the paper.

**Mr. Work:** Yeah. I have to agree with you. There are some features of the electronic system that do increase accountability. As you quite rightly said, one of them is that you can keep track of all the users. What I meant by paper records being more secure was that my paper record probably only exists in one or two places – maybe at my doc's office, maybe at a hospital – whereas an electronic record is in a place where it can be accessed by thousands of people. There are 22,000 users of Netcare right now. Depending on the protocols, the fact is that my record is in a place where, arguably, 22,000 different people could access it.

I don't think you and I are disagreeing. I was just saying that paper records had a more limited exposure. You, on the other hand, are quite right that with electronic records you can control who's been in to see them and who's had a look and so on. That's what happened with the individual that we prosecuted last year for improperly accessing someone's records.

But in order for that to work – we've had this discussion with Alberta Health and Wellness on a number of occasions, and I didn't think to talk about this here, which is why your question is really apropos. Catching misusers depends on, I would guess, one of three things, one being that there's a tipoff. You know, they get caught. Someone sees them. "What are you doing in that file?" "Oh." And they get reported or disciplined or reported to us. The patient thinks something is wrong, like: how did my brother-in-law know that I was confined to Alberta Hospital two months ago? And then they start asking. Or the third one is that there's some kind of audit process that you go through. The system does audit all the uses, as you and I have both said and both agree, but that doesn't mean that anyone is looking at the audit logs because, I mean, there are millions of data transactions a year in there. At the present time I'm not aware of any plans to actively audit those logs.

**Mr. Brower:** There is some active audit capability, but it's limited and difficult to manage.

**Mr. Work:** In other words, even though the system does log this stuff, there's no one checking.

**Ms Blakeman:** That's right. It's complaint driven.

**Mr. Work:** Yeah. Exactly. As Ms Blakeman just said, it's complaint driven. I mean, you can do random audits, right? You can have people go and check. But audits are extraordinarily time consuming, as you can imagine, because you have to ask the person, "Well, why did you go into Frank Work's record?" And they'll say: "Well, because he was referred to me. He's a patient." "Why did you go into Frank Work's record?" "Well, because, et cetera, et cetera." Tremendously expensive to actually audit the logs.

You can do famous person audits. You know, if Ms Blakeman is admitted to a facility, you say: "Ah, she's an MLA. Her name is known. Let's check who accesses her records." Of course, people are curious about well-known people. That's another way of auditing. But there's no one, and it's very hard to do to have someone constantly monitoring the logs.

The thing about people being able to get their own log of disclosures is that they can monitor if they do have suspicions. "I think, you know, this person shouldn't know this about me. I'm going to ask for a copy of my disclosure log and just see who might have talked to whom." Maybe they get the disclosure. Maybe they don't bother. They say: that's not worth the trouble. Maybe they get the disclosure log and say: "Well, that person shouldn't have gone into my record. I have no dealings with that individual." Then they can come to us or they can go to the facility manager or whatever and complain, and it gets looked at.

Without that, the only avenue is going to be: if you've got any suspicion, come to the commissioner's office. Well, no, that's not fair. You could certainly still go to the doctor or the manager of the clinic or Alberta Health and Wellness and say, "I think someone is treating my information improperly," and I'm sure they would investigate, but you would have to just do that on a hunch now as opposed to being able to satisfy yourself. Sorry. Another overlong answer.

**The Chair:** Thank you.

Mr. Dallas.

**Mr. Dallas:** Thank you, Mr. Chair. Mr. Work, thank you for bringing a perspective to this legislation today. I think a key word that you hit on very early in the presentation was a focus on the

confidence of Albertans. It strikes me that what this discussion is really about is: how do we find the appropriate balance to maintain and enhance that confidence that Albertans have?

In our constituency offices we're visited by constituents. Sometimes their concerns are around the issues of sharing of information: what information is appropriate to share, and who saw it? Just as often or in fact, I would suggest, more often the discussion is around accountability, about ensuring that complete medical data is shared with appropriate providers of health care services. They're interested in the timely sharing of it, which speaks to the efficiencies around electronic records. They're interested in making sure that all of the appropriate resources are deployed to appropriately affect their health. Of course, some constituents are interested in the amount of public resource that's applied, and they have an expectation about the efficiencies of that.

Given the discussion – and I suppose we would need somebody with some expertise in this area to speak to the subject – I'm struck that at one extreme in terms of the provision of an allocation to afford privacy for individuals, there are some very difficult outcomes that would arise in terms of health care outcomes. Sometimes they might just relate to the acuity of an affliction; other times lives would be at stake. How do we find the balance in looking to provide for privacy, at the same time having an accountability and an expectation that we're doing our best to produce appropriate health care outcomes for Albertans?

**Mr. Work:** Yeah. That dilemma that you pose has always been there, the dilemma between the needs of the health care system and the needs for patient care and either security or privacy concerns. As I said when I recited the history of our association with the Health Information Act, I think Alberta has got it pretty close to right. I think, as difficult as it was in '99, 2001, the very tough decision to basically go the electronic route and take people's information and put it in this arena was the key decision. That was the most difficult decision, surely, where it was just said: I'm sorry, but you're going to have to relinquish a lot of the immediate control over your personal health information, and that's all there is to it. That being established, I think the rest of the equation is: to what extent are we still going to allow people to be individually involved in these decisions?

I was pretty happy with the status quo, with the way it was. I mean, section 58(2) as it now stands, requiring health care providers to take into account the wishes of individuals, I thought was a good provision. The general principles of the Health Information Act – use the least information you can for the purpose; disclose the least – I thought were very strong features as well. What I see now is that the result of Bill 52 will be, in my view, to wreck a good thing. I think it's good the way it is.

You raise an incredibly important point, that I don't think can be overstated: will this in any way interfere with or compromise patient care? You're quite right. That's utterly the primary question. I've never heard an argument either from Alberta Health and Wellness in this particular situation or prior to this. I have never heard an argument that the masking systems that are available threaten patient care. My understanding of them is that they are strictly an accountability feature, and break the glass literally means break the glass. You break the glass, and the information is visible to you, whoever you are. You're authorized to break the glass, of course. So I'm not aware of any issue of: "Oh, my God. I've got this person in emergency, and I can't get into their record." I've never heard that suggested as a result of masking.

*1:40*

**The Chair:** I just wanted to mention as well that Mr. Dave Quest, the MLA for Strathcona, has joined us. Welcome.

Are there any questions from our members on the phone?

**Ms Pastoor:** It's Bridget. I wouldn't mind getting in the queue.

**The Chair:** You're in.

**Ms Pastoor:** Okay. Thank you, Mr. Chair. Just a couple of comments or thoughts that I've had as I've been listening to this. We keep using emergency as the sort of catch-all for how wonderful this system is going to be for emergency. But my question would be: what are the actual, true numbers of people that use emergent? I mean acute-care emergency in the hospitals or even emergent in the office. I'm not just talking about somebody that goes into the emergency with a flu bug or something. I'm talking about a true acute emergent situation.

What would those numbers be as opposed to the number of people who have health records out there that actually are looked after as patients in a perfectly ordinary way? They go to the doctor: blah, blah, blah. Do we have those kinds of numbers? Is this going to really benefit very few versus a huge number of people who are concerned about their health care records?

As far as going to the commissioner, by the time you get to the commissioner, it's after the fact, and it's too late, and sometimes damage has been done to a person's livelihood or, in fact, a person's whole, I guess, personality or how society has viewed them. Then if that's the case, where is the leeway to be able to sue for having your personality or – what's the word I'm looking for? – your reputation, I guess, sullied?

**Mr. Denis:** Are you talking defamation, Bridget?

**Ms Pastoor:** Defamation. Thanks very much. So just a couple of things there.

Also, in October of '08 I believe that the Auditor General's report stated that he felt that the information the government was using was not secure. So there are about three things there that are kind of comments, and perhaps I'd like the comment back from the commissioner.

**Mr. Work:** I'll do them in reverse order because I hope I remember them all. What you say is that the Auditor General did have some concerns about government of Alberta security over access or potential hacking of government of Alberta entities. But he did say in that same report that Alberta Health and Wellness and Netcare were not to be lumped in with the other government of Alberta databases and systems which he was concerned about.

**Ms Pastoor:** Thank you for that.

**Mr. Work:** Yeah. I don't have his report in front of me, so I can't give you chapter and verse, but I'm pretty sure of that.

**Ms Pastoor:** That's fine.

**Mr. Work:** On the matter of numbers of patients, which was your first point, I don't have that information. I'm sure it is available, but my office doesn't have it. Alberta Health and Wellness would probably have numbers on acute-care cases as opposed to ongoing, wellness-type cases, so I'd have to defer to them on that.

**Ms Pastoor:** Just about the fact that by the time someone gets to you, it's certainly after the fact, and there could be a great deal of damage done in that time frame.

**Mr. Work:** Yeah. Absolutely right. That's just the way of the world. Once something is known, you cannot unknow it unless you're like me and forget stuff.

**Ms Pastoor:** What would be the fallback in terms of suing?

**Mr. Work:** Well, unlike Alberta's PIPA, Personal Information Protection Act, which gives you a right to sue, the HIA does not provide a right to sue although that's not to say that you couldn't do it anyway. A court might in some cases say, "Yeah, you suffered damages here by this negligent disclosure of information," and they might award damages. That's certainly open to the courts. But as you say, there's no right to seek damages under the HIA.

That question gives me a chance to say this: human nature being what it is, we all behave a little better when we know we're accountable. I think the fact that people know that if my office catches people misusing the health record, we will prosecute them – and in the one case so far the court dealt pretty harshly with this individual. If people know that (a) they will be prosecuted if they're caught and if they know that (b) the courts take this seriously and if they know that (c) the patient can check and find out, I think all three of those things are good, preventative measures or good accountability features, which will keep those of us who have access to electronic health records just that much more honest and accountable.

**The Chair:** Thank you.  
Mr. Olson.

**Mr. Olson:** Thank you. I just had a quick question about that. Do you have a case citation for where you did prosecute successfully? You'd mentioned an investigative report and so on. I'd be interested in . . .

**Mr. Work:** Okay.

**Mr. Olson:** . . . where I can find that.

**Mr. Work:** Sorry for interrupting you. You'd think I'd never done this before. When the red light is on, you talk.

I'll leave copies of the investigation report here today. It occurred to me when we left this morning that someone might want that, so we have that with us. In the case where the health care worker was prosecuted, she pled guilty and was fined \$10,000. The citation for that is R. versus MacDonald. My office can provide you with a copy of the case, or you can go online and look for it.

**Mr. Denis:** Can I get a copy of that case, Frank?

**Mr. Work:** Would all the committee, Mr. Chair?

**The Chair:** You can provide it to the clerk, Mr. Work, and we'll make sure that the members have access to it.

**Mr. Work:** Yeah. We'll make sure to do that, then.

**The Chair:** Thank you.  
Ms Blakeman, followed by myself.

**Ms Blakeman:** Thanks. I think what we're all seeking in this process is trying to find that balance between gaining knowledge for research purposes and for health service delivery and balancing that against minimizing the impact on individuals' lives. That's what we're trying to accomplish here. What I'm hearing from you, Mr. Work, is that it's a weak protection in 58(2), but it's the only protection that's there. Once we remove it, then I think we start to move into the territory of public confidence, where it's harder for even us to justify that to people in our offices when there's no protection left.

Part of my concern around the example raised by Mr. Vandermeer is that, you know, for someone who shouldn't be looking at that masked information, if all they have to do is hit the button and say, "I want to see it anyway," they get to see the information. Now the cat is out of the bag. The horse is out of the barn. The information is out there. There is an audit but only if someone knows to go and request the audit trail. So for that individual whose life has been impacted, that information is out there already, and until they notice that their brother-in-law has information about their personal health life that they shouldn't and go and ask for it, that person's life has been impacted, and there's no recourse available. Yeah, there's an audit trail, but it's a complaint-driven audit trail, so it's not the be-all and end-all. I think the masking needs to stay there.

*1:50*

It would kind of be useful if we could have someone that knows the act sitting at the table that could answer some of our questions, but according to what I remember hearing this morning, the audit information is given by custodian, not by individual, so when you got a list of that audit trail, all it would say is Capital health, Capital health, Capital health, Capital health, Capital health. It wouldn't say Capital health pharmacist, Capital health receptionist, who shouldn't be looking at this, Capital health surgeon. It just says Capital health. Even you would have a hard time following that audit trail because it's giving you a custodian but not an individual if I heard that information correctly. I think what I'm hearing is that we do need to keep that masking in place because it's the only protection we're offering right now.

I wish you would expand a bit on your concerns around repositories. You touched briefly on that, but it's another big section of what's being contemplated in the change in scope of this act. I'm hearing quite a bit of concern around it, and I'd like to get a better grasp of what the problems are.

**Mr. Work:** What you say, Ms Blakeman, is correct about what you will get from Capital health. What you will get presently if you ask for the disclosure log is generic titles. There are, nonetheless, specific user logs behind those. You just don't presently get them. If you ask for them, you'll just get Capital health, Capital health. I can get, you know, not just Capital health but Frank Work pharmacist, LeRoy Brower physician log level. So it is possible to thoroughly follow up a complaint.

**Ms Blakeman:** But only if I take it as far as a complaint to your office.

**Mr. Work:** Yes.

**Ms Blakeman:** Which is getting into the big leagues here, and again the horse is out of the barn.

**Mr. Work:** Yes. But, you know, by taking some action, maybe we will cause people to build more secure barns or take better care of their horses in the future by example.

Something you said reminded me that I wanted to add this about masking and stuff. With the arguments I've given, as far as I'm concerned, I don't care if it's only one person a year that asks for masking. I don't think that matters. I don't think this is a numbers game. You offer a feature like this because, if nothing else – and I believe it's far more than just a token – it's a token to Albertans that we care about how you feel about your health information. As a government, as a society, as a health care system we care about how you feel. Even if you never use it, it's there; it's available to you. It's why we put handicap parking spaces in parking lots. You know, it's 40 below and you're driving around and you're cursing those four empty handicap parking spaces, but they're there because it's a principle of our society.

I think this is also a principle even if no one uses these features, unless they are staggeringly, prohibitively expensive. And, yeah, you've got to be aware of that. You know, if this is going to cost an arm and a leg, it's got to be analyzed, and someone has got to make some hard decisions. Or, as Mr. Dallas said, if it's going to compromise care, you've got to have a second thought because care has got to come first. Short of that, if the only reason you've got for not wanting to offer people this feature is, "Well, no one is ever going to use it," I just don't see that as being good enough.

Repositories. We know about the ones that exist in B.C. and Manitoba. We have information on those ones and how they operate, which we'd be happy to give you. We don't know much about what might be done in Alberta because there aren't any. There's one that we've been involved with called . . .

**Mr. Brower:** Alberta data haven.

**Mr. Work:** . . . Alberta data haven, and they have some very ambitious plans. They'd like to do the kind of research I mentioned, where you bring all kinds of social factors and health issues together and, you know, try to find out why people get hurt, why there are accidents, why there are diseases and stuff. We really don't know what form it might take here structurally, whether it would be a part of the University of Alberta or whether it might be a separate foundation or so on and so forth. A lot of this governance material presently in Bill 52 is left to regulation.

I'm going to ask Mr. Brower. He's actually been involved directly with Alberta data haven. Have I represented properly what's going on with these repositories so far?

**Mr. Brower:** Yes, you have, Mr. Work.

**Mr. Work:** You can say no.

**Mr. Brower:** Alberta data haven is not a repository that's in place today. It's a group of individuals and entities that are coming together and doing some planning and forecasting about the need for such a repository in Alberta to make use of the health information that we are collecting today so that we can do research and ensure that we have the ability to make some informed health care decisions. The planning is in process, but we don't know a lot about how it will actually be built or who would be in charge of it and making decisions about access to that information.

**Mr. Work:** The ethical issues with these kinds of databases are significant, with these repositories are significant, just as the ethical issues with medical research are generally significant. For example, if the data repository was part of the University of Alberta, if the repository is physically located and being managed by the University of Alberta, and a University of Alberta researcher gives the

repository manager a proposal to do research and access a lot of this information, potential conflict, right? You know, maybe the researcher who makes the proposal is the dean of internal medicine at the U of A medical school. Well, the manager of the repository – I don't know – maybe works for him. In terms of governance, how are these requests for access dealt with? What do you have to go through to get into the repository?

This happens all the time, right? I mean, there are six research ethics boards in Alberta that approve medical research. They're used to dealing with conflicts, but they have rules when there are conflicts. With these repositories, what are the rules for conflicts going to be? Who gets in? Who gets to take information out? Are there cases where information has to be anonymized? What are the rules respecting when a researcher gets to contact a subject? I go to the repository, and I get a tonne of information about work-related injuries involving hydrogen sulphide, possibly a topic here. There have to be rules about when I can not just have that information but when I can contact those patients to do further research with them: all kinds of questions like that.

I don't expect those detailed questions to be answered in a statute. That would obviously be incredibly cumbersome. If all of those things are established by reg, we don't even know at the present time who's going to make those rules, who's going to be accountable for those rules, who's going to have the ability to decide who gets in, who gets to take what, what the ethical requirements are. We know none of that because we're waiting for it all to come down in reg.

Yes? Okay. I wanted to confirm that with Mr. Brower again, and he nodded yes, that I have not misled you, at least intentionally.

**The Chair:** Thank you. Mr. Work, just a couple of questions. What I'd like to do is make a couple of comments, and then I'd be really interested in your response.

Just as a point of information, I appreciate the issues you raised with respect to governance of repositories and so on. I think that, in fairness to the committee, we probably need to look to the department for specific information about what may be envisioned through regulation on some of these questions. Some of these points were touched on this morning, and some of the presenters that will be coming in subsequent meetings will be able to address this as well, but I certainly appreciate that you're helping to frame some of the issues that need to be considered.

It struck me that you're in a very unique position nationally when I consider the fact that Alberta, as you mentioned, was the first to introduce this type of legislation, in 2001. The impetus was the beginning of the development of an electronic health record provincially. There's been a lot of change in how health services are delivered since that time. I think we find ourselves in the same position in 2009. Having reorganized our service delivery system significantly, it seems to me that part of the intent of this bill is to design a framework whereby an electronic health record does not automate old processes in delivering service but helps to enable new processes.

2:00

I'd just cite, for example, some of the basic tenets of the act. Really what we're talking about here is removing the entire concepts of collection and disclosure – this was discussed with us this morning – and focusing on uses of that information, the case being made that health care, by and large, is no longer simply a transactional relationship between two providers. You used the example of a specialist and a physician. Modern health care in a high-performing system is the function of much more input than can be gleaned by a simple transmittal letter from one doctor to another

requesting a consultation that may take six or eight months or more to occur.

Given that change in the delivery system I'm just wondering. You're in a unique position because we're trying to take another leap forward here in Alberta. Does that inspire any new thinking on your part as to how, either through these provisions or through other ideas you might have, we might adapt the framework for the electronic aspect of health system delivery? It seems to me, with respect, that we haven't really heard that proposal from you to this point.

**Mr. Work:** I cannot disagree with what you said about the changing face of health care. If I understood you, I agree that you're right, that it's not a transactional matter now and drawing sort of boxes. The concept of disclosure within the system I agree is somewhat artificial. We thought about that when we were getting ready to come here today, and I think the situation we're faced with is that while that concept is somewhat outmoded, as you say – that is, identifying disclosures in a system where really everyone is a user as opposed to a separate entity handing paper back and forth – there are still other ways of doing that. I mean, it's just that the act presently predicates logs on the basis of disclosures.

You could still make logs available to individuals on some other basis, on the basis of accesses if you want. It's just that as it falls out in Bill 52, once you eliminate the disclosure-use distinction, you lose the ability to get much of a meaningful log. In terms of a compromise, sure, the technology is there. There are certainly other ways you could provide logs of events as opposed to disclosures.

**The Chair:** Just maybe on this point, if I could pursue it just a little bit more. This morning we heard from the department that one of the next stages, actually probably in the fairly near future, in the development of the electronic health record will be the establishment of a portal specifically for the use of patients. You see this in a lot of countries that have higher performing health systems than Canada in the OECD. In terms of this discussion it facilitates the patient being able to see a record of exactly who has accessed their health information.

It also assists the system in disseminating other information to the patient; for example, with respect to management of chronic disease other information that patients can use to help manage their own health status. Given that we're perhaps talking about a piece of legislation here that's meant to facilitate an evolution, I'm just wondering, first part of my question: does that make a difference to you?

Secondly, I'm just wondering if we were to look at some other large systems where we might draw an analogy. The tax system was one that occurred to me, federally. Really, as taxpayers we have no mechanism to determine whether or not people within the Canada Revenue Agency or associated agencies are authorized to view our tax information, whether they had a legitimate need to review that information, with whom it might have been shared in other parts of government or beyond. There must be operational procedures or auditing procedures that are established already in large systems like that. Are there any examples you could suggest that we could point to?

**Mr. Work:** I'll do the easy one first. On the first point, I'm somewhat familiar with the systems you mentioned in Europe, Denmark in particular, where there's a patient portal. As you say, they're fabulous. I mean, that is really where our system needs to go. The ability of people to have access to that kind of rich health information: yes, that makes a difference.

Certainly, if the patient were able to get a fulsome view of how

their electronic health record or electronic patient record had been managed through a portal, that would be the best possible outcome, but we don't have it now, and I'm not aware of the timelines involved in getting there. So between now and then I would still submit to you that until that portal arrives, there should be a way for patients to at least get some idea of what's gone on with their record and to exert some control in the most sensitive cases.

On the tax system the only distinction I can offer is that in Revenue Canada there are a very limited number of people that are going to see my return. There's going to be the immediate auditor and his or her supervisor, I would think, and then maybe someone who audits whereas in a health care situation there will be dozens of people who will look at any one record. There will be the immediate caregivers. There will be the system administrators who will want to look at the information possibly for benchmarking. You know: why does an appendectomy at U of A hospital cost more than an appendectomy at the Royal Alex, for example?

There are a lot of people looking at health information on an identifiable level, and there's now a lot of sharing of health information across borders, not always necessarily identifiable but nevertheless. So I see the health care information arena as being a much more heavily populated place than income tax, for example. Having said that, I do know of cases where income tax information has been either leaked or disclosed, and all heck broke loose.

I can't think of another specific analogy along those lines for you.

**The Chair:** Thanks very much.

Other questions?

**Mr. Quest:** This feature that they have in Denmark where you're notified when somebody's been looking into your health records: is there a large cost attached to that? Any idea what the cost of the system was?

**Mr. Work:** I don't know, sir. I'd actually defer to Mr. Horne on that because I happen to know that he knows more of these systems than I do. I saw a presentation on the Danish system. I have no knowledge of costs, but in the Danish system you'd be able to go into the portal and basically see the activity that's gone on around your health situation. Also, the ability to communicate through the portal with caregivers, which is not what we're concerned about here, is a pretty nice feature, when you can tell your GP, "The medication you put me on is causing me problems" without having to book an appointment two weeks from now or to run down to emergency and start all over. So, yeah, these portals are very powerful. If that's where we're headed, I say great, but again, in the meantime, until we get there, until we get the portal that can do these things, I still think we need to maintain this kind of control by patients or this kind of accessibility by patients.

**Mr. Quest:** In the short term, if it wasn't two-way, if it just had a snitch feature, if you like, if somebody had been in there and you're notified by e-mail that somebody had accessed that, would you be okay with that?

2:10

**Mr. Work:** Yeah, I'd be okay with that. I think the system people – and I shouldn't speak for them – might gasp at that thought, again, because there will be, you know, millions of transactions a month, so a pop-up snitch feature could be pretty onerous as opposed to leaving it to the individual. You know, several of the committee members have mentioned the dilemma, and the dilemma comes up again. Where do you find the balance? Put it this way. The

ultimate extreme would be what some people still argue for, and that is no disclosure, nothing without consent. There are credible people in Canada who still maintain that every time my health information gets used or disclosed by another person, I should have to say yes or no to it. I just think that's unrealistic as all get-out, but that's kind of the ultimate extreme of control. What we're talking about here now is some place along the spectrum.

In answer to an earlier question I said that I think we've just about got it right. I think we have it pretty near right right now, but I think Bill 52 is going to result in us getting it more wrong than right.

**The Chair:** Thank you.

Any final questions from the committee? Anyone on the phone?

Well, with that, Mr. Work, I'd like to thank you and Mr. Brower for appearing. You're the first officer of the Legislature to attend one of our committee meetings, so it's a great pleasure to have you. Thank you very much.

**Mr. Work:** Well, thank you for telling me that, Mr. Chairman. Thank you all for your kind attention and for your very good questions. I appreciate that.

**The Chair:** Okay. Thank you. We'll just give you a moment to depart. Then we have a small bit of committee business to complete here.

Mr. Work, your document is going to be distributed by the clerk to the committee?

**Mr. Work:** Yes. The clerk has my presentation, and the clerk also has the investigation report that someone asked about. I'm sorry; my offline discussion was about a media release which, I gather, is not needed now.

**The Chair:** Not part of this meeting, no, sir.

**Mr. Work:** I will get out of your room.

**The Chair:** Not at all. Thank you very much.

Colleagues, there are just a couple of business items I'd like to complete here. I'm not sure if one appears on the agenda. It may not appear on your agenda, but under item 5 Ms Blakeman raised earlier and I had some discussion with the department over lunch about inviting officials from Alberta Health and Wellness to be in attendance at subsequent committee meetings, which I think is a good idea and a practice we followed in the past, so that they're here to respond to any technical questions we have about the bill. I'd like to continue that.

I'm advised that it's probably a good idea to have a motion to that effect. Would someone care to move that? Mr. Olson. Any discussion? Those in favour? Opposed, if any? It's carried. I assume, on the phone, you're in favour?

**Mr. Denis:** In favour.

**Ms Pastoor:** Yeah.

**The Chair:** Okay. I also wanted to go back to the question of research that Ms Blakeman had raised. There are a couple of additional items you'd like to add to the list.

**Ms Blakeman:** Thank you. Yeah. I've talked about all of these over the course of the day, but the information I'm looking for that would be helpful in helping me to understand and/or make decisions

about what's before us is just some list – and I understand it couldn't be exhaustive – of who and what kind of health service is currently being provided outside of that descriptor about coverage under public health care. They've given the example of the dentist, but I'm thinking: well, sure, dentist is okay, but who else is on that list? I need an understanding of who is going to be added in, who is going to be included in the scope of this legislation as soon as we remove the descriptor about only those whose services are paid for by public health care being included in HIA. I need some better understanding of who else would now be brought into this, and I don't have it beyond an example of dentists. I understand it wouldn't be exhaustive, but I just need some understanding there.

The second one was if there's any information out there about the lockboxes and if other provinces use lockbox provisions. I'm trying to get around this issue of opening up the access to health care and at the same being able to protect those that honest-to-God need that protection. Is there a way of doing this? Is anybody else out there doing it right now?

The last one was the question that was discussed during Alberta Health and Wellness. They brought up that there is a difference between the health information we collect and what would be on the electronic health network – whatever they're calling it – platform or server. Again, there's a difference there. What's on one list? What's on the other list? I don't know what the two are. Those are the three things I'm looking for to help me understand what we're talking about.

**The Chair:** Okay. Thank you.

**Mr. Dallas:** Mr. Chair, with Ms Blakeman's consent I was trying to visualize the volume of information that would be provided with that last request with respect to the types of information that a variety of different health care providers would accumulate that would not be required on the Netcare record, as it were, and I was thinking that it would probably fill this room. I'm thinking in terms of, you know, if we could pick a couple of disciplines or scopes of practice as examples. I think you referred to examples this morning as what you were looking for. I'm wondering if that wouldn't be sufficient and be a reasonable request for the research staff because I'm thinking this could be, you know, in the tens of thousands of examples of the type of health information that might be collected by a variety of specialists that wouldn't appear on that health record.

**Ms Blakeman:** Well, I hadn't anticipated it being that much information. I'm looking for something pretty simple, but I mean can any of you here tell me right now what the hell we're talking about? What's on this list? What isn't on this list? If we say okay, what have we said okay to? I don't know how to answer that question right now. I certainly can't go out there and tell my constituents that I understand what I'm saying yes to if I open up this scope of practice to add in everybody that's providing health service that isn't covered under publicly funded health care at this point.

**Mr. Dallas:** Well, perhaps I'm misunderstanding, then, because what I thought the question was is: what information is acquired by health care providers – and I guess my mind sort of went to a variety of specialists – that's not a requirement to have on the electronic health record? Was that where we're going with this?

**Ms Blakeman:** Yes, that's the third question. I had three questions I was seeking, and yes, that's the third one. It was brought up by Alberta Health that only certain kinds of information go on the electronic health network, so if I can get some kind of idea of what



that is, that would be helpful. Can you tell me what that is right now?

**Mr. Dallas:** No. That's what I assumed we're looking for, but I thought that if we're going to try and find every piece of information that's excluded from the electronic health record, we're going to be doing a lot of work.

**Ms Blakeman:** I'm not interested in a lot of work. I don't have enough time to read all that. I want some idea of what I'm agreeing to here because I'm going to have to justify this, and two years from now somebody is going to pull me off the sidewalk and say: "What on earth were you thinking? Did you not understand you just agreed to do blah, blah, blah?" I need some idea of what I'm agreeing to here.

**The Chair:** I think there's enough information there for us to be able to satisfy the request.

Anything further in terms of additional research? If it's all right, we've got this on the record, and we'll add it to the list unless you'd like a formal motion. Happy to do that, too.

**Ms Blakeman:** I just want the information.

**The Chair:** Madam Clerk, I believe that's everything that we need to cover businesswise.

Is there any other business? If not, I'd like to thank all of the members here for your attention and your questions, and our thanks again to the staff for all the preparation work that goes into making one of these meetings possible. Our next meeting is on Friday, January 30, at 8:30 a.m., and we'll be hearing presentations from stakeholders further to the earlier discussion.

If there's nothing else, would someone care to move adjournment?

**Mr. Denis:** I so move, sir.

**The Chair:** Mr. Denis. Any discussion? Those in favour? Opposed, if any? That's carried. Thank you very much.

[The committee adjourned at 2:20 p.m.]





