



Legislative Assembly of Alberta

The 27th Legislature  
First Session

Standing Committee  
on  
Health

Wednesday, February 4, 2009  
8:34 a.m.

Transcript No. 27-1-12



## Standing Committee on Health

### Participants

Alberta Medical Association .....	HE-217
Christopher Doig	
Mike Gormley	
Sheldon Chumir Foundation for Ethics in Leadership .....	HE-223
Kelly Ernst	
Consumers' Association of Canada (Alberta) .....	HE-227
Wendy Armstrong	
HIV Edmonton .....	HE-232
Debra Jakubec	
AIDS Calgary Awareness Association .....	HE-232
Susan Cress	
Canadian Mental Health Association .....	HE-235
Tom Shand	
Alberta Cancer Foundation .....	HE-241
Sandy Slator	
Linda Mickelson	



8:34 a.m.

Wednesday, February 4, 2009

[Mr. Horne in the chair]

**The Chair:** Good morning, colleagues. I'd like to call this meeting of the Standing Committee on Health to order, and we'll begin. We're still waiting for a couple of members to arrive, but we do have quorum, so we will proceed and hope that the other members will join us in a moment.

I'd just like to begin by going around the table and asking members and staff to introduce themselves, beginning with Dr. Sherman, please.

**Dr. Sherman:** Good morning. Raj Sherman, Edmonton-Meadowlark.

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

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

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

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

**Dr. Massolin:** Good morning. I'm Philip Massolin. I'm the committee research co-ordinator, Legislative Assembly Office.

**Ms Blakeman:** Good morning, and welcome to my fabulous constituency of Edmonton-Centre. My name is Laurie Blakeman, and I'm delighted to welcome you all today.

**Mr. Quest:** Good morning. Dave Quest, MLA, Strathcona.

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

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

Joining us on the phone, I believe, is Mr. Denis. Are you there?

**Mr. Denis:** That's correct, Chair. Jonathan Denis from Calgary-Egmont.

**The Chair:** Thank you.

We have a little bit of business to take care of before we move into presentations on Bill 52. We'll begin with item 2, approval of the agenda. Can I have a motion to approve the agenda, please? Moved by Mr. Quest. Any discussion? I have one item to add under other business, and that's research materials. Those in favour? Opposed, if any? Carried. Thank you.

Item 3, review and approval of the minutes of our last meeting, January 30, 2009. Can I have a motion to approve the minutes as circulated, please? Mr. Dallas. Any discussion? Corrections? Those in favour? Opposed, if any? That's carried.

Ms Notley has joined us. Do you want to introduce yourself?

**Ms Notley:** Rachel Notley, MLA, Edmonton-Strathcona.

**The Chair:** Thank you.

We'll just take a moment here and help our first group of presenters seat themselves at the table, and then we'll move into item 4.

Good morning. We have representatives of the AMA with us this morning: Mr. Mike Gormley and Dr. Christopher Doig, the

president-elect. Dr. Doig, it's a pleasure to welcome you to the committee. I understand you have some others with you today. Dr. Doig, would you like to introduce those people?

**Dr. Doig:** Yes. Thank you very much. We have Mr. Vic Taylor, Mr. Ron Kustra, Ms Shannon Rupnarain.

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

Well, as I think the clerk discussed with you, we're trying to keep the presentations to approximately 30 minutes. We'd appreciate it if you could apportion up to 15 minutes for your formal presentation and then leave committee members an opportunity to ask some questions and engage in some discussion with you. If that's all right, please proceed when you're ready.

**Dr. Doig:** Yes. Thank you very much, Mr. Chair, and thank you to Ms Blakeman for having such a pleasant constituency. I would have appreciated a little bit more of a chinook wind, but I accept that this is still very pleasant.

**Ms Blakeman:** I'll work on it.

#### Alberta Medical Association

**Dr. Doig:** Mr. Chair and members of the committee, thank you for the invitation and the opportunity to present to you this morning. You have already received the Alberta Medical Association's brief, so I do not intend to review it. However, we are open to your questions and feedback.

Before proceeding, on behalf of the AMA we would like to express our thanks to the staff at Alberta Health and Wellness for their co-operation as we have endeavoured to understand Bill 52. They not only scheduled a two-hour briefing with AMA staff; they have also been prompt in responding to our follow-up inquiries.

As background, I am a physician in the intensive care unit, or ICU, at the Foothills hospital in Calgary. There is only one way to get into my ICU and to have me as your physician: you have to be very, very sick. The mortality rate of patients admitted to my intensive care unit – and this would be similar for the intensive care units in hospitals such as the Royal Alex, the University hospital – is approximately 20 per cent, meaning that 1 out of 5 patients die before they leave the ICU. Thirty per cent of these patients die before their hospital discharge. If this information sounds scary, it is. But, as well, if you're not admitted to my intensive care unit, your mortality rate will approach 100 per cent.

For the physicians, nurses, and others who work in the intensive care unit, what we do is more than a job. This is an opportunity to make a real difference. We truly do save lives. Unfortunately, we are not always successful. I'll provide you a simple example, which occurred to me just before Christmas. One night I admitted three patients to my intensive care unit with sepsis. Now, sepsis is a syndrome of multiple organ dysfunction or multiple organ failure that arises from infection. These individuals all received exceptional care by the physicians and other staff who work in the intensive care unit. For example, two of these patients received novel therapies which are not funded in other parts of our country, therapies that each cost approximately \$20,000.

8:40

For two of these patients, who were side by side, my team and I remained at their bedside for over 18 hours not only caring for the patients but meeting with their family, including having information disclosed by their family about the patients. One of these individu-

als was 37 years old, and the last act that I saw was his six-year-old daughter coming to visit him just before he died. Another was a mother that was 50 years old. One I cannot disclose other information on because there is some information in the public domain about that individual.

However, we also have many happy stories to tell: a 43-year-old with two children admitted to my ICU this weekend who survived despite high odds. These successes are the result of the commitment, the training, and the education of the health care professionals that work in this province. It is also due to the pharmaceuticals and technology available to us, including electronic health records and electronic medical records.

I am not naive to electronic medical records. In 1996 Dr. Dean Sandham, who is now the dean of the medical school at the University of Manitoba, and I introduced the first ICU clinical information system, or electronic medical record, in Canada for ICUs. We regionalized this to all Calgary adult ICUs in 1998. This is still the only one of its kind in Canada.

We, meaning my ICU team, simply could not do what we are able to do without our electronic medical record. It is one of the tools that enables the ICU staff to perform as a real team. Quick access to a patient's health information means that we can provide the best care possible to the citizens of Alberta. But we only require access to the information that matters. We don't need to know everything about every patient, and we should not. If ICU doctors and nurses, who are ultimately responsible for caring for patients in life-and-death circumstances, don't need to know everything about every patient, then I simply ask a question: why should others have access to such personal and private information?

It is very important that the members of the Standing Committee on Health understand that the Alberta Medical Association supports a vibrant, effective electronic health system for Alberta. Our support is based on the AMA's view that the health care system must always put patients first, not just when it is convenient to do so. Electronic health records can help physicians improve the quality of care and can improve patient safety. They enhance team care, and they can result in efficiencies to our system. In collecting this information, however, government must respect the privacy and confidentiality of all Albertans, people who are our patients, people who are our constituents. It is a matter of reaching a fine balance, and we are disappointed that Bill 52, in our estimate, does not reach this balance.

Here in Alberta we are used to computer technology being an everyday thing. For example, this morning, when I logged on to my computer, I received the blue screen of death, which many of you will then chastise me about for not owning a Macintosh. However, Alberta has the highest percentage in Canada of physicians using computer technology – and we are very dependent on it – and a high rate of electronic medical records in our practices.

As well, we have a growing electronic health information system. This system is extremely important. It includes information such as hospital discharge summaries, lab tests, diagnostic imaging results, and every prescription that has been filled in an Alberta pharmacy: extremely important information. Recently, for the first time ever, there are discussions about taking information from an electronic medical record, which may cover the complete medical chart in a physician's office, often covering the patient's entire lifespan, and making it available.

When health information is shared electronically, it becomes more important than ever to find the balance between making this information available when and where it is needed and protecting the privacy of the doctor-patient relationship. Protecting privacy means ensuring that no more information about patients is shared than that

which is strictly necessary. Because I practise in an intensive care unit, information about my patients is already on the provincial electronic health care record. However, for physicians who see patients in their offices, it could be completely different if Bill 52 proceeds in its current form. Bill 52 gives, simply, the minister of health the ability to force physicians to provide any and potentially all information that is currently held in a physician's office. Further, the legislation is clearly written, and if the physician does not cooperate, that physician, if they are like me, a registered professional corporation, is liable to fines that start at \$200,000 and go up to \$500,000.

Please let me reiterate that physicians do not oppose information sharing if it is done appropriately. We are committed to working with the Alberta government and the Alberta Health Services Board to help advance the electronic health record in this province. There has been a great deal of work done over the past few years between the AMA, Alberta Health, and Alberta Health Services to try and resolve fundamental questions such as what should go in, what can be viewed and used, when, by whom, and for what purpose.

One group is looking at identifying a core data set that physicians could provide from their electronic medical records, which could then be accessed by others through the electronic health record. Another group is developing information-sharing agreements so that physicians and Alberta Health Services can both together operate a new kind of shared EMR that may be available in some of the regional centres.

We're also talking about the patients' role in all of this and the rights of individual patients. While I am mentioning patients' rights, there is something very important that has not been happening and needs to happen. Patients and the public must become involved in these discussions. Public representatives must sit at the committee tables where important decisions are being made. The AMA believes that patients can contribute to finding the right balance. Formally engaging the public will do far more to make the EHR grow into the system that everyone hopes it can be.

If Bill 52 goes ahead in its current form, though, the Alberta Medical Association foresees two very probable outcomes, two potentially unpleasant outcomes. The first is that if patients don't believe physicians can protect their privacy, they will stop confiding in physicians. They will stop telling us everything we need to know to make the right diagnosis and provide the best possible care. This has in fact happened to me. I have had the family of a patient not tell me about important health information, specifically HIV serostatus, because of knowing that we have an electronic medical record and fear that other health care workers unbeknownst to them or to me might access this information.

Two, if physicians are afraid that the minister will force them to share certain information, then some may turn their backs on technology, turn their backs on electronic medical records, and return to paper records, or they may keep a second set of records that are hidden, though I would note that in returning to paper, the minister still has the power through regulation to force physicians to provide information from paper records as well.

In conclusion, the government does not need Bill 52 to grow and advance Alberta's electronic health care agenda. Indeed, it may have the opposite result. The Alberta Medical Association supports the development of a vibrant and effective electronic health care system. We have demonstrated this in many ways and through various venues. Simply, at the present time we cannot support Bill 52. For the reasons outlined in our brief and in my presentation, the Alberta Medical Association urges the Standing Committee on Health to recommend that the legislation not proceed.

Thank you very much for your attention. I look forward to your questions and comments.

**The Chair:** Thank you very much, Dr. Doig. I'm sure that we have a number of questions.

We'll begin with Ms Blakeman.

**Ms Blakeman:** Thanks. Thank you for your presentation. I think you have voiced what a number of us are concerned about and, in fact, the problem that's before us. We want this system to succeed, but there seem to be some things that will imperil that. You've said what you think won't work. Could you give us an idea of what you think might achieve a better balance or help us move forward in what we're trying to do here? You've been very thoughtful, so I'm assuming you've covered this one. Could you give me your suggestions on what you think would be a better solution?

8:50

**Dr. Doig:** Well, I think I've covered at least part, which is, first and foremost, the act of involvement of the public at the table discussing these issues. The second is that, clearly, with either current paper records or systems there is a great deal of trust that patients place with their physicians and with their other health care providers. I don't mean to be very simply physician-centric. In placing that trust, they know that we will only disclose this information, number one, with their consent or, number two, to individuals that we believe require the information. There needs to be a system set up whereby that can be enshrined, that patients have the right to disclose some or all of this information, to know when it is disclosed, to whom it is disclosed to, and to know why it is being disclosed.

**Ms Blakeman:** Have you discussed lockboxes?

**The Chair:** Dr. Doig.

**Dr. Doig:** Thank you very much. I think that there are a number of options that are potentially possible on how this may occur, but we do not see that information specifically included within the legislation. The legislation must be a principle document, and we do not see those principles enshrined.

**The Chair:** Mr. Gormley, did you want to add to that?

**Mr. Gormley:** Just to add a little bit, our main concern in terms of policy is that with the EHR the act moves the category from use, rather, to disclosure, which means that the patients' expressed wishes do not have to be considered, and that's what we consider a wrong policy move. The current way that that is dealt with is masking, but there are other techniques, such as a patient portal, such as a mechanism so that patients can look and see who has actually looked at their information. There are concepts, such as HealthVault, in the United States. There are lockboxes, as you mentioned. There are many approaches to this. Our main concern is the removal of even the necessity of considering the patients' wishes. There are many technologies and so on to then deal with how you deal with those wishes and make sure that that's given respect. Our problem is that that's being removed as even a requirement.

**Ms Blakeman:** Thank you very much.

**The Chair:** Thank you.

Mr. Fawcett, please, followed by Mr. Quest.

**Mr. Fawcett:** Thank you, Mr. Chair. Thank you for the presentation. It was very informative. This is, obviously, a challenging and

complex issue. I'm just wondering. You said that one of the concerns is that the patients' wishes don't have to be adhered to. Let's take an example of someone that discloses that they're HIV positive. I mean, they're in a medical situation, whether it's an ER or whatnot. If he doesn't want that disclosed, how would the physician in the ER have access to that knowledge? Are there currently mechanisms in place to do so? What are we talking about here if there are already mechanisms for physicians to access the information that they need?

**Dr. Doig:** Well, currently there are ways for physicians to access that information. For example, if that information is critical, I can speak to the patient. If I have a reason to know that information, I can try and provide a compelling reason to that patient, and then they can weigh whether my reasons appear to be compelling enough and decide to disclose that information. Alternatively, I can also speak with another health care provider. That health care provider can also hear whether those reasons are compelling or not and make a decision and usually will provide a notation, notification, some other means that the patient has a record that that information has been disclosed. The important thing is that certain types of information under the planned legislation will be wide open, meaning that access to that information, whether it is needed to be known or not, could become available.

**Mr. Fawcett:** Just a supplemental: what are the criteria to determine what information is needed to be known and what information is not?

**Dr. Doig:** Well, that's a simple question but a very complex one at the same time. Obviously, there are circumstances when a patient's life may be at risk, and clearly that's one of the compelling reasons to have an electronic health record. If someone cannot speak, can a health care provider gain access to that information to help assist in caring for that patient? Those circumstances are very, very rare, meaning requiring the breadth and depth of the health information released as suggested in this bill. There is certainly some information that's extremely important, but the breadth and depth are not.

**The Chair:** Thank you.

**Mr. Quest:** Well, Mr. Fawcett basically took my two questions, but if I may. Again, you say these are rare situations, but that would be my concern without it. We use the example of the HIV-positive patient. It's Saturday night, and he's been in a car accident or something like that. He's not conscious. His own physician is out or on vacation. What happens? Again, I'm still not clear – I'm not sure that anybody is – on who decides what is and what isn't important. Somebody somewhere has to standardize that.

**Mr. Gormley:** That's part of finding the balance. There are provisions in most systems, including the Alberta system, for a physician to what they call break the glass and look at information, any information. What we're saying is that you also need counterbalancing. The patient should know that that happened. That does not occur today. Patients have the right to know who has accessed their information and in what situation and for what purpose. You can balance these things. You can take account of the wishes of patients and still put the info – we also are working on agreements in terms of what information does have to show up in there and whether or not there are other aspects of a physician's notes that do not have to be and actually would not be shared into the record.

**Mr. Quest:** So if the patient knew every time somebody had broken the glass, that would work?

**Mr. Gormley:** That would provide a way of providing that. It is one important thing that we think should be added to the system through a portal. We do believe that there should be a patient portal and that patients have the right to know who has been accessing their information, yes.

**Mr. Quest:** Thank you.

**The Chair:** Thank you.

Ms Pastoor – and you might want to introduce yourself as well – followed by Dr. Sherman.

**Ms Pastoor:** Thank you. Bridget Pastoor, MLA for Lethbridge-East. I'm the deputy chair and one that has to drive in from the International Airport in the morning because I can't go to the municipal airport. I'm sure that was more information than you really wanted.

However, a couple of things. In terms of HIV, which seems to frighten many people when we even hear that, any health care worker is protected. They don't need that information because they all use universal precautions. So from that point of view, I don't think that that's an argument that would stand up, in my mind. What I'd like to know – and I have asked this question once before in this committee. You sort of alluded to that it's a rare situation that you would need this health record, and I'm thinking more in the ER. When I look at the number of patients that are truly, truly trauma patients as opposed to many of the things that go through the ER that probably shouldn't in the first place – but that's another issue – what are the actual numbers, or do we even have those, of true trauma patients that would need that full record as opposed to the general number of people in this province that use the health care system everyday and want their information protected? Being able to find out who accessed your record is sort of like, you know, the horse is out of the barn. Who cares? The damage is done by that time or could be done.

Do we have those kinds of numbers? What kind of numbers are we looking at that might be overwhelming that you need this full record as opposed to everybody that uses the system everyday?

9:00

**Dr. Doig:** Thank you very much for the question. I will take the opportunity to respond in a few ways, if I could. Perhaps the first response is: yes, I too am quite familiar with the Leduc international airport and wish that I became again more familiar with the municipal airport.

Part of the other work that I do is I'm a health services researcher examining outcomes from critical care. The ICU I work in is also called the multisystem trauma ICU, so I'm quite familiar with the patients that you are describing. I also appreciate your concern that there was perhaps some initial focus with an example used, that being about HIV seropositivity, but there are many other conditions that we could discuss.

For example, if I have full access to your medical record, do I need to know that you've seen a psychiatrist? Do I need to know that 20 years ago a patient might have been admitted to a psychiatric ward? Do I need to know that somebody at some point suffered from sexual abuse? I have had time and time again, because I have a very intense interaction with patients and families, in the quiet of a family room a family member coming forward to me with trepidation and trembling in their voice saying: I'd like you to know

this; I don't know if it's important or not. They will disclose something that is very deep and personal and private, and I fortunately have the opportunity in the circumstance of a patient in the ICU to say: "No, that's not important. Thank you for telling me." I don't record that in the chart. But if I have wide open access to other charts, to other records, I may see that information, and not just me, information which isn't relevant.

I can tell you that there are many, many examples since electronic information systems, electronic medical records, have been introduced into our hospitals where staff have accessed the records of patients, accessed the records where they're not participating in the care of that patient. It might be for colleagues, it might be for so-called VIPs, but clearly it permits access to information, and that is not known. Even though there is an audit trail, that patient will not know if their chart has been accessed until, as you put it, after the fact, when the horse has left the barn.

These are issues that are extremely important. Yes, there are patients where knowing information is extremely important. For example, a young man admitted to my ICU: knowing that he had had a previous overdose with a particular medication was extremely important in the therapy initiated in the emergency department and in the intensive care unit. So there is a fine balance.

**Ms Pastoor:** Thank you.

**The Chair:** Dr. Sherman, followed by Ms Notley, please.

**Dr. Sherman:** Thank you, Mr. Chair. Dr. Doig, thank you for your presentation.

Ms Pastoor, I think I could probably answer that last question of yours, having worked on the front lines in an inner-city trauma centre, where we on a daily basis see undifferentiated patients, and we just pretend everybody has HIV and use universal precautions. So that for us is a nonissue.

Also, having made decisions, I never go to the computer. I go straight to the patient. You go to the computer after you look after the patient. I can't remember after 80,000 patients how many instances where it has been a life and death situation, and being in a trauma centre and having represented all the emergency docs of the province, I don't think that's a huge issue for us in a life and death situation. There are protocols that we follow in those situations, and those are standardized protocols.

I don't need to know the intimate details of what's in a patient's file in a GP's office. I don't need to know the intimate details of what you've discussed with your psychiatrist. When a patient talks to a physician, they talk with the confidence that that conversation is only between those people and not those people and a million people who have access to a health care record, and if there's a breach in the health care record, it ends up on Google and YouTube.

But I will say that when someone comes with a chest pain and they've got certain nonspecific changes on an ECG, we do need to know that there was an ECG done in the office and the office is closed on the weekend or late in the evening, if he saw a physician two or three days ago and certain tests were ordered, or if a certain new medication was started and we don't know what pharmacy they went to. The patients can't remember or they're unconscious or they don't know. Certain things we do need to know, and certain things we should never have access to.

Dr. Doig, may I ask you a couple of questions, if you don't mind, Mr. Chair? You know, I read the bill, and I was quite disturbed about this minimum \$200,000 fine because as a physician I wouldn't put stuff in the health record and I'd probably risk getting the fine. What will this do to attract and retain physicians at a time when



access is a big issue, and what will be the legal liability to physicians? We know the liability of not putting stuff on the record and sharing it. What's the legal liability if something the patient tells you ends up on the web? Have you explored this with the CMPA?

**Dr. Doig:** Dr. Sherman, thank you very much for your questions. I think the committee should be concerned how legislation impacts practising physicians. An overly regulated system or a system which provides onerous penalties potentially runs the risk of deterring individuals who wish to come to this beautiful province and to care for our citizens to seek opportunities elsewhere.

In terms of legal liability to physicians I believe that I would be speculating at the risk, obviously not being from legal training, but I can assure you that physicians do fear being sued. As one of my legal friends says, "There's nothing better than seeing a doc's name on a chart and being able to spell it. In fact, it's even better if you can see 10." I am quite certain that if information was disclosed and made publicly available on a source such as YouTube or on the web in general and the patient thought that that information had been disclosed to their physician, then, yes, the physician would be named in a suit, and I can assure you that when you are named in a suit as a physician, there is a considerable amount of moral distress and anguish that occurs to that individual.

**Dr. Sherman:** A supplemental. May I ask you two questions in one? Number one, were you consulted in preparation for this bill, and number two, can you suggest amendments to the bill?

**Dr. Doig:** ICU physicians are well used to dealing with ER physicians, and having two questions for the price of one is not an uncommon event.

**The Chair:** It's not uncommon in this committee either, so I'd ask you to be concise with the answers.

**Dr. Doig:** Zebras don't change their stripes, I guess.

I do have prior experience with the Health Information Act legislation as it currently exists, having provided advice to components of that legislation. Personally, no, I was not consulted, nor have I sat on an advisory board.

Mr. Gormley will speak for the AMA.

**Mr. Gormley:** No, we were not.

**Dr. Doig:** Thank you.

Your second question, Dr. Sherman? That's another thing I often tend to forget, your second question.

**Dr. Sherman:** Can't the AMA suggest amendments to the bill? There are good positives to having this health record.

**Dr. Doig:** Well, I apologize if I'm not familiar with, you know, the technical workings of how legislation advances through government and through the House. Certainly, we think that there need to be changes made to this legislation, and we think there needs to be broader participation not only from the professions but from the public as well. So you have our recommendation on how we think that the legislation should be handled.

9:10

**Mr. Gormley:** We can certainly provide more detailed suggestions on amendments. The brief focuses more on where we see many of the challenges and so on, but we can certainly provide more detailed suggestions about where we'd see change. They'd be significant.

**Dr. Sherman:** Thank you.

**The Chair:** Thank you.

We're quickly running out of time, so I'm going to ask if colleagues would perhaps tighten up the questions a bit. I'd like to try to fit in three more.

Ms Notley.

**Ms Notley:** Thank you. This maybe flows a little bit from the last question in terms of an element of your recommendations, or questions with respect to what those might be. You mention on page 10, I think, of your brief about this tripartite consultation that had been going on with respect to balancing the principles between privacy and sort of efficacy and need. I'm just wondering if you could tell me three things about that process: first, if you could for the purposes of the committee give us some examples of where you may have already come to some conclusions with respect to how to balance those things, just to see as an example how that process is working; secondly, whether you contemplate ultimately that process having a public input component to it; and then, thirdly, whether that process could in a revised statutory environment with respect to the bill play a role in terms of helping to address some of the concerns you've identified.

**Mr. Gormley:** Yeah. I think that group and its work is critical, and it is the alternative. We are not opposed to information going from physicians' records in the community, GP offices, to the EMR. It's just that it's not all information and it should not be compelled. That's our concern.

We already have a group talking about what information would be useful to providers in the settings that they're in, the exact kind of information that Dr. Sherman's talking about, and that's what that group is precisely speaking about. So we don't see the need for compelling, and in fact we see great danger in terms of that. They've developed a number of proposals in terms of what might go in and so on. It would include information about key kinds of aspects, number of visits, contacts, so on and so forth. It can also provide, say, an indicator of who they can go to for more information, those kinds of things, information around key kinds of vaccinations, all sorts of information and so on. That information is being discussed, what should go in and what's appropriate, and I think that's the appropriate setting.

In terms of ultimately should there be public input on that? Absolutely. I think that, even more importantly, the governance in terms of how an EHR is used, the flow of it, how it will have to change – because no matter what we decide today, it will change, I guarantee, by tomorrow; there will be different views and different ideas – the public should be engaged in that as well and all the way along. So our issue, in fact, is that there should be more public involvement and more ability for patients to be engaged, not less, and compelling and saying it might be anything in the record is the wrong way to go.

**Ms Notley:** Thank you.

**The Chair:** Thank you. Actually, Ms Notley and I, I guess, were thinking along similar lines in terms of exploring this area of consultation. Earlier, Mr. Gormley, Dr. Sherman asked a question as to whether the AMA had been consulted in terms of that bill. So I take your answer to mean, then, that in terms of the specific provisions in the drafting of legislation, you weren't a party to that.

**Mr. Gormley:** Right.

**The Chair:** But I note that in appendix 1 of your submission there's a lot of documentation with respect to the provincial shared health record steering committee. Am I correct in believing that the AMA's been involved with that process for some time?

**Mr. Gormley:** We're very involved in issues of the sharing of information in the system. We're very involved. We have had assistance from Alberta Health in terms of understanding this proposed legislation as well, which I think Dr. Doig mentioned at the beginning. I was answering to the very specifics of these amendments.

**The Chair:** I understand that. My question, then, is that there is provision in the bill under the regulations for a governance structure to be put in place as determined by the minister. Do you have any recommendations, first of all, in that regard? Secondly, assuming that you do, if a governance structure were to be specified at this point, would that change your view at all in terms of your recommendation that the bill not proceed?

**Mr. Gormley:** In terms of involvement in the governance structure, we mostly talked about the need to involve both providers and patients in that on an ongoing basis. The belief that we do believe a governance structure does have to be put in place: I think it would help to some extent, but I don't think a governance structure that then also had over it that the minister could compel actually does work. You'd have to deal with other aspects. I don't think that on its own a governance structure that was then subject to any information being able to be taken away – you would have to deal with that relationship as well.

**The Chair:** Thank you.

The last question, I believe, will be from the deputy chair.

**Ms Pastoor:** Some of it might be comment, but just a couple of instances have come to mind. I've just helped someone do a personal directive. She is on heavy mental medications which keep her stable and is someone that lives on AISH, those sorts of things. In her personal directive I've had to go back to her lawyer and insist that she can have comfort measures but that she not be taken off her medications because it will spin her out into the middle of next week within three days, and then it masks everything that's going on. So to me that is something that has to be written somewhere, should she be declared incompetent at some point.

The other thing, on the opposite side of the coin of that is that in southern Alberta we have a number of communities that don't vaccinate their children. Should at some point they be denied access to schools because their children aren't vaccinated is, I think, another big can of worms that could be opened up for not keeping things private, sort of thing.

I don't know if any of you have a comment on either one of those little incidents.

**Dr. Doig:** Thank you very much. The issue surrounding personal directives, which treatment patients wish to receive but, most importantly, do not wish to receive when they are not able to speak for themselves, is extremely important. It is a common problem when EMS may be called to an emergency outside the hospital and the patient transported to the hospital and even in the hospital, despite legislation that states that health care workers must inquire whether a personal directive exists or not, that that information is either not obtained or not disclosed. Unfortunately, it's extremely costly to the system when we resuscitate a patient who does not wish

to be resuscitated, but more importantly it is an assault on that patient. So disclosing or having access to that type of information is just as vital and critical as having access to information much like Dr. Sherman provided: the ECG that might have been done in that physician's office. Again, it is the scope, breadth, and depth of information and who gains access to it and who permits it to be released that is important.

**The Chair:** Thank you.

Well, Dr. Doig and Mr. Gormley and the other representatives from the Alberta Medical Association that are here, on behalf of the committee thank you very much for coming today and answering our questions and also for the brief that you've provided. It will be very useful to us in our deliberations on the bill.

**Dr. Doig:** Thank you.

**The Chair:** My apologies. There will be a pause here just for 30 seconds or so, and we'll resume.

9:20

**Ms Blakeman:** This is sort of unfair, but since we have two medical professionals sitting here, can I just explore an issue that was sort of explored before? Is that all right with you?

**The Chair:** It is. We're not really involved in deliberations on the bill in this particular meeting.

**Ms Blakeman:** It's information. A couple of times there was clearly a concern that somehow people not disclosing information, particularly around people presenting with possible blood-borne pathogen issues or sexually transmitted diseases, would somehow imperil the public and that there needs to be an overriding release of their health information so that nobody would get infected. Yet what I think I just heard from the health professionals is that it's standard practice that you would treat everybody that way in order to protect the health professionals. I was wondering why I wasn't hearing the health professionals say: "Oh, yes. This is a huge issue." None of the health professionals are saying that to us. That's because you all work with those precautions in place all the time, so it just doesn't come up, so the need to find out their personal health information about that just doesn't exist?

**The Chair:** You'd like the two members to clarify whether that's, in fact, what they said?

**Ms Blakeman:** Yes. They were nodding their heads and things, but it doesn't get it on the record.

**Dr. Sherman:** We just assume that everybody has everything bad out there when it comes to infectious agents. The only thing that we probably really need to know about is who has MRSA if they have the patient in an emergency department because we don't want to spread that to every other patient in the department. With respect to HIV and STDs we as health care providers don't need to know because we should be taking universal precautions with everyone.

Having said that, when patients get tests done, there are certain diseases that are reportable to the chief medical officer of health. If you have syphilis or gonorrhoea or chlamydia, these diseases are reported. They're followed up by the chief medical officer of health. They do patient follow-ups to see where the contacts are so that there's not a spread in the community. But health care workers don't need that on a medical record as a mandatory.

**Ms Blakeman:** Thanks.

**Ms Pastoor:** I'd like to just follow up on that, too. Although I think the first thing that comes to people's minds when we discuss this kind of stuff is STDs, et cetera, TB is increasing as we have more and more people coming in from other countries that TB hasn't been totally eradicated from. Again, by using universal precautions, you're protected against those sort of things as well.

**Ms Blakeman:** Thanks very much.

**The Chair:** Thank you.

Our next presentation is from the Sheldon Chumir Foundation for Ethics in Leadership in Calgary. I'd like to welcome Dr. Kelly Ernst, program director. Welcome, Dr. Ernst. Thank you for appearing before the committee and for your written presentation. I'm just going to give my colleagues here an opportunity to introduce themselves.

**Ms Pastoor:** Yes. Bridget Pastoor, MLA, Lethbridge-East, deputy chair.

**Ms Notley:** Rachel Notley, MLA, Edmonton-Strathcona.

**Dr. Sherman:** Raj Sherman, Edmonton-Meadowlark.

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

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

**Ms Blakeman:** Well, Dr. Ernst, welcome to my fabulous constituency of Edmonton-Centre. My name is Laurie Blakeman.

**Mr. Quest:** Good morning. Dave Quest, MLA, Strathcona, no hyphens.

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

Dr. Ernst, we have approximately 30 minutes.

**Mr. Denis:** Calgary-Egmont.

**The Chair:** I'm sorry. Jonathan Denis.

**Ms Blakeman:** He's in the ceiling.

**The Chair:** He's in the ceiling, yeah. MLA for Calgary-Egmont.

**Mr. Denis:** Beautiful constituency, Calgary-Egmont.

**The Chair:** Sorry about that.

We have about 30 minutes. We'd like you to take up to 15 minutes for your formal remarks, and then leave us the balance of the time to ask some questions and engage in some discussion with you. Please proceed when you're ready.

#### **Sheldon Chumir Foundation for Ethics in Leadership**

**Dr. Ernst:** Okay. Well, thank you very much. I didn't know Big Brother was watching this morning.

On behalf of the Sheldon Chumir Foundation for Ethics in Leadership I really would like to extend our thanks for being invited to this committee. We think this is an important piece of legislation

and are very happy to have the opportunity to give some input into its going forward. The observations I'm going to give to you today were made after consultations with legal counsel and ethics experts and privacy experts, so our perspective is going to be a little bit different than what you heard earlier from the previous presenter. We're going to present more from a civil liberties perspective.

The first thing I would like to do is really outline the proposed recommendations for changes to the amendments and then discuss various scenarios associated with each of these proposed changes, and then hopefully that will lead into your questions about why we would suggest such things. Before I do that, I would also like to acknowledge that we do see that there would be considerable patient benefit for the creation of any electronic health record across the province. However, we do wish to acknowledge and be on record to note that any advances in technology do not eliminate the possibility of system failures, and when those failures occur, they often do so spectacularly, with significant impacts to people's privacy and their personal security and possible civil liberties. With that context in mind we really encourage this committee to take very seriously the various recommendations that we forward as well as those of others such as your previous presenters.

With respect to our recommendations, we have six core recommendations that we wish you to consider, and I'll just go over these briefly. Our base recommendation refers to including some provision for informed consent and inclusion of personal information in the electronic health record.

The second recommendation is to create greater limits on disclosure of information and the ability to mask information in a more comprehensive manner as well.

The third one is to define health information repositories more clearly.

The fourth is to strengthen consent for disclosure of information, including research consent.

The fifth is to retain the need for a privacy impact assessment when providing health information to the minister or to the department.

The sixth is to return Bill 52 to the government of Alberta legal counsel for identification of all possible conflicts with the Charter of Rights and Freedoms and removal of any provisions that do offend the Charter.

With respect to our base recommendation, which is including informed consent for inclusion of personal information into the electronic health record, we recommend that there be an obligation for health service custodians and health information repositories to seek some sort of informed consent from patients to include their personal and health information in the electronic health record.

Furthermore, we suggest that there be some obligation to place reasonable limits of the length of time that an electronic health record can be used without review of that consent. This would include a provision for the patient to also withdraw consent, even give an earlier consent to include their data in the electronic health record. If consent is so withdrawn, we suggest that there are reasonable monitoring systems built into place to ensure that the electronic health information is in fact eliminated, archived, deleted, or in some way removed from view from the electronic health record.

Really, this is our most basic suggestion for improvement to this bill. It is a basic ethical criterion to consider when collecting, using, disclosing, or sharing information to include informed consent. It helps to ensure that the patient and all parties are informed about where the information is used and for what and reduces the ability to use information in ways in which it was not intended. It gives direction not only to the person who is giving the consent but to the

entire system that might use the information regarding what is acceptable and not acceptable with respect to using information. What we're suggesting is that the principle of informed consent needs to be included in a far bigger way and also to help ensure that the culture of the health system is one that values informed consent. We feel that this bill the way it's written right now does not do that.

### 9:30

The second recommendation is for an amendment to include an obligation for our health service custodians and health information repositories to address patient requests to have any part of their personal and health information in the electronic health record masked or hidden from view in some way. In our opinion there appears to be no provision in the amendments to address the individual's request to mask information. Even though it may occur in a technological way now, without a part of the legislation to address this, that may erode in the future. We believe that not having that in the legislation is a fundamental breach of Albertans' rights to privacy. Without provisions for masking information, the opening of health information can have potentially harmful impacts on individuals through custodians' authorized and unauthorized use of information. Completely unmasked information, we believe, has potential harmful impacts to the patient and public.

I'm going to give you a couple of scenarios. The first concerns domestic abuse situations. What we're concerned about in the wide open view of health records is not necessarily the use of information for health purposes but people having access to information that they then may use for other means. For example, in a domestic abuse situation where the abusive person has access through their work or office to health and personal information of the victim of their abuse, if the victim cannot mask the information or hide information about her privacy, it may be violated, and her very physical or emotional security and that of her children may be put at risk because the abuser may have an easier time to track them down. It is possible that further violence may occur or even be facilitated simply because the electronic health record was not limited in its ability to mask information.

We believe that these types of abuses are further augmented in Alberta in smaller communities as well. The reason we believe that is that it takes less information to pick out a person in a small community than a larger one. For example, age and gender alone are not normally identifiable of an individual. However, when it's combined with ethnicity, a place of residence, and in the context of a small village, then those four pieces of information actually might become identifiable. I could extend this example further with the examples used previously whereby a rural person, perhaps in a job application process, as a matter of course takes drug, HIV, or other medical tests. If those tests somehow are entered into the system and then this is disclosed to another member of the small community during a health service, that potential breach of information or knowledge of the HIV testing, for example, could then risk that individual on a social or economic basis to discrimination or other harm from merely taking that test even though the test may itself be a negative HIV test.

The third recommendation that we'd like you to consider is that the definition of the role and responsibilities for a health information repository be clearer and include limits on activities of a health information repository. We do not feel that there is a well-defined description of the role in Bill 52, and that could certainly be beefed up.

Also, we suggest that there be a narrowing of the possible types of organizations that might be eligible to be designated as a repository to those organizations with a health services or health research

mandate. Plus, we suggest that you include an appropriate eligibility review process such as a privacy impact assessment so that that proposed health information repository must ensure that it is not only eligible but has a full complement of processes to protect individual privacy, has qualified individuals to handle health information, has appropriate levels of safeguards in place to protect privacy, and is clearly compelled to protect individual privacy over agency, company, or other entity interests.

We feel that this is rather important, especially given the context of the recent Enron and Madoff disasters. You may think that that's a little far away, but we really wish to give a reminder that we should be very careful whom we allow to hold information and other resources on our behalf. Thus, a better defined role, function, and limits of those entities would give better protection to the public in this bill.

The fourth recommendation would help to strengthen consent for disclosure of information, including research consent. This includes the obligation of custodians and health information repositories to obtain patient consent for research or evaluation on ongoing and active health concerns or other issues. We do not think it is strong enough in this bill. We suggest to include in the types of research requiring consent at a minimum also program evaluation, that this be explicitly stated in the bill, and policy development. We suggest to make health records anonymous for all archival research prior to the commencement of any use or disclosure of information for those research purposes.

It does not appear that in all research activities agencies, companies, or entities would require research consent from the patient, and we feel that this opens up another avenue of disclosure for use of information other than research or for use of information under the pretext that research is going on and that other health services may be occurring but where the information could be used in other ways. For example, data mining, data searching could result in needless disclosure of information and thus risk people's privacy and, again, security.

We also wish to note that there is one part of the act that takes out the need for privacy impact assessments when providing information to the health minister or department, and we suggest putting that back in. We recommend that this occur, again, to help people's privacy because without it we believe it may place an individual's liberty or security at risk, and simultaneously it puts the minister or the department at risk for possible public and legal consequences. For example, without such a provision we could envision scenarios whereby it may be tempting to request or forward information to the minister or department for more detailed information, especially about high-profile cases and especially about cases that may already have some information circulating about them in the public.

If such actions occurred and perhaps in the public there were noted inconsistencies and inaccuracies between the public knowledge and disclosures of information from the minister or department, then these could minimally place the minister or department at risk for significant embarrassment, or in the case where information was available to media and the case went as far as becoming open to court or civil challenges, it would not only place the health system at exposure for public embarrassment but also have it very open in the courts and civil proceedings.

Finally, we suggest as well to return Bill 52 to the government of Alberta's legal counsel for identification of all possible conflicts with the Charter of Rights and Freedoms and have it returned with changes to mitigate any challenges.

Upon consultation with lawyers and privacy experts on the subject our conclusion was that the amendments proposed in Bill 52 imperil Albertans' privacy rights in many ways, and it creates the ripest

environment for a constitutional challenge in the country. This is based on far too many scenarios whereby first the need for informed consent to include information in the health system is omitted at a number of different points. There are also far too many disclosure of information possibilities, including the possibility of requested portions of health records. Because information isn't legislated to be masked or hidden or there's no opportunity for doing such things, it creates just far too many risks of disclosure of information for purposes other than health. Again, one of the best examples is the possible problems that arise if an abused woman's record falls into the wrong hands, say the abusive spouse with whom she is embroiled in a custody dispute. Her physical or psychological security may be seriously compromised.

**9:40**

We wish to remind the committee that this proposed legislation must be viewed within the Charter as the Charter applies to all legislation. The rights to privacy and security of the person more generally are contained in section 7 of the Charter. Those rights may be violated by Bill 52 because the forced inclusion of health information in the electronic system is not carried out in accordance with the principles of fundamental justice. For example, there is no need for informed consent for patients' information in the health system.

I see that time is running out, so I'll summarize now. Again, we really do wish to thank the committee for inviting us here to give a submission and hope that these recommendations are taken very seriously.

**The Chair:** Thank you very much, Dr. Ernst.

We have a number of members that would like to ask questions. Mr. Fawcett, followed by Mr. Olson, please.

**Mr. Fawcett:** Thank you, Mr. Chair. When I look at this issue, I tend to try to look at it through the lens of a patient or just the normal, everyday Albertan: what would they expect us to put in this legislation, and where would their values lie? One of the challenges that I guess we have and that all of us have is that that might be different for each and every Albertan, depending on where their values are. Certainly, civil liberties is one area that people value, but they do value our public health care system as well. I think that anywhere you go in Alberta and Canada, there tends to be a sense of personal pride in sort of a national identity.

I know that earlier on you talked about consent and that needing to be a requirement as part of this as well as the ability to maybe review that consent. Is there that other value, you know, that we have a public health care system and that therefore a lot of services are paid for through public funds and through people paying their taxes and that therefore it's a public good? It's in the interests of the public to make sure that all of the information is shared all of the time. I guess the way that some people might look at it is: if you're entering into the public system and using public dollars through health care, wouldn't that automatically mean that consent could potentially be given to share that information so that that system is the most efficient and effective?

**Dr. Ernst:** I don't think we have any problems with the idea of an electronic health record being beneficial to Albertans. That isn't our issue. Our issue is more the way the bill is written. Having all of the information available to all people all of the time in the health system, as your previous presenter noted, isn't necessary. When you have all of the information available to all of the people all of the time in the health system, what that does is that it opens up informa-

tion to being used under the guise of the health system for other means and other purposes, and it is that principle that I think you really need to consider. Without some sort of informed consent the other thing that occurs is that although our health system may be very valued now, in the future without such basic provisions being put into the system, people begin to distrust the system and perhaps over time value it less. So the inclusion of informed consent can also help to not only protect people but protect the perception of value about an entire system and a culture of the system as well.

There are plenty of examples where the inclusion of informed consent in large systems such as the electronic health record is doable. It doesn't mean to say that people stop giving information into a system, especially when they see the benefits themselves. But what it does do is it allows people the opportunity to give pause and thought about what they are giving, and it also gives people pause and thought and the control over their information when they know that some information they don't want everybody seeing, and they have that right under our Charter to do that.

**The Chair:** Thank you.

**Mr. Olson:** Thank you for your presentation, doctor. As a committee member I think what I look for in all of these presentations is to see if I can kind of pick up a common thread that goes through the presentations, and I've picked up a few here, obviously, consent being one of them. I should say also that I appreciated your presentation from the point of view of not just poking holes in the legislation but also making recommendations. I really appreciate the positive approach. I think what we're all here for is to see if we can come out with the best piece of legislation we can.

I have kind of a detail question, I guess you would say, about your recommendation 1, part (b), where you are suggesting placing a reasonable limit on the length of time a record can be used without review. At first blush that maybe sounds like a good idea, but then, when I start thinking about the practical implications of that, it makes me wonder: how would one actually do that, and would that not maybe make for a pretty cumbersome system that could create a ripple effect of a number of other potential problems? I guess I'm just wondering. I'd appreciate your comments on that particular recommendation and if you have any more detail on it at all.

**Dr. Ernst:** Well, I guess, in my opinion, putting a limit of time on something like that and given the way technology works today, it's quite easy that over a period of, say, two, three, five years that information becomes masked when it's not being used, or it becomes hidden or archived or some similar process when it's not being used. That doesn't mean to say that the information necessarily permanently goes away. It simply means that people know that there perhaps is some information there, but you need to again take some time and pause and ask the patient if that information can then be brought back.

There may be, again, various scenarios where that becomes very beneficial. There may also be scenarios where health care providers as well have to take pause as to: "Okay. Here's some old information here. Do we really need it, or do we have other information that is equally useful?" We really don't need to go way back into the person's history to get information that, again, isn't necessarily useful in a particular scenario.

**The Chair:** Thank you.

**Ms Notley:** I always find it interesting when the lawyers ask questions because, of course, that was exactly the issue I was asking

questions about. But I guess my take on it is a bit different although your answer actually created a bit more confusion. When you talk about that recommendation, does your recommendation suggest that at a certain point sort of a veil comes down over the information when it reaches a certain age, or alternatively is it that at a certain point the consent for however old the information is needs to be renewed? Which is it that you're recommending in that recommendation?

9:50

**Dr. Ernst:** It could be both. However, the point about consent needing to be renewed I think would be a really valuable addition to the bill so that, again, people are given thought and pause about what's in the system – things do change – and what patients might allow to go forward or not. It would also give thought and pause to people entering into the system, knowing that there are pieces of old information in it. Again, you're building a culture to sort of say: we really do value the respect of the individual. That is primary and paramount in every situation, and we really do value the informed consent. It's a very important part of the system.

**Ms Notley:** Can I have a supplemental question?

So, I think, three questions coming from that. How long would you recommend it be before consent needs to be renewed? I guess it's only two questions. Secondly, if we had sort of a negative option kind of renewal process, do you think that would meet the objectives that you're trying to pursue?

**Dr. Ernst:** I have the feeling I'm going to get more questions on this. We weren't suggesting a particular form and time. What you might want to do is go back to a group such as your previous presenter and see if that is an option that they might be in favour of as well. Also, they would probably have the expertise to suggest the best amount of time for that.

**The Chair:** Dr. Sherman, please.

**Dr. Sherman:** Thank you, Mr. Chair. Dr. Ernst, thank you for your presentation. It's quite insightful, and you've got some great ideas here. Just with the consent, renewal of consent on a regular basis, the only concern I'd have is: who would review that consent? The health care workers are quite busy, especially the front-line primary care physicians, discussing health care issues, let alone generating another visit just to discuss consent and which issue. Could it possibly be that there must be minimum information that must be on the web and maybe perhaps the patient can decide what they would want masked or not? It would be truly a challenge for all the physicians just to generate a visit every third year with every patient in the province.

**Dr. Ernst:** I don't think you'd have to generate visits simply for obtaining consent. I think the way it could possibly work is that when the information is being entered and used, it would be at that point that you can seek consent. It also doesn't necessarily rule out the idea of minimally receiving verbal consent. Often people think of consent in terms of: you write out a form and you list a form and you have 20 – you know, it's like a legal document you're almost signing to deal with that consent. Verbal consent could be enough, but again it could be flagged within the system to ensure that that minimally is being obtained.

**Dr. Sherman:** Thank you.

**The Chair:** Thank you.

Ms Blakeman, please.

**Ms Blakeman:** Thank you. The area that I'd like to explore a bit is around health information repositories. I note that in your presentation, at the top of page 3, you note that little direction is given on the role, function, and limit of the entities that would have access to information through health information repositories, and obviously you have some concern that people or companies or entities that have interests beyond or outside of health-related services could get access to this information. I'm assuming we're talking about companies that have affiliates that share information.

Two things. One, were you able to find or give us examples of what gave rise to these concerns? Do you have any examples that would help me understand what made you concerned about this? Secondly, can you give us any suggestions as to any health information repositories that you found, data repositories, that you felt were successful or that did have an appropriate level of both set-up to it but also sort of scrutiny or monitoring to make sure that it actually did what it said it would do?

Sorry. I've asked detailed questions. If you don't have it with you, you could provide it to the committee through the clerk or through the chair after the fact.

**Dr. Ernst:** No. I'm just putting my thoughts together. Thank you, Ms Blakeman.

One of the scenarios that I guess was discussed as we were preparing this is what types of companies could become a health information repository. IBM is certainly within the data business, but maybe they have other types of products that they're providing as well. We don't know that. What if a company such as a health insurance company wants to become a health data repository? Potentially, then, that health information may become available to a health insurance company for purposes of selling their products or selling a wide variety of products, so they may be using identifiable information in a manner for health service reasons, but it's possible that that data becomes available for other reasons.

**Ms Blakeman:** So we're talking about the commodification of personal health information.

**Dr. Ernst:** Exactly.

We don't know if those repositories will be able to do things like sell the information once they do have it for, say, a research purpose or an archival purpose. Could they then sell that for other reasons? The way the act is written, all of those possibilities seem to be possible, and there doesn't seem to be those types of limits put on that particular scenario.

With respect to having examples of entities that were created for the purposes of health or other reasons that manage information, yes, there is at least one in Alberta. The Canadian Outcomes Research Institute is one that may be a model to actually look at. It's an organization that was created with the purpose to actually hold, handle information as one of its purposes, and it's my understanding that they're doing a fine job of it.

**Ms Blakeman:** I'm sorry. Just briefly, what kind of information were they collecting?

**Dr. Ernst:** This is personal and research information in the social services field, but it was an organization created specifically to hold a large data set.

**Ms Blakeman:** For research?

**Dr. Ernst:** For research.

**Ms Blakeman:** Thank you.

**Dr. Ernst:** The people using the information, though, are also using it for their own service delivery as well.

**The Chair:** Thank you, Dr. Ernst.

We have time for one more question. Ms Notley, did you want to?

**Ms Notley:** Sure, I'll just follow up on that question because that was interesting. When you say they're using it for their own service delivery, what kind of organization and how are they using it for their own service delivery?

**Dr. Ernst:** For example, some children's services or charities are using the system to help manage their data, help manage their personal information, but then, more broadly speaking, the information is being used for research as well or can be used for research based on privacy impact assessments and whatnot and proposals that go through their structures that they've set up. They've set up things like ethics committees and that type of thing.

**Ms Notley:** I guess – and I don't know if you can help me – I worry about sort of the distinction between academic research, research that is, you know, academic yet funded by a very major private-sector player and is called academic but is incredibly applied, and then when you move into the area of service delivery, and service delivery in a for-profit health care provider becomes about also not just the efficacy of the service but the efficacy of the profit, right? It must do. I don't know if you know anything about how these types of activities are monitored or structured or distinguished to ensure that there's a clarity of purpose.

10:00

**Dr. Ernst:** Well, for example, in the previous example I just gave, the mandate of the organization was set up specifically for this purpose, and it was set up as an independent charity for that purpose. Because it's a charity, of course, it can't be bought by IBM or an insurance company or other means. It's a model that you might want to consider.

**The Chair:** Very quickly.

**Ms Blakeman:** Does that organization data match?

**Dr. Ernst:** I'm not aware of that. You would have to contact them.

**Ms Blakeman:** Thank you.

**The Chair:** Well, Dr. Ernst, on behalf of the committee I'd like to thank you very much for your presentation and for coming from Calgary to meet with us today. Your ethics perspective is unique in the presentations we've heard so far, and it was very helpful to us. Thank you so much.

**Dr. Ernst:** Thank you for the opportunity.

**The Chair:** Okay. Are we ready to proceed?

**Ms Armstrong:** My apologies.

**The Chair:** Not a problem, Ms Armstrong. We try to keep it moving as much as we can. We allow a little bit of time in between.

**Ms Blakeman:** Mr. Chair, do we have a handout for this presentation?

**The Chair:** It's just being distributed.

**Ms Armstrong:** My apologies for that.

**The Chair:** That's okay. I'll just begin by introducing you. Ms Wendy Armstrong is here on behalf of the Consumers' Association of Canada. Thank you very much for meeting with the committee today, Ms Armstrong. Your submission is being distributed now at the table.

Mr. Denis is on the other end of the phone. We'll see if we can find a way to e-mail that to you, Mr. Denis.

I know that you've sat through a couple of presentations, so rather than take the time with the introductions, if that's acceptable . . .

**Ms Armstrong:** Actually, that's fine, yeah.

**The Chair:** . . . and the advertisements that may arise in the course of the introductions, I think we'll just move to your presentation. If you could keep it to approximately 15 minutes, that'll leave us some time to ask some questions afterward.

#### Consumers' Association of Canada (Alberta)

**Ms Armstrong:** Certainly. Thank you very much, and thank you very much for allowing us to come and make a presentation to the committee. I know that there are a number of new faces around the Legislature these days. I'd just like to point out that our association has been involved in issues related to electronic health records and privacy issues inside and outside of the health care system for a long time, particularly with regard to electronic integrated health information systems here in Alberta since the early '90s. We have quite a bit of experience and background in sort of some of the changes and changing issues around the legislation.

However, before I came here today for the association, I reviewed also the previous minutes in *Hansard* from your meetings. Rather than going over some other different kinds of issues, I thought it would be most helpful to present what I felt were sort of some answers to the questions that your committee eventually raised in other meetings, that I thought were actually very excellent questions.

I see our role here today is to make the point, I think, as the previous presenter made, that people aren't just patients; they're people, too. In fact, they're workers, they're husbands, they're wives, they're moms, they're dads. They have many different roles in life, and these roles are often as significant to their health as, actually, access to health care or the quality of health care. In the lingo that's used in the sort of health policy field, these are called social determinants of health. Whether you can have a job, whether you can go out into the community without being socially stigmatized, whether you can get a loan, a mortgage: all these things have a powerful impact on the health of people. That's a little bit of what we'd like to point out today, that as individual citizens we aren't just patients. We need to consider those parts of people's lives when we're looking at how we manage health information.

I'd just like to briefly touch on about four points: one, putting the cart before the horse; two, how the loss of medical confidentiality affects physical and mental health; three, the larger social and health care context; and four, lessons learned from other realms. I'd also

like to touch on and I'd be very pleased to answer some of the questions that you raised with the last presenter around what is the right way and the wrong way to go with public interest research using health information databases. Just a few months ago I attended and presented at the Canadian Institutes of Health Research conference on this very topic. I'd be pleased to share and answer some of those questions for you.

First, putting the cart before the horse. In our view the current HIA amendments really put the cart before the horse by asking the public and MLAs to make decisions with no practical knowledge of current or future applications of various health information databases. Many of the promises that were made regarding safeguards have been repeatedly broken. It was extremely refreshing for me to hear the previous presenter because those were the same issues that we brought to the table back in 1995. Those are some hard-fought-for rights that, you know, we fought for back then, yet they've been systematically removed since the introduction of the legislation, including the requirement for consent to upload information into a central electronic database. We would really encourage you to perhaps put a moratorium on this bill, put a hold on this bill and begin a meaningful dialogue with people so that we can understand that it's not electronic health records or no electronic health records but how we manage it and in what conditions, how we manage this thing. Then, we think, it would be time to come back to this bill and say: okay, how do we proceed from here?

One of the problems is that while proponents like to talk about the benefits of electronic records, like adverse drug reactions and adverse surgical events, the adverse effects and costs of electronic health records and databases, which are substantial, I can assure you, are rarely tracked or reported.

Two, how the loss of medical confidentiality can affect mental and physical health. Amendments, as we said, in this current legislation include the proposed creation of health information registries, recognition of the inability of system operators to effectively mask sensitive information, if I read your *Hansard* minutes correctly. What's very important, I would say as well, Mr. Fawcett, is the expansion to include undefined, privately financed services in the whole realm of health care.

As a matter of fact, we'd also like to raise the question: what is the health care system? Certainly, many people tend to think of it as our publicly funded health care system, but here in Canada we actually pay more through private insurance and out of pocket than do citizens in many other OECD countries for our health care. Expanding a whole range of new private custodians of health care will have a significant impact with regard to many of the issues that Ms Notley was recently raising.

I guess I would say that plans to incorporate the more detailed clinical records in Netcare will essentially spell the end of any notion of medical confidentiality. The problem is that a widespread and legitimate public fear is the fear of being labelled in a way that leads to social stigma or harm or loss of benefits such as a job, a loan, insurance, mortgage, renting an apartment, opportunities to participate in social activities, access to unbiased medical care, and the goodwill of professionals. Medical labels are also often transient, subject to bias, and easily misinterpreted by people outside the system. Just see how you are treated with a label of mild dementia on your chart or even diabetes. It isn't just HIV that suffers from stigma. There are many other kinds of diagnoses these days that many people can misinterpret and use to stigmatize.

Stigma can also have a powerful influence on one's sense of self-worth and response to others. When people feel threatened, it increases the stress they experience. There is now a fair body of evidence suggesting that chronic social stress can lead to a continu-

ous output of cortisol, which in turn can negatively influence physical health and actually cause disease. Those who feel threatened are less likely to trust, co-operate, or deal in good faith.

#### 10:10

A 1993 survey by the Canadian Medical Association found that 7 per cent of Canadians had not sought out diagnosis or treatment because of worries about how it might affect other aspects of their lives such as insurability or employment. By 1999 11 per cent held back information from a health provider because they were concerned about who it would be shared with. The problem with this is that failing to seek diagnosis or treatment or to disclose information not only limits the ability of a doctor to accurately diagnose and treat; it also puts the public at risk from things like contagious diseases.

While it would be nice to be able to force anybody, the encouragement for people to come forward through the system because of confidentiality is actually key to our public safety. Therefore, what's really important to understand is that efforts of Canadians to protect themselves from such experience will lead to less reliable data for research and increased personal and public health risks.

Now, the larger social and health care context. I think we really have not yet come to grips as a civilization with the impact of the Internet, digital money, and the remarkable collection, collation, and trafficking in personal information that's happening out there as a result of the decreasing costs of data storage. However, while this started initially as sort of some stealth marketing and target marketing issues, uses of this information have now expanded to many other relationships in our lives – employers, landlords, the police, insurers – a phenomenon that's called function creep.

The catch-22 of having the right to control access over one's own medical records or information is that other parties can request authorization for access as a condition of being considered for a service or product or employment. Denying access is then interpreted as having something to hide. Nowadays few people give a second thought to signing an authorization to access their personal information as part of an application for work and insurance – and I would encourage you to look at two examples that I've provided in the handout here – nor are they often aware of the remarkably extensive, often inaccurate, irrelevant information that is collected by individuals in these circumstances. Failure to sign a Verifications, Inc. form out of concerns about the extent of information gathered and the lack of information about the company led to a woman who had been hired for a job refusing to sign the form, and she was summarily fired.

Another example. When a young woman started her own business in Ontario and applied for a disability insurance policy, she was surprised to be turned down because the company said her medical records showed that she had a history of repeat physician visits for psychological counselling. It turned out that her physician, someone her family had gone to for years, because she spent so much time talking when they went in with routine problems, had been billing these appointments as psychological counselling. When the woman confronted the doctor, the physician said: well, how else am I going to get paid for the real amount of time I spend to provide you with good care? The irony is that this visit was also billed as psychological counselling. No disability insurance will touch this woman now because all the information that goes in those applications for health, life, disability insurance is shared in an industry-run database called the Medical Insurance Bureau housed in the U.S., nor does this woman feel that she can destroy her parents' relationship with the doctor by filing a complaint.



I think that another important point we wanted to make is at the back of the handout here. We've included a one-pager about how electronic databases have been used in large, dominant industries such as banking, telecommunications, and energy to segment customers, reduce genuine competition, and penalize customers. One of the dilemmas is that we've also seen over the last decade provincial and federal governments in Canada adopting the use of electronic databases to more efficiently segment citizens and the public. The loss of universality and erosion of public benefits has led to the need for far greater intrusion into the financial and family lives of many citizens due to the demand for detailed information.

I think it's also important for you to know about the increasing commercialization and the powerful influence of the pharmaceutical industry on health research and health care today and how this is driving the creation of many disease and health databases to facilitate clinical trials of new drugs. Clinical drug trials are a growing business in Canada, and more than 80 per cent of these trials are funded by the pharmaceutical industry. The number of phase I trials testing for safety in humans approved by Health Canada in seven days increased from 138 in 2001 to 630 in 2002 and 1,006 in 2005. Interestingly, the federal government just announced reduced evaluation of certain drugs prior to market entry.

My final topic here is lessons learned from other sectors. While the concept of electronic health databases and the manipulation of records and how it can be used and what some of the problems are is relatively new to the health care sector, it's actually not that new to those of us who worked in dealing with the issues in the financial services sector, the credit reporting sector, many other kinds of sectors. And what we've learned, certainly, with the exploding identity theft and fraud that I think many of us are aware of these days is that protecting the integrity of databases holding personal information is not only costly but difficult to assure. Sloppy data entry, coding, confusion with common names, locations, bias or prejudice, breaches, unauthorized uses, and fraud are common reasons for inaccurate information. The existence of electronic databases and ease of access to so much personal information at the touch of a keystroke has been a major driver in the success of the fraud industry dominated by organized crime.

Now, the other thing that we've learned from our experience with identity theft is that the first response to a problem maybe isn't always the right response. The first response to merchants and public agencies is often to collect and store even more personal information in databases in order to authenticate somebody's identity. Ironically, the more information you put into those databases creates an even greater risk of fraud and identity theft should a data breach occur, which they do with remarkable regularity. By the way, in Canada there's no required notification for breaches of databases or information.

What other things have we learned? We've also learned that contracting out to multiple operators in multiple locations is guaranteed to increase the number of data breaches, the errors, and the risk of identity theft. We know that the more uses and users, the greater the problems and the less user friendly applications are for different purposes. We also know that nonidentifiable or anonymous data can often be easily reidentified. Interestingly, one of the questions that we've tried to find out unsuccessfully but we haven't attempted through FOIP yet is that we don't know if and how much of our anonymized health data here in Alberta has been sold to insurance companies or drug companies.

In summary, we believe that there is a great deal of evidence for caution in moving ahead with this legislation or we believe that not only will the quality of the electronic records themselves and the databases be put at risk but what is probably more at risk is the trust

and good faith dealing of patients with the health care system and all of us with each other.

I just want to add a few comments very quickly here about the proposal for research repositories. Although we have long championed the creation of a university-based, arm's-length health policy research centre in Alberta, our support for research repositories is entirely predicated on the limited use of such databases by such a centre and appropriate governance structures. Although there are many – we have CHSPR in B.C., ICES in Ontario – we're actually most impressed with the structure of the Manitoba health policy centre.

You may not realize this, but one of the big issues from a public and patient interest perspective is the lack of disclosure of research results that often lead to misinformation for both physicians and the public. So it's really important that when we give our information to be included in any database, anonymous or otherwise – that's part of our donation as citizens to improve knowledge and enhancement – the research based on that information should be in the public domain and available to everyone.

**10:20**

The question we're left with and we would like to raise is: is the collection of more information in databases and the removal of important protections for citizens going to solve our health care woes, or is it going to increase these kinds of problems? We believe that there is a role for some wonderful applications of electronic technology and computers in health care, but they have to be carefully thought out, and they have to be limited.

Thank you very much.

**The Chair:** Thank you very much. We have a few questions for you.

Ms Pastoor.

**Ms Pastoor:** Thank you very much, Mr. Chair. I'm not sure that it's a question so much as I'd like to make a comment on something and maybe get your comment back. One of the things that I think is an excellent example of what you're talking about in terms of biased behaviour and information out there is a case that comes out of Manitoba, when, in fact, two women revealed that they were lesbians and were refused health care. What kind of a message is that sending to the rest of the health care users in Canada?

**Ms Armstrong:** Absolutely.

**Ms Pastoor:** To me it's an example of where people won't say things. Why would that information, in your mind, even be relevant although, I mean, it certainly is in terms of different things that they may have to do. But how do we protect ourselves from that kind of behaviour? Is that, in your mind, an ethical medical response to that?

**Ms Armstrong:** I was very pleased to hear your comments and the comments of Dr. Sherman earlier here today because in my experience what many people don't realize is that the collection of excess data on clinical charts is actually arising out of the impetus to do more research based on these existing charts. So a lot of things that may not be relevant to a particular episode of care or may be only relevant in a very, you know, small way are now getting captured and included because of the desire to use the same database for multiple different purposes. Certainly, at this conference I was at, there was a tremendous amount of impetus by researchers to want

front-line workers to ask ever more questions and fill in ever more fields in computer systems. I think that's one of the tensions and one of the challenges.

**The Chair:** Ms Notley, please.

**Ms Notley:** Yeah. Well, I wanted to start, first of all, by thanking you very much for your presentation. You, actually, sort of twiggled in me a couple of different aspects to this, which I should have remembered because they kind of arose from my previous life before I was elected. But now, you know, when I think about them in relation to this, I get even more concerned. You talked about bias, and it's only after you raised it that I suddenly, of course, remembered my life of reading through probably 400 to 500 medical files in the course of doing advocacy and discovering one doctor's inclusion of the comment: teary, unco-operative, manic, emotionally unstable. Then that comment followed its way through that person's treatment for years. That was where you saw it on paper.

Then, of course, I'm also reminded as well of a fairly significant dispute that I was involved with right before getting elected around the ability of an employer to compel their employees to give them the right to get on the phone with their doctor and chat up their doctor about any and all issues relating to their employability. Of course, now it occurs to me that if that doctor has got an electronic health record in front of them that has information that is 10 years old on it that includes these sort of chart notes from however long, there's no limit on the ability of the employer to get access to that information.

I know that the consent forms being used in that particular sector get broader and broader and broader, and people advocating on behalf of employees in those situations have been unable to compel a sufficient narrowing to ensure that that information doesn't get out there. I hadn't even thought of it from that perspective, so I appreciate your presentation for reminding me of that whole issue.

Having said that, my question. You talk about data breaches. I'm wondering if you can give us a little bit more information on sort of the frequency of data breaches or where we might find out more about that.

**Ms Armstrong:** Ah, we'd all like to know that one.

**Ms Notley:** My second question is going back to the question of research repositories. You mentioned the Manitoba health policy centre. I always, of course, love it when we refer to Manitoba. Nonetheless, I'm wondering if you could give us a sense of some of the elements that they have there that we don't necessarily see guaranteed through this legislation.

**Ms Armstrong:** Okay. So the first was just the . . .

**Ms Notley:** Breaches.

**Ms Armstrong:** Oh, the breaches. Actually, I can send to the committee a list of some sources, some of the lists of breaches. There are some blog spots and some websites that try and keep track of this information. Actually, if you go and look at the website of probably any privacy commissioner, you would have to go through all their orders to find those kinds of breaches, but there are certainly some remarkable ones. Again, we don't have notification of them, but I'd be more than pleased to send you some resources.

**Ms Notley:** Thank you.

**Ms Armstrong:** Okay. The second was in Manitoba. Now, Manitoba was very lucky. There were a couple of visionaries about 20 years ago, Noralou and Les Roos, who envisioned the opportunities that there would be to do research in the public interest with sort of databases of health information within the public system. So they built this, but they built it with a great deal of integrity, academic freedom, and very, I guess, great concern about the privacy and the protection of the individuals.

One of the things that makes it a little bit different is, well, first of all, it's based in a university in order to ensure academic freedom. Secondly, and I'll just read this to you, is that the Manitoba centre for health policy through the University of Manitoba is the trustee for the population health research data repository. One data repository, not multiple data repositories all over. All data in this repository are collected by public bodies. Research using this data is permitted by privacy legislation if it is used for statistical or research purposes, if it's in the public interest, and if the results remain in the public domain, which are important considerations.

In addition, they have a much more elaborate structure than the research ethics board's approval mechanism that we have here in Alberta. Again, I thought I had the piece here, but it's through the health information act in Manitoba. They have public involvement in the government. The committee has to approve every single research project that's undertaken using this data. It's actually a very impressive model from my way of looking at things.

Thanks.

**Ms Notley:** Thank you.

**The Chair:** Thank you.

**Ms Blakeman:** On breaches, I'm wondering if there is any sense out there of how many breaches occur because of a deliberate individual act. You know, the girlfriend of the unhappy spouse who's trying to find the old spouse and beat them up goes into a database and gets the information. An individual deliberately using – well, we had one here, city of Edmonton police searching around in a database for a journalist.

**Ms Armstrong:** Exactly.

**Ms Blakeman:** Do we have any sense of how many breaches occur because of a deliberate act by an individual versus stupidity, carelessness, or laziness, where the box of Visa slips are put out with the garbage? Do we have any sense of that? Where could we go looking? I'd like some evidence.

**Ms Armstrong:** Well, wouldn't it be nice. You know, I always used to say that information in a database is kind of like vodka: it's colourless, odourless, and tasteless, but when it hits you, it packs a wallop. It's really hard to see what's going on with the data. I guess I would say that I think most people would be astounded at the extent of – I can't remember the word – the actual breaches by hackers. Do you know what I mean? There are deliberate breaches, people . . .

10:30

**Ms Blakeman:** For what? Fun? Why are the hackers hacking?

**Ms Armstrong:** For identify theft and fraud, a whole number of different purposes. People would be actually quite shocked at the degree of assaults that there are routinely on databases – government

databases, university databases, any kind of databases – by people looking for that kind of information for identify theft and fraud purposes. So there are the big hackers. What you're speaking about is how many people go in and just check out somebody else's chart because you know it won't be picked up unless too many charts are picked up, and that's difficult to say.

However, I have to tell you through my experience that the reason we can speak to these issues is because we do get calls, and like Ms Notley, we do follow up on specific cases. Unfortunately, we often can't talk about them because these people are really reluctant to be visible in the public. Some of the things that we've seen, egregious examples of what appear to be sort of private investigators or even sort of some of the tactics of insurance companies to find out information, are really most disturbing. It's not necessarily inside the system but outside the system that actually creates some problems. The system is very vulnerable.

**Ms Blakeman:** Thanks.

**The Chair:** Okay. Ms Armstrong, I'd like to, if I could, just kind of bring you back to the discussion specific to this bill, not that the other points haven't been also very relevant. Specifically in the case of prescribed health information, which is what's encompassed within this bill, you started out your presentation by expressing some concerns about the potential for secondary uses of that information and gave some very good examples. Do you have any specific recommendations for the committee as to what restrictions should apply to secondary use of health information and how the bill might be amended in order to achieve that?

**Ms Armstrong:** Well, the dilemma that you face – I understand this, and I think I've been coming to meetings for a long time, have I not? – is that you actually can't do it with this legislation. The control points are outside this legislation. Even for things like an association, we've been trying to say: how do we control these external uses? Credit reporting or consumer background reporting agencies aren't even required to be licensed in the province of Alberta. Now, they are regulated to some extent, but they're not required to be licensed. We've suggested that there have to be, you know, some controls there.

I'd also like to speak to another point that somebody – I can't remember – brought out with regard to companies and different lines of business because this is a very, very serious problem. For example, we ran into this issue by accident when we were following up on one particular insurance case here in the province of Alberta. We have one data management company in Alberta that actually has the dominant contract for many public institutions, many private insurers. It also runs an insurance risk adjustment service. It also runs various kinds of credit check services. There are many organizations with these multiple lines of services where we're completely dependent on sort of the honour system, and that doesn't work well. What we'd suggest is that it would probably be best not to contract out to agencies with multiple lines of business. Can you do that within this bill? This bill may not be the appropriate place to do that.

**The Chair:** Well, with respect, I don't think the bill contemplates that. I guess what I was trying to get at is that the issue at hand is the exchange of information, which, agreed, the minister could compel to occur under what's proposed, but the exchange of information is between authorized custodians. That's the specific provision in the bill. I guess I would disagree to the extent of your

suggestion that the points of control are outside the system because in and of itself the bill is very specific about where that exchange occurs and under what circumstances.

**Ms Armstrong:** Okay. Yes. I appreciate your point, but as I pointed out with the catch-22, you actually as a government don't have any control when would-be employers, when insurers, when anyone else says to you: "Well, do you want insurance? Do you want a job? Sign this form that gives me access to your health information." That isn't something that is sort of within the aegis of this bill to manage.

I guess the other issue that I would suggest is that if we're expanding it to include undefined privately financed services, we have a lot of concerns and we expressed a lot of concerns in the past with regard to access to these electronic health records in the retail drugstore environment and what some of the implications are there. I appreciate your point, but again I think that for many of the answers, we need to look at far more disclosure to patients, far more public discussions, and we need to look at alternative control points besides this legislation.

**The Chair:** Thank you.

We have time for one last question, and that will be Ms Pastoor.

**Ms Pastoor:** Thank you. I'll try to be very brief. In the Manitoba system, at least if I understood you correctly, you spoke mainly of public information, like through the public system. How do they handle their private information, private clinics?

**Ms Armstrong:** They don't. Well, if it's a publicly engaged service . . .

**Ms Pastoor:** As long as they receive a public dollar, then that information goes into that database?

**Ms Armstrong:** Yes. There are some deficits in that because, obviously, not everything is publicly paid, so they're missing some pieces of information.

Just one other thing that I'd like to add is that there are some other elements that can make a difference. The chair of electronic health records in Ottawa, Khaled El Emam, has done a tremendous amount of work in this area, and there are some good ideas about how we can secure information. He's a strong believer that we need strong oversight, strong audits, that none of this needs to be left to an honour system or self-policing. One of the dilemmas has been that the research community has been reluctant to sort of jump on board with some of these issues.

One other aspect with regard to research. In Canada the aboriginal community has succeeded in bringing forward a very important ethical framework for research, which suggests that if the research is about us and for us, we need to be involved with it. So when researchers have to work with aboriginal communities, aboriginal communities get to have a say in what the question is that's researched, how that information is interpreted, and access to those kinds of results. I think it's a bit of that culture change around research and the public that we also need to change as we move forward.

**The Chair:** Ms Armstrong, thank you very much for appearing. If I could make a small request of you. Your formal remarks at the beginning included a lot of facts and figures. It would be helpful to the committee if those are available in written form. If you could provide them to us through the clerk, that would be of assistance to us.

**Ms Armstrong:** Certainly. Should I just e-mail them in?

**The Chair:** Yes. You can e-mail them to Ms Norton.

**Ms Armstrong:** Super. Thank you very much for your attention.

**The Chair:** Thank you very much. I appreciate it.

So we have a break. Can I suggest that we come back at 5 to 11? We'll just try to pick up a few minutes here if we can because people have other places to be.

[The committee adjourned from 10:38 a.m. to 10:57 a.m.]

**The Chair:** We'll call the meeting back to order. I'd like to welcome our next group of presenters: from HIV Edmonton Ms Debra Jakubec, executive director, and Ms Susan Cress, executive director of AIDS Calgary. Thank you very much, both of you, for being here today. Have you been sitting through the proceedings earlier this morning?

**Ms Jakubec:** No. We've just arrived.

**The Chair:** Okay. Well, we'll take a moment to introduce the members of the committee to you. We'll begin with the deputy chair.

**Ms Pastoor:** Bridget Pastoor, Lethbridge-East. I'm the deputy chair.

**Ms Notley:** Rachel Notley, MLA, Edmonton-Strathcona.

**Dr. Sherman:** Raj Sherman, MLA, Edmonton-Meadowlark.

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

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

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

**Ms Blakeman:** Welcome, both of you, to my fabulous constituency of Edmonton-Centre. Particularly to Ms Cress, who has no doubt come in from the International Airport, welcome to Edmonton-Centre. My name is Laurie Blakeman. You can shop and go to lunch here any time you want or in Edmonton-Strathcona on your way back to the airport.

**Mr. Quest:** Welcome. Dave Quest, MLA, Strathcona, as in county of Strathcona or about half of it.

**The Chair:** And on the telephone?

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

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

As I think you understand from the clerk, we have about 30 minutes. We'd like to ask you to take up to 15 minutes for your formal remarks and then leave us some time for questions and discussion with you after. If that's all right, please proceed when you're ready.

#### **HIV Edmonton AIDS Calgary Awareness Association**

**Ms Jakubec:** Great. Thank you very much. AIDS Calgary and HIV Edmonton would like to thank the members of the Standing Committee on Health for being invited to present today on the amendments proposed to the Health Information Act in Bill 52. Both of our organizations have served people who are living with HIV and AIDS for over 20 years. In our experience the importance of confidentiality for our clients has always been paramount. While we understand the need for electronic health records to improve access to care and treatment, it is equally important to those we serve that their right to privacy be maintained.

Personal health information is considered to be one of the most sensitive categories of information and deserving of special protection. As a matter of public policy the right to privacy is a fundamental human right that implies clear responsibilities on the part of government. Our understanding of the needs of people living with HIV and AIDS will demonstrate that except for narrow circumstances that must be legally and ethically justified, all people, including those living with HIV and AIDS, should have the individual power to decide how, when, with whom, and to what extent their personal health information is shared. Some may question this reasoning and believe that public health policy supersedes privacy. The two do not need to exist in opposition. The public health system in Alberta is very efficient at contact tracing in the event of a sexually transmitted infection and ensuring the appropriate provision of public health services in Alberta.

Privacy is of the utmost importance to the citizens of Alberta. Guaranteeing Albertans' respect for privacy can advance public health goals. As an example, a person is more likely to co-operate with public health and release the names of their sexual contacts if they know that providing this information will be kept private. Protecting individual privacy rights is one of the reasons why the public health system in Alberta works.

Surprisingly, it is precisely the people who will be accessing electronic health records that are the people who are most likely to discriminate against our clients living with HIV and AIDS. AIDS Calgary did a survey in 2005 with people living across the whole province, and the survey found that 46 per cent of the people receiving health care in the past 12 months felt uncomfortable or felt they were treated badly because of their HIV status. Another 31 per cent of the respondents felt that information related to their HIV status was not kept confidential during their hospital stay.

The current public health practice of contact tracing is very successful in Alberta. Broad sharing of personal health information threatens to create an atmosphere of fear and nondisclosure in Alberta that could result in several things. People could avoid testing for HIV and for sexually transmitted infections. There could be avoidance of individuals' releasing sexual contacts, increased stigma and discrimination against people living with HIV and AIDS. There could also be reduced treatment adherence and negative impact on health outcomes. We also believe there could be reduced care levels because of discrimination when our clients go to the hospital for non HIV-related illnesses. There could also be refusal of service by health care providers. A very important point is that patients may choose to not share vital information with the health care provider for fear that it will be recorded and that this information will be accessible to every subsequent health care provider.

Confidentiality of personal health information and the possibility of security breaches are issues of concern with respect to making medical information electronically available. Alberta's Auditor General has warned in the past that government records in the

province are not as secure as they should be. A very important case in point that recently came to the attention of HIV Edmonton was a client who called from northern Alberta. He lives in a small town. He was very distressed that the electronic health system will give his sister, who is a nurse, access to his health records and HIV diagnosis. He does not want his family to know his health status, but how can he prevent her from accessing his records? At the time when we spoke with him, we did not have an answer. It is important that the committee consider a recommendation from the Romanow report which specifies that individuals “should have ownership over their personal health information, ready access to their personal health records, clear protection of the privacy of their health records.”

Thank you. I will hand it over to Susan Cress.

**Ms Cress:** Thanks, Debra. As AIDS service organization staff I have seen stigma and discrimination at work. Confidentiality is crucial to building relationships when working with people living with HIV and with other vulnerable populations. Confidentiality is also essential in prevention work. People must be able to access information and services regarding their health and health management without fear of retribution, judgment, or loss of access to services. AIDS Calgary has done significant work with the Alberta Dental Association in the past year and has revealed on several occasions that when people are accessing dental services, HIV is often used as a screening-out measure in accessing their services.

In consultation with my staff I’ve been alerted to the fact that several youth who frequent our services have expressed that they are worried about their parents finding out that they are being tested and/or about the nature of these test results. Broad sharing of this information would completely hinder our ability to convince youth that they need to be tested for sexually transmitted infections, including HIV. This is of deep concern to the public health because the highest rate of HIV infection per 100,000 people in Alberta is occurring amongst youth aged 20 to 24. In addition, Alberta has the highest rate of sexually transmitted infections per capita.

**11:05**

Shockingly, many health professionals still do not understand HIV transmission and issues related to HIV. Reports from clients demonstrate that health providers often place judgment on presumed background of individuals and refuse or delay service due to their HIV status, drug and alcohol use, and/or sexual orientation. The intersection between human rights law, the Alberta Human Rights Commission and the revision of that work, and this new legislation is important when considering diverse communities, specifically the gay, lesbian, bisexual, and transgendered community. In this province orientation is not protected grounds from discrimination as it is not explicitly written into our human rights code.

Again, the AIDS Calgary 2005 survey of people living with HIV found that 34 per cent of participants indicated that they have had problems getting basic medical services. Women were almost twice as likely to have problems accessing medical services than men, at 43 per cent of the women sampled versus 28 per cent of the men. Eleven per cent of the respondents felt that information related to their HIV status was not kept confidential during a visit to their doctor. Twenty-three per cent of participants believed that information related to their HIV status was not kept confidential while filling out medical forms. Respondents reported having their status printed on medical, hospital admittance, and insurance forms. These issues were of great concern to participants in the survey.

The stigma and discrimination that continues to surround HIV is obvious and still unabated. I would like to ask each and every one of you to consider: if you are or you have a loved one who is living

with HIV, would you want that information disclosed to every health care provider when you were receiving service that was not pertinent to your HIV status? Even if you have never been at risk, I ask that you consider the privacy of those who struggle with the disease every day and the hardship they may incur over your decision on these amendments. Let those who want and need to keep their health status private stay private.

We make several recommendations. We just want to say that in the province of British Columbia they recently set policy related to the very issue of disclosure. The health act enables the ministry of health to implement a system of electronic health records that will be accessible by authorized personnel throughout the province, but the act also requires the minister to allow individuals whose data is contained in the health information bank to make a disclosure directive, therefore allowing people to limit the use or disclosure of their health information.

If our clients did not repeatedly experience stigma and discrimination from the health care providers, the right to privacy would not be of concern for our organizations, but until the system is fixed and discrimination is reduced, our clients deserve to decide when, where, and with whom to disclose. When it is not legally required by law, it is inappropriate to force people to disclose their HIV status. Doing this will drive people underground, avoid testing, and avoid health care visits until the last minute.

Going back to a disclosure directive or something of a similar nature, we would recommend that this should be signed by all, giving each Albertan a choice. This would in effect mask or lock some health information so that it is not available to all users of the system. We go on to make further recommendations: that the primary source of medical information be the individual and their physician and not include a third party or fee-for-service consultant, that collection of the information be conducted only with the consent of the information, that masking of information which could inhibit positive outcomes or support positive outcomes remain in place, and that patients must be allowed to obtain a listing of who has access to their health records.

Thank you very much.

**The Chair:** Thank you, both. I’m sure we have some questions for you from the committee.

Maybe I’ll start with one, then. In reading the report – and I haven’t had a chance to read it in a lot of detail, just to skim through it – your recommendations here are actually directed to governments across Canada. Specifically with respect to individuals with HIV and their families is there any particular jurisdiction in Canada that you think is on the right track, is perhaps standing out in terms of not just compliance with the recommendations you’ve made but in an overall sense? Is there one province that you would point to as potentially a model?

**Ms Jakubec:** I believe that Ontario, Manitoba, B.C., and maybe Saskatchewan, too, all allow for masking of records. That seems to be the norm across Canada. I believe that most of the things Ontario has done are probably the strongest to the way we feel in our recommendations.

**Ms Cress:** I concur.

**The Chair:** Thank you.

**Mr. Fawcett:** Thank you for coming. You certainly brought up some interesting information. I just want to explore something that you mentioned in your presentation a little bit. As I was mentioning

to some of our colleagues here when we were chatting on our break, as we're going through this process on getting presentations, trying to formulate in my head where I see some of the advantages and disadvantages of this legislation and where we can maybe improve things, one of the things I was saying is that my personal perception is that I'm not so concerned about which medical professional sees anything that's on my health record. That's not a big concern for me. But you did bring up something interesting, the person from northern Alberta that had corresponded with you whose sister is a nurse and doesn't want his record exposed to his sister.

We can't contemplate all of the different dynamics and relationships for people. Would an acceptable solution to that issue be, you know, allowing for a mechanism which will allow someone like this individual, if there are particular individuals that they can identify within the system, to, I guess, block or mask their record from them? Would that be a particular solution?

**Ms Jakubec:** That would be a good solution. It sounds like it would be challenging for the health care system to do that and not just block a certain piece of information. Blocking the piece of information instead of individuals may be easier to do.

Two things come to my mind. We know that there is protocol set up for HIV-positive women who are pregnant. The desire is there that if she is an Edmontonian but ends up giving birth in Calgary, if it's related to her giving birth in Calgary, we can access that protocol because she would want her baby to be born with the protocol that her original doctor has. But if she's in Calgary and breaks her finger, her status is not relevant. That's why I kind of focus a little bit more on the relevance of the data and that for certain diseases and things the patients themselves should be able to decide.

We already know in Alberta that this occurs on First Nation reserves. Very, very many First Nations individuals that we work with receive no health care at all on-reserve. They always come to the city because many of their family work on First Nations. So they come to Edmonton, get tested, and receive all their services here. If they had the ability to block their HIV status from those records, they may go for their cold or their broken leg to health care providers on the First Nation.

Does that help?

**The Chair:** Thank you.

**Mr. Quest:** There seems to be a fairly consistent theme here with all of our presenters about the protection of information and how far you go. Just going back to what you were saying about withholding information, if there was a consent form to be signed on day one – and I'm thinking about next time you go to a medicentre or your own doctor or any contact in the system – would that work? You'd have the option of not consenting to that information being uploaded onto your electronic health record. That's agreeable?

**Ms Cress:** I think that's a good start because then people are opting in to share the information, and that leads to choice with them.

**Mr. Quest:** Okay. Just a supplemental. That seems to be a constant this morning. Now, I realize it would be just about impossible to block certain individuals from accessing certain information, but what about the idea of different levels? We're talking about the fellow whose sister was a nurse. If it was different access for different categories, as with an emergency room doctor who would have access to all of that information – perhaps nurses or physios would have, obviously, access to less information – does that help at all, different categories for different access for different levels of health care professional?

11:15

**Ms Jakubec:** No, because you never know who they know. I mean, we could have people who are living with HIV who themselves are health care providers and might not want certain people accessing that information. As long as they practise standard precautions, they're not putting other people at risk.

I'm not sure that you could have certain levels. I think it's more about the information and people's own individual decision. I mean, I know with my health record I tell my doctor everything about myself. I'm very confident with that; I'm very comfortable. But there may be things in the future when I know that anyone can access that that I may no longer want to tell my health care provider, especially if it could affect things like insurance.

**The Chair:** Thank you.

Dr. Sherman.

**Dr. Sherman:** Thank you, Mr. Chair. Ms Jakubec and Ms Cress, thank you for appearing before the committee.

I'd just like to go back – it's my 17th year working now – to the old, dark days when there were no electronic health records. I remember patients who were drug addicts or who had HIV when HIV first came out, you know, and we didn't know anything about it. There was a tremendous amount of fear. Front-line health care workers themselves were scared to even go near patients, let alone touch them, or they touched them with gloves and a gown and a mask.

I will say the good thing has been that much of that stigma – there still exists a stigma – has been greatly reduced. In fact, we don't put markers on the charts anymore warning that someone has HIV or someone has this, so that's a very good thing. What we discovered is we just need to use universal precautions. In fact, it's hepatitis B and C that we're really worried about as workers when we get poked, because it's 30 times more infectious than HIV, or a drug-resistant tuberculosis. So that's a very positive thing for HIV, to realize that it's a medical issue, that it's an infection like any other infection. My hope is that people in society realize and understand that. It's not just a certain segment of society; everyone can get HIV if they're not responsible in their behaviour.

With respect to this it's not just HIV; it's mental health issues and other illnesses. There are stigmas if you're in certain communities. You know, to give you an example, if you're in a certain community and someone's going to marry somebody and if there's heart disease in the family, someone may look at your electronic health record and say: I don't know if I want to marry this person. That is an issue.

This isn't just an Alberta issue. In Canada we're five to seven years ahead of everyone in the country in the area of electronic health records. We've come a long way with the records, and it has improved care. I wonder if you're aware of any issues internationally of how, perhaps, HIV is handled, say, in Europe. I know there are HMOs that use medical records elsewhere. Are there other countries that may be a bit further ahead of us in Europe? Do you know how this issue is handled over there?

**Ms Jakubec:** I actually do not, but we could find that information out quite easily by contacting the Canadian HIV/AIDS Legal Network. I did do some research on the UNAIDS website. It is a very respected international organization. UNAIDS – I think I actually have it written in here – states that “using health data for public health goals must be balanced against individuals' rights to privacy and confidentiality” and “should be based on human rights principles.”

A lot of the work we do is based on human rights principles, and it is a basic principle to maintain privacy. One of the most important parts of privacy is health privacy. People do want that maintained. So I believe that if there's a way that Alberta can allow for the individual to make that decision and that choice on their own, I think that would be a very important step forward, and it could be a model for the rest of the country.

**Dr. Sherman:** Thank you.

**The Chair:** Thank you.  
Any others? Go ahead.

**Ms Pastoor:** Thank you, Mr. Chair. I would just like to perhaps point out to Mr. Quest – and I'm not trying to start a war with my esteemed colleague – that often it's the nurses that do the work in emerg, so they would need to have the same level of information.

**Ms Blakeman:** Well, I mean, all you do is say: give me your access code so I can go get the information. It's done.

**The Chair:** Any other questions for Ms Jakubec or Ms Cress?  
If not, I'd like to thank you both very much on behalf of the committee. We appreciate your time and the written presentation that you've left with us. It'll be very helpful to us in our deliberations.

**Ms Jakubec:** Thank you very much.

**The Chair:** Thank you.  
Colleagues, I've just been informed that our next two presenters haven't arrived yet, so we probably have an opportunity for another break here for a few minutes. I'd like to not take any longer than absolutely necessary. As soon as the next presenter is here, I'd like to move on. Can I suggest that we recess for a few minutes? If you're able, just stay in the lounge area. As soon as the next presenter is here, we'll let you know, and we can get back with the proceedings. Would that be agreeable?

**Hon. Members:** Yes.

**The Chair:** Okay. Thanks.

[The committee adjourned from 11:21 a.m. to 11:27 a.m.]

**The Chair:** Thank you, colleagues. I'd like to call the meeting back to order. I'd like to welcome Mr. Tom Shand, executive director of the Canadian Mental Health Association. Very nice to have you here, Mr. Shand. I believe you presented to the committee during our review of Bill 24, so welcome back.

I'd like to just take a moment and have members of the committee introduce themselves. I think we'll start with Ms Blakeman this time.

**Ms Blakeman:** Oh, boy. Thanks so much. I'm delighted to welcome you. I know that you actually work in the fabulous constituency of Edmonton-Centre, but I always welcome people to the fabulous constituency of Edmonton-Centre. I'm Laurie Blakeman.

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

**Mr. Fawcett:** Hi, there. Kyle Fawcett, MLA, Calgary-North Hill. I'm sorry that I do have to leave a little bit early. If I sneak out, it has nothing to do with you.

**Mr. Shand:** Thanks for the warning.

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

**Dr. Sherman:** Good morning. Raj Sherman, Edmonton-Meadowlark.

**Ms Notley:** Rachel Notley, Edmonton-Strathcona.

**Ms Pastoor:** Hi. Bridget Pastoor, Lethbridge-East, deputy chair.

**The Chair:** Hi. Fred Horne, MLA, Edmonton-Rutherford, and chair of the committee.

As you've probably discussed with the clerk, we have about 30 minutes.

**Mr. Denis:** Jonathan Denis, Calgary-Egmont.

**The Chair:** Oh, sorry. I always forget that voice on the phone. Sorry, Mr. Denis.

**Mr. Denis:** Thank you, sir.

**The Chair:** If you could take up to 15 minutes for your formal remarks and then leave us about 15 minutes at the end for questions and discussion, that would be appreciated.

**Mr. Shand:** That sounds great.

**The Chair:** Please proceed.

#### Canadian Mental Health Association

**Mr. Shand:** I want to thank you all very much for the opportunity, Mr. Horne and members of the standing committee. This is certainly a very important subject to us and, I think, to all of us: the sharing of one's personal information as reflected in this proposed Bill 52, the Health Information Amendment Act, 2008.

I'm here today speaking not only on behalf of the Canadian Mental Health Association but, I believe, more importantly, in the interests of hundreds of thousands of Albertans currently living with mental illness or those who will experience mental illness at some point in their lives. Although it's not the type of illness for which it's possible to obtain an exact number as to how many people will fall within this description at any point, it's conservatively estimated that it includes at least 1 in 5 Canadians, which in Alberta terms would equate to more than 600,000 people living in Alberta. Obviously, it's a broad constituency and one that I'm proud to speak on behalf of today. Although many of my remarks will certainly apply to others as well, I'll focus on putting forward a perspective reflecting what we know of the needs and the concerns of those people living with mental illness.

As I expect is likely the case with the majority of those presenting to you, I'm not here to suggest that electronic record keeping does not have value. Clearly, we recognize that Albertans living with mental illness also require physicians and other caregivers to have accurate, relevant information available to them on a timely basis when they're seeking to make a diagnosis or to effect treatment. However, there must clearly be a balance between a person's right

to privacy and the need for sharing of their personal information for medical reasons.

We believe that the amendments in Bill 52 have exceeded that balance at the expense of the individual's right to privacy. Over the next few minutes I'll outline our greatest concerns in that regard and what we believe could be the consequences should this bill be passed in its present state. In so doing, we've not sought to analyze the wording of each clause or to suggest alternative wording – I'm sure others have done that in due course, and you've got people certainly more qualified to do that than I – but I will try to express our concerns in the most clear-cut manner and then leave it to your resources and expertise to determine if a given clause should be removed or revised.

As is no doubt the case for most of the people in this room, sharing personal information relating to one's health is a very private matter. It's not done lightly and most often with very few people, including one's own physician or medical team. With this group there's a trust. There's a trust that the information shared will be kept in confidence and only given out on a need-to-know basis to a very restricted circle of people. Further, it's expected that should requests come from outside that circle, the individual should have the right to deny permission or access to information not absolutely required or, at the very least, be provided knowledge of what disclosures were made and to whom.

For many even this very limited sharing of information is not comfortable, and any breach of this trust or confidentiality is not soon forgotten. Even if nothing untoward results as a result of this sharing of information, there is a grave risk that the trusting relationship with the caregiver may be damaged, perhaps irreparably, and that is the situation for most people. I think it's the situation, clearly, for most Albertans and probably for everybody in this room.

For a person who has been treated for mental illness, the potential downside is far, far greater. For starters, the comfort level for sharing information about their mental illness, either past or present, is much less. Saying that you were treated for depression three years ago is certainly far removed from saying that you broke your leg skiing. It is not unusual for a patient to fear stigma and fear the potential for discrimination resulting from disclosure of treatment for a mental disorder. That's not something that lives with them today; that's something that may live with them for the rest of their lives regardless of whether their condition has been treated effectively and they're able to function fully. That's even if the person is in perfect health now, let alone those that may not be in perfect health.

Unfortunately, the risk of stigma and discrimination relating to mental illness is real. It's real in the workforce. It's real at school. It's real even amongst one's family and friends. It's certainly real with regard to housing, insurance, and the list goes on and on. There's a good reason that the Mental Health Commission of Canada has made reducing stigma relating to mental illness a top priority and that organizations such as the CMHA are continually fighting that same battle. Reducing stigma and discrimination is a very real and very important step in assisting people living with mental illness to be able to effectively seek treatment and then achieve optimal recovery.

It's difficult enough to discuss your personal mental health issues, either your own or perhaps those of your family members, within your small circle. It's an entirely different matter knowing that these records can be accessed by 26,000 or more people and, worse yet, that your physician may be forced to divulge information beyond absolute need or that there's not even complete control as to who will be able to access those records down the road or, worse again,

that you'll be helpless to control the process or even discover who's accessing those records. Clearly, those risks or even the possibility or perception of that lost privacy are not warranted or, we believe, are not justified. Even if there are no abuses or system breakdowns that could cause actual harm, the realization that such a possibility exists will be harmful and even more so amongst those who have increased sensitivity about others negating their right to privacy.

*11:35*

For many people, particularly those needing treatment for mental illness, we believe the result will be – and I think this is probably the most important point we can bring to you today – that they will not divulge certain medically relevant information to their caregivers or, worse yet, that they will not seek treatment at all. This could be an absolutely catastrophic situation for those living with mental illness, again not exclusive to those with mental illness but certainly applicable to them. Unto itself I think it's reason enough to change the parameters of this bill.

To alleviate these concerns about unreasonable invasions of privacy, the following are our recommendations: put in place appropriate safeguards such that information shared is limited to that information absolutely required and to those with an absolute need to know in the best interests of care for that patient; further, that patients and caregivers not be forced to comply with providing information beyond what they deem to be required and that the ability to mask unneeded information be maintained; that use of information continue to be seen as disclosures and that the patient maintains the right to review such disclosures; that individuals may appeal what is on their record and how it is used; that records not be sold or otherwise made available to outside sources – for example, employers, employee benefit programs, insurers, the justice system, law enforcement, and others – without the express consent of the individual or by subpoena or other form of legal review; that the bill include enough restrictions regarding uses and users to ensure that the necessary safeguards are in place and that such restrictions are not trusted to the regulations, which are too easy to amend at a later date without adequate discussion or without adequate consultation; that public consultation extensively take place before consideration be given to a bill that has the potential to seriously jeopardize one's privacy; and that Netscape or any other means of gathering and disseminating electronic patient records be thoroughly examined on an ongoing basis for potential flaws or leaks.

Unfortunately, we're bringing, I guess, the message today that we believe that, in essence, this amendment has taken something that is essentially a good idea and wrecked it. I don't know whether the amendment is salvageable or if it's back to square one for those putting it together, but I am positive that this bill, if left as proposed, is bad for Albertans and particularly for those many Albertans living with mental illness.

Those are our comments. I thank you for your time and consideration. Before I entertain questions, I'd just like to mention that I'm joined here today by Sharon Sutherland, who is the chairperson of the Alberta Alliance on Mental Illness and Mental Health. I bring that up not only because I'm proud to be here with her but also because they didn't find they had time, with the amount of notice that was given with this, to properly consult with a number of organizations that are involved in that. Unfortunately, I don't think you're getting a full representation sometimes of the views and, perhaps even more importantly, why maybe our view may not reflect fully all the views of that organization, but certainly we're speaking on behalf of those with mental illness today.

Mr. Horne and others, thank you.



**The Chair:** Thank you, Mr. Shand. Just on your last point, the committee will be seeking public input through written submissions and perhaps some additional presentations later on, so there will be an opportunity for other groups to communicate with the committee.

**Mr. Shand:** Well, that's reassuring. Thank you.

**Ms Blakeman:** Two questions, different subjects, so if I could go to the end of the list, please. I'll just do one question now.

You mentioned a couple of times that 1 out of 5 – and I've also heard as high as 1 out of 3 – people in Canada will at some point in their life deal with mental illness, so we're talking 20, potentially 30 per cent of the population in Alberta having something on a health record. Do you have any statistical information you can share with us or provide at a later date that gives us some kind of idea of the consequences if people do not seek treatment and we've got 20 to 30 per cent of the population that won't seek treatment because they're concerned with a breach of confidentiality or a stigma attached to it? Do you have any kind of information about the cost to society of that?

**Mr. Shand:** No, but I believe that in response to that, without looking through various listings of health economic consequences, we can provide you some information in that regard and would be pleased to do so. It's certainly a serious consequence. Certainly, I think that anybody in this room or anybody else that's familiar at all with mental illness knows that oftentimes and most times treatment can be applied and can improve one's consequences. Not seeking treatment or not being forthright with your physician for fear of whatever reasons but for fears of privacy in this case is a serious problem with regard to the implications of what happens if this bill is passed as is.

**Ms Blakeman:** A supplemental. We're now beginning to get an understanding that housing; for example, if we don't help people get housing and be successful to stay in it, has a much larger cost for us through the rest of the services that we provide. If we have people that don't take advantage of a health care system and get better, what does that cost us? What are the consequences of that? That's what I'm looking for.

**Mr. Shand:** I hope to be able to provide some information in that regard.

**Ms Blakeman:** Terrific. Thank you.

**Mr. Shand:** The other end of it. Stigma is used kind of broadly. It's a nicer word than discrimination, but as I know Mr. Horne is familiar with and many of you probably have heard before, there is a real fear of discrimination here, too. It's not just that there's an image that you may not be thought of the same by people that you're dealing with, but with access to records, if you're owning an apartment building and you have the choice between someone who suffered from mental illness or somebody that hasn't, you may very well make the other choice even though the person may be a perfectly good tenant. So those social costs of housing that you're talking about very likely can become a negative outcome of this bill if there are any abuses of it at all, let alone the perception and the fear that people may not want to divulge their information because of it.

Many people have suffered discrimination in the past, so to give them assurance that that's not the intent of this bill or that we have other protections in place if you are discriminated against is not great reassurance.

**The Chair:** Thank you.

Others? Dr. Sherman.

**Dr. Sherman:** Thank you, Mr. Chair. Mr. Shand, thank you for appearing before the committee. You're right: the figures are that anywhere from 1 in 5 to 1 in 3 Albertans suffer from some form of mental illness. If the number is 1 in 5, it's probably because many people, because of the stigma and the shame associated, won't seek care, won't acknowledge that they have a problem. It's an issue that affects all families. I would say that based on these numbers, we probably have 16 to 20 MLAs who at one time in their lives have or will have mental health issues.

I'm glad you mentioned the issue of trust. Health care is really about trust. When you go to a physician, it's like when you go and talk to a priest. Nobody else will find out what you tell them. That's an intimate bond that the physician has with the patient, as a priest or the clergy would have. To us as health care workers when we are students, they tell us that patients will tell you 90 per cent of the time what's wrong with them if, number one, you take the time to listen or you have the ability to connect with them on that personal level so they can trust you and will give you that information. Part of that is so that we don't have to do every test on everyone because tests sometimes aren't positive when there's something wrong, and when there's something wrong, usually you don't need a test to tell you what's wrong.

There are diagnoses on Netcare under the current Health Information Act, so if someone has had some mental illness, it currently already is there on Netcare. Also, on PIN, when you go to a pharmacy and you get a drug, health care workers know what is a drug that you've taken for mental health issues and what's not.

I'm not sure what my question would be here, but I wonder if you could comment on whether we've already gone too far. Do you think that has gone too far, or do you think we need to go a little further?

11:45

**Mr. Shand:** Well, I think that you've probably heard over the couple of days that you've been listening to people speak to you that most people appreciate that there needs to be a balance. There needs to be a balance such that if you're practising and your patient has been seen in Lethbridge or somewhere else and you don't have a full background on them and you need to know it, either in an emergency or other situation, you have access to that. That information as a physician, I think, is fairly well accepted. The fact that you weren't the person that they divulged that information to: most people, I think, can accept that, the fact that there are legitimate usages for the information and that it's in their best interest.

At the same time there are protections now. There are protections so that you can determine when the record has been used. There are ways to mask the information. From my understanding – and I'm not a lawyer or an expert in this – I know that if we line up, for instance, with the Alberta Medical Association or with the Privacy Commissioner and they share the same concerns, those are pretty well-thought-out concerns. We won't necessarily always line up with the AMA or with others, but I think in this case you're probably getting a pretty consistent message that this has crossed a balance. Most things have a balance in life. You folks wouldn't be employed if there weren't those difficult choices to make. Everything has a bit of a downside. I think we recognize that there is some legitimacy to sharing records that are useful, but this has gone a little bit too far.

**Dr. Sherman:** A follow-up. I will say as a front-line provider that the way we have it with the current act it's actually a tremendous

help and resource for when we have someone show up with mental health issues, whether the police bring them in because of something extraordinary happening in the community. Usually when patients come to us, they don't have insight. They're not able to articulate many times who they are or what the problem is. So I would say that currently it's reassuring. My question to you would be: do you have any evidence that with the way things currently are done, it has negatively impacted patients?

**Mr. Shand:** I think we don't have categorical numbers and that type of thing to define the extent of the problem. We know from patients and consumers living with mental illness that come in and express their concerns of how their information has been shared that it's already an active concern. But this, again, extends it to the point where you've exceeded the balance as to what may be in their best interest. A lot of times people don't recognize that something may be in their best interest because they have a particular sensitivity, and this is an area where there is a particular sensitivity. But when you've gone beyond what is practical in terms of even being able to help the person, I think – and I didn't hear the words used so far – often the response is: well, that's not what is intended by this bill.

I'm certain that that's the case here now. I'm certain the intent is not to strip people of their privacy and to create a fearful situation where they're not going to seek treatment. But the reality is that the way it is right now, that's the case. And the way our knowledge of the system, at least, works is that we're not confident that if things are dealt with just in regulations, they'll get the profile or the amount of public input that you need in order to continue to have that balance or that the wisdom of these people that are around the table here today and your other colleagues will be continued in a situation when regulations may be changed five or 10 years from now. Not, Raj, that you won't be sitting here five or 10 years from now but, you know, regardless.

**Dr. Sherman:** Thank you.

**The Chair:** Thank you, I think.  
Other questions?

**Ms Blakeman:** My second question is appearing on page 3 of your submission to us. I'm looking for clarification – well, okay, I'm challenging you. In your third bullet point you say that “the ability to mask unneeded information be maintained.” My understanding of that is that it's not a matter of needed or unneeded because I don't think the patient or the individual can determine that. I think they just request that information be masked. Now, am I misunderstanding that?

**Mr. Shand:** Well, you may understand the bill and its details better than I. But my understanding and in talking to the AMA and the privacy commissioners as well about this is that this is an area that they're uncomfortable with, too, that right now there is an ability to – you can still get access to that information, but you at least have to request, and then there is an . . .

**Ms Blakeman:** An audit trail.

**Mr. Shand:** Yeah. There's some type of trail that you know when somebody has used it. So for fear of discrimination purposes that masking is probably of use. It doesn't prevent, necessarily, information from being shared, but it does limit it at least in terms of your lack of knowledge about who it might be shared with.

**Ms Blakeman:** Okay. A related question, then: has your office done any work on lockboxes around health information?

**Mr. Shand:** No, we have not.

**Ms Blakeman:** Okay. Thank you.

**Mr. Fawcett:** You know, I just had a point of clarification. You just mentioned in your answer to Ms Blakeman that there was an obligation to request. Do you mean request consent from the patient or request to have that information unmasked from the system?

**Mr. Shand:** People can request to see information that is there that has been masked. From what I understand, it's a fairly simple process, but at least there is a process in place.

One of the other fears that the folks from the Alberta Medical Association were speaking of is that they may hear certain types of stories or things. They don't even know necessarily whether they're fully accurate. They may not pertain exactly to the condition that they're discussing with the patient, but they may be forced, even if it's not in the medical record, to include that kind of information in the medical record. You know, that gets beyond the need, I guess, necessary information. It gets on to almost colloquial kind of stories that may or may not even be true and, certainly, may or may not pertain specifically to the information that the caregiver provides.

I think, overall, Dr. Sherman spoke of the trust. The greatest concern is not with the sharing between physicians; it's that that network extends well beyond physicians and that there isn't control of where that network could extend even further. And if it ends up in the regulations, that's too easy to change.

**The Chair:** Thank you.

Mr. Shand, I just wanted to probe a little more from a mental health perspective and ask you to comment specifically on the types of information that might present the most concern for an individual suffering from mental illness if that information should be included in an electronic health record. Dr. Sherman was describing some of the, you know, quantitative information that's routinely included, and certainly there is prescribed health information in the existing act where it lists the information that can be collected. Would I be correct in describing that the main concern might be with chart notes of individual physicians that might describe particular episodes or circumstances of a personal nature not necessarily related to their diagnosis or the specific treatment regimen that they're undergoing? Is that a fair comment?

**Mr. Shand:** I think, Mr. Horne, that that's certainly one of the concerns. Again, it's very easy to take things out of context or to apply them to something.

The other real concern – and someone spoke to where the existing situation is now, and it would exist in the situation now but becomes magnified when the control of the users is not tight – is that you may be referring to an episode of depression that would be on your record that you may have suffered five years ago or at some other point in time. You may be completely recovered. It's unlike a broken leg, where you're going to have – I've still got pins in my ankle from breaking my leg. No one is going to look at me differently for that. They're going to say: “Why didn't you learn how to get tackled better,” or “I've got this or that, too,” and you'll hear the long list of things that they've had.

In this case, that's not going to be the situation. I'm not likely to come forward to somebody, or most people aren't, and say: you know, I had a tough time, and it went beyond a tough time, and I

dealt with depression for a period in my life five or whatever years ago. A person that's looking at you for the possibility of benefits, possibility for employer records, possibility for insurance, getting access to housing, those kinds of things, and is looking at potentially those things, those aren't users that you intend to have included now.

**11:55**

It's very easy to rationalize and say: "Yes. This is in the public good because the police should know this or this person should know this." Well, if I have a secret, I'm not even going to tell it to you. I'm not going to tell it to the person next door. I'm likely to keep it to myself. If I am going to tell it to somebody, maybe I'll tell it to my spouse, and maybe I'll tell it to my physician. It's not a secret but something that's very private to me. I'm not going to tell it to 26,000 people and assume that it's going to be trusted and kept within the scope of what it's supposed to be, let alone other people that may get access because someone deems it's in the public interest, or they find a way to get access.

This is looking at it like a political soap opera, but if you wanted to discredit a politician, you have a story about their son or daughter having had an episode of this or that or having attempted suicide. People not only do not want that information disclosed; it's unfair to the family, and it's unfair to the person, and they may very well step aside from something that they're going to be very valuable and good at doing because of that lack of privacy. To bring it home to you folks, fortunately, it doesn't seem to be as bad in the Canadian context that your personal lives get divulged. But for people living with mental illness, it's a fear they live with all the time. It just goes too far.

**The Chair:** Just as a quick follow-up to that before I pass it on to Ms Notley, the committee has heard that the question of what information is included in the electronic health record in the future is largely a negotiated process between the department representatives and physicians and other groups. So it's consultation, negotiation, and an attempt to arrive at a consensus. As a representative of Albertans living with mental illness or their families or their caregivers have you ever been consulted on the question of what information should be included and would be appropriate from a mental health perspective?

**Mr. Shand:** Not to this point, no.

**The Chair:** Thank you.  
Ms Notley.

**Ms Notley:** Thank you. Part of what I was going to say you've sort of touched on in that often the medical record for someone who has been treated for a mental health issue has far greater levels of intimate information in it, typically, and how you distinguish between that which needs to be and doesn't need to be in the record is an interesting question.

But I wanted to ask you just a little bit. Given the nature of mental illness and given the way that would interact with, say, the system as it exists now, which is based on someone giving informed consent and/or then monitoring whether that consent, you know, is maintained, and then if the masking is removed for a certain set of circumstances and they have to be informed, all that kind of stuff – it involves a certain amount of active attention and involvement. My question is: has your organization ever observed that this sort of intentional strategy applies unfairly to the group which you represent in that you need to be making informed decisions; you need to be capable of making informed decisions; you need to have the capacity to track where the unmasking occurred and then to review it? So

those very skills which you need in order to assert your privacy rights are those which are most likely to be compromised given your illness. Have you observed that there have been any problems in the past with respect to the ability to preserve privacy?

**Mr. Shand:** I think it's an ongoing concern that extends far beyond just the privacy aspect of things. It extends into virtually everything you do if you're not deemed to have the capacity or do not have the capacity to make those kinds of decisions about yourself and then, you know, who should have that right to do it on your behalf. That may vary for one person, let alone within a group of people, from one state of mind or one situation to another, whether a person is under good control and receiving treatment and has their full ability to comprehend and to act for themselves and at other points they don't. So it gets into a much broader issue, but it is a significant issue for this clientele.

**Ms Notley:** Thank you.

**The Chair:** Well, Mr. Shand, on behalf of the committee thank you very much for your presentation today. It's much appreciated and certainly a very important perspective for us to be considering as we approach our deliberations on the bill.

**Mr. Shand:** Well, we appreciate the opportunity to speak to you today as well. Thank you, all.

**The Chair:** Thank you so much.

Colleagues, we're just waiting for the final presenter to arrive. What I'd like to suggest, as we have a couple of items of other business, is that we could use the time now to complete those. The first is with respect to the research that we requested from the Legislative Assembly Office research staff at our earlier meeting, the January 21 meeting. I just want to let you know that most of this is ready as of today, and it will be posted on the internal website for the committee.

The specific pieces are that the cross-jurisdictional comparison is completed. There were four research questions posed, and the answers to those questions will be posted as well. As well, I believe the summary of recommendations from the select special committee which examined the original Health Information Act and an analysis comparing it with the bill that's proposed is also going to be available. That should be available on the internal website later today.

Dr. Massolin, did I miss anything?

**Dr. Massolin:** Yes, there is just one thing. If I could take this opportunity right now to mention to the committee that news clippings on Bill 52 and the issues surrounding Bill 52 from Alberta sources and other jurisdictions around the country have been collected and have been posted under Documents and Resources on the internal website. A new system will be rolled out on Friday along the lines of Alberta Daily News to display those news clippings, so I would ask committee members just to watch out for that.

**Ms Blakeman:** How wide do you cast your net? I noticed an article in the *Edmonton Journal* today that was talking about commercial entities, particularly advertisers, keeping very large databases, which they then start to data map. They combine it. There was a language being used that I found very interesting, which I probably don't have at hand – behavioural mapping. They actually assemble a whole bunch of information about you, which I thought, "Oh, that's relevant to what we're talking about" if we start talking about health

information repositories and data matching. Would you keep an article like that as part of this, or would you consider that too far off?

**Dr. Massolin:** Yes. I mean, it's a good question because we discuss sort of the search terms. The Leg. Library, actually, is the organization that puts this together in consultation with us in terms of talking about what the issues are with respect to the bill. To answer your question directly, no, I don't think that article would have been caught because it's a little bit too broad in terms of not dealing specifically with health information. Having said that, however, I mean, it's a committee decision as to, you know, whether we want to broaden the scope.

**The Chair:** Well, we're not in a position to broaden the scope of the review as it's currently constituted – it's after second reading – but, I mean, this is research that's going to be made available to committee members for their own information. So I'd just make that qualifying comment.

**Ms Blakeman:** Yeah. I've been collecting anything that has to do basically with privacy of people's personal information because health information is part of that. If we see it happening in the larger context around people's personal information, then it's likely, in my mind, going to have an impact on the health information, which is a subset of that. So I clipped it, but I just wondered if you would. The answer is no.

**Dr. Massolin:** No, it didn't appear.

**The Chair:** Any further questions or comments on research?

Just a thank you to both Dr. Massolin and Ms LeBlanc for all your work on this. It's much appreciated.

**Dr. Massolin:** Thank you.

12:05

**The Chair:** The other thing I could just talk about briefly is the next steps following this meeting. You'll recall that we had established a process whereby an advertisement would be placed for public input. I haven't yet been able to confirm a motion in the House to reinstate this bill in the new legislative session. I'm not in a position to confirm whether that's going to be in the first week or the second week. We had hoped for week one. We've got two House leaders in the room, but I need to confirm with the Government House Leader as well.

My suggestion would be, then, that we schedule the next meeting following the deadline for those written submissions to come back to the committee, which we had set I think at March 13, if I'm correct. The committee clerk, Ms Norton, will be posting any submissions as they come in. We won't wait and put them all there the week before the meeting. We'll post them as they're received. By scheduling a meeting after the deadline, then, the committee would have all of the information that's been collected through these submissions, so we'd be in a position where we had a complete set to work from, assuming that the next step will be getting into some specific deliberation on the bill.

**Ms Blakeman:** I appreciate that they'll be made available as they come in, and that's wonderful. My experience of human nature is that they'll all come in on the 13th, which is the deadline. Can we get at least a week to be able to read them before we convene a meeting to discuss them?

Secondly, when we were doing the Health Information Act review, we were able to get some assistance, actually from the

department people – I think it was the department people – who helped sort of organize some of the information that was coming in. Well, this might be better done afterwards. Sorry. I'll just take that last bit away. Just rewind that tape, *Hansard*. Thank you.

**The Chair:** Certainly, we don't have to have a meeting on March 16, for sure. Point well taken.

**Ms Blakeman:** Thank you.

**The Chair:** I'm going to ask Dr. Massolin to comment in a minute, but I neglected at the beginning of the meeting to introduce the two department representatives that are here, Wendy Robillard and Heather Veale.

**Ms McDonald:** I'm Julie McDonald.

**The Chair:** I'm sorry. I understood Ms Veale was going to be here. Welcome to you both.

We will have an ongoing department presence at the meeting. Some of the research that you'll see on the internal website is the result of the LAO research staff working with the department, seeking the information in response to the committee requests. So that link is there.

I don't know, Philip, if you want to add to this.

**Dr. Massolin:** I was just going to pick up on Ms Blakeman's point and ask you, Mr. Chair, if the committee would like the research section to summarize these submissions as we've done for other committees in the past.

**Ms Blakeman:** I thought the summary happened after we had talked about them. Did the summaries happen before? Did that give us a structure to review them?

**The Chair:** I believe that in our review of Bill 24 there was a summary provided of the submissions, a paraphrase of the submissions, and then subsequent to that there was a document prepared – I think we called it a focus document – and it sort of summarized the issues arising collectively from all the presentations.

**Ms Blakeman:** That's following the format that we had with the Health Information Act review, I'm pretty sure.

**The Chair:** I see a few heads nodding. I think that both are still deemed to be of great assistance to the members, so we'd continue with that.

**Dr. Massolin:** Okay. Thank you.

**The Chair:** I find myself in the odd position of chairing a meeting that's running at least 20 minutes ahead of schedule. We don't have the next group of presenters here, so I'm going to call a break.

**Ms Blakeman:** Can we not look at some possible meeting dates? If we got in first, then we'd have our pick of the times.

**The Chair:** Yeah. I'd prefer to do that through the clerk polling if you don't mind. There are so many conflicts. For example, there's a meeting of the Members' Services Committee going on here that wasn't scheduled at the time we scheduled this meeting. So I'd prefer to run that through the clerk if that's all right. I just found it to be an easier way to make a decision that sticks. But, certainly, if

there are specific dates that need to be avoided, please advise the clerk, the earlier the better.

**Ms Blakeman:** Yeah, but can you give me a timeline, the time period that we're trying to avoid now? I guess between the 13th of March and June.

**The Chair:** Well, it would appear the choices – what are the two constituency weeks at the end of March?

**Ms Blakeman:** Yeah. The week of the 23rd and the week . . .

**The Chair:** That moves into April.

**Ms Blakeman:** Yeah.

**The Chair:** So our choice in March would be confined to the week of the 16th and then the break or else coming back after the break. I think that's what we're up against, but I need to check all the dates to make sure. [The teleconference malfunctioned] That hasn't happened before.

**Ms Pastoor:** Are you in or are you out, Jonathan?

**Ms Blakeman:** He's out. Bye, Jonathan.

**The Chair:** Okay. Is there anything under other business that other members want to raise at this point?

If not, I don't think I've got any choice but to call for a short recess until the next presenter arrives. They are here? Okay. Can we take 10, please, and come back. I think we'll be ready to go in 10 minutes. My apologies for that. Thank you.

[The committee adjourned from 12:11 p.m. to 12:21 p.m.]

**The Chair:** Okay. Colleagues, we'll call the meeting back to order. Thank you. Our final presenters today are from the Alberta Cancer Foundation. I'd like to welcome Mr. Sandy Slator, the chair of the foundation's board of trustees. Welcome, Mr. Slator.

**Mr. Slator:** Thank you.

**The Chair:** And Ms Linda Mickelson, the chief executive officer of the Alberta Cancer Foundation. It's a pleasure to have you both here. We'll just take a moment and introduce the members of the committee to you. We'll begin with the member on the telephone, Mr. Denis. He may have stepped away. On the telephone will be Jonathan Denis, the MLA for Calgary-Egmont.

**Ms Pastoor:** Deputy chair, Bridget Pastoor, Lethbridge-East.

**Dr. Sherman:** Raj Sherman, Edmonton-Meadowlark.

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

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

**Ms Blakeman:** Welcome to my constituency of Edmonton-Centre. I'm Laurie Blakeman.

**Mr. Quest:** Hi. Dave Quest, MLA, Strathcona.

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

As the clerk explained, we have about 30 minutes to work with, Mr. Slator. We'd ask that you confine your formal remarks to up to 15 minutes, and that will give us a chance to ask you some questions following. Please proceed whenever you're ready.

#### **Alberta Cancer Foundation**

**Mr. Slator:** Thank you very much, Mr. Chairman, and thank you very much, esteemed panel. I want to thank you for inviting the Alberta Cancer Foundation to make a presentation to the Standing Committee on Health as one of many foundations representing the interests of health care in the province. My name is Sandy Slator, chair of the board of trustees for the Alberta Cancer Foundation. With me is Linda Mickelson, the chief executive officer of the foundation.

Now, by way of background, the Alberta Cancer Foundation was established in 1984 under the Cancer Programs Act, and upon proclamation of Bill 42, the Health Governance Transition Act, is continued and deemed to be a foundation established by a regional health authority under the Regional Health Authorities Act. Our purpose remains the same, however: raising funds in support of world-class cancer research, province-wide prevention and screening initiatives, and patient care programs at the Cross Cancer Institute in Edmonton and at the Tom Baker cancer centre in Calgary and 15 other cancer treatment centres throughout Alberta.

As one of Alberta's health care foundations we are an integral part of the health care system, facilitating community participation and partnership in funding important initiatives and, specifically, advances in cancer care. The Alberta Cancer Foundation provides over \$20 million annually in support of cancer research and patient programs.

Now, Linda and I are pleased to be here today to endorse an earlier presentation made to this committee in November of 2008 by the Council of Foundations, representing 13 health care foundations in the Edmonton area, including the Glenrose hospital foundation. At the time of that presentation there was no bill in the Assembly proposing amendments to the Health Information Act, and we understand that this committee did not have the ability to initiate recommendations back to the Legislative Assembly. With Bill 52 now under review we're delighted to be able to support the Council of Foundations' request for an amendment to the Health Information Act to reinstate limited access to patient information for the purposes of fundraising.

Health care foundations are a primary vehicle for Albertans to make direct and meaningful donations for the advancement of health care. Patients and families frequently want to make gifts as expressions of their gratitude, and this motivation to give or to become involved as volunteers or committee members is an underpinning of any successful hospital fund development program. As a consequence of provisions in the current Health Information Act foundations in Alberta are not able to access patient names and addresses. This has a profound impact on our ability to raise funds and develop relationships with the direct beneficiaries of the health care initiatives we support.

Since 1998, when foundation access to patient information was withdrawn, grateful-patient donations have declined. This not only impacts the financial support we are able to deliver today but potential future support that is cultivated through long-term relationships with donors. If such access is restored, Alberta will join three other provinces – Ontario, Quebec, and Manitoba – in permitting limited access by health care foundations to patient contact information for fundraising purposes. These provinces represent a large portion of the Canadian population and represent diverse political landscapes. It is our hope that health care foundations in Alberta

will be entitled to similar access in order to advance fundraising efforts in the health care sector.

Now Linda will highlight the importance of acquiring patients as donors and outline the changes we are supporting for the Health Information Act.

**Ms Mickelson:** Thank you. Well, it's a pleasure to be here. Thank you for asking us. According to the Canadian Centre for Philanthropy, the number one reason that people don't give is because they're not directly asked. Health care foundations like the Alberta Cancer Foundation provide numerous opportunities through well-defined fund development programs for donors and prospective donors to give in ways that are most meaningful to them. We know that when we ask, we are much more successful in raising the dollars we need to fulfill our mandates.

We invest in professional development staff who identify and build relationships with prospective individual donors, and each year we budget for direct-mail programs, special events, and other programs that reach out to a much broader audience. We are constantly working to acquire new donors with an interest in our work, but acquisition programs are costly and may or may not reach the audience that's most likely to give, the beneficiaries of the specific health care initiatives that we support.

As the Council of Foundations described to you in November of 2008, amendments to personal information acts in Ontario and Manitoba and similar legislation in Quebec have achieved a balance of interests, protecting health information while allowing the use of patients' names and addresses for fundraising purposes under certain circumstances. Specifically, the collection, use, and disclosure of an individual's name and mailing address for fundraising purposes in those provinces may take place with the implied consent of the individual as long as certain requirements are met. Those requirements include fundraising activities that relate specifically to the custodian's operations, access to clear and easy information about how a patient can opt out of being contacted for fundraising purposes, an easy opt-out option from any further solicitation once the foundation has contacted them, and no information about the individual's health or health care. The Alberta Cancer Foundation certainly supports these restrictions as did the Council of Foundations in its previous presentation.

We hope that this committee will see the merit in recommending an amendment to the current legislation that will strike a balance between the protection of health information and giving hospital foundations access to information we require to be able to contact those who are most likely to support advances in health care for all Albertans. Access to patient names and contact information only would greatly enhance the ability of hospital foundations in Alberta to introduce ourselves to the people who benefit from many of the projects that we fund. This is a powerful and cost-effective way to help us raise the dollars that will continue to support leading-edge research, advanced technology and equipment, and programs that directly impact patients and their families.

**12:30**

Information on how patients could opt out would be readily available before our initial contact as well as after, and we are willing to work closely with Alberta Health Services to ensure that filters are in place to deal with sensitive situations and circumstances where it would not be appropriate to contact a particular individual.

The Alberta Cancer Foundation is very respectful of the privacy concerns of our cancer patients and their families. This respect extends to our family of donors and volunteers. We support the position of other health care foundations in Alberta that it is possible to achieve a balance, a balance between the need to protect the

health care information of patients and the opportunity to enlist the support of patients interested in advancing health services in gratitude for the care they've received.

In summary, Mr. Slator and I hope the committee will consider the value of the philanthropic support that is provided by health care foundations and recommend an amendment to the Health Information Act to permit us to access the limited information we require in order to continue as strong funding partners for Alberta Health Services.

We'd like to thank you again for inviting us to speak to you on this issue.

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

Before we go to questions and comments from the committee members, I just want to emphasize for the record. I know you've explicitly asked the committee to consider an amendment specific to the availability of patient names and addresses for fundraising purposes. I just want to make clear – and I've discussed this with Mr. Slator earlier – that these deliberations are as a result of the referral of the bill after second reading in the Legislature, and as such our recommendations at this point are confined to the specific provisions that are proposed in the bill. I think, you know, the question of to what extent we may be able to go beyond the explicit provisions is a question we would seek advice on from Parliamentary Counsel. I want to say that because you did make an explicit request here. So I'll just note that for the record.

**Mr. Slator:** I appreciate that, Mr. Horne, and we were aware of that, I guess, prior to the presentation by reading that excerpt in *Hansard*, which did refer to that. We had been scheduled to appear in any case, and we thought it would be an appropriate opportunity and an appropriate time to be able to express our concerns and requests on the potential change.

**The Chair:** Certainly, and we're delighted to have you here as well. Ms Pastoor, followed by Ms Blakeman.

**Ms Pastoor:** Thanks very much for your presentation and for coming. Anyway, all information is valuable.

If you don't mind, I'm going to be a bit of a devil's advocate here and then would ask for comments later. When I'm a patient in a hospital, I'm not grateful to the system; I'm grateful to my caregivers. I'm grateful to that nurse that actually wiped my face instead of throwing the face cloth at me and saying, you know: go at it, Babe. My gratitude truly is to my caregivers, and I'm not sure that I think about the system per se. As a taxpayer I would assume that that's what I would get with my health care and my health care dollars.

The other thing is that I don't think there's anything in this world today, including condoms, that aren't pink, and that is the result of some marketing genius who has marketed breast cancer research. I'm not sure that they needed a list of names to be able to do that. Perhaps the only one that's better is the guy that runs the Tim Hortons ads, because they're very clever.

That is a bit of a devil's advocate kind of attitude. I certainly don't want to downplay the absolute importance of any foundation that raises money, but just maybe a couple of comments on my comments.

**Mr. Slator:** Do you want to go at that first, Linda, or do you want me to go at that first?

**Ms Mickelson:** You go right ahead, Sandy, and I'll follow up.

**Mr. Slator:** Yes. I'm not sure I tend to agree. I haven't been involved in hospitals all that much, although I did lose my wife to cancer five and a half years ago. I personally did really appreciate the system. I appreciated the caregivers, but I did appreciate the system, and I did appreciate the efforts that all of the people within the Cross Cancer Institute did to support, which is, quite frankly, the reason I'm involved with the Alberta Cancer Foundation today.

On your second point, about the requirement for the additional help, you know, whether it's the pink ribbons, to get us enough of the activity, I think we are currently in an incredible financial crisis throughout the world, if you will. Foundations or those groups that do require the funding through donations need every little bit of help and support that they can get. I mean, if we take a look at the Alberta Cancer Foundation itself, we have had a very significant budget over the past few years, increasing and rising over the past few years. If we take a look at the economic situation this year, the economy in general, we're just going over our budgets right now, and we're saying that we don't think we are going to have an increased budget for the coming year. As a matter of fact, it may even be less. We don't know. We haven't got it set yet. But we require every little bit of assistance we can have in the fundraising efforts that we have. The more funds we raise, the more we're able to invest in research as well.

**Ms Mickelson:** Along the lines of research the Alberta Cancer Foundation right now is providing approximately half of the total cancer research budget that's administered by the Alberta Cancer Research Institute in Alberta. It's a significant amount of funding, that these researchers are counting on. We're certainly well aware that many of our donors contribute to us because they do appreciate the care that they've received. I think many of them recognize that that care is a result of the basic research and the improvements in programs that have happened over the years as a result of research that has been invested in by donors like them. I just entirely support what Sandy has indicated, that we really are looking at every opportunity that we can to enlist the support of the people that are most likely to give. Many of those people are patients and their families.

**The Chair:** Thank you.

Ms Blakeman, followed by Dr. Sherman.

**Ms Blakeman:** Thank you. My first question is: when did the system change? When were you no longer able to get discharged patients' information to follow up with? What year was it?

**Ms Mickelson:** That would have been in about 1997, 1998. It was just before I began with the Alberta Cancer Foundation. I know that prior to that time foundations across Alberta did have access to that information. I don't know exactly how they accessed it, but since I've been with the foundation, 1999, we have had absolutely no access to patient information.

**Ms Blakeman:** Okay. I was pretty sure that it was since I'd been elected because I had had a couple of constituent concerns that I had to deal with in direct connection to that.

What my question is really focused on is that you have asked for implied consent, which really means that it's a negative billing option. They don't get an opportunity to give their consent in advance of their information being released to you. Yet you followed up by saying: well, there'd be all kinds of information provided about how they could opt out, and they could decline any further. If you're going to that amount of effort and having the information prepared, why are you not willing to just deal with an

informed consent basis up front and say: when you're discharged, we'd like to get this information from you; would you release it to us?

**Ms Mickelson:** Well, I think, from some of the people that I've talked to that were involved in preparing the presentation that came forward in November and people I've spoken to, by the way, in other provinces as well, that they feel very strongly that it's not appropriate to raise this conversation with a patient when they have other things on their mind, quite frankly. And who would be the most appropriate person to do it? It's not the nurses; it's not the physicians. They have a limited amount of time to spend with their patients, and really their focus needs to be on making sure that the people are informed about their care and what's the best thing for them at that time.

When we say that there would be information available to them to opt out of the program, it would be really important that we work to make sure that that information was available in the facilities, in their discharge information, so that they would be informed that unless they opt out – they have the opportunity to opt out – they would receive an introduction and some information from the foundation.

12:40

**Ms Blakeman:** I'm still struggling, and I've yet to hear a compelling argument for why we would breach someone's privacy for a fundraising effort. I guess I'm struggling with: if it's not appropriate to talk to them and get information while they're in the hospital, well, then, how is it appropriate to follow up following that to ask them for a donation? I'm still struggling as to why this system cannot be done with an informed consent proviso in place.

**Ms Mickelson:** I think some people may be concerned that unless they choose to give to or get information from a foundation, they may not get the same level of health care, and that would be, I think, a disastrous situation to have. I don't think that's appropriate.

**Ms Blakeman:** You see, that's the episode I have had. In a very short period of time I had to deal with several issues around elderly patients who were genuinely frightened and contacted their MLA because they had received an ask letter upon discharge from a hospital and were most distressed because that's exactly the connection they made: if they didn't donate and they had to go back in because this was a recurring problem, would they now be receiving less health care, and additionally, how on earth did they get this information, that shouldn't have been disclosed to them? I guess I've had the opposite reaction from what you're describing.

**Ms Mickelson:** It may be in some cases that the information was already with a foundation. For example, I've had similar phone calls and have in a panic gone back to find out what the person's background is, and they are in our database as previous donors. It may have been a year or several years ago, but that person is connecting the letter that they've received with their recent visit to a hospital when they're not connected at all. We access our donor information regularly throughout the year and try to build relationships and keep in communication with our donors. They all have an opportunity at any time to opt out of receiving future communications from the foundations. That's a part of the policies that we operate under.

**Ms Blakeman:** No. I appreciate that, and you have great credibility in the community. It's just the informed consent. Why we can't get it up front is my struggle with this. Okay, thank you for your answers.

**The Chair:** Thank you.

We have some further questions. Dr. Sherman, followed by Mr. Dallas, please.

**Dr. Sherman:** Thank you, Mr. Chair. Thank you, Mr. Slator and Ms Mickelson, for appearing before us. I'd just like to highlight the importance of foundations, especially at a time of economic challenge in a hospital. Foundations provide sort of that soul to a hospital. Sometimes, you know, we need a new piece of equipment that's not covered, like a little ultrasound in emergency or a special GlideScope, so we can perform that life-saving intervention, and it's something that's not regularly provided, especially when it's a new piece of equipment that just came, that's newly invented. So thank you for all the work that you've done.

Just a few questions I would have. One, what's your understanding of why they made this change in 1997? The other concern I would have is that, for instance, if a patient has cancer, they're identifiable as having a disease. If it's a penile dysfunction foundation, then all of a sudden they're on this database, this list, with an identifiable diagnosis. Could it not be possible to opt in? When patients are discharged, they're generally well. If they were given some information and, say, look. Can you not opt in versus opting out? This way they have given consent to you to be contacted. They are actually quite grateful when they're discharged. There's no obligation. I think that with electronic health care records it's a great way for you to fund raise if it's done right, a great way for you to do it efficiently and safely. That way the patients have that protection where they are empowered – you know how it is sometimes; fundraisers phone and phone and phone and keep sending letters – versus them considering it a nuisance.

**Mr. Slator:** Linda, I'll let you answer both questions. I'm not aware why the changes were made in 1998. Linda, were you able to find anything out about that?

**Ms Mickelson:** Well, we think actually that there was huge interest, of course, in protecting patient information at that time, which ultimately resulted in the act protecting this information. I think that foundations were all lumped in, and, as I've heard it said, we were collateral damage. I don't think that, really, there was a lot of attention paid to what the impact would be on foundations by not having access to that patient information and, specifically, only names and addresses. We are not interested in any details about the health or condition of the patients.

Now, granted, with the Alberta Cancer Foundation all of our patients have cancer. So we're a little different from a hospital where you might have gone in for an ingrown toenail or a hysterectomy or anything in between. But we are very, very respectful of that, as I say, in all of our communications.

You know, is it possible to have an opt-in? I suppose it would be, but it just becomes a matter of: do they really get that information at that discharge time, is it effectively delivered, and is that the best way for us to communicate with them? I think that we can have a balance, and I think that other provinces have demonstrated that through their legislation, their amendments.

**Dr. Sherman:** Thank you.

**The Chair:** Thank you.  
Mr. Dallas, please.

**Mr. Dallas:** Thanks, Mr. Chairman. I expect maybe my colleague, with better examples than I'll provide, was working in the area where I was going to go. I guess I took to heart your suggestion that

at the time of discharge there's a lot going on and it may not be the best time to be thinking about consenting or not consenting to receiving information or at some point an ask, but I really like the idea that one needs to opt in as opposed to opting out.

Have you given any thought, as an alternative or as a compromise, to what's a reasonable amount of time after a discharge that a patient might be in the right frame of mind to be able to rationalize a decision around securing more information or receiving an ask? If it were on the basis of a fairly generic opt-in in the sense of perhaps there's follow-up work being done, from a patient perspective at some point in that follow-up if there was a question as simple as the patient having an interest in learning more about research and foundations that are working in the area of the affliction, would that be appropriate? Any comment there?

**Ms Mickelson:** Well, I know that in Ontario they do have the opt-out situation. Their first contact would be if they have not had a response or received anything from a patient within 60 days from the time of the discharge. So they would have their earliest communication after 60 days. I specifically spoke to one of the cancer hospitals in Ontario, and they communicate with their patients one time a year. They collect all of the information within a year and 60 days and communicate once with that group.

**The Chair:** Okay. Others?

**Dr. Sherman:** Have any of the foundations across the country actually taken a thousand patients and studied this, the opt-out or opt-in, to see how successful the fundraising was versus the number of complaints? Has anyone actually looked at this?

**Mr. Slator:** Good question.

**Dr. Sherman:** You might actually find that by opting in, you might be more successful or vice versa. Really, this is about getting as many resources as possible without causing undue discomfort to the patient and them feeling like their privacy has been violated.

**Ms Mickelson:** Yes. Well, I reviewed the information that had been collected for the November presentation, so I did not have that specific discussion with other foundations across the country. But I do know that the general consensus was that the opt-in option was not effective and was not the chosen method, particularly in those four provinces that have considered and made amendments.

**The Chair:** Well, I'd like to thank you both, Mr. Slator and Ms Mickelson, for appearing before the committee. We very much appreciate your comments and your willingness to take our questions. Thank you very much.

**Mr. Slator:** Thank you very much. We appreciate the opportunity as well. Thank you.

**The Chair:** Colleagues, I think that concludes our agenda. The next meeting will be at the call of the chair. We'll await a motion in the Legislature with respect to the bill.

I believe lunch is available for us in the lounge. With that, I'll ask for a motion to adjourn. Ms Pastoor. Any discussion? Those in favour? Opposed, if any? Carried.

Thank you very much. I think we had a really productive meeting today.

[The committee adjourned at 12:50 p.m.]





